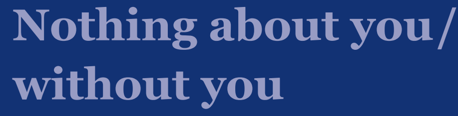
sage
Support & Advocacy Service

Annual Report 2016



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SageAdvocacy.ie

Our Mission

“To promote and protect the rights, freedom and dignity of vulnerable adults and older people through the development of support and advocacy services that address individual and systemic issues”

Contents

4
Introduction

7
About Sage

8
The Organisation

National Advisory Committee
8

Practice and Guidance
9

Education Training and Support
9

Research, Impact and Evaluation
9

Public Awareness & Media
9

Sage Staff
10

Sage Representatives
13

15
The Work of Sage

Overview of Activities
16

Outcomes
20

Case Management
24

Legal and Financial
30

Recruitment and Training of Volunteers
33

Citizens Advocacy Project: South-East
37

Stakeholders & Partners
42

Report on the Atlantic Philanthropies Investment in Dementia in Ireland
48

Forum on Long-term Care
97

49
Advocacy – Case Studies

95
What People are saying

Introduction

Patricia Rickard-Clarke
Chair: National Advisory Committee

The development of Sage as a support and advocacy service has been influenced by two key events: Leas Cross (2005) and Aras Attracta (2014). Its expertise is in working with people who are users of, or who come into contact with, health and social care services. As such it can be an important source of learning for the HSE and other service providers by giving a voice to the experience of service users; through collaboration where possible and through reasoned challenge where necessary. As a major funder of Sage the HSE is entitled to argue that by supporting Sage it shows that it is open to being challenged and values the changes that can result from advocacy. It is also entitled to argue that it has, with the invaluable support of The Atlantic Philanthropies, helped 'carry the flame' for advocacy until such time as other state sectors collaborate in building a proper framework for the development, funding, training and oversight of the advocacy sector. Developments in legislation such as the Assisted Decision Making (Capacity) Act 2015 and the planned establishment of the Decision Support Service, the Disability (Miscellaneous Provisions) Bill 2016, and the Adult Safeguarding Bill 2017 clearly indicate that advocacy is an emergent practice is likely to have a legal standing within the next few years. As such the HSE and The Atlantic Philanthropies can rightly claim to be pioneers of advocacy in Ireland.

This is the second annual report of Sage; the first one covered the 'Establishment Phase' from September 2014 to December 2015. This report for 2016 provides the first opportunity to compare performance year on year. Through consistent work on developing our data recording systems we are able to show an increase in all levels of activity. Importantly, the data shows growth in individual casework in the community and hospital areas with these numbers now greater than the numbers for nursing homes. Patterns have been identified and it is clear that transitionary and financial issues continue to dominate; not surprisingly as many Sage clients face enormous challenges in transitioning between the place they are - often a hospital or a nursing home - and the place they want to be - their own home.

One issue, above all, defines the challenging nature of the work that Sage undertakes; capacity. Sage has to be guided by the principles of the Assisted Decision Making (Capacity) Act 2015 and the presumption of capacity unless clearly proven to the contrary. We are seeing far too many cases where the 'will and preference' of an older person or a vulnerable adult is completely ignored and the 'best interests' of the person are determined by family members, often divided among themselves, and service providers who are sometimes threatened with legal action or media coverage. Significant concerns

emerged during 2016 about a small number of nursing homes denying residents access to independent advocacy (often at the request of family members) as they are obliged to do; both by virtue of basic human rights and because this is a HIQA standard that they are required to meet. This matter will be pursued vigorously by Sage.

Despite these challenges Sage now has over 130 Memoranda of Understanding agreed with care providers; mainly with nursing homes. It has provided support and advocacy to people in hospital and community settings and is receiving referrals from other advocacy services. It is developing a Citizens Advocacy Project in the South-East for people with intellectual disabilities and is increasingly seen as a 'go to' organisation that goes the extra mile for its clients. The calls to the 1850 Information & Advice / Rapid Response Service indicate that many service providers see Sage as a source of support which they are currently unable to get elsewhere.

During 2016 Sage sought to address the issue of outcomes. It commissioned a paper as part of our baseline evaluation process and the recording of outcomes for advocacy was reviewed by two experienced researchers. As a result a 'Three Perspectives' outcomes measure has been developed which aims to capture the perspective of the client or group, where this is possible, as well as the perspective of the service provider and the Sage Representative involved.

In mid-2016 the National Advisory Committee reviewed progress in the recruitment, deployment and retention of volunteers. This in turn developed into a wider conversation about 'The Sage Model' i.e. core paid staff supported by, and in turn supporting, trained volunteers. The resulting discussions, supported by research and organisational insights, have helped to develop a process of refocusing 'The Sage Model'. During 2017 the model will be refocused to ensure that more volunteers are involved in support roles in a wider range of settings, and that volunteers with appropriate pre-existing skills are, where possible, recruited for advocacy and specialist support work.

Sage has a commitment to address systemic as well as individual issues. In this regard I am particularly pleased that the work of the Forum on Long-Term Care for Older People, initiated by Sage in collaboration with Third Age, Family Carers Ireland and Alone, was recognised in November when it was invited to give evidence to the Oireachtas Committee on the Future of Healthcare. The Report, representing a process of public consultation, a nationwide public opinion survey, an analysis of decades of public policy and a public conference underlines, once again, the need for a continuum of support and care in older age and the need for substantial innovation in order to ensure that as many people as possible stay healthy in the place of their choice – their home- for as long as possible.

Finally, I want to thank all those who have worked so hard to build the dream of Sage as a team of people capable of tacking the most complex support and advocacy challenges facing vulnerable adults and older people. Volunteers who gave so freely of their spare time to ensure that the voice of older people is heard; staff who sometimes saw little enough spare time so that they could, as our mission statement says: "… promote and protect the rights, freedom and dignity of vulnerable adults and older people through the development of support and advocacy services that address individual and systemic issues". I also want to thank my colleagues on the National Advisory Committee and the board and executive of Third Age for their ongoing support. None of our work in 2016 would have been possible without the support of the HSE, The Atlantic Philanthropies and the Tony Ryan Trust all of whom helped fund, to a greater or lesser extent, the work outlined in this annual report. Ensuring replacement funding when existing funding from The Atlantic Philanthropies ceases in 2017 is now our greatest challenge.

Our Approach

To collaborate where possible –
to challenge where necessary

About Sage

Sage was established in September 2014. Its development has been influenced by the scandals of Leas Cross in 2005 and Aras Attracta in 2014. It provides support and advocacy to older people and, increasingly, to other adults who may be vulnerable. In circumstances where people may be vulnerable or have to depend on others there is a need to ensure that their rights, freedoms and dignity are promoted and protected. Through support and advocacy the wishes and preferences of a person can be heard and acted on; independently of family, service provider or systems interests.

Most people prefer to live, and to die, in their own home, to participate in meaningful activity, to choose their friends and to make decisions for themselves. But many people face challenges to their independence due to chronic illness, intellectual, physical or sensory disability, lack of family and community supports or an inability to access public services that meet their needs. Some people with disabilities communicate differently and with difficulty. Some people may lose their ability to make and communicate decisions as a condition, such as dementia, develops over time. Some are abused and exploited because of their vulnerability.

Sage is working to expand access to support and advocacy services in all care settings and living situations and wherever disability, ageing or capacity poses a challenge for individuals. We are committed to addressing individual and systemic issues and our work is guided by Quality Standards and the guiding principles of the Assisted Decision Making (Capacity) Act 2015. We presume capacity, unless there is clear evidence to the contrary and we work to enhance peoples' capacity to express their will and preferences and to make decisions for themselves rather than have others decide what is in their best interests.

Sage is a member of the National Safeguarding Committee a multi-agency and inter-sectoral body established to promote the rights of adults who may be vulnerable. www.safeguardingcommittee.ie

third age

The development of Sage was funded by the HSE and The Atlantic Philanthropies with the support and governance of Third Age.

The Organisation

National Advisory Committee

Chair: Patricia Rickard-Clarke

Áine Brady

Dr Sabina Brennan

Tadhg Daly

Karen Erwin

Angela Mezzetti

Brendan Moran

Dr Brendan O'Shea

Dr Amanda Phelan

Greg Price

Prof Cillian Twomey

Meetings:

6th January 2016
7th March 2016
8th June 2016
15th September 2016
15th December 2016

Sage appreciates the contribution of Ann-Marie Coen & Dr David Robinson who stepped down from the NAC in 2016.
We are grateful to them for their support

Practice and Guidance Work Group

Members:

Chair: Patricia Rickard-Clarke
Michael Browne
Dr Ann Coyle
Tessa Digby
Anne Harris
Eileen O'Callaghan
Dr Amanda Phelan
Michelle Rooney
Renee Summers

Dr David Robinson was a member of the Practice and Guidance Work Group from its inception in late 2014 until August 2016.

Meetings:

3rd February 2016
30th March 2016
11th May 2016
22nd June 2016
21 September 2016
2nd November 2016

Education Training and Support Work Group

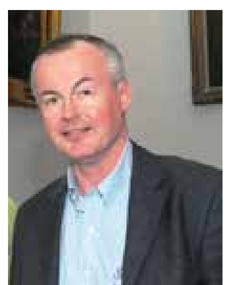
Members:

Chair: Karen Erwin
Ann-Marie Coen
Jackie Crinion
Nora Lillis
Brendan Moran
Dr Meta Reid
Michelle Rooney

The Sage Education, Training and Support Work Group met on three occasions. The purpose of the group was to support and advise the National Advisory Committee (NAC) and the staff of Sage with regard to the development of the education, training and support functions of the service in line with the mission of the service, and included external expertise, independent public representative and Sage volunteer representation. Due to the evolving Sage service and approach to recruitment and volunteer training this group completed its work in June 2016.

Research, Impact and Evaluation Work Group

Members:



Chair: Brendan O'Shea
Helen Fitzgerald
Brian Harvey
Sinéad Hyland
Mary Keys
Anne-Marie McGauran
Kieran McKeown
Fiona Morrissey
Mervyn Taylor
Kathy Walsh

The Research, Impact and Evaluation Work Group met on three occasions and completed its work in December 2016.

Public Awareness and Media Work Group

Following from a review of the membership and working of the National Advisory Committee and its Work Groups in December 2015 it was decided to establish a Public Awareness and Media Work Group chaired by newly appointed NAC member Angie Mezzetti.

Terms of Reference:
To develop awareness of the work of Sage and the diversity of support and advocacy challenges facing older people among special interest groups and the general public.
To build a network of committed supporters across all media forms
To support the Sage Team in the process of recruiting committed and effective volunteers

Members:

Chair: Angie Mezzetti
Barbara Scully
Niamh Griffin
Cathy Herbert
John Gallagher
Jim Milton

Sage Staff

Mervyn Taylor
Programme Manager

Aedamar Torpey
Administrator

Helen Fitzgerald
Recruitment & Information Coordinator

Michelle Rooney
Legal & Financial Coordinator

Mary Condell
Legal Advisor

Eileen O'Callaghan
Development Coordinator & Development Worker – Dublin North

Renee Summers
Case Coordinator & Development Worker – Dublin SE & Wicklow

Bibiana Savin
Development Worker – Dublin SW & Kildare

Brenda Quigley
Development Worker - Support

Caroline Hanley
Development Worker – South East

Sage Staff

Danielle Monahan
Development Worker – North East

Trish Martyn
Development Worker - West

Maureen Finlay
Development Worker – Louth & Meath

Ann Griffin
Development Worker - North West

Michael Cahillane
Development Worker - South West

Emer Meighan
Development Worker – Citizens Advocacy Project

Padraig Ruane
Development Worker - Greater Dublin

Anne Harris
Development Worker - Special Projects /Midlands

Sinead Hyland
Development Worker – Midlands

Tessa Digby
Development Worker – North

Sage Staff

Dr Meta Reid,
Education, Training and Support Advisor

Dr Meta Reid was Education, Training and Support Advisor from December 2014 to February 2016. Meta made an important contribution to the development of Sage's thinking and planning on education and training matters. Her approach was always stimulating, well informed by academic principles and often delivered with a very personal flair. Meta had previously worked as a volunteer advocate with the Third Age National Programme (TANAP) and showed great leadership during the transition from TANAP to Sage.

Noreen O'Brien
Development Worker, Mid-West

Noreen O'Brien was Development Worker for the Mid-West Region between October 2015 and December 2016. She previously worked with the National Advocacy Service for People with Disabilities. She travelled extensively in the mid-west and was extremely committed to promoting the wellbeing of her clients in the area.

Fiona Anderson
Development Worker, Waterford & Kilkenny

Fiona Anderson was Development Worker for Waterford & Kilkenny region between December 2015 and May 2016. Fiona, who had originally trained as a volunteer advocate, undertook important exploratory work in the South-East providing Sage with useful insight into how best to develop in the region.

Sage is more than a service - it is a citizens' movement

During 2016 some 151 people contributed their time, skill and transport on a voluntary basis in the service of vulnerable adults and older people. The work of these volunteer Sage Representatives is acknowledged and deeply appreciated. Their contribution, which cannot always be easily measured, shows the value for money that the Sage approach represents and it demonstrates that Sage is more than just a service; it is also a citizens' movement.

Volunteers active during 2016

Una Barry McDonagh
Joan Bradley
Mary Brady
Carmel Brady
Mary-Elizabeth Brett
Kieran Briscoe
Melody Buckley
Marie Cahill
Gerry Campbell
Marie Carberry
Marie Casey
John Casey
Tom Clarke
David Clarke
Valerie Coghlan
Susan Comerford
Marie Connellan
Teresa Connolly
Mairead Conroy
Esther Cosgrove
Kay Costello
Bridget Crawford
Siobhan Cunningham
John Curley
Caroline Darby
Katherine Dargan
Ann Delaney
Linda Devlin
Deirdre Doherty
Vivienne Dooge
Lily Douglas
Sarah Duffy
Monica Egan
Mustapha ElHasnaoui
Bridget Ennis
Louise Enright
Eamonn Farrell
Catherine Fennell
Mary Finan
Mahon Finlay
Joan Foley
James Galvin
Philip Gargan
Marguerite Good
Bridget Guilfoyle
Mary Hall
Annette Hamill
Carmel Handy
Caroline Hanley
Marian Hanrahan
Aileen Heaphy
Antoinette Hensey
Angela Hillary-Jehle
Maude Hogan
Eamon Hughes
Marguerite Hurton
Aine Keating
Elizabeth Keigher
Rebecca Kelly
Marie Kelly-Fox
Hannah Kent
Jennifer Kidd-Keating
Bill Lloyd
Mary Lynch
John Lynch
Irene Lynch
Peter Lyons
Helen Mackessy
Margaret MacMahon
Eileen Maher
William Mansfield
Ann Marron
Trevor Mccarthy
Liz McCarthy
Clare McCutcheon
Bernard McDonald
Therese McDonnell
Rita McDonnell
Eilish McDonnell
Denise McGrath
Michael McKenna
Micheál McKeown
Darina Merlehan
Jim Milton
Margaret Mlambo
Johnboy Molloy
Brendan Moran
Sean Morgan
Margaret Moriarty
John Morris
Pauline Morrisroe
Breda Murphy
Catherine Murphy
Deirdre Murphy
Linda Murphy
Nini Murray
Kathleen Murray
Anne Murray
Karen Nangle
Rachel Neville
Brid Ni Laochdha
Maire Nic Grainne
Triona NicGiolla Choille
Bridget Noone
Brenda Nugent
Brigid O'Brien
Barry O'Brien
Linda O'Connell

Volunteers active during 2016 (continued)

Carmel O'Connor
Thomas O'Connor
Grainne O'Flaherty
Sarah O'Keeffe
Maureen O'Riordan
Ann O'Riordan
Siobhain O'Sullivan
Jacinta O'Sullivan
Jennifer Peare
Evelyne Phelan
Catherine Plunkett
Jenny Powell
Elizabeth Quinn
Willie Rattigan
Meta Reid
Seamus Reidy
Magdalena Rej
Patricia Riordan
Ed Ronayne
Mary Russell
Anna Ryba
Bibiana Savin
Martin Scully
Brian Sheridan
Claire Stewart
Martin Sweeney
Mags Tuite
Patricia Tully
Patricia Tyler
Leo Van Dam
Suzanne Van Rooyen
Denise Walsh
Mary Watson
Ealish Whillock
Margaret Williams
Gerard Woods

Legal & Financial Group

Patricia Rickard-Clarke
Denis Cremins
Eddie O'Regan
Marian Ahern
Maeve O'Rourke
Paula Scully.
Doreen Shivnen

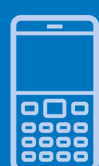
The Work of Sage

1. Overview of Activities 16
2. Outcomes 20
3. Case Management 24
4. Legal and Financial 30
5. Recruitment and Training of Volunteers 33
6. Citizens Advocacy Project: South-East 37
7. Stakeholders & Partners 42
8. Report on the Atlantic Philanthropies Investment in Dementia in Ireland 48
9. Forum on Long-term Care 98

The Work of Sage – Overview of Activities

Calls from the office
3,886
amounting to 1270hrs 6mins & 45 seconds

Mobile calls made
64,615
amounting to 1,818 hours, 11 minutes & 53 seconds



Information & Advice/ Rapid Response Service Calls
292

Emails sent
47,990

Website visits
46,217

Logged calls and case related events
4,057

Case updating events
2,812

Kms travelled
172,566

Advocacy cases
798

MOU's signed
138

Volunteers
151*

Staff
20 (7 Part-time)

Copies of 'New Times' distributed
5,800

Number of engagements
911

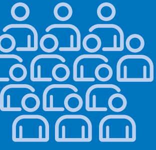
Nursing Home and Hospital meetings facilitated
258

