

List of issues in relation to the initial report of the United Kingdom of Great Britain and Northern Ireland

Response of Alzheimer’s Society, Dementia Policy Think Tank, Three Nations Dementia Working Group and Young Dementia Network to the list of issues

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Introduction and background

This submission has been produced by Alzheimer’s Society and representatives of the Dementia Policy Think Tank, Three Nations Dementia Working Group and Young Dementia Network following a one-day workshop held in London on Wednesday 7th June 2017.¹ The purpose of the workshop was to bring together people living with dementia, carers and professionals to discuss the List of Issues presented to the UK government in March 2017, and how they relate to the experiences of people affected by dementia. After the workshop, a draft submission was circulated to all participants, who then provided comments.

Our submission looks at the experiences of people affected by dementia in realising their rights under the UNCRPD. It focuses on the personal examples and experiences of situations where people with dementia are having their rights denied, which were identified during the workshop. Our submission focuses on England, Wales and Northern Ireland.² Where legislation is mentioned, the nation of the UK in which it applies is detailed in the footnotes.

¹ 11 people with dementia, 2 carers and 6 professionals participated in the workshop.

² Alzheimer’s Society covers England, Wales and Northern Ireland. Please see Alzheimer Scotland for information on people with dementia living in Scotland and the UNCRPD: http://www.alzscot.org/campaigning/rights_based_approach

At the start of our submission we have provided a list of recommendations which were identified by the participants as necessary to ensure people with dementia have their rights under the Convention realised. After this, we have summarised the discussions on particular Articles, and the experiences of people with dementia that were shared at the workshop. These discussions formed the basis for our recommendations. Where there are quotes, initials have been used to protect the anonymity of the participants.

We have also included the Dementia Statements in an Annexe at Section 4, which have been co-produced with people affected by dementia. The Statements reflect the things people with dementia have said are essential to their quality of life. They are grounded in human rights law and recognise that people should not be treated differently because of their diagnosis.

The Dementia Policy Think Tank (as a Disabled Persons Led Organisation) have also produced a submission for the Committee. Although separate, these two reports are complementary, and we all hope that together they will bring a wealth of experiential knowledge to the Committee.

About the submitting organisations

Alzheimer's Society

Alzheimer's Society is the UK's leading dementia support and research charity. It covers England, Wales and Northern Ireland. Our mission is to transform the landscape of dementia forever. Until the day we find a cure, we will strive to create a society where those affected by dementia are supported and accepted, able to live in their community without fear or prejudice. The Society provides information and support to people with all forms of dementia and those who care for them through its publications, dementia helplines and local services. It runs quality care services, funds research, advises professionals and campaigns for improved health and social care and greater public awareness and understanding of dementia.

Dementia Policy Think Tank (DEEP)

The Dementia Engagement and Empowerment Project (DEEP) brings together groups of people with dementia from across the UK. DEEP supports these groups to try to change services and policies that affect the lives of people with dementia. The Dementia Policy Think Tank is a special interest DEEP group. It was founded in 2016 and covers the whole of the UK. Its members all have a strong interest in influencing policy and rights issues at a national level (the group does not make policy for DEEP).

Three Nations Dementia Working Group

The Three Nations Dementia Working Group is an independent group of people with dementia including representatives from England, Wales and Northern Ireland. The group exists to influence organisations and decision-makers on behalf of people with dementia.

Young Dementia Network

The Young Dementia Network is a community of people living with young onset dementia, their family and friends, as well as professionals who work in the fields of dementia and social care. The purpose of the network is to provide opportunities for members to share experience, knowledge and to learn from each other, to encourage improved young onset services across the UK and influence and inform national and local policies. The Network has a Steering Group which guides the work and development of the Network.

Executive Summary

Despite the impairments caused by dementia being recognised as a disability under domestic and international law,³ people face significant challenges in realising their rights under the UNCRPD. Stigma, prejudice and lack of understanding about the condition as well as discrimination on multiple grounds including age and gender, compounds an existing postcode lottery of services for people affected by dementia in the UK. Legislation which aims to protect rights varies between England, Scotland, Wales and Northern Ireland and has suffered from poor and patchy reform, and variable implementation, where people with dementia lose out on the protection these laws are supposed to provide.

