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DEMENTIA ONSET AND SOCIAL EXCLUSION IN LATER LIFE

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PLACED-Lives

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DEMENTIA AS A POLICY CHALLENGE

Dementia is a key global challenge in ageing societies and represents a significant contributor to the global disease burden. It is also one of the fastest growing causes of disability (Livingston et al., 2020). With approximately 50 million people living with dementia world-wide, demographic ageing has led to a 50 per cent increase in prevalence of the condition over the last 20 years, and a projected increase that will see 152 million people living with dementia by 2050 (Patterson, 2018). In Ireland, there are 64,141 people living with dementia (HealthAtlas, 2020), with between 19,742 and 35,736 of those estimated to be resident in the community (Pierse et al., 2019).

Despite this, and despite the availability of a growing body of social and economic research on dementia (e.g. Sabat, 2006; Sabat, 2019; Pierse et al., 2020; Walsh et al., 2021) our knowledge of people's lived experience of the condition remains, in relative terms, poorly developed (cf. Hennelly et al., 2021). In particular, the way in which an onset of dementia can serve as a multifaceted life transition, generating a sequence of changes and impacts in different areas of life is often neglected. More critically, a full analysis of how the transition into living with dementia can give rise to different forms of social exclusion for older people has been largely absent (Beard et al., 2009; Walsh et al., 2017). In its most basic form, exclusion involves the separation of individuals and groups from mainstream society (Moffat and Glasgow, 2009). The limited research that is available points to the potential for multiple disadvantages to accrue to those living with the condition (Eriksen et al., 2016; Grenier et al., 2017). Exclusion may emerge from different levels, including from the disease itself, from provisions made (or not made) for its management, and from the ways in which people living with the condition are viewed within society (Urbaniak and Walsh, 2019). But even with a growing focus on a human-rights perspective within research and policy on dementia, sufficient attention has not been paid to these disadvantages nor the factors that influence their construction.

As a consequence, our capacity to develop practicable interventions, that are implemented at key points in people lives, is still diminished. Existing policies and practices, therefore, may not be as impactful as they should be or may not be sufficiently targeted to ensure people receive the sort of support required, when it is most needed.

What is social exclusion in later life?

Social exclusion of older people can be defined as interchanges between multi-level risk factors, processes and outcomes. Varying in form and degree across the older adult life course, its complexity, impact and prevalence is amplified by accumulated group-related disadvantage, old-age vulnerabilities, and constrained opportunities to ameliorate exclusion. Old-age exclusion leads to inequities in choice and control, resources and relationships, and power and rights in key domains of: neighbourhood and community; services, amenities and mobility; material and financial resources; social relations; socio-cultural aspects of society; and civic participation. Old-age exclusion implicates states, societies, communities and individuals.

(Walsh, Scharf and Keating: p.93, 2017)

PURPOSE OF THIS BRIEFING REPORT

This briefing report examines dementia as a major life transition, and the ways in which this transition is related to multidimensional forms of social exclusion. Drawing on findings from the PLACED-Lives research study, this report presents insights from older adult's lived experiences regarding the nature and sequence of changes related to the onset of the condition, and the sort of challenges to participation and integration that can arise from these changes.

The report is divided into four sections. First, a short summary of the methodology used to collect and analyse the data will be outlined. Second, findings will be presented on the transition into living with dementia, and the key milestones and changes that can characterise these experiences for participants. Third, exclusionary impacts on people's lives are outlined for different areas of participation. Fourth, and based on these findings, policy recommendations are presented.

This briefing report is a part of the PLACED-Lives Briefing Report Series. For more information on the series and the PLACED-Lives study, please go to **https://icsg.ie/our-projects/placed-lives/**.

About the PLACED-Lives study

PLACED-Lives aimed to investigate the influence of critical life transitions in the older adult life course on the accumulation of multidimensional social exclusion, and the role of place in protecting against this exclusion.