Regular visits to Hospitals and Nursing Homes
554

Workshops on legislation and capacity issues
41

20,000
Estimated number of people who benefitted from the work of Sage in 2016

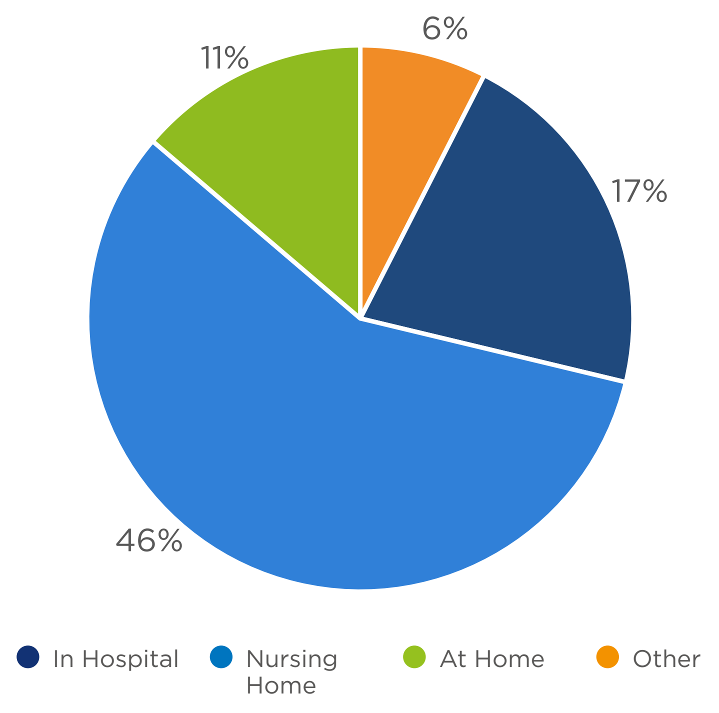
Participation in workshops
2,850



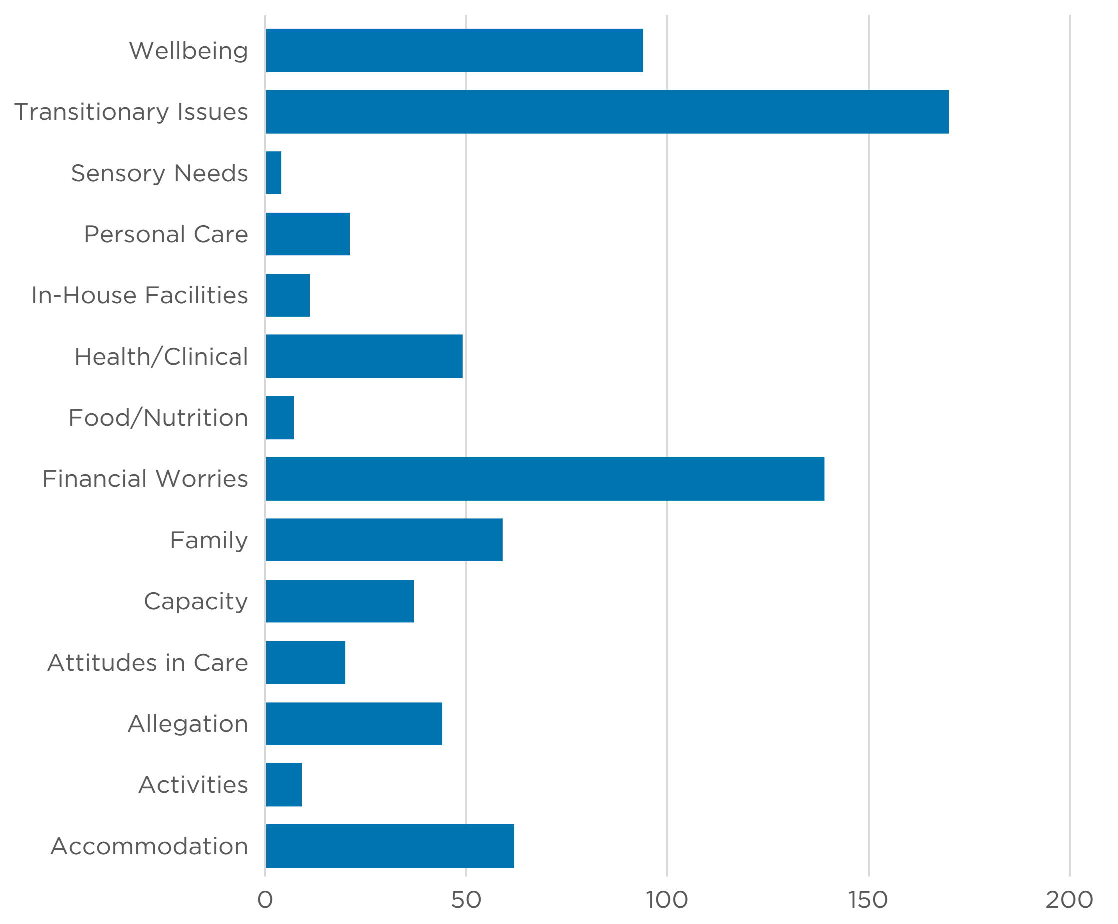
* *The contribution of volunteers is not included in the data provided*

The Work of Sage – Overview of Activities

Where Clients are based, 2016

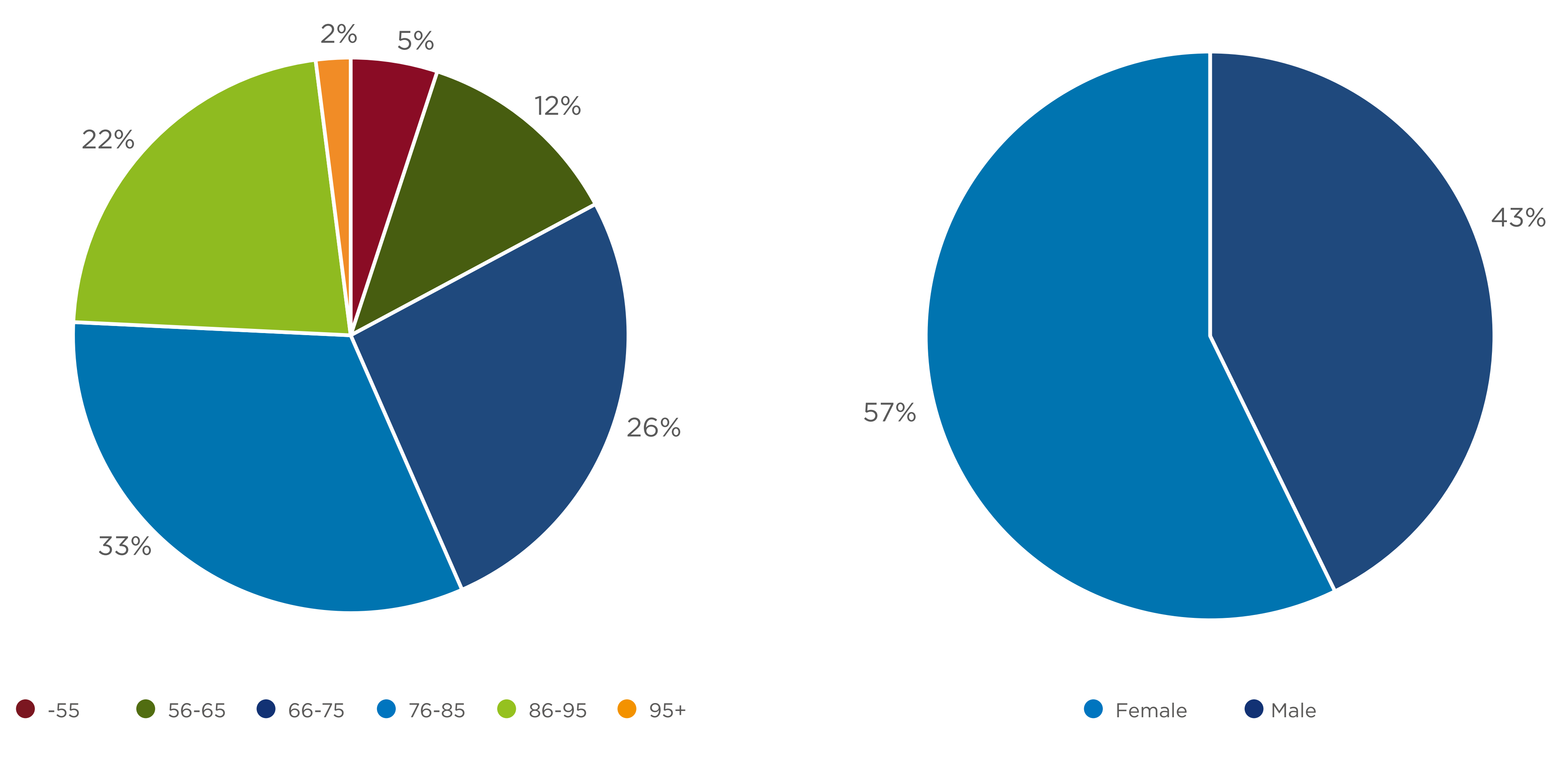


Cases by Issue, 2016

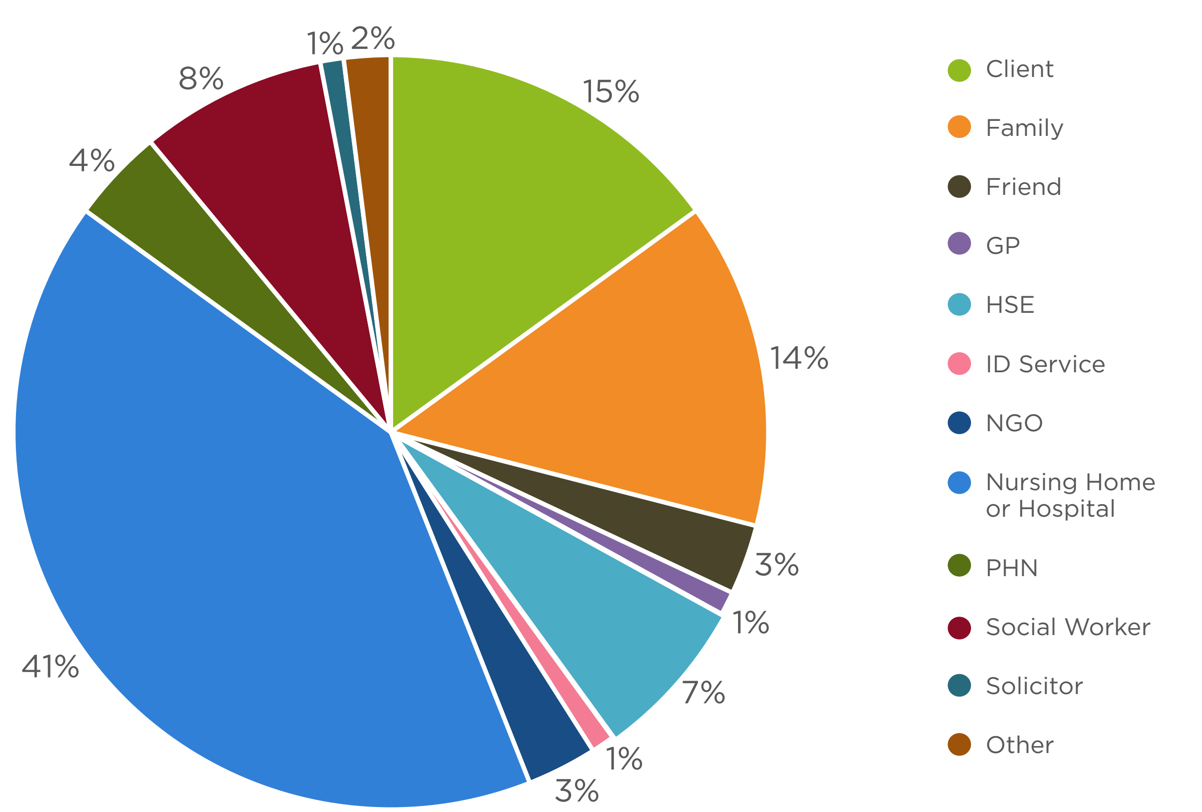


Age Range of Clients

Gender of Clients



Source of Referrals



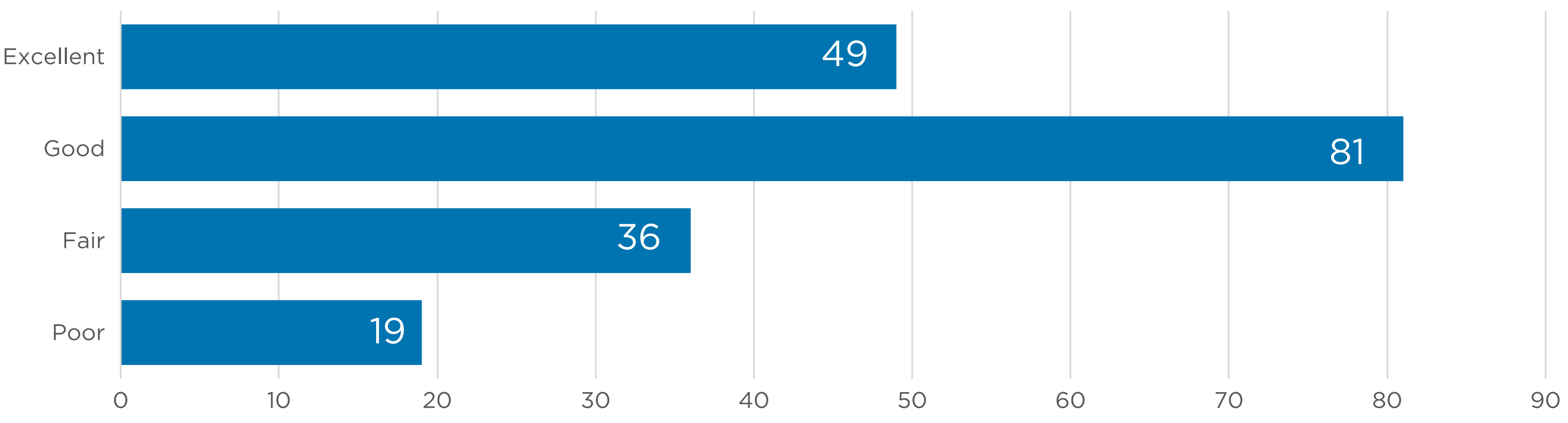
2. Outcomes

During 2016 Sage developed a basic ‘Three Perspectives’ approach to assessing outcomes of its case work. This is based on establishing the view of the client (where possible and a close relative/ friend where necessary), of service providers, and of the Sage Representatives involved. The development of a system for assessing outcomes in advocacy is particularly challenging. Nevertheless, Sage remains committed to developing the best possible approach.

On behalf of Sage researchers Brian Harvey and Kathy Walsh prepared a short paper on advocacy models and services for older people, including other vulnerable adults, specifically considering:

- The activity and services levels necessary to meet such needs;
- The types of advocacy service required;
- Resourcing required;
- The parameters of such a service;
- What should reasonably be expected in the form of outcomes; and how they should be measured (e.g. indicators). This research is cross-referenced to a companion *Outcomes of advocacy for older people and other vulnerable adults* and divided into sections on Ireland, Scotland, England, Wales and Northern Ireland, followed by analysis.

Outcome for the Client



Example of the ratings

Poor

Client moved back into the acute hospital system.

Client wishes to move home but this options is not available as it's a shared flat owned by her family member who does not consent.

Fair

Client now knows he has access to an independent advocate, however, also now knows that his family are very much against this access because of their lack of understanding of our service.

Client got a second opinion from our legal adviser. Few calls were made on her behalf, although without reaching client's expected outcome.

Good

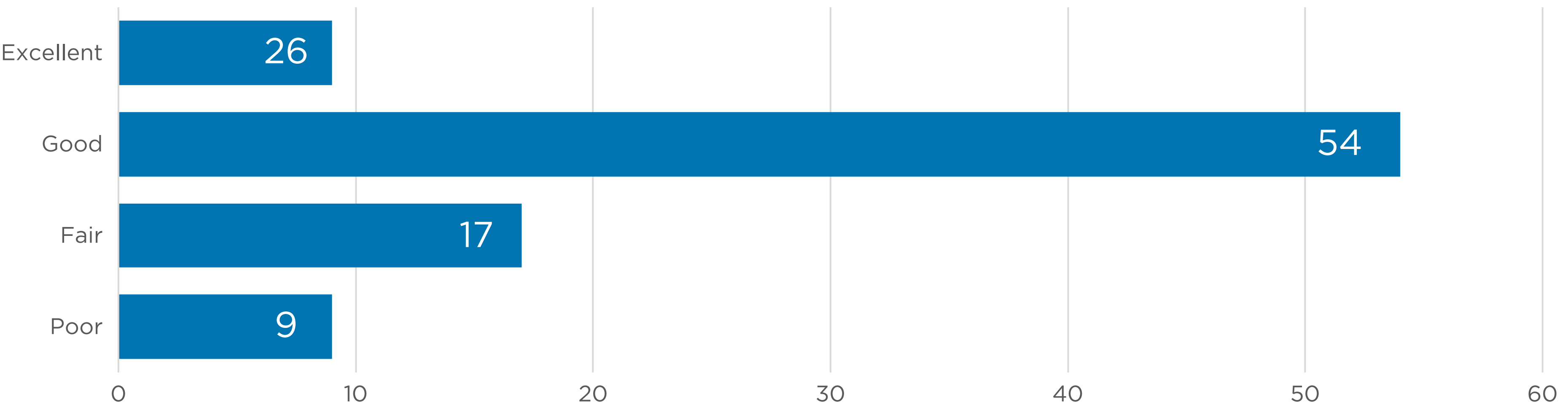
Client wanted to feel she had independent support to engage with complaints process with the hospital re: the incident with her family, she received this support and her capacity was maximised to be able to do this on her own.

Excellent

Client is very thankful to Sage for helping her to go home with a home care package.

Client got a meeting with HSE and nursing home/ owner which led to bills being significantly reduced. Happy to have had chance for face to face meeting and also that large bill is no longer due.

Outcome for the Hospital



Example of the ratings

Poor

The hospital wanted to move to nursing home care due to his medical condition. His decision to return home was reluctantly accepted. He is now at home.

Fair

'Fair' in that client had access to independent advocate working to represent her voice in a complex (hospital) situation, however, as stated above, case was cut short.

Good

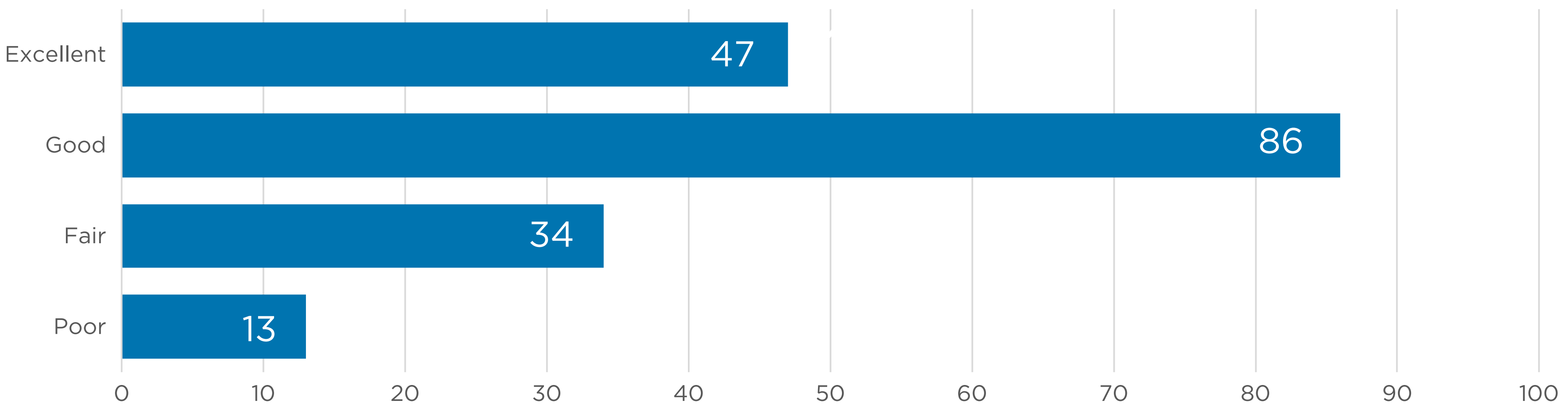
'Good' – nursing home reinforced knowledge that residents have right to our service and that we can be a support into the future. 'Good', especially because they often need to act as mediator between family members and perhaps could use some support.

Excellent

The nursing home was an impressive supporter in everyway.

Very positive transition for clients, supported by service and positive re Sage involvement and support.

Outcome for Sage



Example of the ratings

Poor

Could not get case off ground due to family interference – client made choice that he does not want to continue, but it was clear this was based on not wanting to upset family.

The case could not continue due to the client's mental health and cognitive impairment issues getting in the way of me being able to advocate for/with her, despite several attempts to re-engage. The client is still a 'delayed discharge' in hospital because of disagreements over capacity between geriatrician, psychiatry of old age and primary care.

Fair

We tried our best to engage someone with ongoing mental health/alcohol dependency issues and did indeed successfully support her transition home from hospital, but unfortunately her motivation waned and she never really got back to us.

Good

Client is happy with Sage service, closure of case could have gone better if person made one more contact with development worker.

Excellent

To all concerned Sage intervention was timely, appropriate and in accordance with Sage's mission.

This support allowed confidence for all in accessing info re finances for both of them and ensures nursing home payment for care.

The woman's will and preference was upheld – the nursing home helped support their resident and Sage assisted in keeping the woman as decision-maker for where she wants to live.

3. Case Management

In April 2016, the Case Management Group (CMG) was reformed in order to promote a more structured approach to Sage case management and to facilitate a robust analysis of complex cases, as well as to identify trends in systemic issues occurring around the country. Membership of the CMG includes Anne Harris (Special Projects), Eileen O'Callaghan (Development Coordinator), Mary Condell (Legal Advisor), Mervyn Taylor (Sage Manager) and Renee Summers (Case Coordinator) – this group meets every second Monday and has recurring standing agenda items: Ward of Court cases; Safeguarding cases; complex cases flagged by Development Workers.

The CMG and Sage's Data Administrator, Helen Fitzgerald, developed a mechanism to flag and catalogue these types of cases in Sage's database so that the Legal Advisor can see active wardship cases and Sage's Designated Officer for Safeguarding Vulnerable Adults can see active safeguarding cases at a glance.