Dementia is caused when the brain is damaged by diseases. Alzheimer's disease is the most common cause, but not the only one. The specific symptoms that someone experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia. It is a complex and progressive neurological condition of which cognitive impairment can be a key feature. This means that it is often seen as a 'hidden' or 'invisible' disability, as in some contexts the symptoms are less obvious. People felt that dementia is still viewed through the 'medical model of disability', (which emphasises the person's impairments as a result of their diagnosis), rather than the social model (which emphasises the person's impairments as a result of barriers in society). This means that perceptions about how a person with dementia 'should be', prevail over the person's actual experience.

The themes highlighted above were present throughout discussions on specific Articles, in particular, 19, 25, 27 and 28.⁴ People also face challenges when accessing support that enables them to remain living independently within their communities, and obstacles to realising their rights under Article 12 and 14,⁵ with current practices subject to controversy and proposals for reform. A paternalistic and risk-averse culture in public services and wider society frequently fails to respect people's ability to make their own decisions, meaning their preferences are not respected. Good practice is not widespread and training is often inconsistent.

For the UNCRPD to become a reality for people with dementia, the UK government must act to address the shortcomings outlined in this submission – a list of recommendations is presented in Section 1. Significantly, predominant negative views of dementia, as well as a serious lack of understanding of the condition across all aspects of society and services must be addressed so that people with dementia can access the support they are entitled to.

³ Equality Act 2010 (England, Wales, Scotland) and Disability Discrimination Act 1995, 2010 (Northern Ireland)

⁴ Article 19 – living independently and being included in the community; Article 25 – health; Article 27 – employment; Article 28 – adequate standard of living.

⁵ Article 12 – legal capacity; Article 14 – deprivation of liberty.

Section 1: Recommendations

At the end of the workshop, the participants proposed a series of recommendations which the Government should action to protect the rights of people affected by dementia. A summary of the discussions that led to these recommendations can be found in Section 2.

Articles 1 - 4: Purpose and general obligations

- The Government should place less emphasis on the medical model of care and instead encourage person-centred care. Dementia is a complex condition which affects people in different ways and people must not be defined by their diagnosis.
- Dementia should be right at the top of the priority list for all Government departments. This includes maintaining expertise and consistency in civil service teams and recognising the importance of cross-departmental working.
- Information, care and support for people with dementia must be subject to rigorous monitoring and review to ensure that all Government policy is compliant with the rights of people with dementia.
- The impairments caused by dementia should be seen as disabilities in their own right. Individuals should not have to prove evidence of their disability once diagnosed.⁶
- The Government should systematically collect experience-based evidence on the implementation of the Convention. People must be able to see where the gaps are and what needs to be done to change this.
- The Government must respond and act on the concerns raised by the UN Committee on the CRPD in any reports and recommendations they make.

Article 8: Awareness-raising

- There should be compulsory education on disability and dementia awareness in schools, universities and the workplace, as well as in all healthcare services. This should specifically include awareness of young-onset dementia.

⁶ Under the definition of 'disability' in the Equality Act 2010 in England, Wales and Scotland and Disability Discrimination Act 1995 in Northern Ireland, to qualify for protection under the law a person must prove that they have "a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities".

- When people are working in public-facing roles such as shops, banks, restaurants etc. they must receive training on disability awareness that includes dementia.

Article 9: Accessibility

- There should be a national framework outlining how to make facilities accessible for people with dementia (e.g. appropriate lighting, adequate and clear signage and suitable flooring).

Article 12: Equal recognition before the law

- Access to an independent advocate under relevant mental capacity legislation must be consistent and properly resourced – this is fundamental to protecting people’s rights to be involved in decisions.
- The Government must properly consider and respond to the Law Commission report on *Mental Capacity and Deprivation of Liberty* as soon as possible to work towards reform of the Deprivation of Liberty Safeguards and Mental Capacity Act in England and Wales.
- The Government of Northern Ireland must act to ensure effective and universal implementation of the Mental Capacity Act (Northern Ireland) 2016.
- There should be tighter monitoring to ensure all healthcare staff are fully trained in, and know how to practically apply the Mental Capacity Act.

Article 19: Living independently and being included in the community

- The Government must address and act on regional variation in service provision.

Article 25: Health

- Funding and resources should be dedicated to properly integrating health and social care. This must then be properly implemented at all levels of the healthcare system.
- The social care system must be significantly reformed to end the inequity of experience of people with dementia and other conditions and ensure people with dementia do not end up paying catastrophic amounts for their care.

