# INTERGENERATIONAL INCLUSION FOR PEOPLE LIVING WITH DEMENTIA GLOBALLY AND NATIONALLY: A TWO-PHASE STUDY

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# Dedication

This PhD is above all dedicated to my supervisors, Dr Fiona Kelly, Professor Brigid Daniel, and Dr Kat Lord-Watson. You all joined my PhD journey at different stages – before beginning, just at the start, and somewhere in the middle. If it were not for your enthusiasm, far-ranging expertise, patience, time, and encouragement, I would not be where I am today with this thesis.

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# Abstract

**Importance:** This research explores the topic of intergenerational inclusion for people living with dementia. Both in Scotland and internationally, intergenerational programmes have been implemented with the aim of fostering inclusive relationships between people of different age groups. A sub-set of intergenerational programmes, moreover, have focused on the inclusion and participation of people living with dementia in particular.

Such programmes are perceived to be important due to the potential they have to combat trends of loneliness and social isolation that may affect people of all ages. Programmes are also perceived to have the potential to generate positive outcomes for both younger and older participants, such as increased knowledge and understanding of ageing and dementia among younger age groups and enhanced enjoyment and engagement among older participants.

**Research Gap & Questions**: However, intergenerational practice has been recognised to unfold in the absence of an adequate conceptual framework (Vanderven, 2004). This research uses a comparative and evaluative methodology to analyse how the concept of intergenerational inclusion for people living with dementia has been understood and operationalised internationally and in Scotland. Using insights from this analysis of international and national practice, the research further explores how intergenerational practice and policy can be further developed.

**Methodology**: The research uses a two-phase study design informed by realist evaluation (Pawson, 2013) and thematic analysis. The first phase of the study comprises a realist synthesis review method to explore the understanding and operationalisation of intergenerational inclusion for people living with dementia internationally. The second phase of the study comprises a qualitative, semi-structured interview method to explore the understanding and operationalisation of intergenerational inclusion for people living with dementia internationally. The second phase of the study comprises a qualitative, semi-structured interview method to explore the understanding and operationalisation of intergenerational inclusion for people living with dementia in Scotland. Interviewees involved in the study are Scottish stakeholders with expertise in the provision of dementia services and/or intergenerational practice.

**Results:** Results have been thematically analysed according to the context-mechanismoutcome configuration of realist evaluation. Mechanisms identified at the international level include role provision; matching and preferences; and meaningful and structured activities. Mechanisms identified within the Scottish context include preparation and planning; purpose and roles; preferences, lived experience and personhood; and sharing and learning. Higherlevel findings are presented regarding intergenerational inclusion for people living with dementia, policymaking, and partnership working in Scotland.

**Implications:** The implications of this research include, firstly, presenting a definition of intergenerational dementia programmes along with reflections on current ambiguities and tension in regard to existing definitions. Secondly, synthesised findings regarding how intergenerational dementia programmes 'work' in terms of their contexts, mechanisms, and outcomes are presented, with explanatory factors including the provision of roles for participants, the use of individual preferences to inform programme design, the development of meaningful and structured activities, flexible planning, and processes of sharing and learning between different age groups. Finally, an exploration of how the understanding and operationalisation of intergenerational inclusion is linked to key theories and concepts is undertaken along with recommendations for future theoretical development, encompassing personhood, intergroup contact theory, relationship and activity theory, and generativity. Directions for further research are also presented.

**Key words:** Intergenerational; dementia; intergenerational dementia programmes; realist evaluation; semi-structured interviewing

# Chapter 1: Introduction

## **Research Context**

This thesis explores the topic of intergenerational inclusion for people living with dementia, with particular reference to how attempts to foster inclusive relationships between different age groups can and have been 'operationalised' through intergenerational dementia programmes. The two-phase study has been structured to critically analyse intergenerational programmes for people living with dementia first at a global and then at a Scottish national level. By providing rigorous examination of the concept of intergenerational inclusion and practice across different levels, the study makes a contribution to the field of intergenerational research.

This research is important because people living with dementia, including their carers, may experience social isolation and loneliness both in Scotland and beyond. Social isolation and loneliness are distinct concepts. Social isolation 'refers to the quality and quantity of the social relationships a person has at individual, group, community and societal levels' whereas in contrast loneliness 'is a subjective feeling experienced when there is a difference between an individual's felt and ideal levels of social relationships' (Teuton, 2018: 3). A person may be socially isolated and yet not subjectively experience loneliness, or alternatively be socially connected and still subjectively feel lonely (Teuton, 2018: 3).