The study focused on bereavement, dementia on-set and forced migration as examples of critical transitions. This research was supported by the Atlantic Philanthropies.

The study involved a mixed-methods approach and included qualitative and quantitative components, including: 15 interviews with national and local policy and practice stakeholders; 39 interviews with older individuals who experienced these transitions; and secondary analysis of data from The Irish Longitudinal Study of Ageing (TILDA).

The study objectives included:

1. To gather existing research and policy knowledge on older adult life-course transitions, their connections to place, and their association with experiences of exclusion in later life;
2. To develop an empirical understanding of pathways to exclusion arising from life-course transitions;
3. To explore older people's relationship with place for those who have experienced the life-course transitions, in different kinds of places, and to assess the impact of the rupture itself on this relationship;
4. To investigate how relationships with place can buffer against, and/or intensify, multidimensional social exclusion stemming from life-course transitions;
5. To explore what constitutes social inclusion in place for those who have experienced the life-course transitions, living in different kinds of places;
6. To direct a re-orientation of the role of place in policy and practice intervention models for addressing life-course ruptures.

METHODS & DATA

The data presented in this report were collected from in-depth life-course interviews conducted with ten people living with dementia, aged between 55 and 80 years. Participants comprised of seven women and three men. Eight participants had Alzheimer's disease, one individual had vascular dementia and one person had Lewy body dementia. While only individuals with mild to moderate stages of dementia were included in the study, the participant sample included those who experienced an early-onset (six participants received a diagnosis before the age of 65 years) and those who experienced a later-life onset (four participants) of the condition. Participants lived in different kinds of rural (three participants) and urban (seven participants) environments across Ireland. Consideration was also given to marital status, socioeconomic status, and other socio-demographic variables during participant recruitment.

Interviews lasted approximately one hour and consisted of three parts: an open narrative portion; an in-depth, semi-structured portion; and a series of life-path exercises where participants worked with the researcher to map out (1) their life trajectory up to and after their dementia diagnosis, including other major events and turning points, (2) their residential history over their lives, and (3) particular points of exclusion and integration across the life course. The life-paths were used together to probe on where these patterns may have intersected.

Fifteen interviews were also conducted with national and local policy and practice stakeholders who work with ageing populations, including those specifically working with people living with dementia. Aside from the excerpt 'what stakeholders say' (p.8 of this brief), these interview findings are not described in this briefing report but they have assisted in informing the recommendations presented later in this report. To read about stakeholders' perspectives in detail, please see Urbaniak and Walsh (2020). Ethical approval for the research was provided by the NUI Galway Ethics Committee. All names used in the presentation of findings are pseudonyms.
Data collection took place from 2019-2020, prior to the Covid-19 pandemic.

RESEARCH FINDINGS: DEMENTIA TRAJECTORIES

The transition into living with dementia served as a major turning point in the lives of all participants. It was clear that the transition did not begin and end with a formal diagnosis, and instead was a more graduated, continual process of change, reflecting the progressive nature of the condition. Across individuals, the sequencing of the transition, and the important events that could characterise it, were often diverse. Here, we present just two broad trajectories that were described by participants and that summarise some of the key milestones. Figure 1 refers to the general sequence of events for individuals who experienced an early onset of the condition. Figure 2 presents this sequence for individuals who experienced an onset in later life. Both trajectories capture fundamental shifts in the way participants were connected to their families, communities, and services, and the roles that they fulfilled.

As with the other later-life transitions described in this briefing report series, three broad stages (c.f. van Gennep, 1960) are used to help characterise the dementia onset trajectories. These include: (1) recognising and comprehending the transition; (2) being in-between 'old and new statuses'; (3) incorporating and adapting to the 'new status'.