- A cultural change must take place at every level within organisations so that knowledge is turned into practice and training on rights and dementia is not just a tick box exercise.
- The contribution of informal family carers must be properly assessed, supported and remunerated.
- There should be a penalty for local authorities who do not respond in a timely way to a person's request for assessment of need and ultimately meeting their care needs.

Article 27: Employment

- The role of occupational health in the workplace should be emphasised. Reasonable adjustments for people with dementia and carers should be standard practice and organised well in advance, not ad hoc.

Article 28: Adequate standard of living and social protection

- The welfare system must be significantly reformed so that it works for people affected by dementia. This includes access, implementation and co-ordination between the NHS, local government and the Government departments. Any future plans for welfare reform must also consider the impact on people affected by dementia.

Article 29: Participation in political and public life

- There should be clear guidance on supporting people with dementia to vote.

Section 2: Discussion

Articles 1 – 4: Purpose and general obligations

The impairments caused by dementia are defined as a disability under the definition in the UNCRPD.⁷ The group discussed what it meant to have dementia and be 'disabled', and felt that the medical model of disability still prevailed in healthcare and other services.

MW: *MW's wife visits the lavatory every hour during the night. When visiting the local health services, MW was told that it is common for people with Alzheimer's to experience a lack of sleep and that this would prompt toilet visits. MW contests this and describes the problem as a struggle to maintain bladder and urination control rather than sleep. MW believes that the "system" favours a "jump straight to medication" where people like MW's wife are encouraged to take sleeping pills and sedatives to make the situation easier to manage, Whilst medication would save social services waking night care costs, it comes at the expense of the quality of life for the person with Posterior Cortical Atrophy (PCA)⁸.*

The group also felt that there was a lack of understanding around what it meant to be disabled. They felt that you can have a disability without being less able and that you can, whilst being disabled, still contribute meaningfully to society. The group felt that as soon as you are seen as physically 'able' in the eyes of medical professionals, you stop being 'disabled.'

People also felt they have to 'prove' that they have a disability in order to get support in their day to day lives. Unlike the impairments caused by cancer, HIV and Multiple Sclerosis, the impairments caused by dementia are not automatically considered a disability under equality law.⁹ It was felt that this is made more challenging because dementia is a cognitive disability and therefore 'invisible', despite the fact that some symptoms are physical. One person commented that a doctor had observed that symptoms of some types of dementia (such as PCA) are very similar to those experienced by people with cerebral palsy. People commented on the different experiences faced by people with cognitive, 'hidden' disabilities, compared to those with physical and visible disabilities.

WM: *"Assistance travel doesn't work if you're not in a wheelchair."*

⁷ "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," UNCRPD, Article 1 (Purpose)

⁸ Posterior Cortical Atrophy (PCA) is a rare degenerative condition in which damage occurs at the back (posterior region) of the brain. In the vast majority of people, the cause of PCA is Alzheimer's disease.

⁹ Equality Act 2010 in England, Wales and Scotland and Disability Discrimination Act 1995 in Northern Ireland.

JB: *“I told staff in a restaurant that I could not read a menu easily so they gave me a kid’s menu!”*

Article 8: Awareness-raising

There is still a great deal of ignorance and stigma around dementia. This includes a lack of understanding and awareness of the condition, and portrayal of people with dementia in a negative way. Although there is now much more coverage of dementia in the media, this can sometimes be dramatic, involving people abused in care, in the advanced stages of dementia or at the end of life, which does not reflect an understanding of how a person can maintain much of their independence and quality of life if they get the right support. The group felt more needed to be done to present dementia in a balanced way.

Dementia is a complex neurological condition that affects people in a variety of ways. But, there are many misconceptions about what dementia is. People’s opinions are often based on what people think dementia ought to be based on their personal experiences. People are often told by those around them that ‘they don’t have real dementia’ because their symptoms do not match the expectations of others or their lived experience of dementia.

