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The experience of Sage Advocacy – lessons learned during COVID-19

Eileen O' Callaghan
Regional Manager, South
Sage Advocacy

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Sage Advocacy Mission Statement

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"To promote, protect and defend the rights and dignity of vulnerable adults, older people and healthcare patients."

OUR MISSION STATEMENT

The right to have your voice heard and to participate in making decisions which affect you is a fundamental principle in a democratic society. It is a principle simply stated as "Nothing about you /without you".

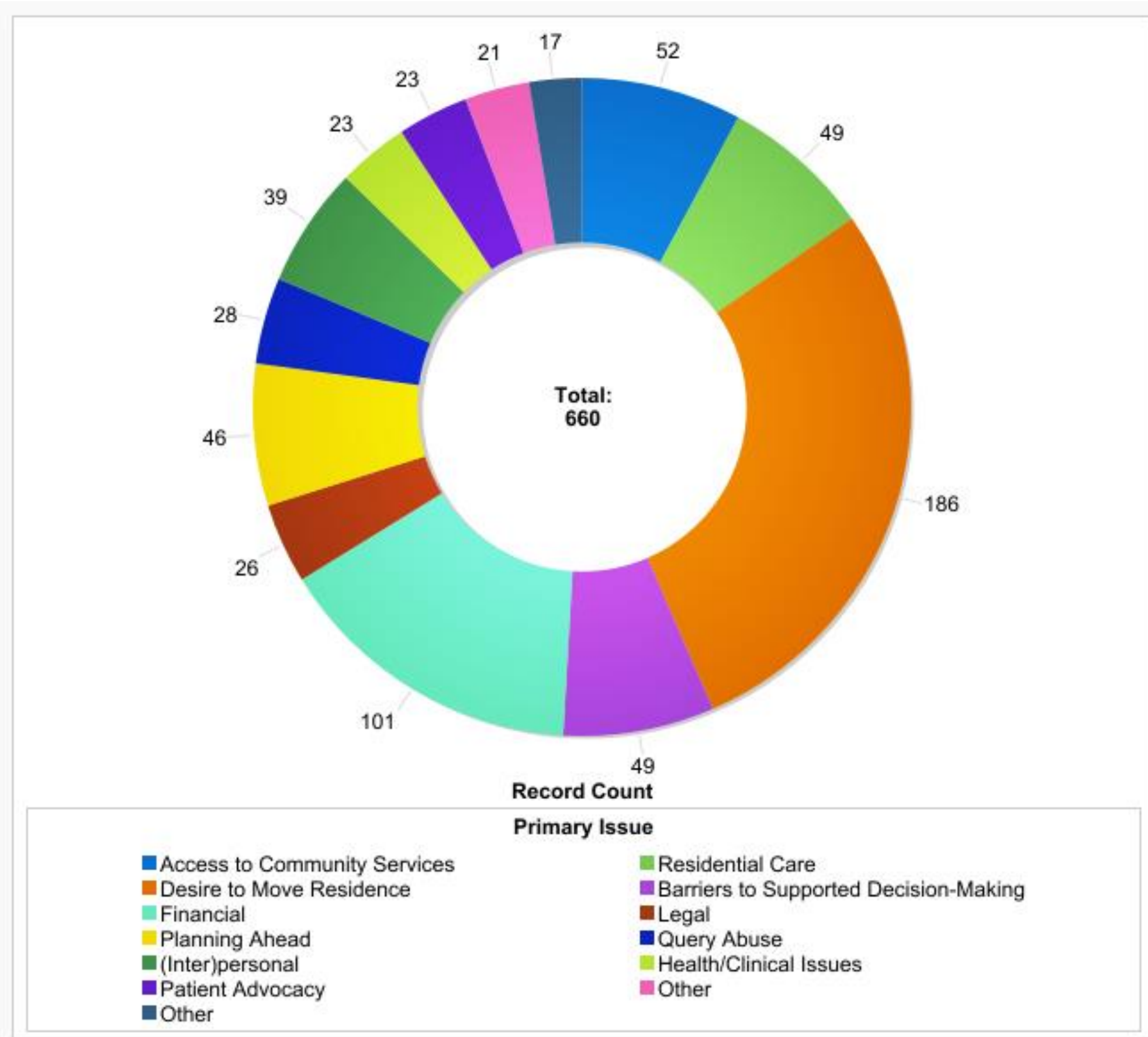
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Sage's work – some recent examples