In its first few months, the CMG reintroduced the Sage referral form to formalise its use across the team and to ensure its use for each case going forward, ideally to be completed by the client themselves, where possible. The four Authority to Act forms were reviewed with the team. The four versions correspond to clients with capacity, clients without capacity, clients who have registered Enduring Powers of Attorney and clients who have capacity but cannot physically sign the form. An initial assessment form was also introduced to help strengthen assessment of clients, prioritisation of casework and to enable consistency in practice across the team. In June and November of 2016, an advisor from Sage's Legal and Financial group, undertook a review of cases focusing on financial issues.

The Case Management Group and the Practice and Guidance Work Group

A feedback loop between the CMG, the wider team and the Practice and Guidance Work Group was established in order to highlight systemic practice issues arrising and to seek guidance and oversight. Some of these issues have included:

- When Sage is asked to step in as 'debt collector', particularly for residents in private nursing homes.
- Boundaries regarding confidentiality and recording resulting in amended Authority to Act Forms.
- Should an advocate sign a nursing home resident's contract of care?
- Should an advocate apply to become a client's Care Representative under the Nursing Home Support Scheme when no one else is available?
- Should an advocate trigger a wardship application (only when all other options have been exhausted) and no other party is willing to initiate the process?
- How to proceed when a client's wishes are to return home from a residential centre when no formal assessment of capacity has been carried out and in the absence of Deprivation of Liberty legislation?

The Practice and Guidance group also provided oversight on the drafting of Sage's Initial Assessment form, the Protocol and accompanying internal application for Sage's (Client) Agency Account and amendments made to Sage's four Authority to Act forms; all of these documents were created and/or amended to address the extremely complex nature of Sage casework, to facilitate the rigorous assessment process needed to carry out sometimes serious interventions and to help Development Workers support Sage clients as fully as possible.

Sage (Client) Agency Account

In July of 2016, a Sage (Client) Agency Account was created to provide an alternative for clients in need of an independent agent to assist them with their finances, and to facilitate their wishes without having to rely on more restrictive measures. The CMG vets each application for the account, making sure that the client and their Sage Representative have exhausted all other options before applying. The Protocol for management of this account is detailed over ten steps and pays particular attention to the assessment of the client's functional capacity regarding finances and a robust auditing system, with the appropriate safeguards put in place to protect the client and their funds. This account is to be considered only as a temporary measure to help Sage clients usually during a transition phase.

CMG Case Reviews: July and December 2016

The CMG held its first review of all active cases on July 26th, 2016 when 340 open cases were reviewed. The purpose of the review, as outlined in Sage's Case Management Policy, is to establish each case's current status and ongoing requirements. A traffic light system to organise each case into one of three categories: Red, Amber or Green. Findings from the first review revealed there was a significant amount of work being done around the country, but highlighted the need to be more rigorous during the referral vetting process, as well as the need to continue our efforts to produce quality data in the database.

A second review of all active cases was conducted on December 8th, 2016, reviewing a total of 388 cases nationwide. For this second review, it was decided to use an objective case rating system, still using the traffic light system, in order to produce a more straightforward breakdown of the complexity of cases Sage is working on. Using this system, Red cases represented very complex legal, financial or otherwise serious issues (e.g. wardship, safeguarding), Amber cases had some complex elements, requiring a lot of the Development Worker's time and Green was designated for cases focused on the 'support' end of advocacy, for example befriending work or assistance with form-filling. The chart below shows this case rating breakdown. Generally positive findings revealed that Development Workers were working on a greater number of red cases than green compared to the July review, that there was greater clarification of client consent when a referral was not a self-referral and that cases were being opened and successfully closed in a shorter amount of time. Areas for improvement included addressing the diversity in skill on the use of the Sage database across Development Workers, the need to identify when a Primary Care or Medical Social Worker is available to work with a client and the need to question sometimes overzealous reporting from nursing home staff e.g. when their referral for an advocate is a tick-box exercise and not because of a genuine need for one.

One of the many benefits of these reviews is that it has helped the CMG clearly articulate to Development Workers what specific skills and knowledge are needed in order to advocate as effectively as possible for Sage clients, so that they can better respond to the systemic and individual issues arising in their respective regions. Other benefits include the 'data cleanse' of the database that results from Development Workers preparing their case data to be reviewed as well as helping to set the agenda for discussing systemic practice issues that need more oversight from the Practice and Guidance group.

Other work undertaken by the CMG in 2016

- Ongoing discussion with the core team on Sage's Case Management Policy, including interpretation of its implementation, guidelines for escalating safeguarding cases and other internal processes.
- Organisation of external supervision to Development Workers and one-to-one meetings with the Case Coordinator

The Work of Sage – Case Management

- Development of a 'case wiki', which will provide anonymised case examples brought to the CMG for learning purposes. This will be available to all Sage Representatives in 2017 through Microsoft 365 app 'Yammer'.
- Ongoing review of data trends in order to analyse and prioritise work across the country and in specific regions.
- Consistent reminders to the team on the importance of quality case data through presenting on this topic at the team meeting and numerous training sessions led by data administrator Helen Fitzgerald.

The CMG held 18 meetings between April and December 2016, reviewing a total of 112 individual cases requiring in-depth followup on each case. These cases encompassed systemic issues ranging from but not limited to:

- The complexity of the Nursing Home Support Scheme
- Gaps in HSE services
- Impact of inadequate numbers of geriatricians and medical social work departments in acute hospitals
- Deprivation of liberty
- Institutionalisation and the nursing home resident
- Misunderstanding of 'next of kin' rights
- Impact of private nursing home fees
- Numerous challenges to the functional approach to capacity assessment.
- Identifying places of concern, communicating with HIQA
- Collaboration with and challenges to disability, mental health and residential service providers
- Understanding of:
    - *safeguarding process, consent*
    - *wardship*
    - *boundaries in casework*
    - *end-of-life practices*
    - *human rights breaches*
    - *HIQA standards and implementation of same*
    - *empowerment vs. rescue of client*
    - *numerous legal and financial issues (e.g. Enduring Power of Attorney/Advance Healthcare Directives /DNAR forms/ Wills/various banking and property issues)*
    - *working with clients with dementia/reduced capacity*

Policies and Operational Guidelines

In 2016 a review of Sage's Policies and Operational Guidelines was undertaken by the Practice and Guidance Work Group with the assistance of Dr. Michael Browne. The review was in the context of the development of Quality Standards for Support and Advocacy Work with Older People launched in 2015 and in the context of the passing into law of the Assisted Decision-Making (Capacity) Act 2015. In June 2016 Version 2 of Sage Policies and Operational Guidelines were approved; changes to existing policies were made to incorporate a rights safeguarding approach and to implement a witness/observer approach. Along with changes to the existing Policies and Operational Guidelines the following policies were added: Policy on Access to and Eligibility for Sage Services; Case Management Policy; Assessment of Need and Risk Management Policy; Working Alone Policy; Support and Supervision Policy. The Policies and Operational Guidelines are continuously under review to respond to the developing service.

Transitionary Issues: Qualitative Analysis of Concerns with Care

Extracts

"Mother had pressure sores and four broken ribs, thus the family had raised a number of concerns"

"Was annoyed that geriatrician entered her room in the previous weeks and completed a capacity assessment without seeking consent to do so and seemed to be aware of confidential issues re her will."

"OT raised concerns as currently staff are stopping gentleman from leaving ward or hospital, mentioned 'absconding' and bringing him back to ward despite having capacity."

"Husband passed away in May 2016. Since then the NH have moved the Client into her husband's bed which is quite distressing for her. Client is very unhappy and wants to leave."

"She felt bullied into moving her parent."

"That he did not want to die and that he did not wish to be peg fed, that his repeated tearing out of the tube afor feeding was a clear form of communication that he did not wish to be fed in this way and he expressed this very clearly and verbally on every occasion that our advocate met him."

4. Legal and Financial

An information publication 'New Times' was produced in 2016, with over 5,000 hardcopies distributed and an online version available through the Sage website. 'New Times' is a guide to the Assisted Decision Making (Capacity) Act 2015 and introduces the Sage A.L.E.R.T. system as a process of supporting decision-making.

sage
Support & Advocacy Service
for Older People

NEW TIMES

Edition 2. 1st June 2016

NOTHING ABOUT YOU / WITHOUT YOU

A guide to the Assisted Decision Making (Capacity) Act 2015

New legislation signed by President Higgins on 30th December 2015

Repeal of Lunacy Regulation (Ireland) Act 1871

The Assisted Decision Making (Capacity) Act 2015 will strengthen the rights of all individuals but it will have particular relevance for people with intellectual disabilities, older people with diminished capacity or dementia and people whose capacity has been affected by traumatic injury. It will also ensure that people with capacity can register in advance their wish not to receive treatment which they perceive as futile in the event that they lose capacity to make decisions. Central to the legislation is the establishment of a Decision Support Service and the introduction of new roles: Decision-Making Assistant; Co-Decision-Maker; Decision-Making Representative. The legislation will be 'commenced' by the end of 2016 and this has been confirmed by the Minister for Justice in response to parliamentary questions. The system of Wards of Court will be phased out over a three year period.

Presumption of Capacity

Throughout our lives we seek advice from others about various matters before we make a decision for ourselves. But sometimes, perhaps due to illness, injury or a disability we may need a little more than just advice; we may also need support. There is international law, and now Irish law, which provides for the support we should be given. The Assisted Decision Making (Capacity) Act respects the right of everyone to make choices for themselves and at all times to be treated with dignity and respect. The old 'status' approach to an individual's capacity to make decisions is replaced by a new 'functional' approach which has at its' heart a simple question: "In relation to this specific issue, at this time, does this person have capacity"? It follows that question with another: "what level and type of support might be needed in order to assist this person make a decision"? The focus is now on the positive, on enhancing whatever level of capacity exists, even where it is considerably diminished, and there is a statutory presumption of capacity unless there is clear evidence to the contrary.

PRESUME CAPACITY

A Legal and Financial Coordinator was appointed by Sage in November 2016. The role was established to coordinate the development of the Sage Legal and Financial Group and to develop the capacity of Sage, to respond to the commencement of the Assisted Decision Making (Capacity) Act 2015 and to directly make interventions of a legal nature either on its own behalf or on behalf of clients. The initial work of the Legal and Financial Coordinator was in developing a work plan, establishing a work group, updating and engaging with existing Sage Legal Financial Group members and in cooperation with the Legal Advisor planning for Sage briefings on the ADM (Capacity) Act 2015 for 2016 and 2017.

Assisted Decision-Making (Capacity) Act 2015

The ADM (Capacity) Act 2015 was signed into law in December 2015. In October 2016 two Commencement Orders were issued for the appointment to the post of Director of the Decision Support Service, and for the establishment of a Working Group.

Sage is engaged on the Education and Training subgroup of the HSE Assisted Decision-Making Steering Group. The HSE Steering Group is currently developing Guidelines for Health and Social Care relating to the implementation of the ADM (Capacity) Act 2015.

Sage will also be engaging with the National Disability Authority as a member of the Code of Practice Technical Group which will be developing Codes of Practice for non-healthcare professionals. These Codes of Practice will include guidance regarding the role of an independent advocate.

Briefings on the Assisted Decision Making (Capacity) Act 2015

In 2016 Sage undertook a programme of delivering briefings on the Assisted Decision-Making (Capacity) Act 2015 throughout the country. 41 events were held with 2,285 people attending from a variety of disciplines. In most cases a two hour briefing seminar was held, and for some audiences the presentation was adapted to meet the needs and purpose of the audience. The feedback from these briefing sessions was very positive, with those attending eager to find out more about the legislation, seeking more information on the implications and practical aspects of the legislation.

Master Class Law Society, 22nd February 2016

The Assisted Decision-Making (Capacity) Act 2015 was signed by the President on 30 December 2015. To mark the occasion Sage and the Mental Health & Capacity Task Force of the Law Society jointly hosted an event led by The Hon. Mr. Justice Jonathan Baker, High Court (Family Division) England and Wales and Court of Protection and chaired by The Hon. Mr. Justice Peter Kelly, President of the High Court.

Human Rights of Older People Working Group

Sage is a member of the Human Rights of Older People Working Group and has contributed to meetings of the group throughout 2016. AAs part of the work of the group in 2016 it has been exploring the potential for Community Care legislation.

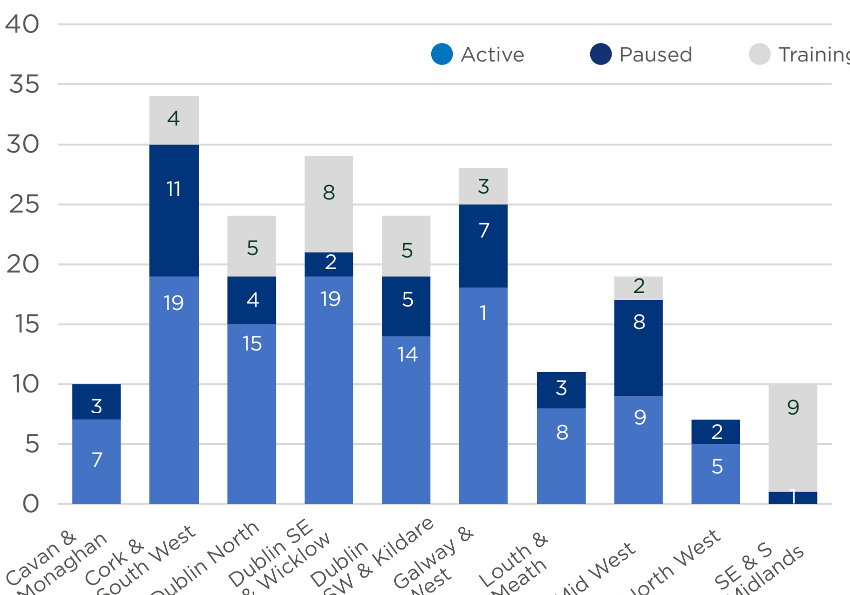
Quality Standards

During 2016 a number of organisations including Cork Advocacy Service and Alone, showed considerable interest in the Quality Standards for Support & Advocacy Work with Older People. For organisations serious about standards in advocacy they have become an important resource and reference point.

5. Recruitment and Training of Volunteers

'The Sage Model' is of core paid staff supported and, in turn, supporting trained volunteers. Our key task is to develop a team of people capable of tackling the most complex support and advocacy challenges presented by our clients. All who work on a voluntary basis with Sage are known as Sage Representatives. During 2016 key volunteer roles included: Facilitator (of nursing home residents groups); Advocate; Legal/Financial Specialist.

In 2016 Sage continued delivering its Advocate Training Programme which was developed and delivered with our partners Irish Times Training. The training programme includes QQI Level 6 minor aware in Information, Advice and Advocacy Practice. In 2016 the Training Programme was delivered over 14 week periods, and consisted of 7 classroom days, online ELearning and completion of assessments for accreditation.



Based on feedback from participants on the Training Programmes gathered through training evaluations and at six month post training period, and in response to the emerging needs within Sage, the Advocate Training Programme was further developed and updated in 2016. This involved enhancing more direct involvement of Sage in the delivery of the training programme and inclusion of Sage related material, role plays and case studies within the programme content, input by an existing Sage Representative on their experiences in the role, Sage delivery of the Safeguarding Vulnerable Adults input by the Sage Designated Officer and Sage delivery on data protection and data management.

Sage Representatives receive their Certificates in Galway

Sage engaged in targeted recruitment for volunteers in the West, South, South East, East and North East utilising local, regional and national print media, local radio, parish and diocesan newsletters, volunteer websites, social media, and electronic distribution methods. Seventeen people completed the Advocate Training in January 2016 on a training programme that had commenced in Dublin in November 2015. Throughout 2016 four more training programmes were commenced in 2016 in Galway, Cork, Wexford and Dublin. Forty one people completed this training in 2016, which also included volunteers who were engaged with Sage in the role of a Sage Facilitator and took up both roles.

Facilitator Training was delivered in Dublin in April 2016, 10 new volunteers completed this training with an additional 5 existing volunteers who also completed this to take up both the role of Facilitator and Advocate. In response to increased demand for facilitation, and to enhance the skills and opportunities for Sage volunteers an adapted Facilitator training programme was delivered in Cork and Galway to existing Sage volunteers who had been in the Advocate role.

Continuous Professional Development (CPD)

In January 2016 Sage CPD on Dementia Awareness and Functional Approach to Capacity was delivered over four sessions in Dublin, Cork and Galway. This CPD training programme was developed with the Dementia Elevator project, and incorporated an input from Mary Condell, Sage Legal Advisor, on the Functional Approach to Capacity based on the Assisted Decision-Making (Capacity) Act 2015. As a product of the CPD training a 3 hour Dementia Awareness training programme was developed, and Sage staff were involved in the delivery of the training programme which is part of Sage training resources. 78 Sage Representatives attended the four events and feedback from the evaluations and that given in individual support and supervision was positive.

In April 2016 Sage linked with the Irish Hospice Foundation who delivered the Sage CPD on End of life issues, Bereavement and Self-care which was based on the Irish Hospice Foundation 'What Matters to Me' workshop. Four sessions were delivered in Dublin, Cork and Galway. 54 Sage Representatives and 9 staff attended the four sessions, and it was evaluated positively by those who participated.

Throughout 2016 Sage Representatives were encouraged to complete online training to be included in their CPD record. Dementia Elevator online training, the MOOC University of Tasmania Dementia Awareness online training, Dementia Care: Staying Connected and Living Well with Newcastle University through FutureLearn and The Many Faces of Dementia with University College London through FutureLearn were promoted.

In 2015 Sage Representatives were supported to attend non-Sage events such as the Forum on End of Life, Sonas apc National Dementia Conference and the Dementia Elevator Showcase and Roadshow.

Sage Representatives Survey

The work of the Sage volunteers is central to the success of Sage. Gathering the views and experiences of the Sage volunteers was therefore seen as a key feedback mechanism in relation to understanding of the views and experiences of volunteers. The survey was open for responses for a period of two months (25th April - 24th June 2016). Key issues emerging from the survey included:

Overall, survey respondents were generally positive both in terms of how they rate their work and how they rate their engagement with Sage as an organisation.

- 77% of respondents rated their work with clients as valuable;
- 71% reported positive engagement with Sage.
- 83% reported positive responses from staff in the care settings where they work.
- A majority also reported seeing outcomes from their volunteer work, with across the board responses that clients came away informed of their basic rights and access to advocacy, and much of the time with small, practical issues resolved – with larger issues solved for a notable portion as well (over 20%).

Where volunteers did not respond positively/responded less positively, many of their answers reflected concerns around the nature of the advocacy work they were doing (too much befriending, too little case

work was the most common complaint, but a small number of volunteers also appeared to be overwhelmed by the work and its complexity) and the levels of support they required from Sage.

Survey respondents identified a number of areas for potential review:

- There was an almost even split among respondents (52% no changes needed/48% changes needed) in terms of whether changes should be made to the current work of volunteers.
    - *Those who are interested in changes largely identified the need for more support from Sage and more training to deal with challenging cases, or patients with various health and ability issues.*
        - *Secondary suggestions for changes centred around interest in more casework (rather than visiting) activities, an expansion of volunteers' work in to more care settings, and a more defined role as an advocate in the settings where they currently work.*

6. Citizens Advocacy Project – South East

Overview:

In March 2016, funding of €150,000 was made available by the Office of the Head of Operations & Service Improvement, Disability Services, Health Service Executive, for the development by Sage of a Citizen Advocacy Project in the South-East (CHO 5), for people with intellectual disabilities. A key objective was a scoping and planning exercise to guide the development of this pilot Citizen Advocacy Project, with the intention of wider national development. A twelve month period was allocated for the development of the Citizen Advocacy Project.

Scoping and Planning Exercise:

On the 27th June 2016 the project Development Worker, Emer Meighan took up post. Sage commissioned Dr. Amanda Phelan from the National Centre for the Protection of Older People (NCPOP) in University College Dublin to assist in the research, analysis and reporting of findings. The research sought to gain understanding and depth into the perspectives of people with intellectual disability on their life world and to generate other stakeholders' perspectives regarding caring for and supporting this population in order to ensure the appropriate development of a Citizen Advocacy Project in the South East occurred.