WM: *“Many people with dementia experience attitudes of disbelief. The ‘invisible disability’ doesn’t help. I have had many comments and expressions of disbelief because I’m capable of writing a blog and speaking in public. People have said “yes, but my mum has dementia and she couldn’t do what you do” and “it’s not real dementia though is it, otherwise you wouldn’t be able to write as you do.”*

NH: *NH is regularly questioned as to whether he has dementia due to the eloquent way he speaks. He finds this questioning inappropriate.*

MW: *MW remarked that a manager from Adult Social Services entered his and his wife’s home and effectively called MW’s wife a liar, intimidating her, ridiculing her, making light of her condition whilst subjecting her to verbal abuse and accusing her of not having dementia. In MW’s view this appalling behaviour is institutionalised within social care which always comes across as being driven by an unhealthy and cruel desire to reduce costs rather than provide for the necessary care.*

The complexity of the condition and its impact were felt to be poorly understood. In particular, because dementia most often affects people over 65, there was a lack of understanding of young-onset dementia which affects people under that age. People reported hostility from healthcare professionals both in the process of trying to get a diagnosis, and then getting support once a diagnosis is established. On occasion, GPs question the diagnosis based on the behaviours the person with dementia exhibits.

WM: *“The district nurse and occupational therapist both had little or no knowledge of young-onset so each time there was a look of surprise as I answered the door. Then the usual conversation had to take place to educate them before we could start on why they were there.”*

The group felt that discrimination in assessment for benefits and other types of support often occurs as it’s all about ‘seeing’ symptoms, and dementia is a ‘hidden’ or ‘invisible’ disability. Re-assessments for Personal Independence Payment (PIP) in particular were described as “humiliating, frustrating and unnecessary” as well as impractical, as dementia is a progressive condition.¹⁰ The effects of the experience left people feeling that they were “penalised for living well.” An example was given that someone’s PIP was withdrawn as they were seen speaking for Alzheimer’s Society, despite the physical and emotional impact of travelling to an event and speaking, including the recovery period afterwards.

WM: *“For 18 months I was entitled to PIP. After an assessment I was suddenly deemed no longer requiring this help to keep me independent. In the written explanation I was told I could now do things I clearly can’t. Having clearly deteriorated since being entitled, I don’t understand a system that now says I’m no longer in need. The assessor did not understand dementia.”*

Article 12: Equal recognition before the law

The Mental Capacity Act (MCA)¹¹ provides a framework for making decisions on behalf of people who lack capacity to make a particular decision at a particular time in England and Wales. The Act is underpinned by five principles¹² and also contains detail about how people can plan for a time when they may lack capacity.

Implementation of the MCA has been inconsistent, with people with dementia often losing out on the empowering principles that the Act intends to embed. People feel they are frequently assumed to lack capacity, meaning decisions are made on their behalf by medical professionals or by family members. Even where people do make decisions or are supported to do so, they felt the reaction of others could be negative.

¹⁰ PIP replaced Disability Living Allowance in the Welfare Reform Act 2012 (England, Wales and Scotland)

¹¹ England and Wales.

¹² Mental Capacity Act 2005 (Section 1): (1) People must be presumed to have capacity unless it is proven otherwise; (2) People must be supported to make a decision; (3) A person does not lack capacity just because they make an unwise decision; (4) Any decision made on behalf of a person who lacks capacity must be made in their best interests; (5) Any decision made on behalf of a person who lacks capacity must be the least restrictive option.

SR: SR recounted how her daughters are frequently told – “You shouldn’t let your mother do that” in relation to activities such as travelling. It was felt that robbing someone of their independence and preventing them performing an activity despite them being able to was the “easy option.”

This is also the case when a ‘best interests’ decision needs to be made on behalf of a person who lacks capacity.¹³ At present, the person’s wishes and feelings are one factor that must be considered when making a best interests decision.¹⁴ However, this is not always done and it is the views of family members (or medical reasoning) that determine the outcome for the person with dementia. The group felt this approach was “outdated”, and fails to acknowledge the preferences of the person themselves. Some of the group felt that this situation was in part caused by fear of legal action on the part of medical professionals in case listening to a person with dementia and acting on their wishes led to an adverse outcome.

It was also felt that access to advocacy services was fundamental. At present, access to an Independent Mental Capacity Advocate (IMCA)¹⁵ is normally restricted to a situation where someone has no family or carer. But, sometimes it is these people who are taking advantage of the associated vulnerability that comes with a diagnosis of dementia. Access to advocacy is also dependent on where a person lives and what services are available in a particular area, meaning provision is not consistent. Having independent advocacy to both support the person in decision-making, and represent them if necessary was seen as a crucial way to protect the rights of people with dementia.

Also vital to ensuring respect for a person’s will and preferences is the opportunity for advance care planning. Again however, the situation in practice is patchy and can depend on the different service models in place across the country. People acknowledged the importance of advance care planning for people with dementia, but also recognised that there were challenges in doing this in practice, for example, not being sure whether you would want cardiopulmonary resuscitation or not in a particular situation. People also need support to engage in advance care planning. This often happens post-diagnosis, which means people must receive a timely and accurate diagnosis in order to access the support they need.