- Advocating for adequate **Home Care Packages** and for a comprehensive and equitable system of home care support and oversight of home care providers
- Challenging unnecessary restrictions on people's liberties and the use of '**convenience medication**'
- Promoting self-advocacy and professional development through **workshops** on capacity and decision making, enduring power of attorney and advance healthcare directives
- Supporting people to **return home** from hospital or care centre
- Assisting people to **maintain control** of their income benefits or property
- Supporting family members in organising care for people with **advancing dementia**
- Advocating with and for people with intellectual disabilities who are trying to develop a life with **meaningful activities** after they leave a congregated setting
- Observing or **facilitating meetings** of residents, family members or staff in nursing homes
- Promoting **awareness** of Sage's services in communities, General Practices, day-centres, nursing homes, hospitals, hospices and hostels

Primary issue / reason for seeking the support of Sage:



How do we support decision making in a context of limited options?



What we learned from Covid 19?

- **Highlighted what we can do well:**

- Volunteerism – responding to the needs of older people in the community
- A flexible approach – ‘vulnerability became everyone's business’, professionals willing to operate outside of their ‘normal’ role
- Increased collaboration was possible
- Urgent Home Care Packages put in place to facilitate discharges from acute settings.

- **Highlighted what wasn't working:**

- Two - tiered system of care
- Lack of engagement between the private nursing home sector and the HSE
- Over reliance on residential nursing homes
- Inadequate clinical oversight in private nursing homes
- Issues with accessing home support and nursing home alternatives.

Lessons for Long term Care – The Perspectives & Experiences of Sage Advocates

- Nursing home staff & residents felt forgotten.
- Impact of visitor restrictions on residents and loved ones.
 - Balance of risk and autonomy and supported decision making.
- Communication & Information:
 - Discrepancies in nursing home provision of information to both residents and loved ones.
- End of Life care:
 - Lack of clarity around visitation and support.
- Isolation:
 - Impact – emotional, physical and mental of confining residents to their rooms.
- Nursing home staffing and resource issues:
 - Staffing levels, emotional impact etc
- Overall cohesive response by acute hospitals:
 - Increased discharges
 - Increased availability of large Home Care Packages
 - The impossible suddenly became possible (resources, funding & mindset).
 - Transfers to nursing home without NHSS applications – beginning to see referrals from residents looking to return home
- Home Care supports:
 - Regional discrepancies re availability & provision
 - E.g. One example of a large package of 27 hours being approved on one area, small home care packages cancelled on other areas.

Changing the architecture of long term support & care

Existing model	Model envisaged
<p>A 2-tier system;</p> <p>A privatised model;</p> <p>25,000 supported by NHSS;</p> <p>54,000 Home Care Packages;</p> <p>Home care supports underdeveloped;</p> <p>Little integration between health and social care supports and housing;</p> <p>Absence of community connectedness by nursing homes;</p>	<p>All people requiring LTC living at home or in a place which feels like home;</p> <p>State-supported housing options that support ageing in place;</p> <p>All services and supports grounded in a strong community connectedness;</p> <p>Multi-purpose community-based hubs providing a continuum of supports, including nursing care;</p> <p>Appropriate remuneration, training and support for care workers and LTC nurses;</p>

Current Challenges in Supported Decision Making

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- Covid 19 being used as a 'blocker' to facilitate supported decision making by both family members and professionals.
- 'Capacity' being used to determine discharge planning instead of first, how to support patient's wishes.
- 24/7 supervision/care is recommended as discharge plan when this is impossible to achieve in community (and often exaggerated).
- Reliance on family / attributing decision-making authority to 'next of kin' – not a legal decision maker – should be a CONTACT person.
- Poor awareness of HSE Consent Policy / Principles of Assisted Decision Making (Capacity) Act.
- Lack of alternatives to Wardship while waiting for full implementation of the Decision Support Service.



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Success is:

- ✓ Person centred – encourages positive risk taking,
- ✓ Integrated working between acute, step down, community and advocacy services,
- ✓ Challenging the status quo,
- ✓ Decision-making from the person's perspective, not legal / medical perspective,
- ✓ Increased home support options,
- ✓ Early engagement of an Advocacy service in complex cases,
- ✓ Maintaining the flexibility & openness Covid 19 brought,
- ✓ Sharing learning through participation in practice development.

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Information & Support Rapid Response Service

1850 71 94 00

8am – 10pm daily

Leave your name, a contact number and a very brief description of the issue. Our aim is to respond to you within an hour. When urgent support is required an experienced Sage Representative can be available nationwide within 24 hours.

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