Alzheimer Europe

*Making dementia a priority:
changing perceptions, practice and policy.*

**Dementia as a disability?
Implications for ethics, policy and practice**

A Discussion Paper
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Contents

1 Preface

As Chair of Alzheimer Europe and in connection with my professional experience in the field of dementia and also my personal experience with dementia in my family, I am pleased to present this discussion paper which addresses the implications of recognising dementia as a potential disability. Alzheimer Europe has long recognised that dementia can result in disability. This is reflected in various reports produced in the context of the European Dementia Ethics Network, which was set up by Alzheimer Europe in 2009 and addresses a different ethical issue every year. However, this is the first time that the organisation has dedicated its annual ethics review specifically to dementia and disability. The exploration of ethical, policy and practice implications is particularly timely and coincides with ongoing developments in the fields of human rights and disability. This paper highlights issues that need to be further addressed but in many places takes a clear stance on potential ethical issues and on implications for policy and practice.

Dementia as a disability is a relatively new and emerging area of exploration in which disability enables us to look at dementia from a different perspective, or through a different lens as it were. Relevant stakeholders need to familiarise themselves with the topics and concepts surrounding disability and see where they stand in relation to these.

This document is the result of a year's work carried out by the ethics working group in close collaboration with the European Working Group of People with Dementia. I would like to express my sincere gratitude to the members of both groups who shared their expertise, experience and knowledge and in so doing helped raise awareness of dementia and disability. The members of the ethics working group, which was chaired by Dianne Gove, include Jean Georges, Grainne McGettrick, Timo Williamson, Sébastien Libert, Helen Rochford-Brennan, Carmel Geoghegan, Helga Rohra, June Andrews and Simo Vehmas. I would also like to offer my grateful thanks to the whole of the European Working Group of People with Dementia and their carers/supporters for providing valuable insight and feedback on the issues covered.

As this is a discussion paper, I hope that it will promote debate and contribute towards future developments in advocacy and policy insofar as this relates to dementia as a disability.

Iva Holmerova

Chair of Alzheimer Europe

2 Introduction

Why did we write this paper?

People experience dementia in different ways, not just in terms of the type and severity of symptoms, but also in terms of how they react to and manage living with dementia. Increasingly, people with dementia are expressing a desire to get on with their everyday lives. They want to avoid being defined solely in relation to dementia and to continue to be considered as valued members of society. This is particularly important as the term dementia often has negative connotations. It is widely considered as a stigma. Neurological impairment may interfere with people's ability to get on with their lives, as may differences in coping skills, financial resources, the emotional and psychological impact of dementia, and access to timely and good quality support. Reactions of relatives, friends and fellow citizens are also important, as well as society's response to dementia. This was highlighted by Kitwood in the 1990s when he outlined what came to be known as the biopsychosocial model of dementia[1]. There are also differences at the level of society, reflected in practices, attitudes and structures. These may, on the surface, seem fair or neutral (i.e. "that's just the way it is"). In many cases, however, they reflect a lack of consideration and failure to act in a responsible, ethical and even legal way towards people with dementia.

Alzheimer Europe has long advocated in favour of recognising dementia as a potential disability. In its Strategic Plan (2016-2020) 'Changing perceptions, practice and policy', it stated,

> *"Alzheimer Europe and its members fully commit to promoting the rights, dignity and autonomy of people living with dementia. These rights are universal, and guaranteed in the European Convention of Human Rights, the Universal Declaration of Human Rights, the International Covenants on Economic, Social and Cultural Rights and Civil and Political Rights, and the Convention on the Rights of Persons with Disabilities".*

Alzheimer Europe believes that policies and research for people with dementia should be based on ethical principles. This is also in keeping with the emerging discourse and focus on dementia as a disability at national, European and international levels, combined with the promotion of human rights, citizenship and social inclusion. When developing the 2017 workplan, Alzheimer Europe therefore decided to:

- campaign for the recognition of dementia as a disability;
- collaborate with Alzheimer's Disease International on an analysis of how the principles enshrined in the UN Convention on the Rights of Persons with Disabilities can be applied to persons with dementia;
- join the European Disability Forum to collaborate with other European organisations on the development of a European disability strategy and the implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRPD);
- focus on the ethical implications linked to the recognition of dementia as a disability.

Alzheimer Europe's interest in disability and dementia is also linked to the desire to promote the human rights of people with dementia. In the World Helath Organisation (WHO) 2011 Report on Disability, disability is described as a human rights issue because:

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[1] See Sections 7 and 8 for more about Kitwood's work.

"People with disabilities experience inequalities – for example, when they are denied equal access to health care, employment, education, or political participation because of their disability.

People with disabilities are subject to violations of dignity – for example, when they are subjected to violence, abuse, prejudice, or disrespect because of their disability.

Some people with disability are denied autonomy – for example, when they are (…..) confined in institutions against their will, or when they are regarded as legally incompetent because of their disability" (Quinn and Degener 2002, cited in WHO 2011, p.9).

People with dementia may experience disability. If so, they should be covered by provisions laid down in various national, European and international documents, laws and conventions. It is important that everyone, with and without dementia, realises this. This will enable people with dementia, if and when needed, to benefit from the same kind of protection and rights afforded to other people with disabilities. This should not be taken to imply that dementia *per se* is a disability. Rather, we are suggesting that the impairments experienced by people with dementia may in some situations be disabling and that people with disabilities have certain rights. This is explained in more detail in section 6.1. Clearly, ethical issues and human rights are closely related and intertwined, with one or the other of these two important societal ideals being at the forefront of discussions.

In this report, we focus on the possible implications for ethics, policy and practice of raising awareness about the potential of framing dementia as a potential disability.

What do we mean by 'implications for ethics, policy and practice'?

In exploring the ethical implications of viewing dementia as a potential disability, we also reflect on what the impact might be in terms of how society is or should be organised and what this means for people's everyday lives. Ethics is not just about big societal issues, which are discussed in the media, such as immigration, war, abortion or euthanasia. Often, everyday matters have an ethical dimension. The term 'ethics' refers to standards which tell us how people ought to behave in various situations and how they should live with one another. This is often framed in terms of rights, obligations, duties, benefits to society, fairness or specific virtues (Velasquez et al, 2010). These standards of behaviour are based on perceptions of right and wrong or good and bad. A few decades ago, Beauchamp and Childress (2001) developed a set of four biomedical ethical principles . These were:

(1) respect for autonomy (respecting a person's independence and ability to decide what should happen or be done to him/her),
(2) beneficence (i.e. doing good, whilst trying to balance possible benefits against risk and costs),
(3) non-maleficence (i.e. avoiding doing harm) and
(4) justice/equity (treating people equally and fairly through a fair distribution of benefits, risk and costs).

We are going to use these principles in this report as a very broad ethical framework within which to reflect on dementia as a disability.

These principles were originally intended to serve as a framework to guide professional medical ethics. They have since been applied in a wide range of contexts. There are also other principles and values which are perhaps equally important such as:

- trustworthiness,
- honesty,
- integrity,

- compassion,
- ensuring well-being,
- confidentiality
- respect for privacy,personhood and dignity.

In addition, it is important to consider the lived experiences of people with dementia and the complexity of human relationships, and not to rely solely on abstract principles and values. So our use of these principles as a guiding ethical framework should be understood quite broadly. It encompasses a wider range of principles and values and takes into account people's lived experience and relationships with other members of society.

> The overriding question behind each section in this report is:
>
> What are the implications for ethics (in terms of respect for autonomy, beneficence, non-maleficence and justice/equity), policy and/or practice of this particular topic?

Who wrote this paper?

In 2017, two working groups drafted, debated and agreed on a final version of this paper over a period of roughly 8 months. They had a total of four face-to-face meetings and numerous exchanges of drafts and comments between those meetings. The two groups had expertise in relevant areas such as:

- dementia (knowledge about dementia as well as the experience of having dementia),
- philosophy,
- disability,
- psychology and psychotherapy,
- law,
- anthropology and
- policy making.

Alzheimer Europe is immensely grateful to the members of these two groups without whom we would not have been able to produce this document. Please have a look at the acknowledgements section where we have included details about the background of each expert.

What's in this paper?

In this paper, we have tried to highlight issues which we feel require attention and may need further debate, discussion and reflection. After this introduction, we look, in Section 3, at disability-related terms and definitions. We then set the scene in Section 4 by discussing how the disability movement evolved and the development of different models (or ways of making sense) of disability.

In Section 5, we consider the relationship between disability and our understanding of personhood and dementia. We then consider how accepting that dementia *can* be a disability might impact on the lives of people with dementia (i.e. how they feel about themselves, how they relate to others and how they are treated by other people).

Section 6 on 'human rights and opportunities' discusses how recognising that dementia can be a disability may be beneficial to people with dementia. It focuses on the United Nations Convention on the Rights of Persons with Disabilities. This section also looks at the relationship between policy and practice, and considers more abstract rights. These are sometimes called capabilities by philosophers. They reflect basic minimum requirements for leading "a good life" that every human being should be entitled to.

The concept of disability is helpful in raising awareness of people's right to be treated equally and fairly. There is an emphasis on empowerment and society's responsibility to make 'reasonable adjustments or amendments' to make this possible. However, many people with disabilities still need care and support or are dependent on other people in some way in their daily lives. In section 7 on care, support, disability and dementia, we therefore look not so much at the right to receive such care and support but at issues related to the nature of care, support and dependency.

Rights, law and obligations are important but we also need to consider what is needed and approaches that have been adopted so far to make society inclusive. Section 8 is about working towards an inclusive society. Here, we examine debates surrounding the dementia-friendly terminology and concept, and consider what is necessary in order to ensure that people with dementia are meaningfully involved in making the societies and communities in which they live inclusive.

This discussion paper reflects a range of expert opinion and a balanced overview of different perspectives on the issues addressed. However, we have also included a set of statements which were developed by the two working groups and adopted by the Board of Alzheimer Europe. These statements are aimed at the general public, governments and policy makers, Alzheimer associations, organisations of or for people with disabilities, and regulatory bodies.

At the end of the report, you will find, as mentioned above, an acknowledgement of the important contribution made by members of the two working groups, followed by a glossary of terms and abbreviations and a list of references. We realise that this paper addresses a lot of complex issues and is quite lengthy. We have tried to avoid the use of jargon and to make the report as accessible as possible to a broad audience. However, if you like to see a short summary of the whole report in a more accessible format and style, please see: XXXXXXX.

3   Disability-related terms and definitions

In this section, we look at some of the key terminology as it both reflects and influences how we make sense of disability. Several factors influence the way we use language, such as:

- the context,
- the mood or atmosphere,
- feelings about the topic
- the level of comfort with the topic,
- history,
- traditions,
- literature,
- beliefs and
- linguistic norms.

When we hear or read something, we engage in a process of interpretation. We look for cues to interpret what is meant. These cues are often constructed around common sense assumptions and expectations about the world. We are not generally aware of these and consequently, not always in a position to question or challenge them (Garfinkel 1967, Fairclough 1995).

It is therefore important to be conscious of the terms we use when communicating about disability. We need to be critically aware of the potential implications of the use of various terms. We also need to look at the big picture, namely 'discourse', which is not just about grammar and words, but about meanings. A term, such as people with disabilities, can represent very different meanings and values, depending on how and by whom it is used (Chadwick 2000).

Impairment and disability:

In section 4.2, we look at different meanings associated with the terms impairment and disability in the context of the different models of disability. The United Nations Convention on the Rights of Person with Disabilities (CRPD), for example, is often considered as reflecting the social model of disability. It states that disability results 'from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others'. In Annex 1, we have provided translations of 'impairment' and 'disability'. Wherever possible, we have used translations of Article 1 of this convention from http://www.linguee.com and more specifically, selected translations from documents available on http://eur-lex.europa.eu. In France, Spain, Finland and Germany, for example, the words for disability are handicap, discapacidad, vamma and Behinderung and the words for incapacity are incapacité, deficiencia, toiminnanrajoite and Beeinträchtung, respectively.

We then asked for feedback from our national member associations about the accuracy of the translations. Some suggested alternative terms, explaining that they were more common or appropriate (e.g. in Spain, Greece, Poland, Belgium and Italy). In some cases, back-translation revealed an overlap between meanings and the existence of additional terms. According to Knoll (2012), confusion and controversies over the distinction between disability and impairment also exist within the disability rights and disability studies movements.

Disabled people and people with disabilities:

Similar disagreement exists about the terms 'disabled people' and 'people with disabilities'. People often use these terms interchangeably. Within the disability movement, the term 'disabled person' is quite common and associated with a political message, namely that people are disabled *by* society. This takes the main focus off people's impairments and challenges the assumption that people with impairments are 'the problem' (Morris 2001). Perhaps it also implies that they are 'passive victims' of society.

The term 'person with disabilities', on the other hand, emphasises something that people have (i.e. "impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" - just as they might also have a degree in chemistry, brown hair, an interest in gardening or dementia).

Whilst many people use the two terms interchangeably, some people and organisations have a preference for one or the other. One possible reason for preferring the term person or people with disabilities is that it puts the person before the disability. Such 'people-first-language', it is claimed, helps avoid dehumanising people. Rather than reducing them to a condition, it emphasises that they are first and foremost a person. This is somewhat similar to using the term 'a person who stutters' or 'a person with schizophrenia' instead of 'a stutterer' or 'a schizophrenic'. Kapitan (2017) argues from a 'person-first-perspective' that people who have an actual condition or disability should be the ones who determine which term is used.

At a recent Public Affairs meeting, organised by Alzheimer Europe, representatives from 17 national Alzheimer associations all indicated a preference for the term 'people with disabilities'. Members of the European Working Group of People with Dementia (EWGPWD) and their carers/supporters did not have strong objections to the use of either term although the meanings they associated with each term varied considerably.