The Law Commission published a report (*Mental Capacity and Deprivation of Liberty*) in March 2017, which recommended reform of the MCA in part to bring it more in line with Article 12 of the UNCRPD. This includes strengthening the provisions on supported decision-making, and placing greater weight on the person’s wishes and feelings in best interest decisions. The Government is yet to respond to this report.

¹³ Mental Capacity Act 2005, Section 4

¹⁴ Mental Capacity Act 2005, Section 4 (6) a

¹⁵ Mental Capacity Act 2005, Sections 35 - 41

The Mental Capacity (Northern Ireland) Act 2016 fuses mental health and mental capacity legislation, replacing the Mental Health Order for those aged over 16. It provides a presumption of capacity, a requirement to support decision making, mechanisms to allow a person to plan for a time when they lack capacity, safeguards when compulsory interventions are made or substitute decisions are required and a requirement for an independent mental capacity advocate. The code of practice and guidelines are currently being developed and a public consultation is expected to take place in autumn 2017, followed by implementation in early 2018. It is imperative that the Act is properly implemented, including building awareness and expertise amongst professionals and the public, to ensure it is widely understood and put into practice for the benefit of people with dementia.

Article 14: Liberty and security of the person

The Deprivation of Liberty Safeguards (DOLS)¹⁶ were introduced in England and Wales following a decision of the European Court of Human Rights which showed that there was no legal process in place for depriving people of their liberty when they lacked capacity to consent to it but needed to be kept safe and cared for in their best interests.¹⁷ This was in contrast to the legal framework for depriving people with a mental health condition of their liberty for assessment and/ or treatment (Mental Health Act). The DOLS were developed to provide a legal process for depriving someone of their liberty including a procedure to challenge a deprivation. Unfortunately, the DOLS have created a great deal of controversy and their implementation in practice is under-resourced. They were reviewed by the Law Commission, which published a report in March 2017, recommending a complete overhaul of the DOLS system, as well as changes to the wider MCA.¹⁸

The DOLS are incredibly important in ensuring people living with dementia, are not arbitrarily deprived of their liberty. But, experiences are variable. People face challenges caused by an unprecedented rise in the number of applications such as delays, not getting the right representation and consequently not getting care that is appropriate and consistent with their wishes. People felt that there were some practices that could amount to a deprivation of liberty that are more subtle (such as placing someone with limited mobility on a high floor in a care home), and people subject to these restrictions might be missing out on the legal safeguards because their situation is not recognised as a deprivation.

Some people at the workshop commented that they would prefer to be subject to detention under the Mental Health Act than the DOLS as they felt that the process is more user-friendly and more established. They felt that public authorities should be

¹⁶ Mental Capacity Act 2005 (England and Wales), Schedule A1

¹⁷ *HL v UK* 45508/99 (2004) ECHR 471

¹⁸ Mental Capacity and Deprivation of Liberty (Law Commission, March 2017)

acting in a way that actively promotes rights, rather than acting retrospectively after a violation of their rights occurs.

Article 19: Living independently and being included in the community

It was clear that the experiences of people with dementia under this Article were patchy and often linked to regional variation in services. The postcode lottery for care and support was described as “the biggest enemy of all disabled people.”

The vast majority of needs that a person with dementia has are deemed to be ‘social care needs.’ This means that their care and support is only provided based on the severity of need and is financially means-tested and provided by local authorities rather than being provided automatically free of charge by the NHS. As a result, people with dementia can end up not only having to pay huge costs for their care, but also face a huge variation in access and quality depending on where they live and the services in their area. A lack of support to live independently and remain in the community means people can be pressured into going into residential care earlier than they would wish or against their wishes entirely. This situation can also be compounded by avoidable hospital admissions, where people end up discharged into residential care as the social care support they need at home is not available.

The provisions in the Care Act in England¹⁹ marked a shift towards putting people who have care needs at the centre of their care and also gave rights to carers. But, its implementation is widely flawed meaning people with dementia are often missing out on the ability both to live independently and be included in their community, often due to budget constraints. The variable provision of services also creates fear and anxiety amongst people with dementia about things happening in the future, particularly if something happens to their carer.