In the first stage, common experiences for both those who had an early-onset and later-onset included: noticing memory difficulties; issues related to every-day functioning; beginning to recognise difficulties as potential dementia symptoms; and receiving a formal diagnosis. In general, and reflecting engagement in more formal spheres of participation, the early-onset group talked about experiencing multiple signs that signified their emerging condition across their professional roles (e.g. co-workers losing trust in their abilities) and civic lives (e.g. diminished personal confidence to volunteer). People within this group also typically experienced a longer pre-diagnosis phase as memory difficulties were not initially recognised and/or formerly diagnosed, as 55 year-old Thomas describes in relation to engagement with his general practitioner (GP):

> *...right, let's say my doctors copped it first five years ago, right, but it took nearly three years to get diagnosed. So that in itself [was frustrating]... Like why initially when they suspect something that they won't do all the scans and scan you for it? It would save years of torture, that's the first thing. It might be this, it might be this, it might be this, we'll talk about it. If you go with a heart problem, a lung problem, a kidney problem, they don't talk about it. They scan you.*

The in-between phase, which followed a formal diagnosis, was sometimes experienced as a period of disengagement across different areas of life. This involved social relations, where people informed significant others about their condition and, initially at least, began to socialise less with their wider social networks. Having to cease driving a car was a substantial event in the trajectories of both groups, and meant more restricted personal mobility, and a greater dependence on others or public and private transport services. For those who experienced an early-onset of dementia, having to stop working was perhaps the most significant adjustment – financially and socially. Together, this collection of changes in people's lives were emphasised as having both practical implications for autonomy and control, and more profound consequences for identity and sense of self.

In the incorporation stage, participants talked about implementing adaptation strategies as an attempt to come to terms with the onset of dementia. In many cases this was about efforts to effectively reinvent their lives within the new parameters of living with the condition. It involved employing every-day strategies (e.g. post-it notes with important information placed

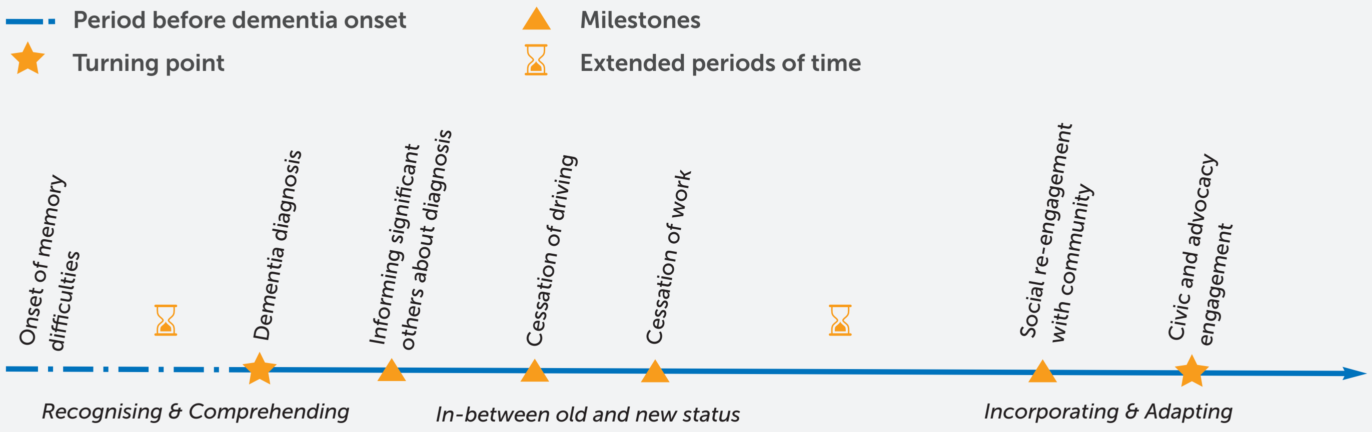

Figure 1: Early onset of dementia (prior to the age of 65 years)