Handicap:

The term handicap exists either alongside other disability-related terms. It is the main translation for disability in some countries (e.g. in Romania, Denmark, the Netherlands, Norway, Belgium and France). In 1980, the World Health Organisation (in the International Classification of Impairments, Disabilities, and Handicaps) defined 'handicap' as follows:

> *"concerned with the disadvantages experienced by the individual as a result of impairments and disabilities; handicaps thus reflect interaction with and adaptation to the individual's surroundings" (World Health Organisation 1980).*

The term is sometimes considered derogatory (and is viewed as rather old-fashioned). This seems to be based on a common misunderstanding that it originates from "cap in hand" and from an association with begging (conjuring up images of people with disabilities having to beg for a living). Its origin, however, reportedly comes from a 17th century game based on bartering called 'hand in cap'. From the late 19th century, people started using the term in connection with horse racing whereby a stronger horse would be rendered more equal to the others by putting weights under the saddle. Finally, in the 20th century, the term was used first in relation to children, and later also for adults with disabilities (Snopes 2011).

Official definitions of disability

Whilst definitions of disability are often based on models and theories, they specify the properties of disability or the characteristics of people with disabilities, rather than having an explanatory purpose (Chadwick 2000). Consequently, certain national, European or international definitions may serve to classify who does and does not have a disability. This may have a considerable impact on people's lives (e.g. by determining who has access to services and support).

In the United Nations Convention on the Rights of Persons with Disabilities (CRPD), in addition to the definition of disability (mentioned above), article 1 states:

> *"(p)ersons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".*

In some countries, however, the International Classification of Functioning Disability and Health (ICF), adopted by the World Health Assembly in 2001, is used as a means to assess disability status. In such cases, the latter might be considered as providing an authoritative statement about what disability is. To some extent, this is based on perceived norms and departures from those norms and on what 'accommodations' (changes to prevent discrimination) are considered appropriate. This neglects, to some extent, individual perspectives and collective experiences (Altman 2001, reported by Knoll 2012). Some of the models of dsability described in section 4.2 reflect elements of these two approaches to disability.

As can be seen from the above summary of definitions and terminology related to disability, people use a range of terms for different purposes and in different contexts and documents. Chadwick (2000) emphasises the importance of having a mechanism to review various definitions (especially those enshrined in laws and policies). This, he suggests, would help ensure that they continue 'to correspond with disabled people's own perceptions of their relationship to the social environment' (p.8) and perhaps equally important to ensure that they are in their interests and can incorporate self-definition.

> **Key messages**
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> - The meanings associated with different terms may change over time.
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> - Definitions, translations and official classifications reflect a particular dominant discourse.
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> - This discourse is open to challenge and change; it reflects the historical and cultural evolution of words, as well as political concerns.
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> - The extent to which the use of various terms and definitions is amenable to change may differ depending on the authority of the people or organisation behind them.
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> - In keeping with the claim of the disability movement "Nothing about us without us", we need to ensure that people with dementia contribute towards the ongoing refinement of disability-related terms and challenge them when needed.

4   About disability

4.1   About the disability movement

The modern disability movement began in the 1960s in America. It was about people with disabilities coming together to fight for a common cause and to bring about changes in their lives. It was influenced by the civil rights movement and the women's rights movement. At the outset, there was a strong emphasis on physical disability. Nowadays, we recognise that disability can arise from impairments experienced by people with a wider range of conditions (e.g. autistic spectrum disorders [ASD], dyslexia, thrombosis, stroke and coronary heart disease, rheumatoid arthritis and dementia). Some people with disabilities may have had various impairments from birth or an early age. Others, such as people with dementia, may have acquired them later in life and therefore may make a distinction between their former and current selves and lives.

The founders of the disability rights movement were primarily people with significant physical disabilities and sensory impairments who developed an independent living movement. They promoted the idea that people with disabilities were best placed to determine what their needs were. They therefore felt that they were best placed to find the most appropriate solutions. This, combined with a call for the de-medicalisation of disability and de-institutionalisation, involved a quest for social, economic and political recognition and to the gradual expansion to include people with other disabilities. This gave rise to the emergence of the social model of disability as an alternative to the dominant medical model (see section 4.2). However, many people with cognitive disabilities found self-advocacy more difficult. This may have contributed towards their under-representation in the early disability movement and their reliance on others to promote their rights.

This movement, which spread across Europe in the 1980s (Driedgner 1989), was preceded by and has led to various developments contributing towards the gradual recognition of the needs and rights of people with disabilities. Examples include:

- large numbers of soldiers returning home with physical and mental impairments after the two world wars. Nearly 8 million European soldiers were permanently disabled as a result of World War 1 alone according to Kitchen (2000). They could not all be institutionalised and this contributed towards a renewed focus in some countries on disability (People with Disability Australia 2017);
- the United Nations declaring 1981 the International Year of Disabled Persons (IYDP). This had a clear focus on the human rights of people with disabilities and the removal of barriers to their social and civic inclusion in society;

- the Americans with Disabilities Act of 1990 prohibiting discrimination based on disability. This resulted in companies with a certain number of employees having to make "reasonable accommodations" for employees with disabilities (similar equalities legislation has been implemented in several European countries). Public buildings, shops and restaurants were required to make 'reasonable modifications' to ensure access to people with disabilities. Conditions were laid down to promote the access of people with disabilities to public transport and their participation in various others domains of public life;
- the founding of the European Disability Forum in 1997. This is run by people with disabilities and their families. It has representation in all EU member states;
- the United Nations Convention on the Rights of Persons with Disabilities (CRPD) of 2006. This focuses on rights but also promotes the social model of disability (described in the next section). This led to a change in the usual and accepted ways of thinking about disability. This, in turn, resulted in a radical shift of emphasis from substitute decision making to supported decision making;
- the European Commission (2010) European Disability Strategy 2010-2020: a renewed commitment to a barrier-free Europe;
- the Council of Europe (2017) Disability Strategy 2017-2023 entitled "human rights: a reality for all".

Many people with disabilities still encounter some degree of discrimination and prejudice. The disability rights movement has nevertheless been a massive force for change across the world and disability activism continues to prevail in social policy and political discourses. Still, it has taken significant time for people with disabilities to have their voices heard. All too often their views have been filtered down. Service providers, professionals, relatives and other people such as carers, supporters or friends have often spoken on their behalf. There are particular challenges to enabling the voice of people with more severe dementia to be heard and these need to be addressed. Meanwhile, many people. with dementia (irrespective of their possible experience of disability) still encounter this problem.

Some of the concerns of the disability movement are relevant in the case of dementia, such as the move away from a medical model, the right to be heard and to influence policy and service development, and the promotion of human rights. This will become more apparent as you read the different sections of this paper. It suggests the need for mutual exchanges, parallel and shared challenges and to join forces with the disability movement if and when necessary in support of common goals or issues.

Key messages

- People with disabilities started the disability movement when they came together to campaign for their rights and in particular against discrimination.

- The initial emphasis on physical disability has broadened to encompass people with a wide range of impairments and disabilities.

- The motto of the disability movement is "nothing about us without us".

- Dementia is recognised as a condition resulting in impairments which can result in disability.

- Despite several important developments at local, national, European and international level to challenge discrimination and to promote the human rights of people with disabilities, there is still progress to be made.

- It is important to hear the voices of people with dementia within the disability movement so as to ensure that subsequent developments correspond to their experiences, needs and wishes.

4.2 Different models of disability

The current emphasis in the field of disability research is the result of a long historical process. For many years, three main patterns (known as models) of disability could be traced in Western culture, namely the moral/spiritual, medical and social models. More recently, these models of disability have been challenged and further elaborated. This has resulted in alternative or different interpretations of disability. In this section, we look at:

(1) the moral/spiritual model,
(2) the medical model,
(3) the social model

and three additional, more nuanced models, known as:

(4) the biopsychosocial model,
(5) the reinterpreted social model and
(6) the human rights model.

We will briefly describe each model and have included a table at the end of the section which summarises how each model relates to dementia and to people with dementia. You will find references to some of these models again in section 8 which looks at their implications for the social inclusion of people with dementia.

Moral/spiritual model of disability

The moral/spiritual model of disability is familiar from religious beliefs and teachings. It was quite a widespread view in Antiquity (before the Middle Ages)[2]. According to this view, disability is often seen as a sign of the moral flaws of an individual, or his or her ancestors. People who see disability this way, may, for example, believe that a child's impairment is the result of his/her parents' moral offences. Similarly, they might consider that a person who is impaired later in life, committed a sin or did something that was immoral. According to this position, disability is a disadvantageous state, usually a visible impairment, visited upon individuals and their families as retribution (e.g. Garland 1995, Silvers 1998, Stiker 1999). Although this model of disability can be traced back to ancient times, many people still make sense of disability in this way. The belief that disability has a religious or spiritual origin or significance may also help some people to cope with any difficulties they might encounter. Some view disability as positive difference and gain inner strength from those very beliefs.

Medical model of disability

From the 18th century onwards, disability started to be explained by scientific methods, and to be reduced to an individual's physiological or mental 'deficiencies'. Disability became "medicalised"[3], alongside other phenomena such as alcoholism, homosexuality and criminality[4]. The expression 'medical model of disability' has become common shorthand for a one-sided view which:

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[2] References to disability in key religious texts, such as the Bible, the Torah and the Qur'an, and their interpretation, are complex and beyond the expertise of this working group. We are focusing here on everyday lay perceptions reflecting a variety of religious and spiritual beliefs.

[3] A process whereby people and societies are explained increasingly in medical terms.

[4] The authors are merely reporting here historical changes of perceptions and not implying agreement with this way of understanding homosexuality, criminality or alcoholism.

- attributes the cause of an individual's deficits either to
  - bad luck (e.g. accidents),
  - inadequate health practices (e.g. smoking or bad diet) or
  - genes, and

- views disability as the inevitable product of the individual's
  - biological defects,
  - llnesses or
  - characteristics.

Disability becomes a personal tragedy that results from the individual's pathological[5] condition (Barnes, Mercer & Shakespeare 1999, Oliver 1990, 1996, Priestley 2003, Silvers 1998).

Since the late 1960s, this one-sided medical understanding of disability has been fiercely criticised. It has been argued that it portrays disability in a biased manner that leads to practices and social arrangements that oppress people with impairments. It also results in interventions aimed solely at the 'abnormal' individual, with the surrounding environment not being considered. Resources are not directed at changing the environment but rather at ways to 'improve' or 'repair' the impaired individual. This, it could be argued, leads to a social and moral marginalisation of disabled people, preventing their full participation in society.

The way we understand and explain a phenomenon such as disability affects the things we do to try and remove the possible hardships associated with it. A certain view and understanding makes only certain kinds of responses and actions possible. In other words, if the cause of impairment and disability is seen to be spiritual, it is only natural to fix the issue with spiritual manoeuvres, such as exorcism and faith healing. If disability is understood in terms of medical knowledge and is conflated with impairment, then the reasonable thing to do is to focus on improving a person's condition by means of medical interventions.

An unfortunate outcome of both of these individualistic approaches to disability has been paternalism. This involves making decisions on behalf of others for what is assumed to be their own good, even if this is contrary to their wishes. Paternalism can also be seen as a kind of expert system whereby the authorities of the relevant knowledge and craft determine how the phenomenon in question should be understood and handled. In the religious framework, the clergy are considered to be in possession of the truth; in the medical discourse, it is doctors and other professionals. In both cases, the autonomy of people with disabilities has frequently been trampled upon. They have become mere passive recipients of the benevolent assistance provided by professionals and other believers of the dominant disability discourse. This has been especially the case for people with dementia. The corresponding medical model of dementia typically focuses on the workings of the brain, over-emphasises incapacity and leaves little room for the voice of people with dementia to be heard.

Social model of disability

The deficiencies of individualistic approaches to disability seem quite clear. The emergence of a social understanding of disability has therefore been a welcome change to the disability discourse and to institutional responses to the lives of people with disabilities. Nowadays, it is widely acknowledged that disability is not merely a matter of biological impairment but also, and perhaps primarily, a social phenomenon. Disablement cannot be explained and understood simply in terms of people's impairment but, rather, in terms of social

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[5] Something that is caused by a physical or mental disease.

arrangements. In other words, it is not only individuals and their alleged incapacities that explain the limited opportunities of people with impairments but society too.

In Europe, the British social model of disability is the most well-known conceptualisation of disability as a social phenomenon. It clearly distinguishes between impairment and disability, whereby:

> impairment is defined as 'lacking all or part of a limb, or having a defective limb, organism or mechanism of the body',

> disability is defined as 'the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical [sic] impairments and thus excludes them from participation in the mainstream of social activities' (Oliver 1996, p.22).

The core idea of the social model is that people with disabilities are an oppressed social group. Their assumed inferior status is not a natural effect of their impairment, but it is produced by unjust social arrangements. Disability is seen as the material product of socio-economic relations developed within a specific historical context. This approach focuses on the disabling barriers and material relations of power (Priestley 1998, Shakespeare & Watson 2001). It should also be noted that it is now generally accepted that impairments can be of a mental or cognitive nature and therefore include people with dementia (Mental Health Foundation 2015).

One criticism levelled against the social model is the role, meaning and significance of body and impairment. It defines disability as a form of social oppression and hence as a phenomenon that should be conceptualised in social terms. Individual properties, such as impairments related to dementia, are not the main focus of this approach. Rather, it focuses on analysing the social causes of disability. As a result, in Britain the study of impairment has been somewhat neglected by disability scholars (e.g. Hughes 2002, Thomas 2002). This is a serious shortcoming in the social model of disability. Any theoretical account attempting to explain and theorise disability satisfactorily needs to take into account corporeal[6] issues (i.e. the lived experience of impairments for people with disabilities) (e.g. Corker & Shakespeare 2002, Morris 1991, Shakespeare 2014, Thomas 1999, Wendell 1996).

The biopsychosocial model of disability

Altogether, one of the most constant and pressing issues in disability studies is the meaning and significance of impairment. To what extent are bodily features the essential nature of the human body and to what extent are they social constructs? What would be proper responses to people's impairment-related needs? Can we really attribute all disability related to dementia to external social factors? The World Health Organisation (WHO) claims that a good model of disability is "one that synthesizes what is true in the medical and social models, without making the mistake each makes in reducing the whole, complex notion of disability to one of its aspects" (WHO 2002, p.9). This synthesis, according to the WHO, results in a coherent view of different perspectives of health (biological, individual and social), which has come to be known as the biopsychosocial model of disability.