***JW:** J has an older carer (her husband who is in his 70s.) J fears him falling ill and the consequences this will have for her where she lives. She is fearful of not knowing where to go for assistance and described it as a “complex web.”*

Social care in Northern Ireland is currently based on a patchwork of community care legislation dating back to early 1970s and has often been characterised as outdated and incoherent to those using it and sometimes to those administering it. As a result, people’s experiences of care are hugely variable.

The group felt that in many areas facilities were not accessible to people with dementia. A lack of signage or poor quality signage can increase the risk of a person becoming lost and anxious, and potentially avoiding those situations in the future. Accessibility in public places is vital for people with dementia to live independently in

¹⁹ Care Act 2014 (England)

their community. Concerns were also raised about the lack of accessibility and assistance when performing daily tasks such as remembering passwords and navigating phone menus. Speaking to an automated machine creates issues for accessibility because the person is not given the option to speak to a real person and explain they have dementia.

JB: *“I once took a lot of coins into my bank as I could not count them and handed them over at the counter in various bags (there were three ladies behind the screens and no other customers in the building). They refused to count them and told me to fill in a form once I had counted them. I had no idea which form or where to find it – they just said it was ‘over there.’ It was only when I sat down and started crying that one of them came out and said she wasn’t allowed to help as she might add them up incorrectly. I then got involved with dementia awareness at another bank to try and do something positive.”*

The stigma surrounding a diagnosis of dementia also has a huge impact on a person’s ability to live independently and be included in the community. People shared experiences of being avoided following a diagnosis as other people in the community are afraid and do not know what to say. All believed that the stigma was greater following a dementia diagnosis as opposed to a cancer diagnosis. One example was given of intimidation in a car park whereupon a woman called the police saying that the person in question had dementia and therefore should not be driving.²⁰

Article 25: Health

The experience of people with dementia in healthcare is frequently linked to capacity. People feel they are presumed to lack capacity in respect of certain medical decisions and best interest decisions are taken without proper consideration of their preferences.

People with dementia also face discrimination on multiple grounds, including when accessing health services. This is often age and disability related and again variable depending on area. There were examples of people being denied treatment or services (such as chemotherapy), purely because they have a diagnosis of dementia. People also experienced ‘diagnostic overshadowing’, where their symptoms were not properly investigated because of dementia.

²⁰ Although a person must inform the Driver and Vehicle Licensing Agency (DVLA) if they have a diagnosis of dementia, their diagnosis does not mean they must automatically stop driving. The ability of a person to continue to drive depends on many things including the type of dementia they have and the stage it is in. People at the workshop felt that there was an automatic assumption that a person should stop driving following a dementia diagnosis, which does not take into account their individual experience. Taking away a person’s ability to drive can have a significant impact on their ability to live independently in the community.

JB: *“When my husband was taken ill with a sudden severe headache I told the hospital staff it was serious. I was a doctor and wanted referral to a neurology department. They wrote in my notes that I had dementia so did not know what I was talking about, and that my husband had a headache due to the stress of having a wife with dementia. I insisted that he had a CT scan. The staff said that there was something there, but that it was an old injury I had forgotten about because I had dementia. He died a few days later from a treatable condition.”*

In some places, people under the age of 65 or with a dementia diagnosis are not entitled to access speech and language therapy. A similar situation exists with access to physiotherapy, which is a locally made decision. This leads to a significant amount of regional variation.

MW: *MW’s wife was denied speech and language therapy. Although her disability is cognitive, it manifests itself in a physical way – in this case affecting her communication.*

WM: *“It took me months to access any services in the East Riding. After my Community Psychiatric Nurse from York referred me to services, I was discharged as I didn’t fit into the appropriate age group. I wasn’t told I’d been automatically discharged – it was after many emails and phone calls that I was told this.”*

There were also issues around accessibility to healthcare in practical situations such as getting GP appointments and the use of phone menus or touch-screen check in systems for appointments.

WM: *“At my hospital, the booking in system relies on memory. It states where you need to go and this quickly disappears from the screen. Attitudes of the staff were less than helpful – no smiley faces, a consultant spoke quickly and threw questions at me. Healthcare professionals address my daughters when I’m stood next to them.”*

People also recognised that there is little consideration of people’s individual needs particularly in terms of organising care, despite them being important to maintain dignity and personhood. MW still has to pay for cutting nails and other female needs, despite the medical services acknowledging that these services are needed.