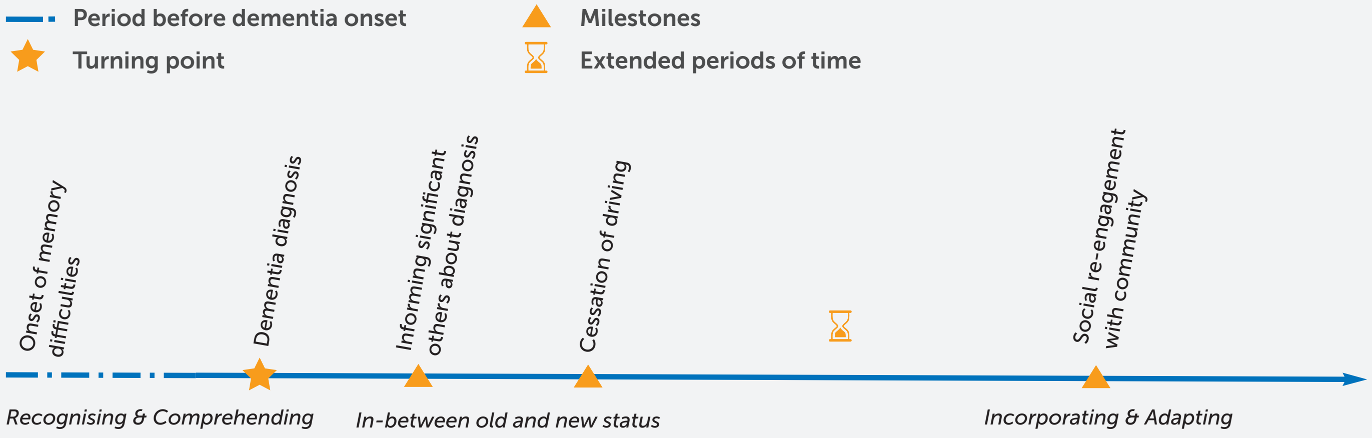

Figure 2: Onset of dementia later in life (after the age of 65 years)

strategically around the house; installing smart home technologies), as well as efforts to re-engage socially and for some taking on roles in their wider community. For the early-onset group, it could also include becoming engaged in civic activities – but these examples were very much amongst a minority. Some participants reported significant difficulties in adjusting (e.g. being unable to adjust; having to rely on others in everyday activities), and most noted that the process of adapting was a continuous challenge. A number of individuals described how life was filled with uncertainty due to the ever-changing circumstances of living with dementia. Sixty-one-year-old Emily reflects on this:

> *But I have Alzheimer's and I don't know what it will be like in six months, or a year, or whatever. So it definitely affects my life, you know.*

RESEARCH FINDINGS: IMPACTS OF DEMENTIA

The onset of dementia was identified as having multiple impacts on participants' lives and on their participation in their communities and wider society. These impacts emerged from the nature of the condition itself, difficulties in trying to access required supports, and the way in which people living with dementia were viewed. While some of the significant changes in people's lives were not without positive elements for some individuals, in most cases these impacts represented exclusionary outcomes. The transition around the onset of dementia, therefore, could serve as a source of significant risk and adversity for individuals.

Five domains of exclusion were evident: services amenities and mobility; social relations; material and financial resources; socio-cultural aspects; and neighbourhood and community.. For those who experienced an early onset of the condition, emphasis was placed on material and financial resources and the consequences of a premature cessation of employment. This group also highlighted the lack of specialized services targeting the needs of those living with an early onset. For individuals who experienced a later onset, the impact of the condition on social relations was especially highlighted. However, socio-cultural exclusion, linked to stigmatisation of those with the condition, was the most dominant form of disadvantage encountered by all participants. Each domain of exclusion will now be considered in turn.