This biopsychosocial model of disability takes into account medical, psychological, social and environmental factors influencing a particular health condition, functioning and disability. It emphasises that everyone may experience a decrement (deterioration) in health and thereby experience some disability. This contributes towards mainstreaming the experience of

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[6] Literally, the physical existence of something.

disability[7] and recognising it as a universal human experience. The medical and social models, in focusing on one particular factor, risk overlooking the complexity of issues related to disability. The biopsychosocial model of disability takes the emphasis off diagnoses for the planning and management of any support, care or treatment that people with disabilities may need. Nevertheless, the medical, social and biopsychosocial models of disability all reflect to some extent fixed assumptions about what is ordinary, abnormal, normal living, a social problem, dependence and interdependence, as well as certain goals, such as being a citizen, and certain states of being which are desirable (Smith 2009). It is important to be conscious of the difference between normal in the sense of what is average, common or standard and normal in the sense of how things *should* be. According to Chadwick (2000), when normality is formally defined, there is a risk of the two ways of understanding 'normal' becoming muddled. This may result in the systematic attachment of negative value judgements to people with disabilities.

The reinterpreted social model of disability

The reinterpreted social model of disability gives greater emphasis to the personal experience of disability, in addition to social and environmental factors. This includes the way a person experiences a particular condition, impairment or disability (e.g. not necessarily as a personal disaster but in terms of personal growth and spiritual, philosophical or psychological benefits). It takes the focus off a socially constructed definition of disability, based on deficiency and departure from the norm, onto one which reflects how disability is experienced by people with disabilities. This might, for example, involve a greater focus on personal achievements, the enjoyment of life, personal identity and self-awareness (Smith 2009, Swain et al. 2003), and in the case of dementia on remaining capacities and just getting on with life. This model does not suggest the absence of social barriers but rather emphasises that people with disabilities should be the ones to define which barriers are most important and relevant to their lives and their objectives. In other words, the model acknowledges personal experience and human agency.

Similarly, there have been criticisms recently of the term 'care', especially in response to the medical model of disability and a desire to reframe it as just one aspect of support. Many people with dementia, especially in countries where there are limited care and support provisions, would like to have greater access to care. They do not see it in a negative light (e.g. as a indication of dependency and passivity) but as something to which they are entitled and which may contribute towards their dignity and quality of life. The current focus on independent living in relation to disability is surely positive. Nevertheless, it also reflects a social construction which must be balanced against recognition of the right to independent thinking and recognition of the experience of people with disabilities (Smith 2009).

The way that people experience impairments or disability may also be influenced in part by cultural differences. This calls for a greater understanding of and respect for cultural beliefs surrounding dementia held by some ethnic minority groups. At the same time, we should not assume that all members of a particular identifiable group (e.g. sharing a common ethnic or religious background) think alike. Moreover, Morris (1991) suggests that lifting the pressure to conform to the aspirations of the majority (without disabilities) can be liberating. She further suggests that by embracing impairments, rather than fighting against them, a person ceases to be disabled by them. Nevertheless, a possible criticism of the reinterpreted social model of

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[7] Ensuring that the experience of disability is considered and central to all activities - policy development, research, advocacy/dialogue, legislation, resource allocation and planning, implementation and monitoring of support etc.

disability is that it might sometimes lead to an over-emphasis on positive aspects of living with disability. This might, in turn, lead to overlooking some of the more unpleasant and difficult aspects of having an illness or impairment, which Shakespeare et al. (2017) label a 'Pollyannaish'[8] approach.

The human rights model of disability

With the human rights model of disability, irrespective of whether a particular condition is seen as a disability or health condition, the emphasis is on:

1. the recognition of the person with a particular condition or impairment as an equal citizen ('rights holder') and
2. others as having duties and responsibilities ('duty holders') towards him or her.

A key aim of this approach is to ensure:

- that people with disabilities have the same rights as other citizens to contribute towards society,
- that they enjoy the same benefits and
- that they take the same risks as people without disabilities.

This may be achieved through rules, regulations and laws, as well as through carefully planned and meaningful involvement of people with disabilities in society. The PANEL principles are often provided as useful guidance for the implementation of a human-rights based approach. The PANEL principles are:

Participation (of rights holders)

Accountability (of duty holders towards rights holders)

Non-discrimination and equality (of duty holders towards rights holders)

Empowerment (of rights holders)

Legality (of duty holders' actions)

The European Commission has provided further guidance to using the PANEL principles in the form of the FAIR flowchart. This consists of establishing the **F**acts, **A**nalysing the rights at stake, **I**dentifying who is responsible for bringing about change and **R**eviewing any action taken (see the Scottish Human Rights Commission leaflet for more details: www.scottishhumanrights.com).

Laws and regulations can be effective when properly designed, implemented, respected and monitored. Unfortunately, they sometimes result in individuals, service providers and official bodies merely doing the minimum necessary to the tick the box, and not striving to ensure full citizenship. Indeed, for meaningful involvement in society (e.g. in local and national decision making, accessing good and services, choosing where and how to live, and having the opportunity to form and maintain relationships with other people), attitudes and interpersonal interactions are also important.

However, as mentioned earlier, not everyone who experiences dementia has the same objectives. Many people with disabilities and disability activists have rejected responses to disability which reflect pity or charity and to being 'friendly' or 'nice' to people with disabilities (which may be well intended but sometimes perceived as patronising). Positive and

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[8] Excessively cheerful or optimistic with a tendency to find good in everything (based on the heroine of a children's story written by Eleanor Hodgman Porter).

supportive actions, based on the principles of solidarity, justice and mutual respect, should nevertheless be encouraged. Similarly, it should not be assumed that government officials, service providers and people responsible for discrimination are non disabled. People without disabilities and those with disabilities are all rights holders and duty holders, even though the latter may require varying degrees of support to exercise those rights and duties.

Finally, disability rights must be properly enforced. They must also be accompanied by coherent policies and strategies for social change, appropriate funding and effective monitoring (Crowther 2017). It is essential that policy makers and those responsible for the enforcement of laws and regulations ensure that these are also applicable to and suited to the needs of people with dementia (see also section 6.2 on policy in practice).

Summary of key points raised in this section

- People make sense of disability in different ways, which are sometimes described as "models" of disability.

- These models have developed over time in a fairly linear fashion but exist alongside each other because different people find meaning in each of them.

- With the possible exceptions of the moral/spiritual and medical model of disability (considered by many as pejorative or an inaccurate interpretation of disability forming the basis for potential abuse, oppression and exploitation), each model aims to be progressive. It builds on some elements of existing models, sometimes responding to a perceived gap or flaw and often having a particular focus (e.g. on societal barriers, human rights or the experience of impairment).

- The way that people make sense of disability can have a considerable impact on the lives of people with disabilities and their family and friends because most models reflect a certain understanding of the cause and hence of the way to address disability.

- Table 1 below provides an overview of how some of the different models of disability relate to dementia and the possible implications of each for people with dementia.

Table 1: (Some) Models of disability in the context of dementia

Model of disability	How the model relates to dementia	Implications for the person with dementia
Moral/spiritual	Dementia is considered a curse or moral flaw in the individual. Dementia is visited upon the individual as retribution or as a divine test.	The person is subjected to prayer, seeking a miracle cure or spiritual "healing" interventions. Some people may feel inspired and able to cope as a result of their religious or spiritual beliefs.
Medical	Dementia is considered as resulting solely from biomedical causes and sometimes perceived as a personal tragedy. The flaw is considered as being in the individual only.	This aims to cure or 'fix' the person with dementia with medical interventions or make him/her fit in. Others (e.g. doctors) are considered to know what is best. There is little or no voice for the person with dementia.

Social	Dementia is considered an impairment causing disabilities as a result of the social/structural arrangements in society.	The focus is on altering the social/structural environments to eliminate or mitigate the negative experience of disability. The person with dementia is involved in leading the decisions and in collective action to achieve change.
Bio-psycho-social	Dementia is considered a multi-dimensional and a health experience that occurs in a context. Disability, ill-health and human functioning involve interactions between *biological, psychological, social* and *environmenta*l aspects.	Medical, psychological, social and environmental influences on dementia as a health condition, functioning and disability should all be addressed. The person with dementia is involved in decision making and in collective action to achieve change.
Reinterpreted social	Dementia is considered a health condition, which together with contextual factors, accounts for the individual's (social and psychological) experience of dementia in the broader social context. The *personal experience* of dementia (and of related physical, sensory and mental impairments) is considered as well as social and environmental factors.	In addition to altering the social/structural environments (as with the social model), there is greater emphasis on how people with dementia experience various impairments (as well as possible resulting disability) and also require care, support and protection where necessary. The person with dementia is involved in leading decision making and in collective action to achieve change.
Human rights	Dementia may be seen as a disability and/or health condition. The human rights model works with the social model(s) and the bio-psychosocial model but recognises the person as an equal citizen ('rights holder') and others as having duties and responsibilities ('duty holders').	The person with dementia has his/her rights upheld and experiences full inclusion and equality. People with dementia are active subjects and fully included citizens (e.g. in keeping with the PANEL principles mentioned on pages 3 and 25).

5   Personhood and the personal experience of disability

5.1   Understanding personhood in the context of disability and dementia

In everyday usage, 'person' is usually just another term for human being. It is used to distinguish us from inanimate objects, machines, plants, animals and 'spirits'. Discussions

about personhood in relation to disability and dementia are pretty similar. They both tend to draw on the same philosophical theories. Having a disability (or an impairment or dementia) does not make someone any less a person than someone who doesn't. However, some philosophical theories of personhood suggest that there are different types and levels of personhood. Sometimes, they are presented in such a way that they may have a negative impact on people with disabilities, affecting the way they are perceived, how some people with disabilities feel about themselves and how they are treated.

Philosophers tend to emphasise mental traits such as consciousness and rationality as the most relevant criteria in the definition of personhood. But to most people these traits are not as important as bodily shape (e.g. looking like a human being). Moreover, animals, however intelligent they may be, are not considered to be persons while humans, including infants and people with severe cognitive impairments, are (Sapontzis 1987, pp.48-49).

Personhood is usually connected to the moral realm. The expression 'person' is generally understood as implying a specific moral status. A person, in a moral sense, is a being whose interests must be respected. When we consider what is morally acceptable or preferable, we are morally obliged to take into account what will promote dignity or demean, benefit or harm, satisfy or dissatisfy, and so on, any being that is a person and that is likely to be affected by our actions. In other words, a person is a being with moral and social rights.

Some philosophers argue that moral personhood has different levels, in the sense that some beings are more persons than others. They state that in a moral sense, children are not full persons in comparison with adults (Sapontzis 1987, p.50). For example, children have rights to life, against abuse, and so on, although they are denied rights to property, marriage and voting. Some of their rights, such as autonomy, may be less fully respected than the corresponding rights of adults. In some cases, they are not held responsible for their actions. Similarly, it has been argued that some people, who are deemed to have very little in common with people in general, are 'non- persons' (Buchanan, 1988). Such philosophical arguments are, at the very least, unhelpful and at most, deeply offensive and damaging to the dignity, wellbeing and, in some cases, even to the survival of people with dementia.

In philosophy, there are competing views about personhood but most accounts regard mental ability as a necessary condition. This includes being conscious of the world, thinking about it and seeking to understand it (see Peacocke & Gillett 1987). John Locke developed a new philosophical framework in Western philosophy for the pursuit of understanding and theorising about 'the person'. According to Locke, a person is "a thinking intelligent Being, that has reason and reflection, and can consider itself as itself, the same thinking thing in different times and places"(Locke 1975/1690, Bk. II, ch. 27, sec. 9).

The Lockean conception of personhood represents the ideas, attitudes or activities that are shared by most people and regarded as normal or conventional in Western philosophy. It is usually agreed in philosophy that personhood is a moral issue warranting reflection and debate. The lives of beings of this sort (i.e. of persons), it is argued, possess a great psychological unity because of their highly developed cognitive capabilities (e.g. linked to conceptual abilities, understanding, problem solving and rational decision-making). Their advanced mental abilities enable their past and future experiences to form a meaningful unity, a biographical life (Buchanan, 1988, Parfit, 1984). In this view, personhood coincides with a threshold of moral worth whereby all beings above a particular threshold are considered equally morally valuable (e.g. McMahan 2002, Singer 1993).

With regard to dementia, Post (2006), argues that this hypercognitive definition of personhood overvalues what are often termed the 'higher cognitive functions' by comparison with other qualities such as humour, kindness and generosity. These other qualities are equally important to a shared concept of humanity and are not compromised when someone has

dementia. The hypercognitive definition of personhood fails to take into account the emotional and relational needs and capacities of people with dementia. Such failure, combined with overlooking the importance of social interaction and considering some people as non-persons, may contribute towards additional loss of capacity and additional disability (Alzheimer Europe 2013).

Much of the most significant work on personhood and dementia has been carried out by Kitwood (1997). According to Kitwood (1997, p.8), the term personhood refers to 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust'. In this view, a person with dementia does not forfeit the status of being a unique, and uniquely valuable individual as the result of a diagnosis of dementia. Rather, those without dementia have a special obligation to validate, maintain and enhance the personhood of those with cognitive disabilities. Beyond this, Kitwood suggests that the 'malignant social psychology' which often surrounds people with dementia in his view, can in fact exacerbate the symptoms of dementia (i.e. make them worse) and hasten the apparent progression of the condition. 'Dementia', he says (1997, p.19) may be

> "induced in part by the stresses of life. Thus anyone who envisages the effects of care as being "purely psychological" independent of what is happening in the nervous system, is perpetuating the error of Descartes in trying to separate mind from body. Maintaining personhood is both a psychological and a neurological task."

Kitwood's concept of personhood was influenced to some extent by the work of the German philosopher Martin Buber (1878-1965). Buber identified two different ways that people relate to one another, reflecting objectification or a genuine exchange (Alzheimer Europe 2013). These two ways are described through the word pairs 'I-It' and 'I-Thou'[9]. The I-It mode of relating is one in which a person relates to the other in a cool, distanced, non-involved way. This fails to fully acknowledge the individuality of the other person as he or she is objectified. The I-Thou mode of relating, in contrast, involves meeting the other person in a genuine human exchange. With reference to the I-Thou relationship, Barich (1998) states, "You become a person (as opposed to an alienated and isolated individual) when you enter into relation with people."