- Five facilitated focus groups were held for people with intellectual disability in each of the five counties in CHO5, 75 people with intellectual disability were consulted.
- Four facilitated focus groups for professionals and service providers within CHO5 were held, with 23 people in attendance.
- A qualitative survey with the intellectual disability section of the Irish Association of Social Workers was carried out.
- Semi-structured interviews with family members, a representative from the Health Information Quality Authority and a representative of the intellectual disability section of the Irish Nurses and Midwives Organisation were consulted.

Five themes emerged within the data;

1. Personhood
2. Service challenges
3. Family experiences
4. Society's approach to people with intellectual disability
5. The need for the voice of a person with intellectual disability be heard

Participants at one of nine regional focus groups.

Five briefings regarding The Assisted Decision Making (Capacity) Act 2015 – "What does it mean to me?" were organised for people with intellectual disabilities, their families and service providers and there was engagement with the Office of the Ombudsman, at their request, in relation to issues raised by families challenging the process of transition of family members with intellectual disabilities from congregated to community settings on the basis the family member with disabilities lack capacity to make the decision as to where they should live.

The work of developing the project is now underway but some initial observations give some sense of the challenges.

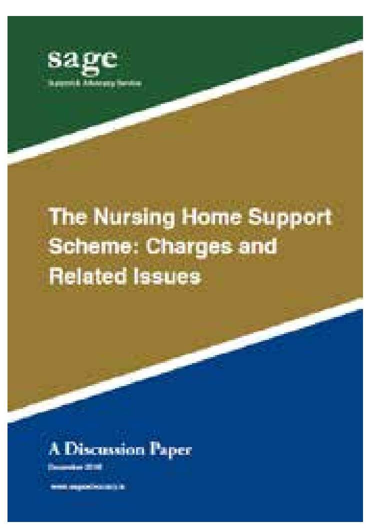
1. Service provision for people with intellectual disabilities in the South-East seem fragmented with many organisations addressing similar challenges independently with varying levels of insight and capability.

2. Statutory provision and oversight seems under developed, under resourced and overburdened. While the skills and experience necessary for change seem to be available in the region a high demand for provision and support have left many, including service providers, feeling neglected and forgotten by the HSE.

3. A psychiatric service for people with intellectual disability is not available within CHO5. General psychiatrists consult infrequently with people with intellectual disability and the waiting period, along with the lack of specific training in psychiatry and intellectual disability is having an effect on the mental health, behaviour and general wellbeing of people with intellectual disability.
4. Changes in practice within some GP services within CHO5 have resulted in increased cost demands for people with disabilities. A lack of clarity regarding the rights of people with disabilities to GP care and the provision of service needs to be addressed.
5. A general lack of housing, including housing that may be suitable for adaptation for people with intellectual disability and physical and sensory support needs must be addressed throughout CHO5. There is an urgent need for a round table discussion with all stakeholders including housing providers, HSE management and disability services to address the deadlock of housing provision in CHO5.
6. The focus must change from what service providers believe they can supply for people with intellectual disabilities to what the people with intellectual disabilities themselves really want. The implementation of the New Directions Policy to truly mainstream a community based person centred approach must occur.
7. There is evidence of good self-advocacy initiatives which deserve to be supported on a regional basis. Service providers are supporting individuals and groups, both within organisations and independently of services access to and education around advocacy. However, a lack of clarity regarding on going funding for and access to independent advocacy initiatives and self-advocacy initiatives is leaving some doubt around the sustainability of these services.
8. There is a need to build a framework within which advocacy can be developed in the region and this framework must include advocacy champions within the statutory and non-government sectors, the Office of the Ombudsman and the Irish Human Rights and Equality Commission. An open dialogue must occur between all sectors, both regionally and nationally, to ensure equity and equality.
9. Independent advocacy needs to be integrated into all services and assessment is required to establish which advocacy method aligns with the needs of the individual with intellectual disability. Advocacy services need to follow quality standards for their service delivery and need to have integrated evaluation and impact measures.

10. On-going peer learning and exploration of wider service provision must be explored by all service providers. A lack of awareness regarding the provision of services and the differing approaches to supporting people with intellectual disabilities is limiting some staff in their ability to know and meet the needs of the people with disabilities they are working with.
11. Education and training is needed to ensure a common understanding of the implications of new legislation such as the Assisted Decision Making (Capacity) Act 2015 and the emerging Disability (Miscellaneous Provisions) Bill 2016 which may cover the issue of deprivation of liberty.
12. There is an urgent need for legislation on safeguarding which must address the right of adults who may be vulnerable to have access to independent advocacy.
13. A regional awareness programme is needed regarding the rights, and responsibilities, of people with disabilities which clearly addresses family and provider concerns within safeguarding.
14. Services, including advocacy services need to provide support for families and to address issues of a wider societal nature.

Nursing Home Charges – Discussion Document



Following many months of consultation and gathering evidence Sage in December published a discussion document on nursing home charges. The report stated that "There is an urgent need for more debate around nursing home fees and charges as these apply to people who avail of the Nursing Home Support Scheme (NHSS), the so called 'Fair Deal'. This issue needs to be looked at afresh in the context of both current provisions for long-term care and support generally and the way the NHSS charging system operates. It should be noted at the outset that the voice of users and potential users of the NHSS has to date been largely unheard and policy and related funding structures are planned without any input from users".

It also raised issues about the role of the National Treatment Purchase Fund (NTPF). "Additional charges in nursing homes not provided for in the NTPF negotiated price means nursing homes can levy charges on residents which are additional to what is covered by the NTPF negotiated fee. As the NTPF contract with nursing homes provides for just bed and board in nursing homes, there are extra mandatory charges in most private nursing homes for activities and other items. These are reported as being as high as €100 a week in some instances. This results in not only a significant additional drain on people's resources but also in some instances of people having to pay for activities in which they do not wish to participate or are unable to participate. Frequently, it is unclear what these additional charges cover".

7. Stakeholders & Partners

HSE

A Service Level Agreement (SLA) was signed between Sage and the HSE for 2016. Sage also participated in the work of the HSE's National Patients Forum. A National Conference was organised through the HSE Quality Improvement Division on February 22nd, 2016 to create an awareness of the Assisted Decision Making (Capacity) Act 2015 and of their implications, challenges and opportunities for health and social care professionals. The Conference was aimed at managers and staff who were involved in planning, managing or delivering services to patients, service users or clients across health and social care settings. This conference brought together key Irish and UK experts to inform staff and managers about the legislation and to explore the impact this Act will have on current practice. Key note speakers were Patricia Rickard-Clarke, Solicitor, Former Law Reform Commissioner and Chair of the National Advisory Committee of Sage and Sir Jonathan Baker, judge of the High Court and Court of Protection in the UK. Perspectives on the implications of the legislation for service users, service providers and families were provided by Mervyn Taylor, Manager of Sage, Paddy Connolly and Sarah Lennon of Inclusion Ireland and Dr David Robinson, Consultant Geriatrician with St James's Hospital.

National Safeguarding Committee

The National Safeguarding Committee (NSC) is a multi-agency and inter-sectoral body with an independent chair. It was established by the HSE in December 2015 in recognition of the fact that safeguarding vulnerable people from abuse is a matter that cannot be addressed by any one agency working in isolation, but rather by a number of agencies and individuals working collaboratively with a common goal. Sage is an active participant in the work of the NSC; both on the main committee and on the Strategy and Resources Sub-Committee.

The launch of the first Strategic Plan on 20th December 2016, by Ms Justice Mary Laffoy of the Supreme Court received extensive coverage from RTE.

Department of Health – National Patient Advocacy Service

The report by HIQA into events in Portlaoise Hospital, published in May 2015, included a recommendation that a National Patient Advocacy Service should be established by May 2016. In this context Sage sought to establish the intentions of the Department of Health. Sage provided the then emergent National Patient Safety Office with a wide range of materials related to advocacy and proposed a simple framework for the development of all advocacy services in Ireland which would involve all stakeholders and address issues such as standards, training and sustainable funding.

HIQA Medication Safety Monitoring Programme Advisory Group

HIQA's medication safety monitoring programme aims to examine and positively influence the adoption and implementation by hospitals of evidence-based practice in relation to medication safety. To achieve this aim, HIQA has designed an evidence-based monitoring programme which will involve announced inspections of public acute hospitals in Ireland. This will enable HIQA to examine and analyse systems in place to support safe practice in relation to medication safety in line with international best practice and research.

An expert advisory group has been formed to assist with the development of this medication safety monitoring programme.

This group has provided advice to HIQA in relation to the medication safety monitoring programme to date and this guidance will continue throughout the programme as it progresses. The advisory group membership includes Sage representation, alongside members with relevant expertise from across the Irish health service.

Irish Association of Social Workers

Formal contact between Sage and the IASW was established to discuss possible areas of collaboration and concerns which arise from the work of social workers and Sage Representatives in specific areas. An issue of particular concern to Sage during 2016 was the lack of medical social workers in a number of the smaller acute hospitals around the country.

Royal College of Physicians

Sage participated in two initiatives of the RCPI. The first was a Policy Group on Ageing, chaired by Prof Des O'Neill, which aims to ensure an input to national strategies- e.g. positive ageing strategy and dementia strategy. The Policy group made a submission to the Forum on Long-Term Care organised by Sage. The second initiative 'Towards 2026'

was a policy forum established tasked with developing a collective vision for what acute hospital care should look like in 2026.

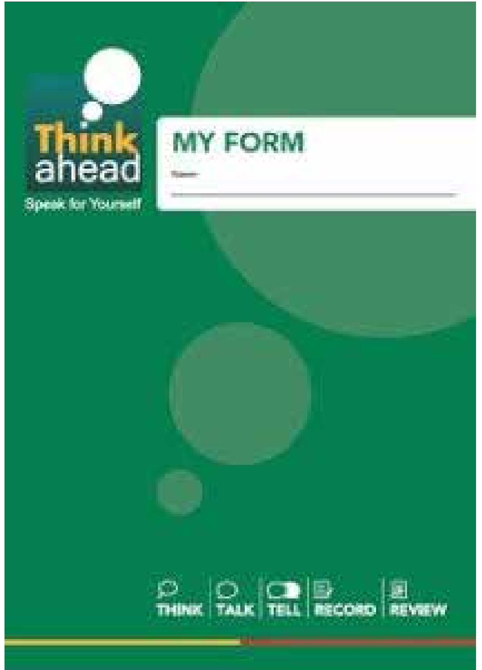
Alone

A memorandum of understanding was signed between sage and Alone committing both organisations to work together in the context of Sage's efforts to develop support and advocacy services for older people and Alone's efforts to build a strong national network of befriending services.

Brendan Moran
Sage Representative lead on Think Ahead Project

Irish Hospice Foundation – Think Ahead Online Project

Think Ahead is a public awareness initiative that arose out of the Forum on End of Life in 2011. To address the issue of what the Forum saw as a deficit in 'conversations' around death and dying the Irish Hospice Foundation (IHF) developed 'Think Ahead'. This is a document that allows and encourages individuals to record a wide range of important issues and preferences in the event of serious illness or death. To date over 40,000 copies of 'Think Ahead' are in circulation.



Acknowledging important research findings by Dr. Brendan O'Shea of Trinity College, a pilot on 'Think Ahead' online, funded and supported by Sage, was commenced in six nursing homes in Kildare at the end of 2015. Most of these nursing homes had self-selected and participated in the original pilot some years earlier when the original document was being developed. Dr. O'Shea, a GP, had shown in his findings how older people in his practice in Kildare felt 'Think Ahead' should be used more widely and that after reading the document they had had end of life discussions with family members.

Phase 2 in the development of 'Think Ahead' was to create the document in digital form. To this end the IHF joined with Patients Know Best (PKB), the world's first patient controlled online medical record system, to pilot an online version of 'Think Ahead' which would allow individuals to safely store and retrieve their end of life wishes and preferences.

The six nursing homes involved were private and based in mid and north Kildare; they were a mixture of small, medium and large. One nursing home opted out of the pilot review early on however, citing work-load as its reason. Over the course of the next six months or so each of the remaining five nursing homes were visited by IHF, PKB and Sage staff. The IHF gave the nursing homes an introduction to

the concept of 'Think Ahead', as well as how to start 'conversations' around death and dying. PKB staff gave relevant nursing home staff training and mentoring on how to use their site as a platform for the online version of 'Think Ahead', while Sage staff supported and ensured linkage between all the parties.

The outcome overall did not replicate the experience of the first pilot; for different reasons. Two additional nursing homes opted out of the pilot early on. The three that remained were, however, positive in their commitment to 'Think Ahead', and saw great value in the pilot and the concept of an online version of 'Think Ahead'. Staff in the remaining homes facilitated a number of residents complete the online form. Compared to the earlier pilot however, the numbers completing the online version were much less than those who completed the hard copy. The nursing homes cited different reasons for this. Technology was limited in some of the homes; a great number of residents suffered some form of cognitive impairment and did not understand what was at issue, while the main reason cited was the available time needed to allow staff in a very busy home facilitate residents complete the online form.

While overall the outcome of the second pilot did not match the original pilot in terms of forms completed everyone involved agreed it was a very positive exercise. Important lessons were learned from the experience which will feed into the final version of the online document.

One of the most important pieces of learning from the pilot is that a nursing home is not the ideal place to introduce 'Think Ahead', either in digital of hard-copy form for the first time. There are a number of challenges that can work against it in that environment. 'Think Ahead' is an important end of life planning tool, and ideally should follow the individual into the nursing home from the community. Creating an online version and giving greater accessibility to the public at an earlier stage makes this a possibility.

Nursing Homes Who Had Signed MoUs With Sage During 2016

Arbour Care Group

Talbot Group

TLC Nursing Home Group

Highfield Healthcare

Desmond Centre

Millbrook Manor Nursing Home

Clifden District Hospital

Hillview Manor Kingscourt

Bray Manor Nursing Home

Dunboyne Nursing Home

Nazareth House

St. Conlan's Community Unit

Maryfield Nursing Home Dublin

St. Kieran's Nursing Home

Tinny Park Nursing Home

Castlecomer District Hospital

ALONE

Redwood Extended Care Facility

St Raphaels Centre

St. Mary's Home Pembroke Park

AnovoCare

Esker Ri Nursing Home

Abigail House

Maynooth Lodge Nursing Home

Ardmore Lodge

St Clare's Disability Services

Ennis Nursing Home (Pairc na Coille)

Esker Lodge Nursing Home

St. John's Community Hospital Wexford

The Marlay

The Moyne Nursing Home

The Park Nursing Home

TLC Nursing Home Santry

TLC Maynooth

Tralee Community Unit

Willowbrook Nursing Home

Beech Park Nursing Home

Beechfield Manor Nursing Home

Farranlea House Community Nursing Unit

Fermoy Community Hospital

Oaklodge Nursing Home

Ocean View Retirement and Nursing Home

Bantry General Hospital

Bethany House Nursing Home

Birr Community Health and Nursing Unit

Bishopscourt Residential Care Ltd

Blackrock Abbey Nursing Home

Brymore House

Glenaulin Nursing Home

Glengara Park Nursing Home

Our Lady of Fatima Nursing Home

Our Lady of Lourdes Care Facility

Padre Pio Nursing Home (Clondalkin)

Parke House Nursing Home

Pilgrims Rest Nursing Home

Powdermill Nursing Home

Bushmount Nursing Home

Cahercalla Community Hospital Ltd

Cara Care Centre

Carlingford Nursing Home

Raheny Community Nursing Unit

Castle Gardens Nursing Home

Castleross Nursing Home

Greenpark Nursing Home

Greystones Nursing Home

Griffeen Valley Nursing Home

Haven Bay Care Centre

Merlin Park University Hospital

Central Park Nursing Home

Heather House Community Nursing Unit

Heatherfield Nursing Home

Howth Hill Lodge

Kanturk Community Hospital

Raheny House Nursing Home

Riada House Tullamore

Our Lady's Hospital, Navan

Clonskeagh Hospital

Cloverlodge Nursing Home Athy

Nursing Homes Who Had Signed MoUs With Sage During 2016

Killarney Community Hospital

Roseville House Nursing Home

Corrandulla Nursing Home

Sacred Heart Hospital (Carlow)

Sacred Hearts Nursing Home Monaghan

San Remo Private Nursing and Convalescent Home

Shrewsbury House Nursing Home

Cuil Didin Nursing & Residential Care Facility

St. Anne's Community Hospital

St. Joseph's Hospital Ardee

St. Luke's Home Cork

Abbot Close Nursing Home

Dalton Community Nursing Unit

Dalkey Community Unit for Older Persons

Leopardstown Park Hospital

Lourdesville Nursing Home

Lucan Lodge Nursing Home

Lusk Community Unit

Aras Ghaoth Dobhair

Maynooth Community Unit

St. Mary's Community Unit

Aras Mhuire Community Nursing Unit Galway

Aras Mhuire Nursing Home Kerry

Arás Ronáin Community Nursing Unit

Mount Alvernia Hospital

Mount Hybla Nursing Home

Nazareth House Cork

St. Anne's Community Nursing Unit

St. Anne's Private Nursing Home

St. Brendan's High Support Unit

Ashford House

Ashley Lodge Nursing Home

Ballincollig Community Nursing Unit

Deerpark House Cork

Deerpark Nursing Home

Drakelands House Nursing Home

St. Brigid's Hospital Shaen

St. Brigid's Nursing Home

St. Camillus Community Hospital

St. Colman's Residential Care Centre

St. Columba's Hospital

St. David's Retirement Home

Bandon Community Hospital

Dunabbey House

Elm Green Nursing Home

St. Finbarr's Residential Hospital

St. Ita's Community Hospital

Sunhill Nursing Home

Talbot Lodge Nursing Home

Phoenix Park Community Nursing Unit (PPCNU)

West Kerry Community Unit

Peamount Healthcare

TLC Citywest

St. Vincent's Hospital Athy

Oakdale Nursing Home

New Lodge

Bellvilla Community Unit

Fairlawns Nursing Home

8. Paying Dividends: A Report on The Atlantic Philanthropies Investment in Dementia in Ireland

Eamonn O'Shea and Patricia Carney
National University of Ireland Galway

Advocacy is a continuum which requires a whole range of skills, including brokerage, mediation and befriending as well as legal, financial and healthcare expertise. Recruitment and training of volunteer advocates is key, therefore, to the success of the programme. Advocates have to know about many different things when it comes to dementia, ranging from the disease itself, care trajectories, personhood, rights, models of care and family dynamics. As well as conducting one-to-one casework, SAGE aims to strengthen the natural support structures of family and community in partnership with relevant professionals and local development organisations. The service is committed to building Circles of Support so that older people can, wherever possible, live and die in the place of their choice and be supported as they experience transitions between home, hospital, nursing home or hospice. The complex job description means that the ability to communicate and engage directly with many different stakeholders is an important part of the skill-set of advocates. This is particularly the case when advocacy intervention may not always be welcome by the families, providers, regulators or funders.

Advocacy – Case Examples

These selected Sage Case Examples are based on detailed case notes and related file documentation collected by Sage as part of its Case Management system.

These case examples provide a snapshot of Sage advocacy and support work. While it is difficult to be totally definitive about the impact of Sage in individual cases, what is clear is that, broadly speaking, Sage involvement makes a crucial difference people's lives in many instances.

Advocacy – Case Examples

The cases selected here refer to four types of outcomes arising from Sage involvement:

1) Positive observable outcomes for clients, e.g., home care package secured, house repairs carried out, people regaining control over their finances

2) Less tangible outcomes, e.g., confidence-building, increased choice and control, independence, safety and security, well-being and improved morale

3) The vindication of people's legal and human rights, e.g., right not to be made a Ward of Court, right to live independently, right to make decisions, right to take risks

4) The identification of systemic administrative blockages and policy issues, e.g., inadequate collaboration between different services/units and underdeveloped interdisciplinary working

The primary role of Sage is to bridge the gap between citizens' rights and the wide range and complexity of health and social care services, particularly in relation to long-term support and care.

The Case Examples cited show that where people had a significant difficulty in asserting their rights and having their will and preferences implemented or in getting or retaining the supports they required to live their lives as they wished, Sage played an important advocacy role and acted as a significant intermediary between individuals and the State as well as between individuals and relatives. In many of the case examples, access to a particular service or support was achieved as a result of either information provided by Sage or sustained support for and representation on behalf of individuals. Some of the cases point clearly to Sage's role in enabling people to vindicate their basic human rights, e.g., right to self-determination, right of access to their property/money.