Exclusion from services, amenities and mobility included difficulties in accessing and utilising general services, health and social care, and appropriate transport. Participants spoke about the absence of a coordinated service infrastructure with consequences for them and their families. This is highlighted by Marie, a 69-year-old woman, who reflects on the lack of specialised services after she received a diagnosis:

> *And I've a husband and [family] and it was heartbreak for them, because when I was diagnosed there were no services, and they didn't know what to do[...]. Or there was nobody there to tell them, look, she's going to be okay [...]. So for me, it was just the lack of services, the lack of somebody being there... And so, that spiral was there that could have been eliminated really, if we had the right services in place at the time.*

Both rural and urban dwellers spoke about how using public transport was sometimes just not feasible. Issues frequently mentioned include those around service frequency, difficulties in negotiating the transport system and as Deirdre, a 66-year old woman, notes, distance to bus stops:

> *Even if there was say a small shuttle bus that would go from here and drop off say at the community centre [...] I don't mean they have to drop you at your door but somewhere safe to even walk safely back to your house it would make a huge difference. It would make a huge, huge difference. Whereas our closest bus stop is up there, and we live down there. So the bus stop to our house is three miles.*

Regardless of the service type, many participants talked about challenges in interacting with service providers, and how the lack of basic knowledge of how to support people living with dementia could exacerbate service access issues. Fifty-nine-year-old Eimear speaks about the degree to which this can be a barrier in accessing services:

> *And I've had that, the rudeness, the ignorance that people [in service outlets] can say to you when you try and say, 'I'm having this difficulty'... It would deflate your confidence.*

Exclusion from social relations was pervasive within the accounts of interview participants. For people living with dementia, this form of exclusion could include a decline in social opportunities, a reduction in the quality of interpersonal relationships, and disconnection from some members of social networks. Alan, a 65-year-old man, reflects on the negative impacts of memory difficulties on his ability to take part in conversations, and to socialize with others:

> *There is a possibility [to be left out from the] conversation. Not being able to recall. If I'm reminded, I might get a flashback about it or something like that. But sometimes I just can't remember.*

In some cases, issues arose first when participants felt unsupported in trying to inform their close family members about the diagnosis. But as with a number of other participants, Caroline, a 71-year-old woman highlights how managing dementia sometimes meant limiting social contacts and withdrawing from the local community:

> *I'm sick [of] looking at the people there [local pub]. I know them all my life' and I don't want to be walking in there and feel that they have to feel sorry for me.*

While a number of interviewees spoke highly of the support that they received and how some relationships had even become stronger, these kinds of challenges were evident to one degree or another for most participants. Such experiences could culminate in more intense feelings of social isolation and loneliness. As Valerie (aged 69 years) illustrates, it was sometimes the perceived possible reaction of others that led to participants limiting their social engagement, and creating a further potential for isolation and loneliness:

> *I thought, 'God, this is it like, people won't talk to me now or won't want to know me' like.*

Exclusion from material and financial resources in this research was concerned primarily with the consequences of a lack of employment, and the sense of exclusion that people experienced when having to leave work. As referenced earlier, these concerns were most frequent amongst those who had an early-onset of dementia. Jane, a 56-year old woman, describes how her condition became an issue for her employer and the sort of impact that losing her job had on her personally:

> *Losing my job was very hard. It was kind of the boss in one sense and then it went from that to not being trusted with anything so that's kind of, it's hard on your ego so everything has changed.*

For others, such as Marie, the focus, was on the material effects of an accelerated departure from employment, and the consequences for career ambitions, pension entitlements and later life income:

> *And I had planned to work until I was 67, 68, so I mean, all of a sudden, five years were taken off my pension. Five years that I was going to work to give us lots more holidays, to do lots of things [...] And then Alzheimer's happened, and it was low point, no question, it... had a devastating effect on my life, it has changed my life completely. It has robbed me having a nice long career and maybe much more involvement in my community. And that makes me extremely sad sometimes.*

For some interviewees economic exclusion meant direct experiences of poverty. Rationing resources and prioritising activities had become a part of the daily routine of some participants, such as Michelle:

> *And so it's a struggle, there are some weeks where there is just not a penny. And so, it really does impact you, even just getting out and minding diesel so you can go and do something.*