More recently, some philosophers have also argued, in the context of disability and personhood, that an individual's moral worth can also be based on his/her relation to others (e.g. Curtis & Vehmas 2016, Kittay 2005, 2010, Vehmas & Curtis 2017). They maintain that the 'human community relation' is a significant, special relation that bestows moral value on those individuals who are part of that relation.

According to this view, a person can be considered by others as having value on the basis of a relation to something/someone else. The idea is that once value has been bestowed[10] in this way, that value then functions to bind all concerned, not merely those who bestow it. In this way, some human beings, who might otherwise be considering as lacking the necessary psychological properties to be persons, are recognised as persons as a result of certain relations they have to other people. But what relations are these? One example would be the relations that a person with profound intellectual disability or advanced dementia has to others as a result of having being born and cared for by human beings within a human community.

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[9] 'Thou' means 'you'. This term is old-fashioned and is therefore not used much nowadays except in poetic or religious texts.

[10] To bestow means to give or present something to someone.

These relations must be strong enough to generate obligations and as strong as those that exist towards any other person. Importantly, these relations are not purely biological. This is why they should not be called 'species membership relations[11]' but rather 'human community relations'.

Precisely what this relation amounts to is difficult to describe. It is the relation that exists between each of us and every other human being. It is the relation that exists between a human and the rest of the human community as a result of having been born of human parents, brought up and cared for by humans, and in general, treated as a human within the human community. Naturally, the relation holds between different individuals and the rest of the community in different ways. For example, most people vote, work, pay taxes and engage in emotional and social interactions with others. However, it is not necessary for everyone (including people with various impairments, dementia or disability etc.) to participate within the human community in the same way or to the same extent. All that is required for the relation to hold is that an individual is taken into the human community and treated by the community as a human. Speaking at a conference on Alzheimer's disease in 2014, Longneaux concluded that every person must be treated as a person, based on the premise that a human being who has feelings, even if unable to express them or to exercise autonomy, is a person.

Key messages

- For many people, 'person' is simply a term used to refer to a human being or to distinguish humans from non-humans (e.g. animals, machines, robots and even supernatural beings).

- Some philosophers associate the term 'person' with the possession of certain capabilities such as memory, reasoning and language, which unfortunately implies that some people (e.g. with memory problems) are not 'persons'.

- Others suggest that personhood is based on relations between and towards other people.

- These relations imply obligations and the recognition of value (not just based on being a human being but on having been born, brought up and cared for by humans, and treated as a human within the human community).

- Being part of the human community is not dependent on the level to which a person can or does contribute towards society.

- All that is required is that a person is taken into the human community and treated as a person.

5.2   The individual and group response to disability

Your experience is not my experience

The sub-heading above is taken from an article by Devlieger and Albrecht (2000) who point out that we often implicitly assume that everyone experiences disability in a similar way. Another common assumption is that being recognised as having a disability can be empowering. Disability activists emphasise that discussions about disability should be led by people who are directly affected by disability, which in this case is people with disability resulting from dementia-related impairments. But this begs a series of questions:

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[11] A preference for the interests of beings belonging to the species group to which one also belongs over the interests of those who don't.

- Do people with dementia want to identify with people with disabilities?
- Do they feel that they have enough in common?
- Do they face the same issues and have the same priorities as people with other disabilities?
- How would they feel about being described as having a disability or being disabled?
- Do they feel it labels them pejoratively?
- Do they feel that the potential empowerment sufficiently outweighs possible perceived disadvantages of being considered as having a disability?

These questions are difficult to answer, partly because literature is lacking on this topic and partly because people with dementia are not a homogenous group. Tuija Takala (2009) highlights the danger of one-dimensional classifications (i.e. identifying solely with one group) and of failing to acknowledge that people choose their identities to some extent and belong to a number of communities[12]. This may also lead to overlooking the fact that some groups have a political agenda which does not reflect the needs of all the sub-groups. There are many sub-groups of people with dementia. Examples include:

- homeless people,
- Roma people,
- people from ethnic minorities,
- women (or men),
- people with learning (intellectual) disabilities,
- people from the LGBT+[13] community
- and people who are in prison.

The origin and development of the impairment may also affect how it is experienced. As pointed out by Shakespeare and Watson (2001, p.12), "Congenital impairments[14] have different implications for self-identity than acquired impairments. Some impairments are static, others are episodic (occurring only sometimes, not regularly) or degenerative (getting worse over time)." Within and across these sub-groups, there are varying similarities and differences in the way that disability is experienced.

Disability is not my sole identity

People have multiple, intersecting and overlapping identities. They may, therefore, find that at one point in time and in a particular context, they identify with disability and with people with disability, and that in another, they don't. Disability should therefore not be viewed as a person's sole or significant identity (Shakespeare 1996). People may also feel differently about disability depending on their perceptions of disability and who defines them as having one.

> *"There is an important difference in my associating myself with a particular group and others giving me the label" (Shakespeare 2006, cited in Takala 2009, p.131).*

Not everyone wants to openly state that they have a disability or to advocate for people with disabilities. As one woman with disabilities stated:

> *"I'm not interested in celebrating a status, or not celebrating a status. I am just interested in living my life. I don't have to have a banner that has to say, "disability is*

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[12] This is discussed in more detail in section 8 (see sub-section on intersectionality and social inclusion).

[13] See glossary for definition.

[14] Present at birth.

delightful." I don't have to have a banner that says, "being female is fabulous." I'm female. I'm disabled. Don't get in my way. Don't bother me. Don't deny me opportunity. That's my basic political view" (Adrienne Asch, cited in Kroll 2012, p.65).

As Shakespeare points out, the goal of disability politics should be 'to make impairment and disability irrelevant whenever possible, not to seek out and celebrate a separatist notion of disability pride based on an ethnic conception of disability identity' (cited in Takala 2009, p.131).

It is therefore important to respect everyone's right to accept or refuse, partially or fully, disability as part of their identity. We need to hear the voice of people with dementia from all walks of life, identify common experiences of disability and see people with disabilities as individuals (rather than as caricatures of a group we think they represent, Takala, 2009).

Emotional and psychological impact

Accepting that one has a disability may have an emotional and sometimes psychological impact on a person. Some people may feel embarrassed or fear rejection or devaluation. Accepting or being labelled as having a disability may also have an impact on a person's autobiographical and social self and on their self-concept. According to Harré (2004):

- the autobiographical self is a person's story of who they are,
- the social self (or selves) consists of the qualities a person displays in encounters with other people and
- the self-concept consists of the beliefs people have about who they are (about their qualities, the kinds of lives they lead etc.).

Many people who live with dementia will already have experienced some change in their self-concept and in their autobiographical and social selves (sometimes in a positive sense, recognising qualities they didn't know they had). Some may have experienced social positioning (i.e. finding that their rights and duties are influenced by shared assumptions about what having dementia means) (Harré 2004).

In focus group discussions with the EWGPWD whilst drafting this report, some members described feelings of guilt, shame and anger linked to their experience of using or requesting services for people with disabilities. They described negative and even hostile reactions from other people which they felt were based on a lack of understanding of impairments and subsequent disabilities associated with dementia. Often such reactions seemed to be linked to their impairments not being visible.

> *"Like when you come out of the rest room and people look at you as if to say 'What are you doing in there? There's nothing wrong with you'" (member of EWGPWD).*

> *"Sometimes when she is in the 'disabled lane' in shops, people question why she is there. They say she should get out of that lane. She refuses but also does not think that she should have to explain about her condition" (carer/supporter).*

On the other hand, a clear theme, which emerged from the focus group discussion involving the EWGPWD, was that some felt that having a disability was considered more acceptable than having dementia and more likely to result in a positive response from others:

> *"I can't speak for anyone else, but in XXX being disabled is much more acceptable than having a diagnosis of dementia. It's a better label" (member of the EWGPWD).*

> *"I would feel very happy saying I have a disability. If I say I have dementia, you know, they are going to say 'oh God, she's mad' and kind of 'see you later!' but you know, when you're saying you have a disability – and maybe it's where we live in all fairness*

– at home it's a much much more accepted word. It's totally accepted" (member of the EWGPWD).

Nevertheless, and in keeping with our earlier comment that people don't all share the same experience, one member of the group expressed quite different views about identifying as a person with a disability. She later linked these to being considered abnormal:

"But then again, I think each one of you thinks differently. It's how you think about yourselves. I've got a problem with it to be honest but we're all different. Some people would be upset to go down that road. So, it's for the individual. .....I really wouldn't like to class myself as being disabled. I wouldn't go about saying I've got disability. I think it would make me feel a bit…. you know" (member of the EWGPWD).

Stigma

Both dementia and disability are frequently associated with stigma. This also includes private stigma whereby a person or group internalises the perceived stigmatising attitudes of others and experiences or anticipates discrimination (Rüsch, Angermeyer & Corrigan 2005, Thornicroft et al. 2009). This may lead to people feeling devalued and fearing discrimination, even in the absence of any negative reaction from other people[15].

Accepting that everyone may experience some degree of disability at some point in their lives may eventually blur the boundaries, in a positive sense, between people with and without disabilities. Indeed, there is a growing awareness that 'the disabled are same and different' (Devlieger, Rüsch & Pfeiffer 2003). However, in many contexts, people with disabilities are still considered as 'the Other' (Murphy 1987) and people without disability continue to define themselves in relation to this 'Other', which is perceived as a kind of pathological population (Branson & Miller 2002).

In this section, we have emphasised the importance of recognising how people with dementia experience disability in different ways and the extent to which they may or may not wish to identify with people with other disabilities. The next section looks at some of the ways that identifying with disability may be beneficial. In particular, we look at how it can give access to certain rights, but also at some of the possible limitations of rights-based approaches to disability in the case of dementia.

Key messages

- Disabilty means different things to different people.

- People with disabilities do not constitute a single, unified group of people, do not all experience disability in the same way and do not all have the same goals.

- It can nevertheless be helpful, for those who want to, to group together to campaign for rights and raise awareness about disability.

- Not everyone with dementia wants to identify with disability. Doing so can have an emotional and psychological impact.

- Some people fear that they will be stigmatised if they identify with disability. Others, may feel that disability is less stigmatising than dementia, and that being considered as having a disability is empowering.

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[15] See Section 8 for more about stigma in relation to social inclusion.

> - More effort is needed to find out what people with dementia think and feel about dementia as a disability.

6 Human rights and opportunities

6.1 Disability, dementia and rights

Nation states and international institutions alike have recognised that people with disabilities require legislation to have their rights upheld. People with disabilities are a minority group in society who are deemed to experience discrimination, inequality and exclusion.

In many countries, legislation on human rights, equality and disability is highly relevant to people with dementia. General data on how people with dementia specifically utilise national legislation is not available. However, it is likely that it is not routinely used as a way of upholding rights or addressing the inequalities and discrimination that people face. There are a number of reasons for this. One such reason is that historically dementia has not generally been viewed as a disability for the reasons already described. According to the UK Dementia Engagement and Empowerment Project[16] (DEEP 2016), there is 'confusion and ignorance' with regard to people with dementia, rights and disability law. DEEP states that people with dementia are often unable to insist on getting what they are entitled to by law and many are reluctant to frame their issues in terms of rights, even if they are aware of them.

From an international law perspective, a number of pieces of legislation are relevant. The focus of this section is on one specific piece of international legislation on disability, namely the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

The main components of the Convention on the Rights of Persons with Disabilities

The CRPD is an international treaty passed by the United Nations in 2006 and ratified (made legally binding) by 168 countries worldwide (including 27 European Union member states). The essence of the CRPD is to promote and protect the rights of people with disabilities. It aims to ensure their enjoyment of human rights and equality under the law and represents a legal framework for applying generic human rights legislation that is meaningful for people with disabilities. It is far-reaching and calls for fundamental change in terms of society's approach to understanding and responding to disability (Mental Health Foundation 2015).

The CRPD adopts human rights principles (Article 3, General principles). It defines disability as including "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (United Nations 2006).

Convention on the Rights of Persons with Disabilities and dementia

There are 38 cross-cutting articles in the CRPD, all of which are relevant to people with dementia. Specific articles that are highly relevant include:

> Article 9: Accessibility (ensuring accessible environments, transport, information and services),
>
> Article 19: Living independently (choosing where to live, having access to supports to live in community),
>
> Article 25: Health (right to quality health services),

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[16] A national network of independent groups led by or actively involving people with dementia.

Article 26: Habilitation and rehabilitation (maximising independence via comprehensive habilitation and rehabilitation services),

Article 28: Adequate standard of living and social protection (the right to adequate standard of living and social protection),

Article 29: Participation in political and public life (having the equal right to participate in public life).

It is worth specifically highlighting Article 12, 'Equal recognition before the law'. This is extremely important for people with dementia as it refers to the person with disability as having legal capacity (decision-making ability) on an equal basis in all aspects of life. It also includes a section on supported decision making which respects the person's autonomy, will and preferences. This differs from substituted decision making/guardianship models where someone else can have the authority to make a decision on a person's behalf. Article 12 promotes and protects legal personhood (Crowther 2016) and the autonomy of people with dementia who otherwise would have been considered as lacking capacity. It is highly relevant as people with dementia often find their 'autonomy automatically undermined or removed following diagnosis or who do not presently enjoy access to independent advocacy for support with major decisions such as in relation to heath, financial matter or their fitness to drive or travel'. However, the Mental Health Foundation (2015) paper states that it is unclear if there are any existing mental capacity legal frameworks in the world that are fully compliant with the CRPD. This is partly because it requires a total supported decision-making legal regime, which poses significant challenges in the case of people with advanced dementia (and profound intellectual disabilities). Shakespeare (2017) also concludes that the wording and implications of Article 12 are 'very hard to elucidate or implement practically'. The implications of Article 12 have been subject to considerable scrutiny and debate elsewhere (see for example the work of the Essex Autonomy Project (2014 & 2016)).