16 cases are presented here where people had experienced difficulties in accessing an appropriate support package or where their will and preference was being ignored or where their decision-making capacity was not being acknowledged. A key question arises from the case examples cited, viz., what happens in situations where people are not able for whatever reason/s to avail of the services of Sage or other similar agency.

The level of Sage intervention varied according to the needs of the individual clients and included writing letters, making telephone calls, supporting people with appeals and acting as a referral source to other agencies. In some of the cases, the Sage involvement required engagement with relatives of the client. While self-advocacy by citizens is a key goal of Sage, the reality was that in many of these cases, for various reasons, Sage had to become directly involved in advancing the matters in question. Sage undoubtedly made an important contribution to helping the people in these cases to access services and supports and to assert their rights, will and preferences.

Advocacy – Case Examples

The cases cited are as follows:

- Supporting a person to return home (3 cases)
- Supports in understanding contracts of care for residents in a facility for people with disabilities
- Person experiencing mental health difficulties being transferred from hospital to a nursing home
- Assisting a person returning to live independently in the community
- Ward of Court issue and capacity assessment
- Assisting a person in getting a social welfare pension and accessing the Nursing Home Support Scheme
- Finding long-term care accommodation for person with an acquired brain injury
- Safeguarding of a person with mental health difficulties
- Assistance to a person living in unsafe accommodation
- Resolving alleged non-payment of nursing home fees
- Ensuring proper assessment of a person’s capacity
- Dealing with issues identified at nursing home residents’ meetings
- Enabling a person gain access to information about their finances

Apart from one case (Case Example 5) which is already in the public domain, any names and identifying features used in cases have been changed to facilitate, as far as possible, client anonymity. Service provider personnel are referred to by way of job title or role.

A number of Testimonials from service providers, relatives and a client are included as an Appendix. These testimonials clearly show that the work of Sage is very much appreciated by many service providers, by relatives and by clients.

Case Example 1

Supporting a person to return home

How Sage involvement came about

The referral to Sage originally came from Colin's Medical Social Worker (MSW) on the basis that Colin was expressing a wish to move out of the nursing home where he then resided and to return home. However, because his capacity was in question and he had a history of non-engagement with community supports, it was deemed necessary to seek additional support for Colin.

Personal information about the client given to Sage

Colin is in his 60's and had spent most of his childhood living in institutions and homeless accommodation as an adult but finally acquiring his own council flat. However, following a stroke, he moved from his council flat into a nursing home. It appeared to Sage that the nursing home was privileging keeping Colin in a safe environment (the nursing home) over Colin's wish to return home. Initially, the nursing home advised that they did not think it was in Colin's best interests to support a move home because of his history with antisocial behaviour, inconsistency in engaging with his key worker and primary care team and that he was unlikely to be able to take care of himself outside of the residential care setting. ***"The major concern appeared to be risk aversion rather than Colin's will and preference"*** (Sage Advocate).

What Sage did

The first few months of the case were centred around several multidisciplinary team meetings involving Sage's Development Worker, the nursing home CEO, Medical Officer, Director of Nursing, Assistant Director of Nursing, Occupational Therapist, and Physiotherapist.

The Assisted Decision Making (Capacity) Act had been signed into law in late 2015 and Sage was able to reference this legislation in focusing on Colin's rights instead of risk aversion. Specifically, Sage advocated for the use of a functional approach to assessing capacity to determine Colin's ability to decide where he wants to live, rather than using cognitive screening tools like the Mini Mental State Exam. Sage conducted its own informal functional capacity assessments with Colin, who was able to clearly articulate his wishes about returning home. Sage took the view that what he needed was additional practical support to do so but that this was not being offered. Sage referenced the responsibility of the nursing home to enhance Colin's capacity in accordance with the Assisted Decision-making Act. There was, therefore, a need to empower Colin to move towards independent living in accordance with his will and preference, rather than remain focused solely on safety, risk aversion and best interests. When the case reached a stalemate over agreeing an appropriate timeline for Colin to be facilitated to return home, Sage met with the nursing home's CEO and legal representative, following which the nursing home agreed to put in place a schedule of home visits where Colin would be assisted in visiting his Local Authority flat with the Medical Social Worker, Occupational Therapist and a Sage Representative in order to assess what skills and supports Colin would need to transfer home safely.

At this point in the case, the nursing home staff and Sage, while still acknowledging our different roles and perspectives, were able to work together on this schedule of visits over a number of months, going at Colin's pace. Eventually, it became clear that he was not yet able to make the move home because of a number of factors, possibly including Colin having become institutionalised because of his past history and the long period that he had spent in the nursing home.

Key Outcomes

- **Colin knows that he has the right to decide where he wants to live and can contact Sage again at any point in the future for support;**
- **Nursing home staff came to appreciate fully that Colin had a right to choose where he lives and to take responsible risks in this regard;**
- **The Sage intervention resulted in the option of exploring alternative accommodation for Colin becoming very much a reality.**

Case Example 2

Supports in understanding contracts of care for residents in a facility for people with disabilities

How Sage involvement came about

The Director of Nursing of a residential service for people with disabilities contacted Sage for support following a HIQA inspection of the facility. HIQA requested that they obtain an external independent advocacy service to discuss details of contracts with seven residents, who have no next of kin.

Personal information about the clients given to Sage

The seven individuals who were referred were regarded as people who would benefit from the support of Sage with specific reference to understanding what was in their contracts of care.

What Sage did

Following the referral, Sage contacted the Director of Nursing to request more details. It was established that the normal practice in the service was that contracts of care were signed by the resident or next of kin. In compliance with HIQA Standards, the service provider is required to provide all information in an accessible format and provide supports so that residents can understand what is in their contracts to the best of their ability.

Sage reviewed the contracts of care for the seven individuals and determined that they were the standard contract for the organisation. The service had developed an easy to read version of the contract.

Sage met with the seven individuals and determined that the level of understanding varied from individual to individual. Where possible, Sage discussed the contract of care with the individual involved.

The service provider agreed to amend the contract of care for the individuals.

Key Outcomes

- **The individuals were provided with supports to understand what was in their contracts of care as much as possible;**
- **The involvement by Sage in this process provided Sage with an opportunity to explore its role in cases where people have diminished decision-making capacity and do not have a next of kin;**
- **Important questions about oversight of contracts of care in such instances were highlighted;**

Case Example 3

Person experiencing mental health difficulties being transferred from hospital to a nursing home

How Sage involvement came about

Peter was in hospital, having been admitted there following a fall. A family member was informed while visiting Peter in the hospital that Peter was being transferred to a nursing home. The family member was further asked to sign the Nursing Home Support Scheme (NHSS) application form to activate this process. The family member refused and was then asked to attend a meeting in relation to Peter's care, and did so along with another family member. Sage was told that they were not listened to at this meeting and felt that they were being regarded as simply unhelpful and not co-operating in Peter's care because of being unwilling to sign the NHSS application form.

They stated that they felt the State was abdicating its responsibility for Peter and believed Peter was 'being written off'. Peter had the right to be afforded an opportunity to have a better quality of life.

Family members had refused to attend any further meetings with the HSE and had spoken to local and national politicians about the matter and were now seeking support from Sage, details of which they had found on the website.

Personal information about the client given to Sage

Peter is in his late 50's and had been resident in Mental Health Services since aged 19 years.

Peter had been living in a semi-independent unit on the grounds of a psychiatric hospital. He appeared content, went for regular walks in the grounds. Peter was said to have formed good relationships with staff. However, he was deemed 'to lack capacity'.

Following a fall, Peter had been admitted to the acute hospital. Because of fall and swallowing difficulties, he was assessed as 'too high a risk' to return to the mental health services unit.

What Sage did

Sage's role was to support Peter's family members directly and indirectly to ensure that their voice was heard in relation to care planning and that their request to continue to be included in their family member's life should be appropriately supported. This required visits to Peter and engagement with hospital staff.

Initial Assessment by Sage

Peter's Care Plan appeared to focus on bed management in the hospital and risk in relation to a return to semi-independent living in mental health services. It did not appear to consist of a holistic assessment based on Peter and his presenting needs.

At a day to day level, while his family members believed that Peter was reasonably well cared for, they felt he should have the opportunity to improve his mobility. They disagreed with the emphasis being placed on the 'swallow' issue. The emphasis on moving to a nursing home excluded any visible plan in relation to family involvement and any opportunity for Peter to be offered an enablement programme and a further capacity assessment.

This further assessment was agreed with Peter's family.

Three visits were made by Sage to Peter in the hospital. These were essentially observational visits since Peter did not speak. He was dressed, lying on top of the bed watching television. He looked anxiously from side to side. He appeared to recognize the use of his family members' names and appeared to relax when their names were mentioned. He appeared visibly relaxed when a care staff member who passed by greeted him. ***"He responded non-verbally, but with direct eye contact when I wished him well and said goodbye"*** (Sage Advocate).

Three different multi-disciplinary team (MDT) meetings attended by Sage highlighted the following aspects of Peter's case:

1. Peter had been medically discharged some months previously;
2. If some family member did not sign the NHSS Application, Wardship proceedings would commence for Peter;
3. It was suggested that Sage should actively work towards getting Peter's family member to sign the NHSS form – this would be in Peter's best interests;
4. While Peter could potentially benefit from an enablement programme, he did not have the capacity to process learning required for a rehab programme;

It was agreed that the issues around Wardship, including Capacity, would be discussed by Sage with Peter's family members as would the use of nursing home care in the context of long term planning.

Sage requested a fuller assessment in relation to Peter's eating and walking and, supported by the Mental Health Social Worker (MHSW), requested a comprehensive assessment of need. It was agreed that an assessment in relation to fall and swallow would be requested by the Discharge Co-ordinator.

Sage subsequently met with the family to give feedback and to highlight to them the need to put their views/position in writing. Sage facilitated this exercise in letter format. This letter was circulated to the Discharge Co-ordinator with a request that it be included with the documentation for the Wardship Application and also copied to the MHSW and Manager of Older Persons Services.

Sage met informally with Director of Older Persons Services to discuss Peter's situation and to clarify the availability of supports. While no transition beds were available at that time, it was noted that there would be opportunity, in the near future, to work with the family, other professionals and Sage in order to progress Peter's case.

Six weeks later

- There was no record of a Wardship application having been lodged;
- The family maintained contact with Peter and reported that he was having an opportunity to walk further around the ward, that he was becoming more mobile and slightly more verbal and was being assisted with eating.

The Manager of Older Persons' Services worked with Sage and mapped out a person centred communication and action plan which involved a move to a transition bed which was now available in a nursing home.

An MDT meeting was held in the nursing home attended by two of Peter's family members. The following points were clarified:

1. The Wardship Application was not lodged – this was reported, however, as being related to lack of staff resources rather than being a change of plan;
2. Peter's family are now pro-actively involved in the transition care plan which will include opportunity for an enablement programme and a review to consider if the current setting still meets Peter's needs;
3. Provision is to be made for a capacity assessment;
4. The family will continue to build a relationship with Peter through visits in the nursing home.;
5. The family have expressed their confidence in the setting and the opportunity it affords Peter;
6. A commitment has been given from all services that while they are responsible for Peter's care and well-being, the involvement of the family is essential in this process.

Key Outcomes

- **Peter moved from the acute hospital to a nursing home setting, supported by both hospital staff and family working collaboratively;**
- **Peter's voice will lead the process of providing for his needs from now on;**
- **The family is actively involved in ensuring that this principle will continue to inform the process;**
- **Sage's intervention resulted in a more holistic and respectful approach being taken to meeting Peter's care and support needs.**

Case Example 4

Assisting a person with returning to live independently in the community

How Sage involvement came about

Sage received a call from a Director of Nursing in a community hospital about Sarah who had been in hospital for 5 months and who required help with securing accommodation prior to discharge.

Personal information about the client given to Sage

Sarah was medically fit for discharge but her home was not fit to return to and she had no money. Sarah was assessed as not needing full-time care and, therefore, could not apply for the Nursing Home Support Scheme (NHSS).

What Sage did

Sage visited Sarah in hospital and got her permission to visit her house to assess the situation and was provided with a key for this purpose.

The house was found to be in a state of disrepair with serious roof leakages and, in Sage's view, completely uninhabitable. Sage took photographs of the house which Sarah agreed Sage could use with the housing authority for a housing application or grant application.

Costings for repair of house

Sage contacted builders with the client's permission to assess the cost of repair and discussed with the client the matter of applying for grants to repair the house and the need for the client to have some savings in order to pay the 5% share of the repairs for which she would be liable. Sage also met with a family member of Sarah and the builders to discuss the work needed. It took several weeks to obtain quotes for the necessary work on the house.

Grant applications

Sage completed the grant application forms with Sarah. This involved getting a valuation of the property. It was intended to help her apply for grants in order to do repairs under the Essential Repairs for the Elderly and Housing Grants for People with Disabilities and also SEAI grants.

Three aspects of Sarah's housing situation emerged during the process of making the applications:

1. It became obvious that the work needed was so extensive that no grant would cover the cost, estimated at €70,000;
2. Because Sarah was not regarded medically as disabled, no grant under that heading would be available and the other grants would not come near to meeting the cost of completing the works;
3. One builder indicated that he believed that the house was unsafe unless extensive work was carried out on the chimneys;
4. Also, and most importantly, it transpired that Sarah was not the sole owner of the property making both the grant application impossible and the sale of the property.

Application for LA housing

An application for local authority housing was then made by Sage on behalf of Sarah and contact was made with the Housing Officer. After several emails, phone calls and advocating on behalf of Sarah about the urgency of her case, the Housing Officer visited Sarah in hospital. She ascertained that Sarah was willing to live in rented accommodation in her local village. The Housing Officer agreed to put Sarah on the housing list which made her eligible to apply for Rent Supplement or the Housing Assistance Payment (HAP).

Sourcing suitable accommodation

However, finding suitable accommodation locally was difficult as it is a country area with little movement in the rental market.

After checking the available rental homes on Daft.ie and the newspapers, Sage found a suitable apartment next door to Sarah's own home which was suitable and exactly where she wanted to live as it was also 2 doors away from where a family member lived.

Sarah agreed to the move but was somewhat reluctant to move from the hospital as she was comfortable there and well looked after. The Director of Nursing explained to her that it was not possible for her to stay in hospital and eventually, she became enthusiastic about the move.

Housing Assistance Payment HAP

An application for HAP was made by Sage on behalf of Sarah.

Exceptional Needs Payment

Sage also applied for an Exceptional Needs Payment to buy some home items for Sarah – bedding from a charity had already been sourced.

New Home

Sarah moved to her new home with the assistance of a family member.

Other services

Sage plans to arrange Meals on Wheels if Sarah wishes and to put her in touch with the local Day Centre where she could get lunch. The Public Health Nurse was made aware of her return to the community as she will need some nursing care.

Key Outcomes

- **Sarah moved to an apartment which is located next door to her own house.**
- **Although her house is in a bad state of repair, Sarah loves her garden and will be able to use it as often as she wishes. She is able to see her garden from her new apartment;**
- **Through Sage's intervention and sustained engagement, an appropriate course of action was found and Sarah was enabled to return to independent living in her own community.**

Case Example 5

Ward of Court issue and capacity assessment[1]

How Sage involvement came about

The referral to Sage was made by the local Safeguarding Vulnerable Adults Social Worker who had in turn been contacted by the nurse in charge of the ward in the general hospital where MB had been a patient for 18 months.

1 The judgement case appears on the website of the High Court as a reported case. The link is http://www.courts.ie/Judgments.nsf/bce24a8184816f1580256ef30048ca50a8c749c1ea97d2f380257fa8003c2957?OpenDocument

Personal information about the client given to Sage

MB was in her early 90's, unable to walk, doubly incontinent and physically very frail but otherwise, apart from a condition which restricts what and how much she can eat, on no medication for any illnesses.

She had, prior to her admission to hospital, been living with her sister and together they ran a small local pub.

MB had been served with wardship papers apparently as she was indicating that she wanted to go home rather than into a nursing home.

The nurse indicated that she was concerned about MB being made a ward of court as she felt that MB did not lack decision making capacity.

Sage Involvement:

The Advocate attended on MB in her hospital room in October 2015.

MB indicated to the advocate that she wished to return home.

The advocate worked with MB to afford her insight into her own physical needs and MB came to see and accept, albeit reluctantly, that she couldn't return home. Instead she agreed to the advocate enquiring about a place for her in a nursing home, specifically the one where her sister already lived.

The advocate's opinion of MB was that she did have decision making capacity and took instructions from her (based on information which MB herself provided) to apply for Nursing Home Support Scheme (NHSS), and to apply to Dept. of Social Welfare for a top up on her UK pension and back moneys.

The advocate quickly found MB a place in the nursing home where her sister lived MB was happy to move there.

MB explained to the advocate that she owned a small pub and that a relative was by agreement with her opening it 2-3 nights a week. She stated that she was happy with this and for him to keep the profits as he paid for the stock. She knew that she had recently signed a cheque for the licence.

Based on the view that MB did have decision making ability Sage tried to "call off" the HSE wardship application. This was unsuccessful. Sage made the solicitors acting on behalf of the HSE, who were applying for wardship, aware that Sage would be resisting the application on MB's own instructions.

In order to do this Sage arranged for the advocate, Sage's legal adviser and Dr Q to visit MB to jointly assess her capacity.

Following this Sage assessment wrote to, and then sent a formal Report to the President of the High Court.

Notwithstanding that Sage had advised the hospital authorities that MB was prepared to move to the nursing home before Christmas 2015 the hospital indicted that the move could not take place until a further formal medical assessment of her ability to decide to move had been done. The advocate became aware that the move had finally taken place in January, apparently as a result of that further medical assessment indicating that she did have capacity to make that decision.

Sage, through its legal adviser, obtained a copy of that medical report directly from the doctor who prepared it, Dr G, who turned out to be the doctor who had been requested by WOC to act as the court's own medical visitor's and to provide a report.

As a result of Sage's correspondence with WOC Sage was informed of the Wardship hearing date.

The advocate and legal adviser again visited MB to inform her of the hearing date and ask her what she wished Sage to do for her. She told Sage that she wished Sage to appear for her and to tell the court that she didn't want to be made a ward of court and didn't want a certain relative to be her committee. She also signed a formal court document requesting an "inquiry". The legal adviser asked her about NHSS and ancillary state support and she fully understood it, finishing off the legal adviser's sentence about the sums being repaid "out of the money I get when I sell the pub".

As requested the legal adviser advised the court of MB's objections to wardship and handed in the inquiry request, a copy of Dr G's second Report indicating MB's capacity to decide to go to a nursing home and Dr.Q's report. She also told the court that she was legal adviser to Sage, not MB's own solicitor and was appearing in court on behalf of MB's Sage advocate in order to allow MB's voice to be heard in court as she was unable to be there herself.

The President of the High Court, having read the report of Dr G, said that there was clearly a clash of medical evidence. He then ordered a full exchange of all medical reports between the parties and ruled that Sage's legal adviser could accept them as an officer of the court.

The Sage advocate and Sage legal adviser again visited MB. MB said she didn't want to instruct a solicitor of her own. It was explained to her that the Court may not allow Sage to speak for her. She asked that Sage try anyway and she completed an Authority to Act form indicating that she wished Sage to appear for her in court in order to have her voice heard that she did not wish to be made a ward of court.

The legal adviser handed to the Court the Authority to Act form. The President indicated that he was accepting it as a request for an inquiry and would allow the legal adviser to be heard on the basis that "he would be coming back to that".

He indicated that he was concerned about Dr G's second report and therefore wished both he and Dr Q to be cross examined.

Dr Q was first to give evidence and an issue was made about her clinical experience in the area of capacity assessment and that she had not herself questioned MB having instead just observed, although she indicated that that was sufficient for the functional test for capacity. Dr Q was also limited to what she had witnessed herself. That meant that what had been said or experienced by the advocate or the legal adviser, such as MB's ability to understand the NHSS was not admissible as evidence.

Dr G then gave his evidence. He was consultant psychiatrist of old age and had been a court medical visitor for some years. He confirmed that MB had dementia and that as part of the dementia process, MB had significant impairment in her insight and judgment. He stated that she did not have an awareness of the level of her disability and her need for assistance in her activities of daily living. He also said that MB does not have an understanding of her day to day financial affairs. It was Dr G's opinion that MB was of unsound mind and was unable to manage her affairs.