Socio-cultural exclusion was related to the stigmatisation of living with dementia, and was considered to be evident across different facets of society. Participants felt that this stigmatisation could be manifest in how they were only viewed by others in terms of their dementia condition, ignoring their other roles, contributions and their personal identity. This is often referred to as identity exclusion. But participants also felt that stigmatisation was manifest in the ways in which people encountered negative language that had the effect of homogenising all those living with dementia. This is referred to as symbolic exclusion. Both forms of exclusion could give rise to direct discriminatory behaviour that cross-cut other kinds of disadvantage, e.g. in relation to social, economic, or service domains. For instance, John, who is 55- years old, and Michelle, who is 59- years old, both described how stigma around dementia affected the way they are treated by some of their family members:

> ***John**: My parents want nothing to do with me. I have three other brothers who want nothing pretty much to do with me and I have a sister; she wouldn't look at me because I got dementia and brought shame on the family.*

> ***Michelle**: I have a sister-in-law who says I'm an absolute disgrace, how dare I [tell people] I have Alzheimer's, a disgrace, an embarrassment to the family.*

Neighbourhood and community exclusion often referred to localised forms of other exclusions within the immediate home and local environments of participants and how these exclusions changed the relationship that people had with their places. Eimear, who is 59 years of age, highlights this in relation to service exclusion and talks about sometimes adjusting her daily use of services within her community due to attitudes of some personnel within local service outlets:

> *...I know there are days when if I was quite low there are probably some shops I wouldn't go into if I needed a bit of help. Or I probably wouldn't attempt to go near the bank. I would do without, rather than doing it [using a service] ...*

Although many participants spoke highly of their supportive neighbours and friends living near-by, a lack of anonymity could present other challenges. Interviewees described the sort of personal anxieties and the sense of embarrassment that they experienced when initially having to disclose their diagnosis and their reluctance in using particular local services. Caroline highlights this in relation to the early stages of living with her condition:

> *I would not have told anyone, not even my own family, that they [the community nurse] had said it to me [to consider meals on wheels]. It wasn't that I felt even disadvantaged, it just felt [embarrassing] […] I'm not embarrassed now, I probably was.*

For others, it was clear that community change processes had altered the availability of social and informal support networks. Sharon describes this sort of challenge in light of population turnover, and changing patterns of work and socialisation:

> *So, they're out working all day [new neighbours] and he's working all day but the new bride, she doesn't even know me, you know.*

What stakeholders say

Lack of implementation of National Dementia Strategy

> Well, I think we've enough documents out there that we just have to implement. We have a problem, as you know, that there's, as we say, implementation deficit syndrome. So, I think it's - we don't need more action plans or strategies, we just need implementation. *[9_D_N]*

Importance of communication and raising awareness, without stigma

> So we try to convince people to tell their family and friends [about their dementia diagnosis]. Tell their community [so] that they will build supports around them, you know. Tell their local policeman so that if they ever go wandering, they will know immediately, they'll get a call or somebody rings. *[3_D_N]*

CONCLUDING REMARKS

This briefing report investigated the onset of dementia as a major life transition, and drew on findings from a recent study to examine how living with dementia can be linked to experiences of multidimensional social exclusion. The findings presented in this briefing report are not unexpected. They instead reflect the experiences that many stakeholders and advocates have come to encounter, and the realities that many older people living with dementia have had to adjust to and negotiate. They also reflect the sort of circumstances that led to the introduction of the National Dementia Strategy, significant cross-sector commitment, the national awareness campaign Dementia Understand Together (to address the stigma surrounding the condition) and a series of positive developments in policy and practice to improve the lives of people living with dementia in Ireland. This includes the establishment of the National Dementia Office, within the Health Service Executive (HSE), and the Irish Dementia Working Group.

