



Mental Health
Foundation



Values, Equalities and Rights in Dementia: Learning from a National Network

2016-17 Report

**“Nothing about us,
without us.”**

Agnes Houston MBE

The Values, Equalities, Rights and Dementia network (VERDe) has connected people with dementia, carers, practitioners, policy makers, services, organisations and communities across the UK. Through a series of events VERDe has aimed at increasing awareness and understanding about how values, rights and equalities affect people with dementia and can help improve dementia policy and practice. VERDe has been coordinated by the Mental Health Foundation, supported by Innovations in Dementia, and funded by the Joseph Rowntree Foundation and the Life Changes Trust (which is funded by the Big Lottery Fund).

In the past ten years, the landscape has changed significantly and the profile of dementia has risen in policy, research and practice. It is also encouraging that a more preventative approach to dementia is beginning to achieve traction in public policy debates. The growing focus on the links between public health and dementia is promising in reflecting how dementia is beginning to be seen through lenses that go beyond the more traditional disease-treatment-care models. However, as the paradigm changes, we are still facing considerable challenges in taking dementia into wider policy spheres, which is why a focus on fundamental values, equality principles and human rights is urgently needed. We have tried to address this gap with the VERDe project.

Since January 2016 we built a network of 250 interested participants and stakeholders and held six engaging events in England, Wales and Scotland. A total of 113 people attended our events (an average of 37 people per meeting), which included people with dementia, carers, clinical practitioners, co-ordinators of local dementia networks, and policy officers and advisors from leading charities or government.

In our first meeting, Jim Pearson from Alzheimer's Scotland, reminded that dementia rights start in "*small places*", a phrase Eleanor Roosevelt used to describe the application of human rights. These small places can be in the daily acts of care and support for people with dementia.

Also early on, Dementia Champion, Joy Watson, spoke about the strength of VERDe, in particular the vast expertise of those living with dementia in attendance; "*Our passion is for people to come together*".

A key part of VERDe, the Dementia Engagement & Empowerment Project (DEEP), played a big role in these events. It is a UK-wide network of over 80 independent groups led by or actively involving people with dementia in influencing policy, practice, and the communities they live in.

In the course of the VERDe events:

We heard several examples of how health and social care services often seem unaware of rights when providing care and support, and people with dementia and carers are frequently too busy or overwhelmed trying to sort out the basics to have time to think in terms of rights.

We learned that more women than men experience dementia and there are more women caring for people with dementia. There is “*a sandwich generation*” of women looking after children, parents, and often grandparents. Dementia policy and practice needs to be more sensitive to the differences in experience of dementia between women and men.

We identified that over a third of people with dementia (incl. families and carers) do not seem to have a voice in choosing how they can live their life. We agreed that a national dementia strategy needs to be inclusive and underpinned by values like non-discrimination and empowerment.

We heard of research that has shown that people with dementia are less likely to have a palliative care plan. Barriers to having advanced plans on death include: poor recognition of dementia as a terminal condition, ineffective advance care, lack of timely diagnosis, inconsistency in care standards, and inequality of access.

VERDe has been successful in communicating and publicising such issues. In this context, our discussions focused on proper involvement of people with dementia and carers, the role of advocacy, engagement with excluded or disadvantaged groups such as women and minority ethnic communities, and collecting and sharing examples from across the UK.

Key dementia policy experts have shared insights in our events:

Philly Hare, Director at Innovations in Dementia, consistently emphasised the need to “*focus on people with dementia as citizens and rights holders*”, not solely as patients or service users. The importance of community solutions to support people with dementia to live well has been a common thread, along with challenging conventional views about dementia trying to offer important insights and solutions. Further, identifying the gap between the medical and social model of dementia has been vital to raise awareness of rights-based approaches with health professionals.

Anna Buchanan, Director at Life Changes Trust, highlighted the values that need more consideration by the national governments when developing policies, including: listening to people living with dementia and their families as the true experts in what they need, incorporating robust annual reporting that is clear to people with dementia, fostering relationships between national and local government, and third and private sectors, central in getting it right for people living with dementia.

Simon Chapman, Director of Policy & External Affairs at The National Council for Palliative Care, encouraged use of existing legal frameworks and place-based approaches to understand how dementia affects the needs of people; he asked: “*What if dying becomes a social event again?*”

Peter Mittler, Emeritus Professor of Special Needs Education at the University of Manchester, stressed that in 2017 the UK government is meeting the UN Committee which will ask detailed questions about abuses of human rights of those with disabilities, including dementia. Sharing experiences and examples of abuses of rights through VERDe and DEEP is important.

The events have also been a forum for practical suggestions:

People living with dementia talked about principles that can be followed post-diagnosis, including: living hopefully, being treated well and with respect regardless of age and ability, attending local groups to give and receive support, participating in research equally, participating in society, (e.g. doing shopping and using public transport).

We saw demonstrations of useful practical developments to support and empower people living with dementia, such as ‘The Salford Way Dementia App’, developed in collaboration with around 120 local stores and co-produced with people with dementia.

Belonging to social groups has been raised as being particularly important as it gives a sense of identity, not as disadvantaged individuals but as active members of society.

Innovations through digital support or ideas like making blue badges available for those living with dementia received widespread support, as we learned about the independent living movement and explored how the learning from it can be applied to dementia.

In general, participation and empowerment have been highlighted as good examples of a human rights-based approach in action.

VERDe has coincided with several relevant important events:

Our third meeting was at the heart of current development by the Welsh Government of a Dementia Strategy, and was attended by the National Mental Health Director for Wales. In Edinburgh, we interacted with people directly involved in influencing the Scottish Government’s 3rd Dementia Strategy 2016-19, focused on improving community support.

We saw the publication of the high profile “*Our Dementia, Our Rights*” guide co-produced by The Dementia Policy Think Tank and Innovations in Dementia CIC. Mental Health Foundation’s report “*What is truth? An inquiry about truth and lying in dementia care*”, commissioned and funded by the Joseph Rowntree Foundation, was also published this year.

We hope that the learning, network and momentum generated by the VERDe project will be sustained in the years to come. The energy and learnings from VERDe will be harnessed going forward from DEEP.

“Overall, people diagnosed with dementia are humans and the people who care for those with dementia are humans too, thus a lot of the issues discussed are, above all, human rights issues.”

Nigel Hullah, Dementia Policy Think Tank