Convention on the Rights of Persons with Disabilities and dementia advocacy

While acknowledging that international legislation is only one element of bringing about change, the CRPD is very relevant for people with dementia from a number of perspectives. The history of the disability rights movement indicates that disabled people have not only successfully advocated to have their rights enshrined in a specific international legal instrument but that they have used it successfully as a catalyst for change in many countries across the world. Quinn (2009, p.2), one of the architects of the CPRD, argues that the real added-value of the CRPD is its ability to trigger 'a new kind of disability politics worldwide'.

In a similar way, dementia advocates can utilise the CRPD as an instrument for social change and as a potential advocacy tool. Furthermore, regardless of their status as being inside and/or outside of the disability rights movement, the CRPD can be used by dementia advocates in realising people's human rights, altering how dementia is perceived and influencing how policy and services are developed.

Crowther (2016) argues that the use of the CRPD as a tool for social change could be particularly useful in countries to achieve practical outcomes in access to health and everyday services, reduction in the use of restraint and anti-psychotic medication and the availability of high quality social care and support. The CRPD is particular relevant to addressing stigma, discrimination and social isolation that is commonly associated with the lived experience of dementia. Crowther (2016) sees stigma as a barrier to the participation in society of people with dementia and to achieving the social change necessary to secure their inclusion and well-being.

Shakespeare et al. (2017) agree that whilst people with dementia will vary in terms of their willingness to be identified as disabled, they, like other groups in society, can still use the

CRPD as a 'tool to advance their rights'. Dementia Alliance International (2016) suggests that Alzheimer organisations and self-advocacy organisations can use the CRPD to lobby and advocate for dementia policies and future plans to reflect the CRPD principles and articles. It can be utilised to guarantee that people with dementia are enabled to participate as equals in developing policy.

Furthermore, Alzheimer organisations can also use the CRPD to hold national governments to account, in terms of their progress with its implementation, to the United Nations (UN). In the United Kingdom, two reports were submitted to the UN Committee responsible for the CRPD in 2017, co-produced with people with dementia. These reports outlined key issues regarding the lack of compliance with the CRPD as it relates to people with dementia (Alzheimer's Society 2017, Dementia Policy Think Tank et al. 2017). The issues raised by the Dementia Think Tank's report (2017) are cross-cutting and include themes such as stereotyping and prejudice, accessible transport, independent living and community inclusion, accessible care and work. The Alzheimer's Society (2017) concludes that the stigma, prejudice and lack of understanding about the condition, as well as discrimination on multiple grounds including age and gender, compound an existing postcode lottery[17] of services for people affected by dementia in the United Kingdom. .

In conclusion, an international convention in the form of the CRPD, combined with a range of other advocacy tools, offers a meaningful opportunity for people with dementia to move away from being 'trapped within the dominant medical discourse' (Shakespeare 2017, p.4). However, using it in a meaningful way requires more effort and time as highlighted by the EWGPWD[18]. While members of the EWGPWD were strongly in favour of recognising dementia as a disability they raised concerns about how the rights associated with this could be realised in practice and be of benefit to the lives of people with dementia on a day-to-day basis.

Key messages

- National and international law has relevance to the lives of people with dementia to ensure their rights are upheld.

- The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is one important piece of international legislation that is relevant to help people with dementia enjoy human rights and quality under the law.

- Article 12 of the CRPD, recognition before the law, is critical. It states that the person has legal capacity (decision making ability) on an equal basis in all aspects of life.

- The CRPD is a tool that dementia advocates, Alzheimer and other organisations can use to advocate for change.

6.2   Policy in practice

The recognition of dementia as a potential disability resulting in the right to "reasonable accommodation" (e.g. in relation to employment, mobility and housing), and the difficulties surrounding the translation of ideas and attitudes into actual practice, were highlighted recently in relation to nurses who develop dementia. In an article, which appeared on the BBC news website, Dreaper (2017) reported discussions which took place at the Royal College of

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[17] A random variation of service access and availability according to where one lives.

[18] During focus group discussion with the whole European Working Group of People with Dementia on 14 May 2017 in Luxembourg.

Nursing's (RCN) Annual Congress in Liverpool (United Kingdom). The RCN decided, on the basis of a vote, that nurses who have dementia should be supported to continue their work for as long as they are able. Some members nevertheless raised concerns about nurses who have dementia putting others at risk. However, Jo James, a dementia nurse from London, put this in perspective, pointing out that dementia does not lead to instant loss of capacity or disability.

> *"A dementia diagnosis is likely to signal the end of a nurse's professional life. In a single moment they will go from nurse to patient, regardless of the severity of their dementia or how it's affecting them. We have robust laws in place against discrimination - but dementia is often seen as the exception to the rule and stigmatised"* (Dreaper 2017).

National laws are important in seeking to ensure that conventions are respected and properly implemented. Important discussions are also taking place at European level (e.g. in relation to the Accessibility Act). Similarly, the Disability Strategy 2017-2023 of the Council of Europe (2017) seeks to achieve equality, dignity and equal opportunities. It does this by targeting action and policy development, involving civil society organisations and organisations of people with disabilities, in five key domains:

1. participation, co-operation and coordination,
2. universal design and reasonable accommodation,
3. gender equality,
4. multiple discrimination and
5. education and training.

The European Disabilty Strategy 2010 – 2020 (European Commission 2010), on the other hand, seeks to empower people with disabilities and calls for consistency. It identifies actions at EU level to supplement national actions, whilst focusing on eight main areas. These include:

1. accessibility,
2. participation,
3. equality,
4. employment,
5. education and training,
6. social protection,
7. health and
8. external action.

There is plenty of commitment to making a positive change in the lives of people with disabilities. However, existing measures (e.g. to promote accessibility) are not always carried out consistently, or implemented correctly. Similarly, they do not always sufficiently account for the needs of groups of people with certain impairments[19] (which would include those typically associated with dementia).

At a more local, grass roots level, several groups of people with dementia that are part of the DEEP network in the UK[20] have been involved in a project called 'Our Right to Get Out and About'. The aim of the project was to make rights meaningful in the day-to-day lives of people with dementia (and their carers/supporters). It focused on the accessibility of buses and trains

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[19] As reported in the EDF online newsletter of 8 October 2017.

[20] For more details about the work of DEEP, please see: http://dementiavoices.org.uk/

for people with dementia, and getting a disabled car parking dispensation (known as the 'Blue Badge' scheme). The groups have engaged with public transport providers, and local and national government to lobby for changes in accessibility and information regarding transport that takes into account the cognitive impairments and disabilities that dementia can cause.

The social model/human rights principles have emerged in policy, specifically in relation to national dementia strategies, albeit in a limited number of countries. The second Scottish National Dementia Strategy (SNDS) made very explicit reference to human rights principles. These permeated not only the development but also the implementation of the SNDS. The Scottish Dementia Working Group was one of the key actors in contributing to the development of the policy which followed a rights based approach.

It is encouraging to see, in addition to high level guidance, strategies and even local initiatives, the recent development of fairly concrete guidelines and recommendations (e.g. linked to specific professions or work situations). Mental Health Europe, for example, has produced a toolkit on Article 27 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) to guide employers, human resource personnel, employment support services, and any other interested stakeholders, on how to apply a human rights-based approach to work and employment for people with psychosocial disabilities. At the same time, it is important to distinguish between a conditional right (e.g. the right to carry on working but not to put other people at risk) and an absolute right (e.g. the right to be treated with dignity - which is not dependent on anything else). It may be difficult to achieve the right balance. There are likely to be stong differences of opinion but in a fair society, respect for everyone's rights, non-discrimination and respect for dignity must be key objectives.

Whatever support is available for people with disabilities must be available for people with dementia. So with regard to cognitive impairment, if this affects a person's ability to do things and be involved in society, reasonable adjustments must be made (e.g. to continue working). If that is not enough, a person must be entitled to financial support for loss of income. The two approaches to support, which may reflect and stem from different policies, must be coordinated. It would be unacceptable, for example, for a person to lose his or her job because of impairments resulting in disability and then not be considered eligible for appropriate benefit/support.

Similarly, protective measures forpeople with disabilities must also be applicable to people with dementia. The latter should not be considered an exception due to the nature of their impairments.

The need to translate ideals and goals into coordinated policies, with appropriate funding behind them and effective monitoring, is essential for people with disabilities. People with dementia should be entitled to the same type and level of protection, respect for human rights and social inclusion as other people with disabilities. Any policies or practices which promote or condone a different treatment of people with dementia must be based on ethically defensible grounds.

Key messages

- Laws, regulations, conventions and strategies etc. promoting the rights of people wtih disabilities all need, at some point, to be translated into actual practice and real-life situations.

- It is important to ensure that such rights are respected and implemented in a consistent and fair manner. They must take into account the needs and wishes of people with dementia and balance these with the rights of other members of society.

- Initiatives are needed to make disability rights meaningful in the day-to-day lives of people with dementia (and of their carers/supporters). People with dementia and their

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carers/supporters must play a key role in such initiatives and in the development of policies and guidance.

- Policies to promote the rights of people with dementia and disability must be coordinated, have appropriate funding and be monitored.

6.3   Capabilities and agency

So far in section 6, we have considered issues related to the promotion of the rights of people with dementia who experience disability and issues surrounding the possible consequences of having such rights. In this sub-section we will look at disability and dementia from a different perspective, namely that of capabilities. We will base this discussion on the ideas of the philosopher Martha Nussbaum (2011), amongst others and reflect on the concept of agency in relation to people with dementia in the framework of the CRPD.

But first, what do we mean by agency and capabilities? In its broad sense, 'agency' means 'intention or consciousness of action [enacted by the agent], sometimes with the implication of possible choices between different actions' (Barnard and Spencer 2002, p.891). Boyle (2014), on the other hand, defines agency as the ability to intiate social action or at least influence one's own personal circumstances.

The concept of 'capability' stems from the theories of the economist Amartya Sen (in the early 1990s), which were later developed by the philosopher Martha Nussbaum (mentioned above). According to Harnacke (2013, p.769), "the capabilities approach views society as having to provide certain capabilities for everyone, which are substantive or real opportunities, at an appropriate threshold level for each." More concretely, Harnacke explains that frameworks such as the CRPD and the capabilities approach both aim for societal measures to empower individuals regarding their own abilities.

Very often it is assumed people with dementia have no agency. In this section, we explore how the concepts of agency and capabilities can be meaningfully applied to the specific experience of dementia. Indeed, as Eva Feder Kittay argued, "ensuring equal opportunity to people is admirable when people are in a position to take advantage of the opportunities on offer, but some who are disabled are not in this position" (2011, pp.55-56). This may be applicable to some people with dementia (due to the progression of the disease which often renders choice and empowerment increasingly difficult), especially for people with more advanced dementia. Hence, we will briefly review the capabilities approach and its limits, and then move on to consider new ways to extend the possibility of agency to people with dementia.

Nussbaum reminds us that these limits to inclusion are the fundamental challenges posed to philosophical theories of justice (2010). In her explanation, she provides three examples (case A, case B and case C) of adaptation of the legal framework to the needs of people with cognitive disabilities. These examples are structured around the participation of a person with cognitive disability in a jury for a trial (Nussbaum 2010, p.88).

- Case A describes how the participation of the person with a cognitive disability – which could easily include a person with dementia – is achieved by providing external support (e.g. by summarising documents to make them easier for people with dementia to understand). Useful guidelines can be found on the website of the DEEP network (see references section).
- Case B describes a person in a similar situation in which the impairment is more severe but the person can 'communicate his or her preferences to a guardian, who can then exercise the function on his or her behalf'. Case B, as Nussbaum reminds us, is still 'conceptually' easy, even though it involves a series of challenges which must be overcome.

- Case C describes a situation in which communication between the guardian and the person with disability seems to be impossible. This is particularly interesting as it calls into question the very roots/basis of inclusion and highlights some apparent limits to more conventional forms of inclusion. The challenge is perhaps for us to find ways to ensure equal citizenship for all.

In Nussbaum's argument, case C calls for the intervention of a guardian who is 'empowered to exercise the function on that person's behalf and in her interests', a measure often not taken (Nussbaum 2010, p.91). This highlights the apparent challenges to more conventional forms of inclusion. As we will see, these categories and the solutions proposed to ensure more equal citizenship are relevant to the issue of promoting the rights of people with dementia. Futhermore, we will see below that novel methods of communicating with people with dementia can enable them to be better heard and move towards greater autonomy and agency if they wish to, hence to move towards case A or B.

Indeed, recognising dementia as a potential disability, in keeping with the capabilities approach, makes it possible to access a framework which offers a structure to further enforce the rights of people with dementia, regardless of the level of impairment. In this respect, Toby Williamson (2015) describes the PANEL principles, in which the last letter of this acronym stands for legality of rights and the 'recognition of rights as legally enforceable entitlements' (Williamson 2015, p.12). Hence, raising awareness about the CRPD in relation to the rights of people with dementia enhances our ability to propose new and more appropriate possibilities for people with dementia to enact their rights as equal citizens. This includes their capabilities, as described by Nussbaum (2011). The next step is therefore to find ways to ensure that the voices of people with dementia are better heard.

A wide range of methods and appropriate support should be considered to ensure that people with dementia can participate in and contribute towards society on an equal basis with others (addressed in more detail in Section 8). New approaches to inclusion could enlighten us about ways to achieve this. Boyle (2014) provides an interesting practical case and novel way of thinking about the agency of people with dementia. Based on research involving people with dementia and their carers/supporters, she criticises the over-emphasis on rationality and claims that we need a broader concept to understand the agency of people with dementia. Indeed, she argues that we need to take into account the way in which agency is exercised by people with dementia in a creative manner which was not previously considered, namely by looking at more 'socio-emotional' forms of agency. She sheds light on the way in which the wishes and desires of people with dementia are expressed through body language as well as through subtle emotional changes and changes in mood. As Boyle reminds us (citing Morris 2005), this is particularly relevant in the context of various relations of 'assisted autonomy' which are sensitive to such changes. Such sensitivity could be a step towards fulfilling some of the capabilities listed by Nussbaum (2011) (e.g. in relation to sexuality and consent which reflects the third core capability, namely bodily integrity[21]).