The legal adviser asked the court if she could adhere to the fact that she had talked to MB about the NHSS and ancillary state support and found she did understand it.

The President indicated only if the legal adviser took the witness stand. The barrister instructed by the HSE objected to this.

The President, having read through a number of documents decided that he preferred the professional opinion of Dr G to that of Dr Q and was therefore admitting MB to wardship and appointing the general solicitor as her committee.

Key Outcomes

This case highlights the importance of an integrated and holistic approach to capacity assessment. While the outcome of the case was not what Sage advocated for, the case highlighted that there was an alternative perspective on this woman's capacity and whether or not wardship was necessary. To that extent, the Sage engagement in the case was highly significant and suggests the need for an alternative approach to similar situations in the future. This will be vitally important once the Assisted Decision-Making (Capacity) Act 2015 is fully implemented. The 2015 Act does provide that a person may have non-legal representation in a court application.

Case Example 6

Assisting a person in getting a social welfare pension and accessing the Nursing Home Support Scheme

How Sage involvement came about

The Manager of a day care centre had very serious concerns about an older man who was in financial difficulties and about his health and wellbeing. The centre manger wanted to afford him privacy and respect his independence and so had mentioned Sage to him and asked if he would agree to meet with Sage. He agreed and she arranged the meeting.

Personal information about the client given to Sage

Tim is in his 90's and is frail, undernourished and worried about what was going to happen to him. He is very articulate and well aware of the critical situation he is in. He lives on his own but he has a very kind neighbour who helps him when he needs assistance. All other relatives live abroad.

Tim has no income but has a small amount of savings that are dwindling and therefore he was taking less and less care of himself. He was becoming more frugal, not eating, not using the heating and going out less. He was becoming isolated and withdrawn. He was attending the day care centre only one day a week as there was a charge of €10 per day to attend. He applied for the old age pension (non-contributory) but his application was not successful. Tim's main concern now was about running out or money and what would happen to him in that eventuality.

What Sage did

At the first meeting Sage held with Tim he was very willing to accept help and appreciated the difficult position he was in. His pension application was discussed and why it was not granted. He told Sage that it was because he had given his property to a relative some years previously because he wanted it to stay in the family and that the Department of Social Protection had serious questions about why he did this.

Sage appealed the decision to refuse Tim the pension and this appeal was successful.

Case management

The management of this case involved liaising with the family abroad, his neighbour, his solicitor, along with coordinating the multiple agencies involved. These included the day care centre, hospital, private and public nursing homes, HSE, a rehabilitation facility, Department of Social Protection, Community Welfare Officer, bank, Nursing Home Support Scheme (NHSS) support office and politicians whom Tim wanted involved.

The following points were relevant in processing Tim's case:

1. Since his assets were disposed of many years previously, there should be grounds for appealing the decision not to grant him the pension;
2. On the same principle, he should also be eligible to apply for the NHSS;
3. A nursing home bed could only be applied for when NHSS and pension approval was granted;

Tim then had a fall at home and was found on the floor by his neighbour; the emergency service took him to the local hospital where he was admitted with a hip injury. Tim was discharged to a community hospital for respite and physiotherapy and then sent to a nursing home for additional respite.

An application for a supplementary welfare interim payment was refused on the basis that Tim had been admitted to a nursing home and was not, therefore, entitled to supplementary benefit – this meant that Tim remained without income.

Sage had visited Tim in the community hospital. He had stated that he really enjoyed living in the hospital and would like to spend the winter in a nursing home if possible. Tim agreed to an application being made to the NHSS.

The manager of the day care centre and Sage assembled the relevant documentations for the NHSS application. This was difficult because Tim's bank account was operated by the old system of a book and no card had been issued to this account A statement had to be requested which could only be posted to the account holder (an electronic statement was not applicable in this instance) which the bank agreed to do. The account had 3 signatories and 2 lived abroad.

Sage sought their assistance in getting a bank statement to expedite the NHSS application as well as requesting some comfort money that would make Tim's living conditions better.

As Tim's respite care period was due to end the HSE agreed to provide Tim with 3 weeks additional emergency respite in yet another nursing home; his fourth move in two months. Tim's private nursing home of choice would not put his name on the waiting list until he had obtained NHSS approval.

Sage visited Tim in all three nursing homes and provided him with support and reassurance that representations on his behalf were ongoing.

Finally the Department of Social Protection contacted Sage to say that Tim's pension appeal had been successful, that he would be in receipt of a non-contributory pension, that it would be back dated for 3 years and that monies would be lodged into his account within a fortnight.

Tim's respite care period was now up and as the private nursing home wanted payment in advance of the NHSS approval in order to cover the period of Tim's care while the NHSS application was being processed Sage contacted the bank signatories abroad. They agreed to transfer adequate funds to the nursing home thus ensuring that Tim could secure a place in his nursing home of choice where he now resides.

Key Outcomes

- **Tim got his old age pension (backdated) to which he was entitled;**
- **Tim got the NHSS support to which he was entitled;**
- **His family re-engaged in the process of supporting Tim;**
- **He now lives in an environment where he is relatively contented and feels secure.**

Case Example 7

Finding long-term care accommodation for a person with an acquired brain injury

How Sage involvement came about

VP was referred to Sage by the HSE Nursing Home Support Scheme (NHSS) support office who were concerned that as VP had a brain injury he could not commit to the scheme.

Personal information about client given to Sage

VP is in his early 40's and is a resident in a nursing home. He was transferred there from hospital where he had been admitted following a stroke. He is an EU national living in Ireland for some considerable time. In the nursing home, VP totally lacked stimulation and, also, the wheelchair in which he sat daily, was most unsuitable.

What Sage did

Sage visited VP in the nursing home and assessed his needs on a non-instructed advocacy basis. Based on this assessment, Sage contacted the Rehabilitation Unit in Dun Laoghaire who agreed to admit VP for assessment. Sage visited there on a regular basis to monitor his progress. A multi-disciplinary team (MDT) meeting was held to consider VP's longer term care and the possibility that he might wish to return to his home country. Sage communicated with his relatives via an interpreter and they agreed to source possible long-term accommodation for VP. However, as VP continued to improve with intensive therapies, he stated, via a communication device, that he did not wish to return to his home country. He had lived in Ireland for a long time and had paid his social welfare stamps for many years.

Sage, together with VP's social worker, then looked for alternative long-term care which proved difficult as all of the disability (brain injury) units charge significantly higher costs than nursing homes and the HSE were unwilling to bridge this gap in costs. The nursing home that VP had initially come from was seeking his return to their care but eventually agreed that they could not meet his needs to the same extent as the rehabilitation unit.

During the period that VP's hospitalisation was in train, his social welfare payments had not been collected. Sage wrote to the Department of Social Protection requesting that Sage be allowed to provide an Agent Account for VP as he had no bank account in Ireland. Over a period of months this was agreed and Sage now monitor his income which is used to contribute to the cost of his care. While VP remains in the rehabilitation unit, there is now agreement that he will soon be transferred to a suitable care home.

"The process of advocating for this client has taken almost one year to complete and while there have been successes it has been slow and painstaking work.

(Sage Advocate)

Key Outcomes

- VP had his support needs comprehensively assessed;
- VP's finances were organised and an NHSS application was made;
- While there remains a question about a suitable residential facility for VP, the fact that his needs have been identified and documented creates the necessary platform for addressing his care and support needs on an ongoing basis.

Case Example 8

Safeguarding of a person with mental health difficulties

How Sage involvement came about

Bridget was a resident in a nursing and had received 14-day notice to quit and Sage was asked to assist in finding a new nursing home.

Personal information about client given to Sage

Bridget has a long history of mental health issues and has been in the care of a psychiatric team for some time. She originally lived at home with a family member. When her needs increased the family member was unable to provide care for her and she was admitted to a nursing home. This began a process whereby Bridget was needlessly moved from one nursing home to another over several years; always as a result of concerns expressed by one or other members of the family.

At this latest nursing home a family member felt that the care being delivered did not meet Bridget's needs and started to interfere in her care plan. Eventually the situation became unacceptable to the nursing home and Bridget was issued with a notice to quit.

What Sage did

Sage was approached and asked for help in finding a new care setting for Bridget. Sage met with Bridget's family member and discussed the eviction notice and the family member's involvement in Bridget's care. The family member indicated that the plan was to have Bridget admitted to the emergency department in the local hospital as a social admission. As the nursing home was very clear that they had no issues with Bridget and the problems were all associated with this family member, Sage asked the family member if, in the event of a new care setting being found for Bridget, they would allow the care to be delivered without interference. The family member agreed.

Bridget transferred to a new care setting and settled in very well. After a few weeks the family member again began to interfere in her care and staff became concerned that history was repeating itself. The manager of the nursing home and Sage met with the family member to discuss the concerns and provided reassurance that Bridget was receiving good care, had settled in well and appeared to be happy. The family member, however, indicated that a new care setting was being sought and Bridget would be moved as soon as possible. Sage explained that it would not support this move as Bridget was now happy where she was.

Sage was then informed that the family member had contacted the emergency services to say Bridget was at risk and that an ambulance and Gardaí had arrived at the nursing home and Bridget had been taken to the emergency department of an acute hospital. Sage received a call from hospital stating that they could find no clinical reason for Bridget to be there and indicating that this unnecessary visit to the hospital was putting Bridget at risk of infection. Bridget was discharged back to her nursing home with the support of Gardaí.

As this incident was a cause of great concern to the nursing home they requested a meeting with Sage to discuss safeguarding options. Sage explained the safeguarding process and contacted the HSE Safeguarding Protection Team. A safeguarding plan was put in place which included visiting conditions and restrictions on the family member which would be reviewed monthly. Despite considerable concerns on the part of the nursing home about possible future incidents Sage continues to work with the nursing home and the HSE safeguarding team to ensure Brigid's welfare.

Key Outcomes

- **The cycle of actions which resulted in a vulnerable older person being regularly and needlessly moved from nursing home to nursing home was ended:**
- **Clear safeguarding structures and protocols were put in place;**
- **Sage developed important linkages with Gardaí and hospital staff**
- **Close working took place between Sage and the HSE's Safeguarding team to protect a person's basic human rights which is a useful model for the future.**

Assistance to a person living in unsafe accommodation

How Sage involvement came about

Sage got a call from a public health nurse (PHN) to seek support for Hannah. A member of a local voluntary organisation had found the electrical wiring of her house to be in a dangerous state. The house had been wired in the 1950s and had not been upgraded.

Personal information about client given to Sage

Hannah is in her late 70's and lives in a remote rural area. She has lived alone for over 8 years since her only relative died. She had farmed all of her life but a few years ago had sold all of her cattle as she realised that managing the cattle and farm had become too much for her. This was a big change in her life and she missed her livelihood and being around animals a lot. She has some health issues.

Her house is a one-storey house which she has lived in for most of her life. While an extension had been built to her house some years previously, the old part of the house was left as it was.

What Sage did

Sage visited Hannah with the PHN and found her to be clear and articulate. Her wish was to get the house rewired so that it would be safe for her to continue living there.

Sage identified that there was a possibility of applying for a local authority Housing for Older People grant worth €8,000 and Hannah was happy to start the application process. Sage sought quotations from electrical contractors for rewiring the house. However, it emerged that the work was more complicated than initially envisaged as the older part of the house had an asbestos roof which had holes in it. Quotes now had to be sought from an asbestos removal company and from builders/roofers as well as electricians. It was also necessary to carry out repair work on the chimney. Quotations for removing the asbestos roof were organised using photographs taken by Sage. It also emerged that Hannah could not get insurance for her house because of the existence of an asbestos roof.

The grant application process was complex and some of the information sought seemed to be inappropriate and overly arduous. Hannah's GP had to sign a part of the form although the works being undertaken were not being done because of Hannah's health but for safety reasons. The surgery charged for this. It was also necessary to prove that Property Tax had been paid for the property which was accessible enough for someone who had internet access and the knowledge of how to use the internet but Hannah had neither.

Work was completed in one month. The total cost of the works was more than was covered by the grant, but all the work had to be done together.

Hannah was asked by Sage, when her case was closed, if she was happy with the job done and the price paid and she replied that she was happy to pay for the good quality work done.

Key Outcome

Hannah is now safer and more comfortable in her home and knows that she can call on Sage in the future should she need further help.

Case Example 10

Resolving alleged non-payment of nursing home fees

How Sage involvement came about

The referral to Sage was from the HSE Safeguarding Protection Team social worker. Matthew's family had contacted the Safeguarding team but as there was no safeguarding issue, the latter could not get involved.

Personal information about client given to Sage

Matthew had a stroke and after rehabilitation was transferred to a nursing home where he spent 4 years. He did not want to be in a nursing home and very much wanted to return home which he eventually did and now lives at home with his partner.

He had lost his speech due to the stroke and so had trouble communicating. His family lived in the UK and were asked to organise an application for the Nursing Home Support Scheme (NHSS). This eventually came through and paid for the last 3 years of the nursing home stay but the first year was not paid for. There appeared to be a mix up on who was supposed to pay for that first year. The nursing home had started legal proceedings to get the outstanding fees of almost €40,000. Matthew cannot afford to pay this back and felt it should be paid by the HSE.

What Sage did

Sage got in touch with the nursing home owner, the NHSS, the HSE's Manager of Older People's Services and Matthew's solicitor and GP. in order to build a complete picture of the matter. The following points emerged:

- The Manager of Older People's Services believed the issue was due to confusion over how the NHSS loan worked and the mistaken belief it had been approved and signed;
- The NHSS office did not think there was anything more to be done as letters had been sent out and they were no longer involved;
- The GP remembered confusion at time over who was next of kin. He felt Matthew was unfairly treated;
- The solicitor involved with the family felt there is little that the family can do to fight against the charges.

Sage visited Matthew and his partner. They told Sage that they wanted a meeting with the HSE as they wanted to have their story heard and to get explanations for what had happened. Matthew said that he had not been consulted and could not speak for himself at the time, and had no representation. They asked if Sage could arrange a meeting as they had not been able to.

Sage arranged a meeting between Matthew and his partner, the Manager of Older People's Services and the nursing home manager who both agreed to come to Matthew's house.

At the meeting:

- *Matthew's partner questioned why Matthew was left in the nursing home and not engaged in discussions about his care.*
- *The nursing home manager explained that a relative was acting on his behalf and had started the NHSS application, they did not feel there was a need for an advocate. He said that to the best of his knowledge, the application was not approved.*
- *The Manager of Older People's Services explained that HSE does not decide if someone goes into or stays in a nursing home. If a person does not have the capacity to decide then it is up to the family to deal with the matter;*
- *It emerged that the application itself was approved but the Nursing Home Loan had not been applied for. It is necessary to be approved for the scheme in order to apply for the loan so it was assumed that when they proceeded with the loan application it must have been approved.*
- *The nursing home manager stated that he never got any payments under the NHSS and was not aware that it had been approved. He never sent in a confirmation of admission to the NHSS or invoiced them for Matthew's stay.*

The Manger of Older People's Services agreed to look into this – if it was approved, the nursing home should have received payments from the HSE. If it was not approved it cannot be done retrospectively.

- *It emerged that a relative did not follow up on the NHSS application. The partner had never received any correspondence about the NHSS and so assumed it had been sorted by the relative.*
- *Three possible things could have happened:*
    1. *The NHSS application was approved and accepted but somehow paper work was wrong or it was not invoiced correctly;*
    2. *The application was approved but not accepted;*
    3. *The application was not approved.*
- *The Manager of Older People's Services agreed to check whether or not the NHSS application was approved and accepted and to contact Sage when the information as available.*
- *Matthew made clear his feelings about remaining at home and not returning to the nursing home under any circumstances and all assured him this would not happen.*

Key Outcomes

- **The family felt they were listened to by the HSE and had the opportunity to air their grievances about the treatment the client received from the nursing home and the HSE;**
- **A key question arises as to how what appears to have been a basic accounting error resulted in considerable trauma for a family and why it took so long to get to the root of the issue;**
- **Sage's intervention in bring 'all sides to the table' was crucial in resolving this issue.**

Case Example 11

Ensuring proper assessment of a person’s capacity

How Sage involvement came about

A Sage Representative visiting a nursing home on a regular basis became aware of a client whose husband had died suddenly. He had managed all her affairs and money and visited every day. The nursing home owner reported that her GP had said that she does not have capacity to make decisions for herself. A family member who is now her next-of-kin had been trying to help sort out her finances but did not have any authority to do so. The nursing home was unsure what way to go and were considering a Ward of Court application.

"Frances was happy with how the meeting went and felt great relief to have those matters settled".

(Sage Advocate)

Personal information about client given to Sage

Sage had built up a relationship with Frances as a result of frequent visits to the nursing home. She was very depressed over the loss of her husband and she was overwhelmed with everything. She had asked a particular family member to help her sort out her affairs.

What Sage did

Sage felt with support and patience the client would be capable of making her own decisions and establishing authority for her family member to assist her in sorting out affairs. Sage took the view that a wardship application was unnecessary as the client was quite lucid and would be able to manage her affairs with some assistance.

At subsequent meetings with Frances, Sage found her to be alert and communicative. She got upset when offered condolences on the death of her husband. She remained consistent in her wish that her relative should manage her affairs for her as the only person she trusted.

Sage got in touch with the family member who had been attempting to get a meeting with the GP to discuss Frances's capacity. Sage arranged a meeting with the family member, Frances, the Director of Nursing (DON) and the GP.

Frances had stated that she did not wish to be brought to hospital in any circumstances. She was very clear about her wishes and showed no signs of confusion. The GP agreed that this wish should be noted in her Care Plan.

Frances also stated that she would like to be cremated after her death and have no religious service. She stated clearly that she wanted a chosen family member to look after her affairs. The GP agreed to write a letter to Frances's solicitor to state her wishes.

Sage attended a meeting with the solicitor and the family member regarding Power of Attorney to allow the family member to sort out immediate financial issues such as dealing with the husband's estate and paying care bills and funeral expenses. The setting up of an Enduring Power of Attorney (EPA) was also discussed which would come into effect if her capacity became compromised in the future. It was agreed that Sage would discuss an EPA with Frances and that, if she wished to do so, the Solicitor would then visit her to complete the necessary paperwork in accordance with her wishes. During the meeting and, prompted by Sage, Frances agreed to consider making a will and include in it a statement of her wish to be cremated after her death and not to have any religious service.

Sage facilitated a meeting with Frances and her solicitor at which the solicitor went through both Power of Attorney and EPA. Frances agreed both and remained clear in her wishes to have her chosen family member act on her behalf. The solicitor was satisfied that Frances was giving clear instruction and not coerced. The solicitor then asked if she wanted to discuss making a will and she stated she would like to do so. Frances gave clear instructions about what was to be in her will only having difficulty with certain details such as names and addresses. The Solicitor was satisfied with information collected and undertook to prepare the will for signing accordingly. With Frances' permission, it was agreed that Sage would witness Frances' signature as well as the Solicitor. The solicitor gave Sage the EPA to have the GP sign it and return it to the solicitor's office.

Sage followed up with Frances' chosen family member once the Power of Attorney was enacted so that all bills could be paid.

Sage followed up with the nursing home in the months that followed and found that Frances' family member had been able to sort out her finances and had paid her nursing home fees as well as other outstanding bills.

Key Outcomes

- **Frances was able to express her wishes, was listened to and consulted about all her affairs;**
- **Frances' wishes in respect of treatment in the event of another stroke or other medical emergency were identified and noted in her Care Plan;**
- **An EPA is in place in the event that her capacity diminishes to the point where she can no longer make decisions for herself;**
- **Frances was facilitated to make a will which include specific instructions about her funeral arrangements.**

Case Example 12

Dealing with issues identified at nursing home residents' meetings

How Sage involvement came about

Part of the Sage remit to date has been to facilitate Residents' Groups in congregated care settings to articulate and represent residents' issues and interests. Arising out of this engagement, systemic issues are identified on an ongoing basis. The following is an illustrative snapshot of these issues.