However, even though people with dementia have been long-recognised as an at-risk population within ageing-related policy and health and social care strategies, multifaceted forms of disadvantage have still to be sufficiently addressed for this group. As conveyed by participants in this research, dementia onset appeared to increase exponentially the potential for weakened ties between individuals and general society. In this study, this was evident across social relations, services, amenities and mobility, material and financial resources, socio-cultural aspects, and neighbourhoods and communities. The impact of dementia for some participants was of sufficient magnitude to suggest a rupture in the bond between people living with the condition and social structures and institutions.

Dementia symptoms were certainly recognised as one of the contributors to this exclusion, and were hugely challenging in their progressive nature and influence. But participants' concerns were often more focused on the ways in which living with the disease was considered, and structured in policy, practice and public realms. People highlighted the absence of formal services and infrastructure that made the management of the condition difficult. They highlighted the apparent withdrawal of support, and the lack of consideration shown by some members of their networks, and by service providers. They highlighted how their participation in major economic and social spheres was impeded, or simply not facilitated. They also highlighted what could be framed as a reconstitution of their social and personal identities in terms of a stigmatised, biomedical condition. Together these factors and exclusions challenge the possibility of equitable treatment for people living with dementia, and again raises concerns for the recognition of this group's basic human rights standards (c.f. Cahill, 2018).

Further work to embrace a multifaceted understanding of how people living with dementia engage, and need to continue to engage, is important to address these deficits. The development of the condition maps onto a life-course trajectory of participation and social citizenship that does not dissipate with the onset of the disease. Greater recognition is also required as to how exclusionary processes do not just emerge from the biological transition of the condition itself, but the social and cultural transition that is entangled with how we choose to provide for its management, and how we position people with dementia within our society. The Dementia Understand Together in Communities programme which aims to create inclusive communities for people living with dementia, and is led by the HSE in collaboration with a multi-agency partnership, holds particular worth in enhancing this recognition and potentially in ameliorating these processes.

Although the two transition trajectories presented in this report are simplified representations of the sequence of changes related to dementia onset, they help illustrate how disadvantages can ebb and flow as the different stages of the transition progresses. This creates very practical points of intervention around diagnosis, around social engagement and informing personal/professional networks, around mobility, and around promoting and facilitating continued economic and community participation. In this regard, the trajectories also illustrate the differences in relation to the timing and the nature of onset, and the distinct challenges that both groups might face. For example, those who experience early onset of the condition may need specialised supports with respect to employment and pension related challenges. Those with a later life onset may encounter greater challenges with respect to gaining sufficient consideration, and as demonstrated by other research, comorbidities. But just as a person living with dementia is unlikely to experience all forms of exclusion universally, these trajectories demonstrate that exclusion and inclusion are not static over time, and nor is the intensity and form of support required. This also points to the significant agency on the part of individuals and families to ameliorate/negotiate disadvantages, adapting to practical constraints and having to continually reconcile deeper more personal notions of self and identity over time.

The findings presented in this briefing report are based on interviews with only ten participants. Despite significant recruitment efforts, and the assistance of many of the key regional and national stakeholders in the sector, the study sample is not likely to be representative of hard-to-reach or the most excluded individuals. Nevertheless, the findings reaffirm the rationale and the continued need for the developments and progress that has been made with respect to dementia in Ireland. This is especially in terms of highlighting the need for integrative approaches, and the importance of understanding and giving voice to the perspectives of those living with dementia. In this respect, the work of such initiatives as the Understand Together public support, information and awareness campaign has been and continues to be especially valuable. However, there remains a significant need to elevate our collective expectations and ambitions in relation to living with dementia in Ireland. Recognising and accounting for how dementia in all its constructions can detract and impede multifaceted engagement is an important step in this regard.

RECOMMENDATIONS

Based on the findings of the research presented in this briefing report, we make the following recommendations:

1 Building on existing efforts to foster a psychosocial understanding of dementia, there must be greater acknowledgement that the changes associated with the transition produce a range of needs, risks and sometimes opportunities across different areas of people's lives over time, and that people must be supported to address these needs, negotiate these risks and harness these opportunities.