Clearly, there are many possible novel and alternative ways to explore agency and these could be further explored in future research. Indeed, some of these capabilities might present very complex challenges with regard to enhancing agency and autonomy. Case C, described

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[21] "Nussbaum defines bodily integrity as: 'Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction' (2011, p.33). See https://en.wikipedia.org/wiki/Capability_approach for a complete list with the nine other central capabilities defined by Nussbaum.

above, appears to be one of them. Moreover, Boyle (2014) highlights the need to explore this idea of socio-emotional agency among people with severe dementia. In many ways, exploring the wishes of people with the most severe forms of dementia touches on ongoing debates around the concept of personhood. Some of these debates have been explored earlier in this discussion paper and will be considered in the next section, particularly in relation to person-centred care.

In presenting both challenges but also new possibilities to reinforce the agency of people with dementia in a framework of rights such as the CRPD, Boyle's approach is helpful. It offers a new way of understanding the wishes of people with dementia and supporting them to perform their agency in novel, alternative ways. More research and the promotion of more positive attitudes towards people with dementia, in a framework of human rights and equality, could further open the door to greater enablement of people with dementia. Arguably, recognising dementia as a potential disability could favour such discussions in situations, and for example in public debates, in which dementia often remains invisible.

Key messages

- The capabilities approach (based on the work of Sen and Nussbaum) is a framework of protected rights that allows people to be 'empowered regardless of their own abilities'.

- The CRPD could, according to Harnacke, be considered as reflecting the characteristics of such a framework. It allows for people with dementia to have their rights recognised as 'legally enforceable entitlements' regardless of their actual capabilities. This represents a move towards equal citizenship.

- It may be helpful to combine such a framework with an exploration of novel ways to take into account the agency of people with dementia (e.g. building on Boyle's concept of 'socio-emotional agency').

- Paying attention to subtle emotional changes, as well as to changes in mood, and to body language, may improve our understanding of the wishes of people with dementia.

- Exploring new ways to take into account the agency of people with dementia within a relevant framework of rights, such as the CRPD, may help ensure that people with dementia have the opportunity to take part in society and in decisions related to care and support.

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7   Care, support, disability and dementia

Promoting the concept of care and support

In addition to discussing access to rights and equal recognition before the law, it is important to consider the level and quality of care and support for people with dementia. According to an OECD report (2015, cited by Shakespeare et al. 2017) dementia is still one of the conditions that receives the lowest quality of formal care in the developed world. This is particularly significant when we consider that a lot of informal care and support (which more often than not is essential) is provided by families, friends and neighbours. It is also a major concern for many people living with dementia, especially for those with more advanced dementia. We might therefore ask whether recognising dementia as a potential disability would lead to any improvement in the care and support (both informal and professional) of people with dementia. This is a matter of concern, especially if we acknowledge that the social model of disability, which developed out of the disability movement, promotes autonomy as one of its most central values. The concept of care has been criticised recently, in relation to dementia, as being too narrow and potentially leading to the framing of people with dementia as having certain needs of a more medical nature and rending them passive. For this reason, wherever possible we refer to care and support in the broader sense.

However, in certain places in this text, the debate is fundamentally about the provision of care and this is therefore reflected in the terminology used.

Questioning the focus on autonomy

Within the social model of disability, care and dependency do not appear as priorities. In a previous section of this discussion paper, we have looked at the importance that is attached to independence, both in daily life and in legal frameworks such as the CRPD. We fully support efforts to promote more independence and rights for people with dementia for whom care is often an integral part of their lives. However, due to the nature of dementia, and the range of impairments that are associated with it, it is essential to reconsider what it means to be dependent upon relations of care, whilst still being able to exercise agency.

Recognising dementia as a potential disability should therefore also involve an attempt to reinstate the importance of care and the validity of certain forms of interdependency. For example, a person with dementia may be dependent upon his/her partner for care or support but the partner may be emotionally dependent on him or her. According to Boyle (2014), the concept of interdependency represents a departure from current definitions of agency which tend to be 'over-individualistic'. She points out that 'throughout our lives, all of us go through varying degrees of dependence and interdependence' (Boyle citing Tronto 1993, p.135). Interdependency therefore describes the way in which people are never fully independent and always rely in some ways on others. Taking this perspective allows us to question relations of 'dependence' and not consider these as problematic *per se*.

To explore this idea of care and interdependency, which may appear paradoxical[22] at first sight (in the context of the social model of disability), we will draw on Eva Feder Kittay's work on the 'ethics of care'. Kittay (2011) describes how taking relations of care and interdependence into account when developing theories of justice provides the means to achieve more autonomy for people with disabilities. The principle of justice reflects the moral obligation to act on the basis of fair adjudication[23] between competing claims. It is linked to fairness, entitlement and equality. With reference to Aristotle, Gillon (1994) argues that it is important to treat equals equally and unequals unequally in proportion to inequalities which are morally relevant. In other words, in some situations (e.g. when a person has an impairment and experiences disability), it would be right to treat a person differently (unequally) as treating him/her in the same way as others would actually be unfair.

Kittay draws attention to traditional schools of thought which take justice as a starting point for reflection on the position of the moral agent (in this case, the person with a disability). She explains that this results in a tendency to conceptualise this person as 'an independent, autonomous self who is equal, or potentially so, to all moral agents' (Kittay 2007, p.4) and calls for dependency to be reinstated as a central part of any human relation. For Kittay (2011), assistance is a resource, not a limitation. She suggests that the relation of care, should be perceived as supportive, rather than paternalistic, adding that:

> *"paternalism is the only alternative to autonomy when autonomy is the norm of all human interaction" (Kittay 2011, p.55).*

Therefore, if certain aspects of the social model of disability were to be applied to people with dementia experiencing disability, this might challenge the current over-emphasis on the

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[22] Seemingly absurd or contradictory.

[23] Making a judgement on a disputed matter.

importance of autonomy. It might also contribute towards a more nuanced understanding of disability. Such nuances are brought about through the re-evaluation of dependency and by recognising the validity of individual experiences of impairment.

During discussions linked to the preparation of this paper, a member of the EWGPWD emphasised the importance of such an approach to care. Based on her own understanding of care in dementia, she emphasised the need to distance herself from paternalism. Her use of certain terms in relation to her own experience of dementia such as 'requiring support' and 'care partner' are in keeping with this transformation of our understanding of care. A distinction was also made between being 'cared for' and 'caring about'. 'Caring for' sees the person with dementia as a passive recipient of care. 'Caring about' reflects a relationship that is dynamic and involves give and take, in which the person with dementia and the care partner interact in a relationship with each playing a 'caring' role. These roles such as husband, wife, partner or friend would have existed prior to the diagnosis of dementia. In this way, she emphasises equality in moral status and enablement as part of the construction of meaningful relations of care. This is echoed by Boyle (2014), in the context of 'assisted autonomy', who highlights the importance of promoting supportive relations of care.

Care as a new opportunity to improve the recognition of disability within society

Recognising the importance of the relation of care and support, and of the experience of impairment, provides an opportunity to improve the inclusion of people with dementia in all aspects of life. Indeed, Kittay (2011) explains that 'the scope of care extends beyond intimate relations' and 'can introduce new values into the public domain'. An ethics of care should therefore be a central part of any message to the public if dementia is to be recognised as a potential disability. The importance of a revaluation of the relation of care was also expressed by some people with dementia:

> *"Care should be enabling, something that enhances my autonomy and allows me to participate in civil society, whilst promoting my dignity. For this to be possible, future therapists and healthcare professionals must be properly trained, and a more holistic, person-centred approach to both formal and informal care should be promoted.*

> *For me personally, this would focus on meaningful activities (e.g. based on the arts and relaxation) and a reduction of psychoactive medication to regulate mood and anxiety. Such person-centred care can bring about improvement and better account for the wishes of people with dementia"* (both extracts from a member of the EWGPWD).

In contrast to the establishment of meaningful and enabling relations of care, Kittay highlights a certain set of behaviours that she considers unhelpful:

> *"dependence may in various ways be socially constructed, and unjust and oppressive institutions and practices create many sorts of dependence that are unnecessary and stultifying[24]"* (Kittay 2011).

Instead, she argues in favour of 'cooperative, respectful, attentive relations' (2011, p.55). We can therefore conclude from these two statements, and from the statements in the previous section, that it is not sufficient to argue for care as a means to support independence, or to give too much importance to autonomy, as is sometimes the case in the social model of

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[24] As we understand it, the adjective 'stultifying' used in this quote characterises the way in which certain relations of dependence can be psychologically distressing.

disability. Rather, it is essential to question the relation of care itself, and differentiate those relations of care that are disabling from those that are enabling.

Person-centred care and enablement

Person-centred care, which emerged from the work of Tom Kitwood, has been described as involving the tailoring of a person's care to his/her interests, abilities, history and personality (Alzheimer's Society, 2017). Indeed, person-centred care appears to be a valuable means to enable, or sustain as much as possible, the active involvement of people with dementia in decisions related to care. In this framework, relations of care are established in such a way as to overcome the impact of a 'malignant social psychology'*,* which is associated with a process of 'othering' of the person with dementia following the progression of neurological impairment (Kitwood 1992). According to Kitwood (1992), this process of 'othering' creates and reinforces a distinction between *us* and *them,* jeopardising the experience of empathy between the person with dementia and his/her carer, but also between the person with dementia and the rest of the world (see also section 5.2 on stigma). Indeed, in the context of a 'new culture of dementia care', Kitwood (1997) explicitly recommended considering dementia primarily as a disability. He suggested that how a person is affected by dementia depends crucially on the quality of care. Care and support should therefore be central to any discussion about the recognition of dementia as a potential disability.

Indeed, person-centred care could be seen as a step towards sustaining a broader 'ethics of care'[25] (an idea that we mentioned earlier in this section). As such, it could apply to many different types of care and support, regardless of who or with what means it is provided (Morris, 2001). Reducing the impact of otherness by reinforcing empathy towards people with dementia may therefore be a means to both promote the dignity of people with dementia and respect their human rights. Morris further argues[26] that an ethics of care should allow people to state their opinion and participate in decisions which affect their lives.

The 'ethics of care' debate has implications for formal/paid care for people with dementia. It also has direct implications for how paid carers are educated and trained. The recognition and promotion of agency as a concept and how that rolls out in practice in the formal care sector need exploration. This will undoubtedly give rise to ethical questions about the extent to which formal services set parameters on the enablement of people with dementia.

We also need to bear in mind criticisms that have been made about such concepts in relation to disability, which may be particularly relevant with regard to dementia. To broaden the discussion, we should examine in more depth a point made by Morris about participation in the provision of care (2001, p.15):

> *"Whatever "care" is - whether it is in the form of formal services, cash payments, or personal relationships - if it does not enable people "to state an opinion," "to participate in decisions which affect their lives," and "to share fully in the social life of their community," then it will be unethical."*

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[25] Whilst we propose broadening the concept of care to include, or even focus on, support, the term "care" is occasionally used in isolation when referring to other people's work and ideas.

[26] Drawing on statements from the first edition of "In from the cold" (1981) – "a liberation magazine for people with disabilities".

Morris's statement, which rightfully highlights the importance of enabling choice, begs a series of questions about the limits of enablement, such as:

- What if such an emphasis were to lead to misunderstandings about the difference between ethical and unethical care?
- What about care which is simply performed to the best of a carer's ability, with due consideration for dignity and agency, but unsuccessfully (in terms of recognising and promoting agency)?
- Would the non-fulfilment of such objectives be perceived as unethical?
- What if the socio-economic context makes it difficult for both the carer/supporter and the person with dementia to establish an effective relation of care and support?
- Should these be considered unethical relations of care and support?

Some of these reflections about the social context have been considered by Gilleard and Higgs (2010) in relation to negative perceptions of impairments in later life and the impact this may have on care and support. We still have a lot of issues to explore but it is nevertheless clear that dependency and care/support should not be perceived as interfering with the recognition of dementia as a potential disability.

Key messages

- New 'socio-emotional' approaches to agency and the exploration of these new approaches could be a better means to account for the wishes of people with dementia with regard to their own care, support and lives in general.

- It is nevertheless important to acknowledge that in the case of more advanced dementia it may be more difficult (but not impossible) to 'listen to the voice' of the person with dementia.

- Recognising dementia as a disability is not only a matter of claiming rights, autonomy and independence. It should also address care and support needs, and give more focus to a positive conceptualisation of interdependency.

- Promoting care may appear to challenge the idea that disabilities are the sole result of 'oppressive institutions and policies, prejudiced attitudes, discrimination, cultural misrepresentation, and other social injustices'.

- Improving the lives of people with dementia, as well as the recognition of their needs and associated disabilities, comes with the establishment of an 'ethics of care' to use Kittay's term, and a nuanced understanding of care, dependency and interdependency, as well as the importance of support.

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8 Working towards an inclusive society

In this section, we discuss the impact which re-framing dementia as a disability might have on social inclusion for those with a diagnosis. We consider the kinds of measures and shifts that are needed for all people with dementia to be fully included in society. In doing so, as mentioned earlier, we necessarily move away from individual 'personhood' as a concept, to consider dementia also in the wider contexts of human rights and intersectionality (i.e. different social identities such as gender and race which overlap and are generally associated with discrimination).

Two broad questions arise here. The first relates to the potential advantages for people with dementia of moving away from the still-prevalent medical model of dementia as a disease,

towards a social model of dementia as a disability[27]. The second relates to the problems which may then arise for those who do not wish to accept the label of disability in order to achieve social inclusion. Such opponents may well argue that they do not want to be socially included as people with disabilities, but simply as people on the same terms as anyone else. People with dementia clearly have the same right as anyone else to be fully included in society. It might, however, be argued that re-framing dementia as a disability is not necessarily the best way of achieving this for everyone.

This section covers the ethics of social inclusion, the part played by the medical model of dementia in perpetuating social exclusion, the importance of intersectionality in thinking about social inclusion for people with dementia, and the appropriateness or otherwise of the 'dementia-friendly communities' concept. It considers how re-framing dementia as a disability might enhance social inclusion for people with dementia. Finally, it looks at the potential shift that is taking place in the dementia field from thinking in terms of the dependency needs of people with dementia, to their unassailable human rights.