Increasing dementia diagnosis rates has been a key Government priority in recent years and although there has been progress, there are still areas where it is lacking, particularly in the case of people with young-onset dementia. People are frequently not taken seriously and struggle for a long time to get an accurate diagnosis which then enables them to access the right information and support. People under 65 reported being “turned away” by GPs being told that “dementia isn’t possible at this age.”

WM: *“When I asked my GP why there were no memory services in our area and why I only had him for support, he told me he “didn’t think much of Aricept so I wouldn’t worry.”²¹”*

The group acknowledged the importance of training staff on rights, but questioned whether this was helpful if it is not translated into practice. This is compounded by a prevailing litigation and ‘blame’ culture, as well as short term commissioning contracts which impact on staff confidence and security. It was felt that there were “pockets of excellence” but what was needed was a culture change at all levels that puts people at the centre of their care. Examples of this can be clearly seen in respect of certain legislation such as the Mental Capacity Act in England and Wales, where implementation has been patchy.

Article 27: Work and employment

Many people are forced to give up work following a diagnosis, without any attempt at reasonable adjustments.²²

JW: *JW had to give up her job within nursing without being given any information about whether she could do a non-nursing role.*

WM: *“Managers and occupational health openly admitted that they had no knowledge of how to support someone to continue to stay in work with dementia. My manager asked “how long have you got?” I had to come up with my own plan and the only help I received was in completing the ill health retirement application forms.”*

Carers also reported a lack of reasonable adjustments in employment to enable them to perform their caring responsibilities. There is also a lack of understanding or compassion for a carer or supporter to take time off work and a lack of understanding of rights and employer responsibilities.

MW: *MW reported that he has been headhunted for several highly paid jobs as an IT Director. However, no reasonable accommodation was offered by employers. MW also felt that a disclosure of his responsibilities as a carer would disadvantage his application against other applicants.*

Similar experiences were shared by people who had tried to get voluntary roles for which there were also barriers in place and a failure of organisations to make

²¹ Aricept is the brand name for Donepezil, which is a drug sometimes offered to people with Alzheimer’s.

²² Required under Equality Act 2010 (England, Wales, Scotland) and Disability Discrimination Act 1995 (Northern Ireland).

reasonable adjustments. An example was shared of a person with dementia unable to volunteer in a charity shop because they had difficulties operating the till.

***JW:** JW runs a group in Manchester for people with young-onset dementia at a local community centre. There are restrictions on when people are allowed to use the kitchen to make hot drinks due to their dementia diagnosis.*

Stigma is also preventing people with dementia from remaining in employment.

***PM:** At the time of the workshop, the UK was in the middle of a General Election campaign. PM would like to have campaigned politically in his marginal seat but did not feel as though he could because he may be stigmatised because of his dementia (for example, accused of making mistakes with information), and this would be used against him and the party.*

It was felt that occupational health was a fundamental part of enabling people with dementia to remain in employment and therefore live independently. While all occupational therapists should have dementia training and some are brilliant, they were described as “islands of excellence in a sea of nothing.”

There are also challenges for people with dementia to access benefits in relation to employment.

***CN:** CN was able to access Employment Support Allowance (ESA) but a friend was facing re-assessment every three years, despite dementia being a progressive condition. Whilst eligibility for ESA was agreed, the assessment experience was appalling, lacking compassion or understanding of the impact of dementia on CN's life. He was “dreading” future assessments due to past humiliating experiences.*

Article 28: Adequate standard of living and social protection

In England, Wales and Scotland, welfare reform has had an overwhelmingly negative effect on people affected by dementia. This is particularly the case for people with young-onset dementia, as many of the changes affect benefits for people of working age, and many people have had to give up work.

The introduction of PIP (to replace Disability Living Allowance) in particular has had a profoundly negative effect on people with dementia, with many people being found ineligible for PIP despite qualifying for DLA for over a decade. One person recounted that an individual in a support group they attended committed suicide after being found ineligible for PIP. Another person lost her PIP completely, which had a huge impact on her income. It was described as “a gross scandal that her needs were ignored.”

Welfare reform has been based on the aim of keeping people in work, rather than on the rights of people to remain independent and living in the community with an adequate standard of living, and what their needs are in order to be able to do this. People felt that they were being “penalised for living well”, because they took part in activities and did things that assessors saw as them ‘coping’ and being independent without the need for support.

JW: J lost PIP after DLA of 11 years – “They don’t understand how long it takes me to prepare a talk. I stay up all night! They don’t understand that what I do is therapeutic.”