2 The potential for multidimensional social exclusion to affect the lives of those living with the condition, and their access to choice and control, resources and relationships and power and rights must be accounted for in the design and delivery of supports that target social, service, economic, spatial, and symbolic forms of disadvantage.

3 In line with the ethos of the National Dementia Strategy and the National Dementia Office's forthcoming Dementia Model of Care, a complete model of inclusion for people living with dementia that spans all areas of life, and that seeks to secure integration for individuals and their families as full members of society must be implemented and must cross-cut all major policy domains.

4 It should be recognised that these disadvantages have structural-, community-, and individual-level components, with exclusion arising from symptoms of the condition itself, deficiencies in support infrastructure, and the attitudes towards people with dementia within our society.

5 As population diversity increases in older age-groups, intersectional identities, including those related to established and new ageing populations must be considered when tracking and combating individual and group disadvantage related to dementia. This includes gender, ethnicity, sexuality and socio-economic status.

6 To compliment the valuable work of the Understand Together campaign, further efforts are required to promote the diverse individual identities and life-course experiences of people living with dementia, and their different sets of needs, agency and preferences for engagement that have to be supported.

7 Economic risks that people living with dementia encounter as a result of (premature) cessation of work must be addressed through employment support initiatives, and, where necessary, longer-term financial supports.

8 The level of locality and place must be focused upon as a basis for the creation of interventions to support the social reengagement of people living with dementia in their communities, capitalising on their past and existing embeddedness and connectedness within their areas.

9 In line with the ethos and existing efforts of the Irish Dementia Working Group, the voices and experiences of a heterogenous group of people living with dementia must be incorporated within the policy and practice development process, to enhance the timing, efficacy and relevance of interventions.

PRACTICE INTERVENTION CONSIDERATIONS

Based on the key turning points and milestones associated with dementia onset, we identify the following intervention points and present illustrative examples of the type of interventions that may be necessary to combat exclusion. While some of these suggestions build on and complement existing efforts within the sector, others have received less attention.

Intervention Point	Intervention type
Onset of memory difficulties	1. Continue to educate general society on dementia symptoms and supports for assisting in the diagnosis process, including through the continued resourcing and development of school awareness programmes. This will support help seeking behaviour when symptoms are experienced. 2. Building on proposals within the National Dementia Office's draft Dementia Model of Care, enhance the efficacy and integration of diagnosis processes across primary, secondary and specialist services with the aim of improving diagnosis rates.
Formal dementia diagnosis	1. In line with the draft Dementia Model of Care, develop comprehensive multi-disciplinary diagnostic teams that support a continuity of care that extends to post-diagnostic supports. 2. Provide in-depth training for health professionals on delivering a dementia diagnosis and assisting in the development of an "action plan" in conjunction with the person receiving the diagnosis and their families.
Informing significant others about the diagnosis	1. Promote the development of peer-support groups of people living with dementia that share experiences and provide support on how to inform/educate significant others. 2. Increase sign-posting to and ensure accessibility of dementia literacy programmes to educate family members/friends/co-workers on dementia, the needs of people living with dementia, and the available services and supports.
Cessation of work	1. Promote the development of initiatives to harness skills and knowledge of people living with dementia that allow them to stay connected to their career and other roles that they value. 2. Educate employers on dementia-inclusive job opportunities, and strategies to allow people living with dementia to remain involved with their employer organisation.
Cessation of driving	1. Expand and enhance the provision of dementia-inclusive public transport services.
Implementation of adjustment strategies and social reengagement with community	1. Building on some of the work of the Understand Together communities programme, develop initiatives that promote civic and social (re)engagement in conjunction with people living with dementia (e.g. community-based social inclusion programmes that target those hard to reach; support for personal adjustment and promoting sense of self; practical techniques around living with dementia on an every-day basis).

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