The ethics of social inclusion

We start from the assumption that people with dementia have a fundamental right to be included in all aspects of society in which they wish to participate. This right should not diminish as dementia progresses, although the wishes of the person concerned may, of course, change over time. Working with a social model of disability, we can see that many existing obstacles to full social inclusion and citizenship for people with dementia are not directly caused by dementia itself. Instead they are the result of external factors and social attitudes. If these factors and attitudes were to change, then both the nature of dementia and the experience of having dementia would also change. Indeed, Kitwood (1997) suggested that if social responses to people with dementia were appropriate and supportive from the start, then much of the 'disease progression' currently taken to be inevitable might be avoided. This is a profoundly ethical issue. From the perspective of ethical principalism (Beauchamp & Childress 2001), non-maleficence (avoiding causing harm) towards people with dementia and ensuring beneficence (doing good whilst trying to balance possible benefits against risks and costs), equality and justice, requires the full social inclusion of people with dementia. We will argue below that we can only ultimately achieve this if we move from thinking about the *needs* of people with dementia, which can be met by others, to a concept of inalienable human rights (i.e. which cannot be taken or given away).

Why are people with dementia socially excluded? The contribution of the medical model

As outlined in section 4.2, the medical model of dementia places the 'problem' of dementia within the individual mind and body of the person with the diagnosis. This suggests that additional contributing factors such as the reactions of others are of little importance. The impact of social, psychological and environmental factors on the experience of people with dementia has been recognised in numerous forms over the past two decades. Examples include Lawton's concept of 'excess disability', Kitwood's (1997) work on the involuntary (meaning 'inward turning') spiral of dementia and Post's work on hypercognitivity (which was mentioned earlier).

Bartlett & O'Connor (2010), for example, highlight the ways in which the experience of dementia affects social status. Birt et al. (2017, p.200) refer to 'discourses of deficit' which

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[27] The distinction between the medical and social model made in this section should be understood as reflecting two possible extremes along a continuum, with the social model incorporating the elements described in Section 4.2 of the biopsychosocial, reinterpreted and human rights models of disability.

stigmatise people with dementia and negatively impact on the recognition of them as citizens with rights. A growing body of work has demonstrated, for instance, that, post-diagnosis, walking may be negatively reframed as undesirable 'wandering', which is then constructed as a 'symptom' of dementia (Brittain et al. 2017). Kate Swaffer, the founder of Dementia Alliance International, and herself a person living with dementia, has argued persuasively that the language used to describe people with dementia is a large part of the way in which stigma is perpetuated (Swaffer 2014). Much of the terminology noted by Swaffer, which is detrimental to the interests of people with dementia (e.g. demented, victim and sufferer), has been inherited from the medical model of dementia.

A diagnosis of dementia, in the context of the medical model, therefore attaches a stigmatising 'disease label' to the individual. This sets him or her apart from the rest of society. McGettrick and Williamson note that for other groups of people with disabilities,

> *"The medical model was used…to explain disabled people's exclusion from mainstream social and economic life, their oppression (especially through the use of institutional care) and their lack of recognition as having basic human rights" (Mental Health Foundation 2015, p.14).*

George (2010) notes that,

> *"The everyday language we use to describe dementia shapes our perceptions of brain ageing and even contributes to what has been called the "social death" of those most severely affected."*

The extent to which a person diagnosed with dementia to some extent 'becomes' his or her diagnosis is problematic, particularly when we consider the many differences between people with dementia and each person's experience.

Intersectionality and social inclusion

One of the most striking aspects of the medical model of dementia is its assumption that people diagnosed with dementia cease to belong to any other reference groups or interest groups. As mentioned earlier, Takala (2009) points to the dangers of such a one-dimensional view. Such a view fails to consider that people with dementia continue to belong to a wide range of other social groupings (e.g. based on gender, social class, sexual orientation, ethnicity, religion, political belief, former occupation, roles within families, hobbies and interests, and many more including having other disabilities in addition to dementia).

The term 'intersectionality' is used to refer to this difference among people with dementia. It was originally used by feminist theorists to reflect how in everyday life one is not only a woman, but also, perhaps, black, living in poverty and having a chronic illness. Indeed, there can often be as much that divides women as unites them, unless these additional facets of experience are also taken into account (Yuval-Davis 2006). People with dementia continue to be treated as if they were all the same (on the grounds that they share a common diagnosis). Commonalities between people with dementia and others (including other groups of people with disabilities) are less frequently noted. Paying attention to potential commonalities might lead to a more active/political/advocacy-based approach on the basis of rights and discrimination etc.

Dementia-friendly communities or universal design?

The recent move toward the creation of 'dementia-friendly communities' (or DFCs) may be seen as a positive one. It involves environmental and social change, rather than expecting the person with dementia to change and adapt. However, what is friendly to a person with dementia is, in most cases, friendly to all. Equally, things that everyone finds difficult about contemporary life (such as noisy, crowded, uncomfortable places, the fast pace of

technological change, and confusion created by poor design lighting and signage in public spaces) are also likely to be upsetting and anxiety-provoking for someone with dementia. For these and other reasons, some people with dementia find the term 'dementia-friendly' somewhat patronising. This has led to debates about what is really needed – dementia-friendly communities, or a more universal 'design for living' that is adapted to everyone's needs and wishes. As Swaffer (2014, p.713) comments,

> "I have been uncertain that 'dementia-friendly communities' is the right phrase as I am worried it encourages division rather than includes people."

A member of the EWGPWD also talked about her desire to 'get rid of' the term dementia-friendly communities (DFCs) and instead talk about an inclusive society. She feels that DFCs are exclusionary and that dementia-friendly should not be part of our language. A DFC might be considered one which compensates for the problems people with dementia do have, but without adding new ones. However, steps such as taking more time, offering alternatives, giving a helping hand, where it is needed and appreciated, should be markers of any humane community, not one unique to the needs of people with dementia.

People with dementia should not therefore be singled out as in need of special measures. A society in which people offer to help anyone experiencing difficulties is one to aspire to. There is nothing unique to the experience of dementia which could not be experienced, in some way or to some extent, by any member of the community (e.g. getting lost, experiencing sensory overload, forgetting a name or address needed in order to complete an errand or appointment and not being able to find the right bus or train etc.). Reflecting on our own experiences of this nature may therefore be one of the best ways to develop empathy with people who have dementia. This should also foster social inclusion within mainstream communities. This is better than putting people with dementia in separate hermetically-sealed safe spaces.

At the same time, we need to find out what people with dementia experience as barriers to social inclusion and not simply assume that everyone finds the same things difficult. Age-friendly initiatives, for example, do not necessarily respond to the needs of many people with dementia (who are increasingly being diagnosed at a younger age but also have certain needs which are not as relevant to older people in general). This is another reason why it is important to involve people with dementia in decisions about issues potentially affecting their incusion in society.

Initial work to develop dementia-friendly communities (DFCs) has had the benefit of drawing attention to a very real problem, namely the extent to which many existing environments disadvantage and are inhospitable to people with dementia. In this, the DFC initiative is to be welcomed as an early indication that the social model of disability is beginning to have an impact on thinking about dementia. It might, nevertheless, be argued that dementia-friendly or dementia-accessible communities imply that people with dementia are fundamentally different and have problems that are not shared by other members of the community. We still need to hear much more from people with dementia themselves - including those whose voices are not currently being heard – about their responses to initiatives such as DFCs. The DFC concept and various DFC initiatives vary considerably across Europe. Some DFCs have a fairly limited scope whereas others empahsise rights, citizenship and the active involvement of people with dementia (Alzheimer Europe 2015, Williamson 2016).

Levels of participation and inclusion

Clearly there are different degrees to which any one person with dementia might be socially included. Arnstein's ladder (Arnstein 1971) is often used to represent different levels of citizen participation, ranging from manipulation at the lowest level to full citizen control at the highest rung. DFC principles suggest that the views of people with dementia should inform the

development of DFCs. If people with dementia are not actively involved in the design and delivery of particular interventions, these may be considered more tokenistic.

In the box below, we highlight six ways to include people with dementia in society in a meaningful way. These have been taken from an adaptation of Arnstein's ladder by Capstick et al. (2016)[28] to apply to the social inclusion of people with dementia.

Citizen Power: forms of participation which involve having a genuine influence on public awareness or consciousness raising. The person with dementia has autonomous influence on others in society, and decides on the nature of the influencing activity (e.g. taking part in an action group or campaign) and its desired outcomes.

Delegated Power: participants are helped to take part in an influencing activity or form of action involving contact with the wider community (e.g. writing a report; producing guidance).

Partnership: the person with dementia is actively engaged with members of the broader community on mutually-identified projects which have a shared goal, or co-produced outcomes (e.g. giving feedback on a service or intervention).

Placation: the person is involved in personally meaningful activity, but in a relatively passive role (e.g. being taken to events as a spectator or audience member).

Consultation: activity initiated by others that involves exchange of information, and/or meaningful social interaction with persons with dementia, who are nevertheless recognised as equals, able to express of choice, and/or share decision-making.

Informing: the person with dementia is given information intended to inform his or her choice about whether to take part in an activity or event or not. He or she may be told in advance about things that are going to happen, but not asked to make suggestions. Information provided is not necessarily in user-friendly format.

The above approaches to social inclusion build on a perception of different levels of participation in relation to the exercise of power which date back almost 50 years. Nevertheless, most (with the exception of therapy and manipulation which have not been included in the above box) are still relevant to the issue of social inclusion. In the original version, the means of involvement were presented as rungs of a ladder. This suggested a hierarchy. But it has been argued that 'the process of increasing participation should not be simplified to a one-dimensional parallel of climbing a ladder' (Maier 2001, p.716). Not everyone is interested in the same level of involvement. One person may feel involved and valued as a result of having been informed about something, whereas another might prefer to play a much more active role. Each form of involvement should therefore be equally valued.

More recently, there has been an emphasis on patient and public involvement and a whole range of approaches to the involvement of people with dementia in research, policy making and service provision. This involves people with dementia working alongside researchers, policy makers and service providers on a more equal basis, albeit with appropriate support if needed (in keeping with the principle of reasonable adjustment)[29]. Such approaches are often described in terms of 'co-production', 'co-creation' and 'citizen involvement' to name but a few.

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[28] Adapted from Capstick et al. (2016).

[29] See position paper on PPI and dementia by Alzheimer Europe, INTERDEM and the European Working Group of People with Dementia (Gove et al. 2017).

From needs to rights: biopolitical life and dementia

Following the work of Kitwood and others, it may be argued that much of the apparent progression of dementia is already the result of society's responses and reactions. In this respect, anything that we can do to keep people with dementia socially included is, in itself, likely to reduce the deterioration that can result all too easily from loneliness, boredom, lack of interpersonal communication and absence of meaningful activity. It is not enough to move beyond merely 'doing no harm' in a context in which people with dementia are harmed daily by society's response to them. We need to go further, moving towards ethical principles of equality and justice as well as beneficence.

The work of Agamben (1999) draws attention to the way in which civil society divides its citizens into those who have biopolitical life (i.e. the status of political beings) and those who are relegated to a lesser status of 'bare life' only (also described as a 'state of exception'). Currently, many people with dementia are relegated to this state of exception, and it becomes increasingly likely as their circumstances change over time. The agenda may therefore need to shift to reinstating full human rights to people with dementia rather than attempting to meet their needs through initiatives that give them in a passive role. Katz (2002) coined the term 'experts by experience' to capture the sense that older people, including those with dementia, are in the best position to inform others about what it is like to have the condition, what is needed in order to make improvements, and how to shape the kind of society they wish to live in.

Applying human rights principles to dementia promotes autonomy and decision making, which includes recognition of the right to take certain risks. Some members of the community, including many family members, do not consider it acceptable for people with dementia to take risks which may result in injury, or to make choices that others may see as resulting in a threat to their personal dignity. It may be argued, however, that preventing people from doing things which involve or result in some degree of risk is an abuse of human rights.

As Clough (2014) notes, a narrowly medical model of dementia, which is disease/condition specific, is no longer supported by evidence. Instead we need a bio-psycho-social model of cognitive disability that is inclusive, and one that actively seeks social justice for and alongside people with dementia. We also need to recognise the personal experience of impairment, and the diversity of the experience, needs and interests of people with dementia. Shakespeare et al. (2017) advocate a human rights approach to dementia and disability, suggesting that this would open up space for collaboration between people with dementia and other disability rights activists.

Key message

- There has been a shift of attention away from the medical model of dementia as a condition, requiring predominantly medical research and pharmacological remedies.

- The adoption of a social model or framework for thinking about dementia is being increasingly encouraged. A social model of disability, applied to dementia, reinforces the idea that we are all responsible for each other's well-being or ill-being and that there is a great deal to be done to improve the lived experience of people with dementia.

- A social model framework for thinking about dementia and a human rights approach challenges concepts and practice concerning the development of 'dementia-friendly communities'.

- Dementia is a human rights issue with equality and justice to the fore, and which locates those living with dementia within a socio-political context that is largely missing from current discourse.

- If everyone has the same human rights, then these rights are not compromised when someone has dementia.

- People with dementia may find it helpful and empowering to identify as a person with disability. However, a person with dementia should not have to accept the label of either disease or disability in order to have their human rights upheld.

9 Conclusions

The disability movement began over half a century ago but it is only in recent years that a dialogue has started about dementia as a disability. The main impetus for this emerging dialogue came from people with dementia themselves who have started to articulate their right to be treated as full and equal citizens. People with dementia must play a key role in identifying the issues at stake, contributing towards discussions and developing possible recommendations for governements, policy makers, Alzheimer associations, disability organisations and regulatory bodies. For this reason, we are pleased to have been able to include people with dementia in this work in two ways:

- firstly, in the ethics working group responsible for the drafting of this paper, together with experts in disability, ethics, policy making, mental health and advocacy, and
- secondly, in the context of an email survey and a one-day focus group discussion in which the members of the European Working Group of People with Dementia and their carers/supporters shared their experience and views with regard to the topics addressed.