Assessment for benefits currently takes place on the basis of need, rather than condition. But, assessors must have an understanding of a condition in order to understand the person’s needs. It was clear that this is not happening for many people and everyone present felt that assessors do not know anything about dementia. Information provided to assessors by Independent Assessment Services (previously known as ATOS), which conducts PIP assessments on behalf of the Department for Work and Pensions is limited and does not take account of the individualised impact of dementia on a person’s life.

Article 28 was also discussed in the context of carers. Many carers also have to give up work following a diagnosis to provide full-time (frequently unpaid) care. Accessing support (both financial and respite) is difficult, time-consuming and hugely variable.²³

MW: MW has been headhunted for various jobs but cannot take these as he cares for his wife who requires 24 hour care. MW undertakes many more hours of care than is paid for by the local authority. MW began with 1 hour of care per day between Monday and Friday from the local authority. MW then lobbied for more hours with the assistance of his local Member of Parliament. MW had meetings with the council from which he understood that the local authority believes it is MW’s familial duty to care for MW’s wife without consideration for MW’s needs. As a result, he and his wife are forced into a situation by unsympathetic social care to live below the breadline.

Article 29: Participation in political and public life

The group discussed voting and the barriers that people with dementia face in exercising their right to vote. Although there is no requirement for someone to have mental capacity to vote, there was a fear that people were being denied the

²³ The group discussed the recommendation which has been given to those devising the Welsh dementia strategy for better care for carers - a carer should be entitled to payment of a percentage of their expected salary had they not the caring responsibilities they have which prevents them from working rather than a uniform payment for all.

opportunity because people presume they are more easily influenced. People shared reports where postal votes were filled out by someone with dementia, but that these had not been posted by carers who felt they may be seen to be tampering with votes. The group felt this would not happen if they had a physical disability.

People have also reported barriers at polling stations. One woman informed Alzheimer's Society of her husband (who has Alzheimer's) experience when trying to vote. At the polling station, she asked the staff if she could help him. Staff refused and insisted on helping him themselves. They kept asking him if he remembered who he voted for last time, which he didn't, which resulted in him getting distressed.

Section 3: Conclusion

The discussion from the workshop and the recommendations we have made demonstrate that people with dementia are having their rights under the UNCRPD denied. We urge the Committee to consider the experiences of people living with dementia in their investigation of the UK, and to make recommendations accordingly.

Section 4: Annexe

The Dementia Statements

The Dementia Statements reflect the things people with dementia say are essential to their quality of life. Grounded in human rights law, they are a rallying call to improve the lives of people with dementia and to recognise that they shouldn't be treated differently because of their diagnosis.

“The person with dementia is at the centre of these refreshed Statements. They represent everyone living with any type of dementia regardless of age, stage or severity. The ‘we’ used in these statements encompasses people with dementia, their carers, their families, and everyone else affected by dementia. These rights are enshrined in the Equality Act, Mental Capacity legislation, Health and care legislation and International Human Rights Law.

We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.

We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.

We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.

We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.

We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.”

Background to the Statements

In 2010, the organisations that went on to form the Dementia Action Alliance (DAA) asked people affected by dementia, and other key stakeholders, what type of care and support they would hope to receive in the future. Informed by these

conversations, they created the National Dementia Declaration, a set of seven expectations or Statements of what life should be like for people with dementia. These Statements were used to inform the Prime Minister's Challenge on Dementia published by the Department of Health in 2012.

Between 2016 and 2017, Alzheimer's Society led a review of the Statements on behalf of the DAA alongside people living with dementia to ensure they reflected what people want today.

Over 80 people with dementia and carers were reached through 15 different groups. As well as these groups, there were one-to-one interviews with people living with dementia and carers. There was also an online survey with organisations who were members of the DAA, which aimed to gather their views on the previous statements and how they used them. Five key themes were identified through this research - identity, care, community, carers and research.

After summarising the evidence, a Drafting Event was held, attended by nine people with dementia (three of whom were accompanied by their carers) and three former carers. Members of the group produced draft statements based on the themes that had come through during the evidence gathering. After this, there was a Consensus Event, where the final set of statements – the 'Dementia Statements' were agreed. This was attended by people with dementia and carers (some of whom were also at the Drafting Day) as well as representatives of DAA organisations.

Articulating the needs of people affected by dementia through a rights-based lens gives urgency and weight to this movement, and makes dementia something that no one can ignore.