

What can countries in the UK learn from each other about values, equalities, and rights in policy and practice affecting people with dementia?

Values, Equalities, Rights and Dementia network (VERDe)

Report of the first VERDe meeting – 25 January 2016, Edinburgh

Introduction

What's the relevance of issues such as rights, equalities, inclusion, and empowerment for people with dementia and their carers? Are they just luxury add-ons to awareness raising about dementia, improving diagnosis rates and care pathways for dementia, and research into disease-modifying treatments or fundamental to the lives of people with dementia, carers, practitioners, services and communities involved in supporting people with dementia? The Values, Equalities, Rights and Dementia (VERDe) is a new UK network that held its first meeting in Edinburgh in January 2016 aiming to answer questions like these and demonstrate how thinking, policy and practice involving these issues is vital in order to improve and develop policies and practice, services and communities for people with dementia and their carers. There is more background information about VERDe at the end of this report.

Report on the day

Fifty people attended the first VERDe event in Edinburgh in January 2016. Participants included people with dementia, carers, practitioners, academics and policy makers. The majority were from Scotland but there were also participants from England and Wales.

The day was co-chaired by **Toby Williamson** from the Mental Health Foundation, and **Agnes Houston CBE**, who lives with dementia and is a former chair of the Scottish Dementia Working Group. A key element of VERDe and rights-based approaches to dementia is the active participation of people with dementia and each VERDe event will involve a co-chair who lives with dementia.

Presentations used on the day can be found [here](#).

Toby and Agnes opened the day by welcoming participants, describing the background to VERDe and the aims of the day. Agnes emphasised the links with the Joseph Rowntree Foundation's (JRF) *Dementia Without Walls* programme, the importance of involving people with dementia and VERDe being a UK wide network, enabling learning across all four countries – “*transcending Hadrian's Wall*” as she put it.

Philly Hare, the programme manager responsible for *Dementia Without Walls* described the programme and its key values, and made the links with VERDe (presentation not available on the website):

- A focus on people with dementia as citizens and rights holders, not solely patients or service users;



- The importance of community and community solutions to support people with dementia to live well;
- A focus on groups affected by dementia who experience exclusion and inequalities such as women, or people with more severe dementia;
- Challenging mainstream and conventional views about dementia where different ways of thinking may offer important insights and solutions.

Anna Buchanan from the Life Changes Trust (LCT) in Scotland then talked about the work on dementia that the LCT is supporting. She set the work of the LCT in a wider context of VERDe and policy making that incorporated rights-based approaches. However, she concluded her presentation by asking the audience, and VERDe, how could rights be made real and meaningful for people with dementia and their carers?

Following a break **Toby** described the work of the Mental Health Foundation that illustrated the key components of VERDe (these included are in the slides which introduced the day). Values were demonstrated by a national inquiry into different realities and beliefs experienced by people usually with more severe dementia. Equalities was illustrated by a project mapping European dementia friendly communities, and rights were the focus of a report published by the Mental Health Foundation in 2015 called *Dementia, rights and the social model of disability*.

Steve Milton from Innovations in Dementia, described the work of the Dementia Engagement & Empowerment Project (DEEP), a UK-wide network of independent groups led by or actively involving people with dementia in influencing policy, practice, and the communities they live in to improve the lives of people with dementia. Participation and empowerment are good examples of a human rights-based approach in action and Steve reminded the audience of how far the involvement of people with dementia has come over the last 10 years – there are now over 60 groups connected with DEEP compared to only 20 four years ago.

Lunchtime had a good buzz of people talking connecting and making new contacts.

After lunch the focus was on Scotland and heard firstly from **Irene Oldfather** from the Scottish Health & Social Care Alliance. She described the work she and the Alliance had been involved with in supporting the development of a Charter of Rights for People with Dementia and Carers in Scotland. However, despite the Charter, there are still plenty of examples where awareness/ understanding about rights is lacking. Irene emphasised how it's everyone's duty, "*a moral duty*", to change this and ensure human rights are applied meaningfully.

Following Irene **Michelle Miller** from the Scottish Government illustrated the need and effectiveness of a human rights-based approach with two stories about people with dementia, one of whom was Michelle's grandmother. It was a reminder that while more work needs to be done, rights articulated in the Charter are making a difference, such as the right to post diagnostic support.