Throughout this discussion paper, we have highlighted the potential impact of recognising that dementia can lead to disability. At the same time, we have acknowledged that such disability may be experienced in different ways by different people with dementia and that some people with dementia will prefer not to take on an identity based on disability. We suggest that, overall, the ethical, practice and policy benefits of viewing dementia as a disability, such as the opportunity to campaign for rights, advocate for change and be covered by legislation promoting human rights (e.g. based on the CRPD), outweigh the disadvantages. We have therefore drawn attention to the challenges that dementia (and human agency) poses to existing models of disability and emphasised the need to retain and promote a positive attitude and more nuanced understandings of care, support, dependency and interdependency within society. In addition, we have emphasised the need to challenge theories of personhood and approaches to social inclusion which serve to exclude and devalue people with dementia, with or without disability.

In terms of different ethical frameworks, the biomedical ethical principles highlighted by Beauchamp & Childess, Nussbaum's capabilities and Kittay's approach to the ethics of care provide solid grounds to argue in favour of the benefits of recognising dementia as a potential disability. Furthermore, specific ethical and related concepts (such as respect for autonomy, beneficence, non-maleficence, justice, equality, agency and relationships of support and care etc.) dovetail with a rights-based approach, which is clearly framed in terms of disability rather than a disease-specific model. This, as the paper makes clear, further reinforces the benefits of viewing dementia as a disability. Though dementia has come late to the 'disability table', it provides a set of filters for human agency, disability and rights to come together and actually enable theory and practice about disability to be taken forward in positive and helpful ways for the whole of the disability movement.

Furthermore, examining dementia as a disability brings a new complexion to the more traditional views of dementia. This paper calls for a progressive and positive change in society's response to dementia, based on recognition of potential disability, accompanied by a change in attitudes and the provision of coordinated, appropriately funded and properly

monitored polices, services and support, thus leading to a positive change in the lived experience of dementia. None of these potential benefits should require a particular person with dementia to identify with disability. We need to be careful to recognise and respect difference and individual choice. It is hoped that this discussion paper will contribute in some way towards improving the lives of people with dementia who experience disability. We hope that it will also provoke thought on how to create a more inclusive society in which people with disabilities and dementia are not considered as 'other' or 'them', but simply as 'us' with the same rights and opportunities as everyone else to enjoy life.

We have provided a lot of information in this discussion paper, raised and defended certain arguments, drawn conclusions and even made recommendations. However, the whole area of disability and dementia is 'under construction'. It is early days and a lot still needs to be achieved in terms of understanding and action. We look forward to the continuing debate and to future developments in relation to ethics, policy and practice, which will hopefully have a positive impact on the lives of people with dementia.

10 Recommendations

The general public

- Bear in mind that impairments related to dementia may, in combination with other external factors, result in disability.
- Strive to ensure that people with dementia have access, if and when needed, to the same rights and support as people with other disabilities.
- Be sensitive to and respect people's preferences regarding the use of the label 'disability'.
- Aim to offer support and consideration in response to a specified, apparent or suspected need.
- Avoid making it necessary for people to state that they have dementia or disability in order to access any support they may need.
- Involve people with dementia in the development of initiatives to ensure their full citizenship and equal social inclusion in the local and wider community.
- Look for ways to promote the full citizenship and social inclusion of everyone rather singling out people with dementia as a separate group (i.e. most if not all barriers are also encountered to some extent by people without dementia).

Governments and policy makers

- Use the ongoing evaluation of progress with the implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) as an opportunity to highlight whether national provisions apply equally to people with dementia. If this is not currently the case, take necessary measures to rectify this in order to ensure that dementia is considered in relation to all policies linked to the application of the CRPD.

- Involve people with dementia in the CRPD vetting process (e.g. by asking them to provide testimonies and commentaries).

- Audit, and revise where necessary, official information and guidance regarding people with disabilities aimed at government departments and agencies, employers, businesses, organisations, and members of the public. This includes appropriate references to dementia as a condition which can give rise to impairments that can constitute a disability, and how disability legalisation and rights would apply for people with dementia.

- Ensure that people with dementia have equal access to provisions and services for people with disabilities (e.g. disabled parking badges, free travel on public transport, appropriate support in the work place etc.).

- Audit, and revise where necessary, training provided to all public sector staff with responsibilities for applying and upholding disability legalisation and rights, to ensure they are aware of and understand their duties and responsibilities to people with dementia when the impairments it causes constitute a disability.

- Audit, and adapt where necessary, public spaces and buildings to ensure they are accessible to people with dementia and other cognitive disabilities.

- Use the PANEL principles[30] to inform policy and service development in a way that incorporates a rights-based approach and ensure that people with dementia are included in this. This is particularly important when countries are decveloping national dementia strategies.

- Meaningfully involve people with dementia and carers/supporters in the policy and service developments, and audits described above, in accordance with PANEL principles.

Alzheimer Associations

- Support people with dementia and carers to be on the boards and decision making structures of Alzheimer Associations.

- Support the active participation of people with dementia in relation to their own self-advocacy in policy development/research and political engagement.

- Enshrine the prinicple of elevating the voice of the person with dementia and placing the person with dementia at the centre in the organisation's overall principles and ethos, whilst also recognising the vital role played by carers and supporters.

- Audit and revise where necessary, services and information provided to ensure they meet disability legislation and rights as they apply to people with dementia.

- Use the PANEL principles to inform organisational and service development in a way that incorporates a rights-based approach and ensure that people with dementia are included in this.

- Actively pursue opportunities for taking test cases to court regarding possible disability discrimination against people with dementia.

- Meaningfully involve people with dementia and carers in the service developments and audits described above in accordance with PANEL principles.

Organisations of, or for persons with disabilities

- Audit, and revise where necessary, services and information provided to ensure they comply with disability legalisation and rights as they apply to people with dementia to ensure they include appropriate references to dementia as a condition which can give rise to impairments that can constitute a disability, and how disability legalisation and rights would apply to people with dementia.

- Meaningfully involve people with dementia and carers in the service developments and audits described above in accordance with PANEL principles.

Regulatory bodies

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[30] For details, see: http://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf (p.1) and pages 16-17 in this document.

- Review and amend guidance on health and social care law and ethics to incorporate a social model of disability, disability legalisation and rights, as it applies to people with dementia and other cognitive, physical and sensory disabilities.

11 Glossary/list of abbreviations

Beneficence: doing good whilst trying to balance possible benefits against risks and costs.

CRPD: abbreviation for the United Nation's Convention on the Rights of Persons with Disabilities, which came into force in 2006.

Dementia: a set of symptoms, including loss of memory, mood changes, and problems with communication and reasoning. There are many causes of dementia, the most common being Alzheimer's disease and vascular dementia. Dementia is a progressive condition. This means that symptoms become more severe over time and that people with dementia typically need support and eventually care as their dementia advances.

Disability: "results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (Source: CRPD 2006, Preamble e).

Discourse: how we think and communicate about people, things, the social organisation of society, and the relationships among and between all three. Discourse typically emerges out of social institutions like media and politics (amongst others), and by virtue of giving structure and order to language and thought, it structures and orders our lives, relationships with others, and society (Cole 2017).

Equity and justice: treating people equally and fairly e.g. ensuring that they have the same opportunities and access to goods and services.

Homogenised: rendered uniform or similar.

Homogenous: of the same or a similar kind of nature; having a uniform structure or characteristics.

Impairment: any loss or limitation, albeit physical (e.g. loss of limbs), physiological (e.g. kidney disease), cognitive (e.g. Alzheimer's disease), sensory (e.g. loss of hearing or vision), psychological (e.g. behavioural problems), or mental (e.g. psychosis) in nature, that may contribute to disability.

Interdependency: the way in which people are never fully independent and always rely in some ways on others.

Intersectionality: the interconnected nature of social categorisations such as race, class, and gender as they apply to a given individual or group, regarded as creating overlapping and interdependent systems of discrimination or disadvantage (Source: Oxford Living Dictionary).

Justice/equity: the moral obligation to act on the basis of fair adjudication between competing claims. Involves treating people equally and fairly through a fair distribution of benefits, risk and costs.

LGBT+: abbreviation of "lesbian, gay, bisexual, transgender and other minority sexual orientation and gender groups (apart from heterosexuual and cis gender groups[31])", typically used as a self-designation and typically covering anyone who does not consider themselves to be heterosexual or whose gender identity does not match the sex that they were assigned at birth.

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[31] Cisgender – where an individual's experience of their own gender corresponds with the sex they were assigned at birth.

Non-maleficence: not doing what might be harmful or hurt somebody.

Paradigm: a philosophical and theoretical framework or school of thought with underlying theories, laws, assumptions and generalisations which influence the way we make sense of a particular issue e.g. in the field of dementia, disability, research or psychotherapy. If we think of the phrase "thinking inside the box", the paradigm might be the box.

Pathological: caused by or related to a disease.

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13 Acknowledgements

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Members of the ethics working group on dementia and disability

Professor June Andrews (OBE,FRCN, RMN, RGN, MA, FCGI) is a psychiatric and general trained nurse and professor emeritus based in Scotland, specialising in the public understanding of dementia. She is a writer and broadcaster and works internationally as a consultant on service improvement. Her particular interest is in the care of frail older people in housing, hospitals and care

Andrea Capstick, EdD is a Senior Lecturer in the Centre for Applied Dementia Studies, at the University of Bradford, UK, where she leads the MSc Dementia Studies programme. She has experience of carrying our participatory research with people who have dementia and of leading Patient and Public Involvement in a variety of dementia research studies. Her previously published work focuses on the ethics of social inclusion for people with dementia, and creative methods for engaging people with dementia in social research.

Carmel Geoghegan became the primary carer for her Mum in January 2011 and supported her to end of life in January 2014. Since this life changing experience, Carmel has been campaigning to keep the spotlight on dementia and end-of-life care as a national health priority in rural Ireland. Her vision is that communities will be inclusive of all those living with a dementia diagnosis. Carmel has successfully organised two conferences on 'Living with Dementia in Rural Ireland', which brought together experts from all sections (e.g. people with dementia, GPs, academics etc.) to work together to help feed into policy and practice at a national level.

Jean Georges has been the Executive Director of Alzheimer Europe since 1996. Prior to this, he worked as a journalist and as a parliamentary assistant to members of the Luxembourg and European Parliament. He was responsible for setting up the European Dementia Ethics Network in 2008 and has since contributed towards several ethics projects in that context.

Dianne Gove is Director for Projects at Alzheimer Europe and Chair of the Ethics Working Group on Dementia and Disability. Her background is in psychology, education (focus on gender and disability) and psychotherapy (analytical Gestalt therapy). In 2013, she was awarded a PhD for her research into general practitioners' perceptions of dementia and stigma. She is also an Honorary Visiting Research Fellow at the University of Bradford.

Sébastien Libert is a PhD student based at University College London, and part of the Interdisciplinary Network on Dementia Using Current Technologies (INDUCT). His research looks at the interaction between the use of technologies relating to dementia, and society's representations of ageing, dementia, and cognitive decline. He developed his interest in health and society during his studies in Medical Anthropology and Sociology, mainly through his Masters degree at KUL, (Leuven, Belgium) and KU (Copenhagen, Denmark) and his Bachelor's degree at ULB (Brussels, Belgium).

Grainne McGettrick (BSc, MA) has spent her career working in field of disability and in dementia in the NGO sector. She has lead out on several national and international research

and policy advocacy projects in the sector and has significant experience of working on rights-based agendas and community development for marginalised and disadvantaged people. She worked for more than ten years as the Policy and Research Manager with The Alzheimer Society of Ireland. In 2014, she moved to work with Acquired Brain Injury Ireland, where she is responsible for managing the policy and research functions.

Helen Rochford-Brennan is from Tubbercurry in County Sligo. Helen spent many years working in the US and the UK before returning to Ireland to work in the tourism and disability sectors. Helen was diagnosed with Early Onset Alzheimer's. She joined the European Working Group of People with Dementia in October 2014. She recently stepped down as Chair of the Irish Dementia Working Group and is currently Chair of the EWGPWD and a member of the Board of Alzheimer Europe.

Helga Rohra is, from Germany. She was a language interpreter and was diagnosed with Lewy Body dementia in 2008. She has been a member of the European Working Group since it started in 2012.

Simo Vehmas

Toby Williamson is an independent consultant working in the fields of adult and older people's mental health, mental capacity and safeguarding, with a particular focus on dementia in the last 10 years. He has many years' experience in frontline mental health services, research, evaluation, practice and service development, and policy work (both inside and outside government). He has particular expertise in rights, values, social inclusion, empowerment and working with seldom heard groups. He has co-authored a book on mental health and mental capacity legislation and is currently co-authoring a book on rights, values and dementia.

Members of the European Working Group of People with Dementia and their carers/supporters

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14 Appendix 1 – Translations of impairment and disability

The table below contains translations of the terms impairment and disability in several languages. These terms have been taken, where possible, from examples provided on http://www.linguee.com, focusing on terms used in translations of the second paragraph of article 1 of the CRPD (often derived from documents on http://eur-lex.europa.eu). The text is as follows:

> "Persons with **disabilities** include those who have long-term physical, mental, intellectual or sensory **impairments** which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

This text was chosen as it makes a distinction between the two terms but it should also be borne in mind that it reflects the social model of disability. In everyday life, many people use other terms and in some cases do not make a distinction between the two (e.g. in the Czech Republic and Bulgaria). Translations are not included for a couple of countries due to failure to reach consensus on the translation of either term.

We did not have access to qualified translators with expertise in the field of disability. The following table is only intended to help non-native English speakers have a better idea of the terminology being used in this report. We welcome any feedback (info@alzheimer-europe.org).

Language	Translation of impairment	Translation of disability
Bulgarian	увреждане	увреждане
Czech	zdravotní postižení	zdravotní postižení
Danish	funktionsnedsættelse	handicap
Dutch	beperking	handicap
Finnish	toiminnanrajoite	vamma
French	incapacité	handicap
German	Beeinträchtung	Behinderung
Italy	menomazione	disabilità
Luxembourgish	Aschränkung	Behënnerung
Norwegian	funksjonsnedsettelse	handikap
Polish	naruszoną	niepełnosprawnych
Portuguese	incapacidades	deficiência
Romania	incapacități	handicap

Slovakian	porucha	zdravotne postihnutie
Spanish	deficiencia	discapacidad
Swedish	funktionsnedsättningar	funktionshinder