Wheelchair Accessibility in Nursing Home Vicinity

A resident attending a nursing home residents' meeting raised the issue of significant problems with wheelchair access in the vicinity. All roads in the estate were unfinished, resulting in incomplete drop curbs, poor signage, limited pedestrian crossings and a lack of textured pavement. In the case of the resident, this had a significant impact on his quality of life, as he was no longer able to go out on his own. In addition, residents using electric wheelchairs were regularly seen on the main avenue, which was of serious concern. To assess the problem, Sage agreed to conduct a walkability survey of the estate and to engage the estate management in dealing with the issue.

Outcome

After lengthy delays, due to problems with tendering, procurement and terms of access to the site, remedial work commenced in February 2016 and was completed in December 2016.
The re-instatement works included: repair or replacement of all drop curbs in the estate, upgraded and new pedestrian crossings, textured pavement, new signage and road marking.

The nursing home and estate Management Company plan to mark the completion of this project with a celebration in spring, 2017. This will involve nursing home residents and staff.

Fire Safety

A relative of a nursing home resident told Sage said that there had been smoke coming out of a television and that this had caused disruption over a number of days. The relative was concerned that there were not proper fire safety measures in place as the fire doors did not close. The issue of fire safety was raised by Sage with the nursing home management. A power surge had affected 5 rooms damaging the power supplies on electric beds and televisions.

Outcome

Once the investigation by the electricians and fire safety officers was complete, a fire safety talk was arranged for the residents' meeting and an information session was planned for relatives.

Irish Human Rights and Equality Commission – consultation with residents

Sage was approached by the Community Action Network (CAN) regarding a request for input from nursing home residents as part of an ongoing consultation by the Irish Human Right and Equality Commission (IHREC).

A meeting was arranged by Sage and representatives from the IHREC and CAN met with residents from 5 nursing homes. Issues discussed included:

- Aging: feeling 'invisible' with nothing to offer society
- Financial concerns: little money left after NHSS payments to cover activities, prescriptions and other essentials
- Difficulty accessing appropriate wheelchairs
- Difficulty accessing information about entitlements
- Hospital appointments: long waiting lists and long waiting times
- Staff shortages and heavy workloads in nursing homes
- Problems in the interactions between people with and without dementia
- Boredom and lack of stimulation in some care settings
- Care homes are not always near public amenities and transport
- Residents having little or no input into the planning and design of care homes.

Outcome

This consultation and engagement created a valuable platform for nursing home residents to articulate their experiences and perspectives. This was hugely important given that such opportunities are not regularly available. new approaches to care in congregated settings and to alternatives

Medication issues

In July 2016, a nursing resident informed the meeting that she was given all of her medication together and wondered if they might interact with each other. The Director of Nursing raised the issue at the Drugs and Therapeutic committee meeting and it was determined that the two specific drugs should not have been given together. As a result of this discovery, the administration of medications for all residents in the nursing home was reviewed.

Nursing home residents with different types of needs

Residents in many nursing homes regularly raise concerns around the impact other residents' challenging behaviours has on them. The following are frequently mentioned:

- Excessive noise at night from people calling out and ringing the call bell
- Aggressive behaviours - both physical and verbal
- Lack of assistance to dependent residents during meals
- Residents walking into other residents rooms e.g. theft, getting into other residents' beds etc.
- Toilet issues e.g. using halls or rooms as toilets, using other residents' toilets etc.

Dealing with these issues

Sage has facilitated the establishment of a focus group in one nursing home to help residents better adapt to living in a communal environment. Members include: representative residents, an academic specialist from DCU, nursing home staff and a Sage Development Worker.

The aim of the group is to look at dementia and develop tools to assist residents in communicating with other residents and managing their behaviours.

A poster has been developed and a residents' guide to dementia is currently in development. These will be piloted and inform the development of a short training programme for residents.

Some pioneering work is also being undertaken in conjunction with DCU in examining how residents can be helped to adapt to living in a communal environment and living alongside those residents who have dementia.

Difficulty with shared room

A female resident shared a room in the nursing home with her husband and both attended Residents' meetings together for over three years. When her husband died, the nursing home moved another female resident into the room within two weeks. The resident found this extremely distressing. A residents' meeting was held the following week and the resident discussed her concern with Sage after the meeting. The resident asked Sage to contact the management on her behalf.

Outcome

The issue was raised by Sage with the nursing home management and two weeks later, the resident was moved into a single room.

Repatriation of Resident

The resident was a EU national who had moved to Ireland. He had a stroke and was found on the floor in his apartment. He had also suffered a hip fracture. After hospital treatment, he recovered well, with unimpaired mobility and speech and moved to the private nursing home.

At his first meeting residents' meeting, the resident spoke about his wish to return to his home country. He said he had an excellent relationship with his two children but that they had been unable to assist him in getting home.

Outcome

Sage made contact with the resident's family and the authorities in his home country. A guardian was appointed for the resident in his home country who located an appropriate facility there. The resident then returned home.

Case Example 13

Assisting a person return home from a nursing home

How Sage became involved

Thomas self-referred to Sage after the Director of Nursing informed him of the service. The Director of Nursing knew of Thomas's desire to return home but was of the view that he needed support in achieving this.

Personal information about client given to Sage

Thomas is in his 60's and has been residing in a nursing home for over 2 years. Prior to this he spent 9 months in an acute hospital following a stroke and alcohol related issues and now has a diagnosis of alcohol related dementia. In the 2 years Thomas spent in nursing home care his physical and mental health and overall cognition improved greatly.

What Sage did

Sage spent several months discussing with Thomas his options regarding his proposed return home. It was evident to all involved that Thomas had functional capacity regarding the decision to move home. Despite Thomas's improvements, his family, the nursing home and the HSE primary care team had a number of concerns regarding the risks associated with Thomas's alcohol consumption, his mild cognitive impairment and the proposed move home.

There were significant risks associated with this proposed move and Sage aimed to acknowledge and address these while recognising Thomas's autonomy and his right to make an unwise decision. Sage organised a multi-disciplinary meeting with Thomas, the nursing home and HSE community care service providers. While the community care services acknowledged the need for support for Thomas, they could not plan any support until he was residing in the community. The duty of care to keep Thomas safe versus Thomas's right to leave was discussed extensively.

Sage had to advocate for Thomas's right to make this decision, in light of his functional capacity. This involved a number of difficult and challenging conversations with both the professionals involved and Thomas's family. Sage continued to liaise with HSE staff regarding community involvement and organised supplementary private care paid for by Thomas.

After 5 months of Sage involvement, Thomas moved home and for a number of months he managed very well. However, after about 6 months, Thomas began to drink heavily and his short term memory became impaired. This resulted in Thomas's family submitting complaints regarding the role of Sage in supporting Thomas to move home.

Sage advocated for increased supports as Thomas's care needs became more complex and family tensions increased. Sage continues to support Thomas as he reassesses his long-term care options.

Key Outcomes

This man's right to choose his place of residence was upheld

Thomas's autonomy and right to make what might appear to be an unwise decision were highlighted

Case Example 14

Enabling a person gain access to information about their finances

How Sage became involved

This case was referred to Sage by a nursing home in accordance with the HIQA requirement that all residents have access to an independent advocate. Luke had expressed a wish to return home.

Personal information about client given to Sage

Luke is a single man in his 60s who had been resident in a nursing home for 5 years.

He was in a dementia unit in the nursing home despite the fact that he was not diagnosed with dementia. He was unaware of his financial circumstances and had no access to cash or to statements of his finances. He had no outdoor footwear and the Director of Nursing confirmed that he was attending hospital appointments wearing his slippers. Luke was not aware that his house, which he co-owned with a family member, had been renovated and now occupied by other family members.

What Sage did

Sage arranged for Luke to be moved into another room with easy access to other public areas, accompanied Luke to buy shoes and clothes, and engaged with nursing home staff, family and other professionals in exploring options for Luke to return home.

Sage discovered that the nursing home held a considerable sum of money belonging to Luke in a nursing home account which was not a Patient's Private Property Account. Sage worked with the nursing home's accountant in setting up a system of regular financial statements to be presented to Luke.

Sage engaged with Luke's family to retrieve documents related to former bank accounts and assisted with regaining control of Luke's own bank account. Bank statements which were being accessed by family were now sent to Luke at the nursing home.

Sage also restored Luke's access to his own income, by supporting him in his request to change the payment method from agent PO collection (relative) to direct bank transfer into his account. On Luke's instruction, Sage requested the nursing home to have overpaid funds transferred from the nursing home account into Luke's bank account.

Subsequently, Luke was supported by Sage to set up a system to have his nursing home fees, and other regular payments, deducted by standing order from Luke's account.

Luke had worked for almost a decade abroad and asked Sage to assist with finding out if he would be entitled to receive a pension and to make necessary arrangements for this to be transferred to his bank account.

In the future, Sage will, if necessary, assist Luke in understanding his financial statements on 3 – 4 occasions a year.

Sage supported Luke in attending multi-disciplinary team and family meetings because of the negative attitude of his family towards plans for his discharge home. Sage helped Luke to access Free Legal Aid regarding access to his property.

When the family refused to hand over the funds belonging to Luke as identified and agreed at the initial family meeting, Sage referred the case to the HSE Safeguarding Service and currently co-works the case with the Safeguarding Protection Team social worker in supporting Luke to either regain access to his former home, or if needed, to find another place where he would be happy to live. Sage was able to assist Luke in obtaining information related to the ownership of the house from the Registry of Deeds & Probate Office. The case is ongoing.

Key Outcomes

- **Luke was enabled to gain direct access to and control over some of his finances;**
- **He now has his own bank account and receives financial statements;**
- **The matter of his co-ownership of the house where he had lived was referred for legal advice and this issue is ongoing;**
- **The respective roles of the nursing home and relatives in creating a situation where Luke did not have direct control of his finances was highlighted;**
- **Possible financial abuse is being explored by the HSE**

Case Example 15

Assisting a person to return to live at home

How Sage became involved

Mary was referred to Sage by her neighbour who was very concerned that she had been in hospital for six months. This neighbour visited Mary regularly and was worried that she would be going to a nursing home against her wishes.

Personal information about client given to Sage

Mary is in her late 80s and had been living independently in her local area. She became ill and was admitted to hospital. It was deemed that she had the beginnings of dementia and needed long-term care.

Mary is quite wealthy and, therefore, does not qualify for the Nursing Home Support Scheme (NHSS). According to her relatives they were advised by the hospital social worker to apply to make her a Ward of Court.

Mary told Sage that one relative had her pension card and was collecting her pension and paying her bills. The relative also had her chequebook and had changed the locks on her house.

What Sage did

Sage arranged a visit with Mary in the hospital but arrived to find that she had just been moved to a nursing home. Sage met with her in the nursing home.

Mary seemed very happy to be out of the hospital but did not want to stay in the nursing home long term. Mary seemed to be very coherent and to have decision-making capacity in relation to going home. She gave Sage details of her solicitor and Sage rang to arrange a meeting. The solicitor was of the view that Mary did have capacity but he was blocked from moving her out of hospital due to medical reports stating she has dementia. Sage's legal advisor met with Mary and her solicitor. At this meeting, Mary clearly demonstrated decision-making capacity about where she would like to live. It was noted that she might need support with her finances.

Sage met with senior hospital staff and arranged for another assessment of her capacity. The professionals involved reported that Mary did indeed have capacity. This meant that the Ward of Court proceedings could be terminated. When her relatives were informed that Mary did have capacity, they dropped her house keys and pension card and a large sum of cash into the nursing home for her.

After further discussions with Mary, her solicitor and her neighbour, it was agreed that Mary would set up an Enduring Power of Attorney (EPA) with her solicitor and neighbour as attorneys. ***"Mary seemed very pleased with same as she was very upset and angry that she might have been made a Ward of Court"*** (Sage Advocate).

Due to the fact that she had been in the hospital for six months and now in a nursing home, Mary had not been home in all of that time and asked Sage to arrange a visit home. She met her solicitor and neighbour at her home.

"This was a very emotional day for Mary as the house was not as she had left it with her personal papers etc. moved around. She was anxious to find some pieces of jewellery and a large sum of cash, which we did find. She brought the jewellery and some cash to keep in the nursing home and gave the rest to her solicitor".

(Sage Advocate)

Mary's solicitor was now able to sort out her finances and to pay the arrears owed to the nursing home. and set up a direct debit to pay ongoing charges. Arrangements were

"It will be a big change for her to move home but she is adamant that it is what she wants as she does not like living in residential care and especially does not like the food".

(Sage Advocate)

also made for her pension to go into her bank account to pay bills such as property tax. A further capacity assessment for the EPA was also organised.

Mary decided that she wanted to go home. Sage did some research for her with different home care companies. Mary has a GP card but does not qualify for a Medical Card. Sage helped her apply for a Home Care Package and the community nurse deemed her to need 24/7 care. Sage contacted a manager of a home care company who indicated that they can do day time calls as well as overnights and do any necessary personal care and chores e.g., shopping, cleaning.

Sage is arranging to meet with Mary's neighbour and the manager of the home care provider company to get the house ready for Mary's return. Mary knows that she must give the nursing home four weeks' notice to leave and it will take the same amount of time to arrange home carers.

Mary is very concerned about money and even though she has a substantial amount she thinks that it will run out. However, she has agreed to have a carer at night and a few calls a day which she can reduce or increase as needed. Sage continues to work to ensure that all necessary supports are in place so that Mary can live in the place of her choice.

Key Outcomes

- **Structures were put in place to enable Mary to return to live at home in accordance with her will and preference;**
- **A Ward of Court application, which was inappropriate in Mary's case, was not progressed;**
- **Mary regained control over her own home and finances;**
- **The importance of carrying out a proper assessment of capacity was highlighted through this case;**
- **The role and contribution of a supportive neighbour was maximised.**

Case Example 16

Supporting a person in hospital to return home

How Sage became involved

This referral to Sage came from the HSE. Orla was in hospital and was in urgent need of support. She had been trying unsuccessfully to get an advocate to work with her.

Personal information about client given to Sage

Orla is a young woman and lives alone in a small Local Authority house and is very happy there. She is in receipt of Disability Allowance and has a Medical Card. She previously had a Home Care Package (HCP) - 3 hours x 7 days, then reduced to 2 hours x 7 days. These supports were taken away completely following a case conference when Disability Services informed her that she no longer came under their remit for services.

Orla had been in hospital for the past 3 months having been transferred there following surgery and treatment in other hospitals. She was told that her stay would be for 2/3 weeks for rehabilitation in preparation for her return home. She remained in the hospital even though she had been clinically and medically discharged for over 3 months. She has a history of medical problems over a number of years - some dating back to early childhood.

Orla walks with the help of crutches and a frame. She spends most of the day alone in her hospital room with little contact except at meal times or when she requests her medication.

While she has been both clinically and medically discharged, she is adamant that she cannot return home unaided and the longer she remains in hospital the more difficult it will be for her to return home. She is not receiving physiotherapy at the level required. She is suffering both mentally and physically as a result. She wants to go home and try to get her life back together but needs a proper package of care to be put in place for her. She feels all the services have let her down very badly, she needs to be supported as otherwise she believes she will still be in the hospital for some considerable time.

Sage Advocate's observations

Orla presented as a very pleasant and intelligent woman, well able to express her opinions and use her laptop to assist her in her research on her condition.

Sage spoke to the Care Service Manager who confirmed most of what Orla had told Sage. The manager felt that Orla is inclined to self-diagnose and that this can lead to conflicts with hospital staff.

The Care Service Manager was pleased that Sage was coming on board and hoped that Sage might be able to move the situation along both for Orla's sake and for the hospital.

Sage undertook to organise a meeting of all the services involved and to attend any such meeting as Orla's Advocate. Sage expressed the view that it was completely wrong that Orla remained in hospital with no discharge plan and this was not disputed.

It was suggested that if Orla's Home Care Package was restored, even on a temporary basis, then, perhaps, the option of her returning home could be explored with her. There was ongoing and substantial cost to the HSE for her care in a hospital room which seemed likely to continue indefinitely unless a serious effort was made to put a satisfactory and adequate Home Care Package in place.

A multi-disciplinary team (MDT) meeting was held which was attended by Orla, Sage and by 11 people all of whom were familiar with Orla's case history. The Disability Manager made it very clear from the outset that Orla no longer came under their remit as she did not meet the criteria and was therefore not entitled to a Home Care Package. Sage indicated that, in the absence of a Home Care Package, Orla will continue to take up an acute hospital bed in a private room at enormous cost to HSE when she could be at home. It was finally agreed that a further review would take place as it was clear that the current situation was very bad for Orla and for HSE staff working to provide more integrated and person centred care.

Numerous emails, phone conversations and meetings took place between Sage and HSE staff over the next few weeks with little obvious progress. Orla became increasingly frustrated with this lack of progress and her general health also appeared to be deteriorating.

"It appears to me that she is refusing to leave the hospital unless she gets a proper package of home help but no one wants to make a decision on her situation and discharge her or ask her to leave".

(Sage Advocate)

Sequence of events

- An email was received by the General Manager stating that following further discussion with Service Lead for Social Care and Business Manager of Social Care it was decided to increase the home package to 10 hours so that Orla could be discharged from hospital. This was still short of the requested 14 hours.
- There was difficulty in finding a home care / support provider that had the capacity to provide a proposed 10 hour package for Orla on her discharge.
- Sage noted in email correspondence to the hospital and community service managers that it seemed that despite all the meetings and correspondence no progress had been made in securing an adequate Home Care Package and that the situation had now reached crisis point.
- Sage pointed out that Orla's right to live in and to be cared for in her own home was being ignored. "Orla is a very vulnerable woman and every week that passes makes her situation more difficult to cope with. … you are all aware that Orla has been medically and clinically discharged for over 4 months now … Nothing has been done despite Sage's best efforts to seek an agreed plan of care".
- A further email from the Disability Services Manager highlighted the difficulty in sourcing a Home Care Package to meet Orla's needs and suggested that Orla or her family might be able to identify individual(s) not related to her who would be willing to provide her home support. Sage took the view that this option would not work and would in any case take several months to achieve. It was dismissed out of hand by Orla when she was made aware of it.
- Sage received a call from the hospital manager stating that a costing for Orla's Home Care Package of 14 hours was with the Manager of Community Care and was awaiting a decision and that a home care agency had been identified who were willing to deliver the package. However, this agency subsequently withdrew their offer.
- An email from the Disability Services Manager reported that a home support agency had finally been identified and a package had been approved by senior management in the HSE."To the absolute delight of Orla and indeed also the Hospital Manager and staff, I was there to see Orla leave the hospital and return home in time to get settled in before Christmas. Her 14-hour – 7 days a week package is in place. (Sage Advocate.
- The Hospital Manager expressed his sincere thanks to Sage for working with all services to bring about a positive outcome for all concerned.

"I found great co-operation with management and staff whilst working on this case but unfortunately some of the service providers proved difficult and very rigid in their approach to joined up thinking in order to get a speedy resolution to a difficult case" (Sage Advocate).

Issues arising from this case:

1. *Why was this situation allowed to continue for such an extended period without an urgent resolution being sought much earlier in this complex case?*

2. *Why do the various services i.e. – disability, mental health, primary care, not have a more joined up approach to cases such as this one and work together rather than simply protect their 'own' budgets?*

3. *In the matter of Home Care Packages suppliers/contractors, this case highlights the difficult situation that exists for people for whom a home care service provider cannot be found.*

4. *Further clarification is required regarding how people in Orla's situation who, for whatever reasons, fall outside the remit of Disability Services are to be catered for within the system.*

5. *Sage can be of considerable support to service providers by helping to keep the focus on the person needing support and acting as a force for collaboration.*

6. *The cost of keeping someone in an acute bed in a hospital for long periods after discharge.*

"I cannot understand why we are being told a Home Care Package cannot be put in place because there are no carers available to take up the hours required. If this in fact is the case then the problem needs to be addressed at the highest level otherwise Orla will remain in hospital with no hope of returning home for the foreseeable future".

(Sage Advocate)

Cost factors in this case

- This woman spent **22 weeks – 5.5 months** in hospital before the matter was resolved.
- **22 weeks** at an approximate figure of **€850 per day** for basic care works out at **850 x 7 x 22 = €130,900**, and this is not taking into account extras such as scans, X-Rays, blood tests, etc.
- Compare this figure against a Home Care Package of 14 hours per week over 7 days.
- **14 x 22 weeks x €20 per hour = 14 x 22 x 20 = €6,160**. (the €20 per hour is based on anecdotal information about the cost of private home care.