The last speaker, **Jim Pearson** from Alzheimer's Scotland, reminded how rights started in "small places", the phrase Eleanor Roosevelt used to describe the application of human rights. These small places could, and should, be in the daily acts of care and support for people with dementia. To help make the Charter meaningful in these contexts roadshows around Scotland were being used.

The final session of the day posed the question for roundtable discussions, '**how can VERDe influence and enhance dementia policy and practice in Scotland and the UK?**'. Here's a selection of some of the responses:

- Identifying the gap between the medical and social model of dementia – vital to move to the social model for early support and having local/practice examples of this
- Importance of evaluation and involving the "unconverted" e.g. media, citizens' organisations, etc.
- Local groups doing "group peer support"
- Connecting with excluded groups affected by dementia e.g. Black, Asian and minority ethnic groups, carers, etc.
- Challenging the stigma associated with dementia
- Raising awareness of rights-based approaches with GPs, other health professionals, etc.
- Continuing to raise the importance of early diagnosis
- More information needed about pathways/descriptions for legal frameworks (e.g. Adults with Incapacity (Scotland) Act, Mental Capacity Act etc.) relate to people with dementia and carers
- Relevance of advocacy in supporting rights-based approaches especially for people with more severe dementia
- Working in and with communities
- Action, not just words!
- Use Dementia Without Walls website to collect practice examples, case studies of a rights based approach in action e.g. using PANEL¹ principles
- Enabling participation in VERDe at different levels and in different ways – On our Radar²/DEEP to ask people the question – what do values/rights/equalities mean to you?

Feedback on the day

Feedback from participants indicated that the majority of people found the day extremely useful and well organised were very positive although some people would have liked more time for discussion and to hear more practical examples of rights-based approaches.

¹ PANEL is a tool for operationalising human rights and stands for Participation, Accountability, Non-discrimination and equality, Empowerment, Legality.

² On our Rada is a media project collecting thoughts, views and feelings directly from people with dementia.

Some quotes from feedback forms

What did you find most useful about the day?

“The naming of the issues (Philly, Anna, Toby, Agnes) and the outline of the resources available to tackle them (Anna, Steve)”

“Learning about the peer support which is taking place and influence of people with dementia in policy making”

What did you find least useful about the day?

“1 less speaker, 1 more roundtable [discussion]”

Summary

A theme from the days was that it's all very well talking about rights and producing policies, documents, words using rights-based approaches but how do they actually get turned into something positive and transformative in the lives of people with dementia (the *“grittiness of rights”* as one participant put it)? Several examples were given of how health and social care services often seem unaware of rights when providing care and support, and people with dementia and carers were frequently too busy or overwhelmed with trying to sort out the basics to have time to think in terms of rights.

These challenges are for VERDE to communicate and publicise, but also address in subsequent events. A focus on rights in practice through the proper involvement of people with dementia and carers, the role of advocacy, engagement with excluded or disadvantaged groups such as women and Black, Asian and minority ethnic communities, and collecting and sharing examples from across the UK, are some of the ways these challenges will be met.



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About VERDe

The Values, Equalities, Rights and Dementia network (VERDe) aims to embed different thinking and a rights-based approach in policy and practice for people living with dementia. It is doing this through holding six events across the UK over an 18 month period, bringing together a network of influencers, community activists, project providers, practitioners, people living with dementia, their families and friends established by different thinking and a rights-based approach to policy and practice concerning rights and ethics for people living with dementia. Each event aims to attract 50-60 people. Information about the events including presentations and a report is available [here](#).

VERDe builds upon the Joseph Rowntree Foundation's (JRF) Dementia Without Walls (DWW) programme which finished at the end of 2015, to sustain, promote and develop the themes, values and work that DWW has supported. As well as the events VERDe aims to expand the UK-wide network of individuals and organisations brought together through the DWW programme and to identify, and wherever possible, implement, practical and achievable ways for the network to have a lasting impact for people, policy and practice. People, communities, equalities and rights are VERDe's central themes.

The Mental Health Foundation is co-ordinating VERDe, supported by Innovations in Dementia. The Mental Health Foundation is a UK social research, development, policy and public affairs charity that does work and provide information on issues affecting people with mental health problems, dementia, and learning disabilities. Innovations in Dementia is a community interest company (CIC) that works on issues with people with dementia.

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