What people are saying…

"This has been a very successful relationship for our residents who have built up a trusting partnership with their advocate. Independent, impartial support, advice & advocacy has always been given to our residents by their Sage advocate & this has led to mutual respect, transparency & a caring environment for all."

"Our Sage advocate has really helped people be fairly treated who might otherwise have been left unaided."

"The Sage advocate has a challenging role at times and this was not always welcome and some families vehemently objected to this role of advocate."

"Unfortunately staff can be resistant to the support offered to the older person, but (advocate) always managed to refocus their perspective.

"(Advocate) is a real champion for the rights and respect for older people"

"I found this role to be a reassurance where a vulnerable person is involved, despite the challenges that this may present to the service/staff. The focus is always with the resident first."

"Sage runs a very valuable and relevant Resident's Council here in (nursing home). This can put me under pressure at times but rightly so!! The residents are given a strong voice through this forum"

"The Sage Representatives are courteous, respectful and are very aware of the challenges faced on a daily basis in nursing home life. They manage to balance strong advocacy while at the same time build healthy relationships with nursing home employees and managers. It seems genuinely like a partnership with the well-being of the resident at the heart of the process."

What people are saying…

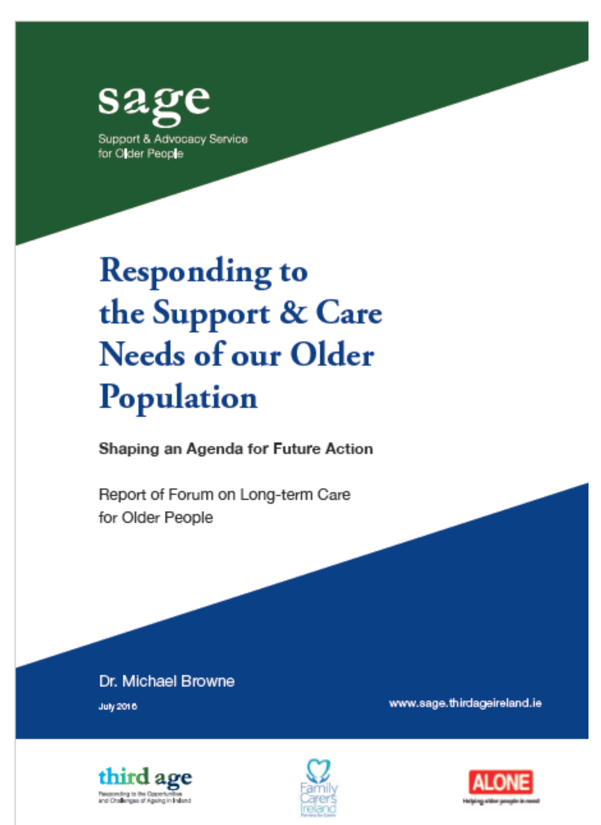
"(The advocate) has supported me as Person in Charge through some very difficult times with problems associated with inappropriate placements of residents from the Disability Services and Mental Health Services, and I greatly appreciate her support and advice."

"The work of Sage is so important giving frightened, vulnerable elderly people a voice and helping them take back power and control of their lives and enabling them to live out the remainder of their life with dignity, peace and tranquillity."

"My Mom is not going to get better, but she is living at home which would have been her wish and I feel that because Sage helped me when I needed it, we now have a good plan in place and great support within the community from the HSE. Sage has been invaluable to my Mother and us her family in our ongoing care journey."

"I will forever be indebted to you for all you have done to help me gain access to my life again."

9. The Forum on Long-Term Care for Older People


sage
Support & Advocacy Service for Older People

Responding to the Support & Care Needs of our Older Population

Shaping an Agenda for Future Action

Report of Forum on Long-term Care for Older People

Dr. Michael Browne
July 2016
www.sage.thirdageireland.ie

third age
ALONE

The Minister for Mental Health and Older People, Helen McEntee T.D, opened the public session of the Forum on Long-Term Care for Older People on 15th June 2016.

The Minister said: *"Today's forum initiated by Sage and supported by Third Age, Family Carers Ireland and Alone, is a wonderful opportunity to discuss one of the most challenging issues facing some of our older people – long-term care."*

Left to right: Áine Brady, Third Age; Prof Cillian Twomey; Helen McEntee, Minister for Mental Health & Older People; Patricia Rickard-Clarke

"Growing old should never be considered a burden on society. We need to be able to cater for the needs of a more diverse, ageing population and older people are clearly the best people to inform us how to do this."

Nationwide Public Opinion Survey

As part of the work of the Forum, Amárach Research was commissioned to undertake a public opinion survey. The Forum heard the results of this survey which sought to establish the views and preferences of the general public with regard to: how long-term care should be funded; where they would like to receive long-term care should you need it; who they think should provide long-term care to older people who require it; what importance specified supports might have in enabling people who require longterm care to continue to live in the community.

KEY FINDINGS:

- In terms of funding long term care, the greatest overall preference is through general taxation.
- 'Downsizing' accommodation to generate additional funds is a much less popular option to provide funding. This may have more of a tangible effect on peoples everyday life and a less accessible option overall.
- 'Funding through general taxation' is preferred more as respondents increase with age from those aged 25-34, this group are possibly entering into a steady career are therefore least in favour of this option.
- Being cared for in their own home is the most preferred option for respondents if they should ever need long term care.
- Being cared for by 'another family paid to do so' is least preferred by respondents. Although there is a greater level of preference for this option by those in the C2DE social class compared to those in the ABC1 social class.
- The second least preferred option is being cared for in nursing home care, despite the fact that there is an entitlement to health service in this case (through the NHSS).
- Overall, there is greater preference for the HSE to be responsible for providing long term care to older people who require it.
- 'The Voluntary sector funded by the state' was selected as the lowest preference by the greatest amount of respondents across all options, for who should provide long term care.
- 'Family and relatives' living close are ranked as most important for enabling those with long term illnesses to remain in the community, this does not appear to extend to neighbours and friends.

Oireachtas Committee on the Future of Healthcare

Opening Statement on behalf of Sage by Dr Michael Browne,
9th November 2016.

Introduction

In January 2016 Sage, in partnership with Third Age, Family Carers Ireland and Alone established a Forum on Long-Term Care for Older People. Submissions from the public, a nationwide public opinion survey and a conference produced a report which has been made available to the committee. The key message from the work of the Forum was that despite three decades of policy recommendations to the contrary there is still a systemic bias towards care in congregated settings. The same theme of bias towards the acute side of the health services is reflected in almost all other reports on the health and social care services.

In the face of such an overwhelming consensus of public policy around home and community supports and care, and of a nationwide public opinion survey which reinforced the popularity of such policies, it can be difficult for the public to understand the depth of administrative resistance to change and the lack of political will to challenge this resistance. The public opinion survey showed:

- Being cared for in their own home is the most preferred option for respondents if they should ever need long term care.
- In terms of funding long term care, the greatest overall preference is through general taxation.
- There is greater preference for public provision of long term care for older people, considerable support for social enterprise and least support for provision through the private sector.

There was also a consistent message coming through the proceedings, and reflected in many of the submissions, that the issue is as much to do with the basic support infrastructure, often minimal but nevertheless necessary, as it is to do with care and the intervention of providers whose focus can often be as much on the priorities of their profession or department/agency as on the needs, and the capabilities, of those requiring services and supports.

The gap between the decades of rhetoric supporting home and community care and the reality that congregated settings have become synonymous with long-term care, is large. It can however be tackled by effective and determined action.

What the main issues and concerns are

- There is a major discrepancy in the Irish health care system between the way care for people with acute illnesses and those with a slow debilitating illness (such as dementia) is funded – a core question to be addressed by society and by Government is whether or not this is it is right or equitable.
- While there is broad acknowledgement of the principle of enabling people to exercise their will and preferences in the way care is provided, the reality is that some people regularly end up in nursing homes against their will because of a lack of community-based alternatives.
- There is still much to be done to ensure that the design and location of nursing homes caters for key quality of life considerations – community access, maximising individual capacity and self-expression and individual preferences.
- People's inability to access the therapies that they require in order to optimise capacity (e.g., occupational therapy, physiotherapy, speech and language therapy) at a level commensurate with need impacts greatly on their quality of life and general well-being – addressing this deficit in provision is clearly possible within existing resources.
- While there is a need to bring in new legislation to achieve equality of access to care in the community and nursing home care, the funding of care and support in the community commensurate with need does not require new legislation – rather it requires social consensus on the matter and related political will to allocate the resources required.
- Multi-purpose community-based units providing a continuum of support and care (day facilities, sheltered accommodation, nursing units) can contribute enormously to enabling people to live independently or semi-independently and should be made an integral part of the community care infrastructure – such models could be developed initially in locations where existing public long-term residential care facilities have been deemed to be no longer fit for purpose.
- A community-based social enterprise model of support and care delivery supported by the State has significant potential to target interventions at the lowest appropriate level and to optimise quality of life accordingly.
- Inter-agency collaboration and interdisciplinary working at local level needs a dynamic impetus and energy on the part of all those charged with delivering supports and services to older persons and inter-disciplinary working needs to be more embedded in the community care delivery system.
- The potential of appropriately designed housing has not been developed to date in Ireland; there are appropriate models of 'housing with care' that have been developed in other jurisdictions and some in Ireland that can and should be replicated nationwide. There is a need for Local Authorities to take on much more responsibility for the provision of sheltered and supported housing.

Need for a gerontologically-attuned approach[1]

More attention is required to ensure that best gerontological practice is always applied in meeting the specific nursing, medical and personal care requirements of people with complex care needs in both residential care settings and in the community. There is a dearth of appropriately designed and staffed dementia-specific accommodation, including both assisted living housing and full residential care – this gap in provision needs to be addressed a s matter of some urgency;

The Nursing Home Support Scheme (NHSS)/'Fair Deal'

While the NHSS is a large area of health expenditure, there is little focus on outcomes, quality of life domains or on the creation of greater choice to reflect and respect the will and preference of people who require nursing home care. The current model of fee negotiation between the National Treatment Purchase Fund (NTPF) and nursing homes in respect of the NHSS is unsatisfactory, particularly, because it only provides for 'bed and board' and takes no account of different individual care, support and quality of life needs.

A preventative approach

Much more can be done at local community level to prevent or delay the onset of conditions that require more extensive and more expensive care and support, including, in particular accessible transport and initiatives to combat social isolation and loneliness. Housing policy should include provisions for future proofing in respect of adaptations required to cater for reduced mobility.

Building on best international practice

Ireland can learn much from practice in other jurisdictions with particular reference to:

- Models of financing
- Eligibility and access criteria for health, housing and social care support
- Models of financing
- The individualised payments approach
- The optimal balance between funding for community-based care and for residential care
- The devolved responsibilities of local government (municipalities) in providing long-term care accommodation, support and services
- Integrating mainstream housing provision and specialised accommodation provision
- Legal frameworks relating to people's rights in respect of long-term care

1 This is an approach to support and care based on a multidimensional assessment of the needs of a person with increasing dependency, including medical, physical, cognitive, social and spiritual components. It is an integrated and interdisciplinary response to an individual's assessed needs – medical, nursing and psychosocial.

Next Steps

Develop a Popular Vision: We will not make the changes we seek unless we develop a popular vision of how things could be. Home, hospital, hotel, hospice – all share the same common denominator – hospitality – care for others. We need to develop a vision for long-term support and care which is as compelling as that of the hospice movement at its best.

Commission Based on Outcomes: Commissioning[2] should be based on outcomes, rather than block grants and outsourcing for particular aspects of care. The percentage of older people being supported and cared for in the places of their choice according to their will and preference and their changing needs – this has to be seriously considered as one of the objectives of commissioning. The Report of the Expert Group on Resource Allocation and Financing in the Health Sector[3] stated clearly that "… the key issue is not whether Ireland has a social health insurance model or continues to fund health care out of taxation, but rather how to structure the financing system so that it supports the stated health-care objectives". If there is to be a continuum of support and care then funding for it must reflect that continuum.

Link Housing & Health: Housing and health and social care can no longer remain parallel lines. They must converge. For this to happen we need to focus as much of our energy on local government as on national government; on housing policy as much as health and social care policy. The public sphere must be enriched through innovation and this can best happen at local level[4]. County development plans need to reflect the valuable economic and social roles of older people as well as their healthcare needs.

Best Use of resources: Resources are limited so we need to make the best use of them. We may also need more resources. Providing more hospital accommodation and related services is, in the current circumstances, entirely consistent with necessary moves towards primary and community care. It may also be the case that the provision of a wider range of nursing roles at community level, such as advanced nurse practitioners, employed and organised by public health services may be as useful as the provision of more GPs.

Measure the Scale of the Problem: What gets measured gets focused on. Almost all the popular indicators of shortfall in supports and services for older people are focused on the acute sector. The lives of 'quiet desperation' experienced by some older people in their homes do not assault the national conscience in the same way as they might if they were in hospital. The social realities (frequently hidden) of people in the community who require long-term care and support and their families need to feature much more strongly in the public discourse.

Think Nationally – Act Locally: National thinking now needs to be matched by well planned initiatives at local level so that communities can get a real sense of what 'good' looks like and can play a part in

2 Broadly speaking, Commissioning is best understood as a process aimed at linking resource allocation with meeting assessed needs and achieving positive outcomes for service users in a cost-effective manner. This applies to all such services whether they are provided directly by a statutory agency, by the private or voluntary sector or through public–private/voluntary partnerships.

3 http://health.gov.ie/blog/publications/report-of-the-expert-group-on-resource-allocation-and-financing-in-the-health-sector/

4 See 'Housing for Older People – Thinking Ahead' http://isax.ie/housing-for-older-people-thinking-ahead/

shaping it[5]. This is consistent with evidence of a growing realisation within the state sector that more consideration needs to be given to developing alternative models for the delivery of services for older people and people with disabilities and that commissioning of services needs to be focused on outcomes for individuals rather than grants to organisations. Too often local communities and concerned relatives are left 'defending the indefensible' by rallying to save outdated and outmoded institutions in the absence of alternative models that they can look to.

Change and innovation in the way services are delivered

We fully endorse and are encouraged by two of the key points made by HIQA in their submission on the Department of Health's Statement of Strategy 2016-2019 which stated (a) that there is a consensus that Ireland needs to move away from the current hospital-centric model of care and introduce integrated care pathways across primary, community and secondary health and social care structures and urge that this be expedited. (b) the need for alternative social care models. In this regard HIQA state that"more consideration needs to be given to developing alternative models for the delivery of services for older people and people with disabilities. Such models would potentially provide incremental pathways of support and care aligned with the changing needs of the person, thereby allowing them to be supported to remain in their own homes for longer, nearer their families and friends. This process should be supported by local commissioning arrangements".

Alternative approaches have been carefully researched for a report 'Individual Needs – Collective Responses' which suggested that social enterprise – business with a social purpose – can be used to protect and enhance the added value of community participation and civic innovation in the context of increased outsourcing of health and social care and the development of public service 'markets'.[6] This work was presented to the National Economic and Social Committee in 2014 and to the then Secretary-General at the Department of Health and Minister for Older People. Despite their clear statements of support for the development of new models there was no follow up from the department. This, together with the lack of progress in implementing consensus policies developed over decades, suggests that there is an urgent need for innovative leadership at central and local government, departmental and HSE levels.

Such innovative leadership is required in order to broaden the policy discussion to embrace human rights principles and to achieve a different balancing of priorities and resourcing within the health and social care sector and by Government.

5 Sage is planning a further event to explore how national policies on ageing, urban and rural community regeneration and public service reform can be aligned at local level. It will explore the potential for using strategic infrastructure investment, public realm improvements and adaptive reuse of old buildings (some traditionally used to care for older people) can be used as catalysts in pump priming wider community initiatives for the regeneration, vitality and viability of towns, communities and local economies. Crucially it will explore how a combination of architectural design, public service redesign and a focus on outcomes can help communities create physical and social environments and systems which support the will and preference of older people, build a strong sense of civic pride, and act as centres of national and, perhaps, international learning.

6 Individual Needs – Collective Responses: The Potential of Social Enterprise to Provide Supports and Services for Older People Assessment of the National Business Case. Kieran McKeown, Jonathan Pratschke, Trutz Haase. January 2014.

This requires, *inter alia*:

- Providing a legislative framework for equality of access to community care services
- Promoting an open and honest discussion about the respective responsibilities of the State, families and local communities in providing long-term care for those who require it
- Fundamentally reviewing the NHSS model and the role of the NTPF therein
- Examining how the financing of long-term care is to be provided for in a manner commensurate with need
- Exploring ways of delegating functional responsibility and related funding for integrated housing and care supports to local government and local administrative structures
- Developing realistic alternatives for the provision of support and care to people who do not wish to spend the last years or months of life in a nursing home
- Developing structures to pioneer and develop innovative housing with care initiatives by:
- Building on the strong track record of NGOs in this area
- Developing social entrepreneurship initiatives

Phased Developments

There is a need to acknowledge in a fundamental and open manner the shortcomings of the present situation:

- Primary and community care continues to be relatively underdeveloped in Ireland;
- Acute care in all forms is privileged over other health and social care; and
- Planning, provision and payment for both is disjointed and lacking in transparency

In doing so, it is essential that the response is not based on a 'big bang' approach such as characterised the establishment of the HSE. Rather, a considered move is recommended beginning with alignment of acute and primary/community care structures and budgets, development of outcomes for the different areas of intervention guided by national guidelines followed by a series of steps involving commissioning based on outcomes and single funding sources which are both informed by evidence and tested through pathfinder areas. It is absolutely essential that a single funding source be created so that clear incentives are available to use available funding in the best possible way rather than have people leaving the primary / community sector because funds have run out to enter a high cost acute system because it has more funds available.

Legislation

My colleagues here today Professor Cillian Twomey and Patricia Rickard-Clarke, from their respective professional backgrounds of medicine and law, will be able to provide detailed insight into specific aspects of the challenges facing the health services. In 2011 the Law Reform Commission in their report Legal Aspects of Professional Health Care[7] provided a DRAFT Health (Professional Home Care) Bill to provide for the regulation of professional home care. This draft legislation could easily be updated and developed to ensure that the provision of supports and care in the home and the regulation of same could be legislated for within a reasonably short time frame[8]. The issue of charges for such services might well be left until an outcomes based approach to commissioning is developed. Otherwise the focus may remain on the charges and not on what is needed to achieve the determined outcomes.

Addressing the challenge of long-term care financing

The matter of funding long-term care needs to be addressed urgently by society generally and by Government with particular reference to:

- What is the optimal level and type of care and support?
- How much are we as a society prepared to invest in this area?
- What are the respective responsibilities of the State and individuals in financing and planning for long-term support and care?
- How do we get from where we are now to where we want to be?

There is a need for a national consensus (political and civil society) approach based on the existing broadly agreed parameters of how long-term support and care should be delivered and funded and the development of an agreed action agenda accordingly.

Long-term Care and Support Strategy

An evidence-based National Long-Term Care and Support Strategy is required which would include:

- The dimensions of support and care
- The options that are desirable and possible
- The likely cost of each of these options
- How these might be funded in the short, medium and long-term
- An implementation framework and timescale to include national, regional and local dimensions and respective departmental/ agency responsibilities

7 http://www.lawreform.ie/_fileupload/reports/r105carers.pdf
8 Sage is currently exploring this approach

Conclusion

There is a broad consensus on the direction that our approach to supporting older people who need care should take. This includes enabling people to stay at home and in their own communities for as long as possible, the need to cater for people at the lowest appropriate level of complexity and the need to provide high quality residential care when and if this is needed.

We know what needs to be done but actually doing it requires new thinking, innovative approaches and the availability of a mix of accommodation choices to enable progression as support and care needs change. We need to develop a vision for long-term support and care which is as compelling as that of the hospice movement at its best.

A commissioning approach to service provision which responds to the will and preferences and changing needs of people and related outcomes has to be seriously considered as a key component of a Long-term Care and Support Strategy.

If there is to be a continuum of support and care, then funding for it must reflect that continuum. Housing and health can no longer remain separate silos.

Nothing about you/ without you

SageAdvocacy.ie