A recent survey of 1,445 people living with dementia across England, Scotland and Wales found that 'approximately a third of respondents, 30%, reported being moderately lonely and a further 5% were severely lonely' (Victor et al., 2020: 6), demonstrating a loneliness prevalence which was 'broadly comparable with that of their peers who did not have dementia' (Victor et al., 2020: 7). However, older adults in particular settings such as care homes may be more at risk of severe loneliness, with estimates suggesting that '61% of older people living in care homes may be moderately lonely and around 35% may be severely lonely' (Gardiner et al., 2020: 752). Loneliness and social isolation, moreover, have been associated with the risk of developing dementia later in life (Goldberg et al., 2021: Sutin et al., 2020). Conversely, having access to multi-tie social networks comprising both familial and non-familial connections has been associated with better cognitive performance among older adults (Cohn-Schwartz, 2020: 500), and social relationships and participation in social activities may have a protective effect against cognitive decline and dementia (Heins et al., 2021: 2).

Loneliness and isolation among people living with dementia and among younger age groups thus represents a cause for concern and has been on the Scottish policy agenda since 2015 (NHS Health Scotland, 2018: 2). Scotland's recent national strategy to tackle loneliness identified the ageing process as having an impact on social isolation, specifically emphasising that 'people with dementia and their families have traditionally been at risk of losing touch with wider family, friends and community connections as a result of the condition – and are potentially at risk of other mental health problems such as depression and anxiety' (Scottish Government, 2018: 32). Loneliness in Scotland has further been exacerbated during the COVID-19 pandemic (Mental Health Foundation, 2022), with groups such as people living with dementia who live alone reporting a rise in symptoms during the lockdown (Alzheimer's Society, 2020).

Combined with isolation, discrimination against and stigmatising behaviours towards people living with dementia continue to persist within communities despite advocacy and awareness raising efforts (Alzheimer's Disease International, 2019). In Scotland, dementia policy aspires to social inclusion, for example, clearly stating that people living with dementia in Scotland have a right to be fully included in the community (Scottish Government, 2017: 21). However, the degree to which community inclusiveness for people living with dementia is consistently realised in meaningful ways can be variable due to social, geographic, economic, and other factors. Health and social care legislation in Scotland has emphasised greater inclusion, fairer opportunities, and steps to tackle inequalities (Scottish Government, 2021*b*: 3). Therefore intergenerational dementia programmes could have increased impacts by focusing on lowincome groups (Matheson-Monnet, 2020: 704), and by taking a heterogenous view of how dementia is experienced across different groups, incorporating gendered, socioeconomic, and geographical analyses (Bartlett and O'Connor, 2010: 6).

# Definitions and Terminology

Intergenerational dementia programmes can be positioned as a specific activity-based intervention involving people living with dementia and younger age groups with the aim of promoting intergenerational inclusion, solidarity, and other benefits, both reciprocal and individual. In terms of policymaking, intergenerational dementia programmes may be capable of tackling the 'gap' that exists between policy aspirations, such as a right to community for all people living with dementia, and the reality on the ground whereby social

isolation and loneliness continues to be experienced across the population in Scotland today (Scottish Government, 2018).

Intergenerational dementia programmes form an important, though less common sub-set of broader intergenerational practice. The field of intergenerational studies first emerged in the 1960s with a focus on programmes, initiatives and interventions that brought children together with 'seniors' (Ayala et al., 2007). Traditionally, intergenerational programmes were premised on the idea of 'special' characteristics belonging to those at each end of the lifespan, namely young children and post-retirement adults, and presupposed at least a standard generation (twenty years) difference between participants (Vanderven, 2004: 79). Intergenerational practice today continues to draw upon this core conceptualisation in many ways, recognising that intergenerational approaches are 'particularly relevant for older adults and children since both childhood and older adulthood [continue to be] characterised by greater leisure time, need for close long-term connections, and a proclivity for learning and teaching' (Peters et al., 2021: 2). These factors have been perceived to support 'a unique, natural and reciprocal care partnership between children and older adults' (Peters et al., 2021: 2).

In more recent times, however, the definition and understanding of intergenerational practice has diversified to include programmes encouraging and enabling interactions between multiple age groups in a wide range of different settings without necessarily adhering to specific generational configurations. For example, some more recent, influential definitions are flexible and people- rather than age-focused, such as the definition proposed by the UK-based Beth Johnson Foundation:

"Intergenerational practice aims to bring people together in purposeful, mutually beneficial activities which promote greater understanding and respect between generations and contributes to building more cohesive communities. Intergenerational practice is inclusive, building on the positive resources that the young and old have to offer each other and those around them." (Beth Johnson Foundation, 2011: 4)

For the purposes of this research, I developed a definition to encapsulate intergenerational dementia programmes specifically and thereby distinguish this type of programme from other formulations of intergenerational practice. This definition was grounded in Ayala et

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al.'s summary of three broad characteristics of intergenerational programmes, including 'the purposeful bringing together of different generations in mutually beneficial, planned activities', with the activities themselves designed to increase 'cooperation, interaction or exchange' between the generations and, finally, with intergenerational programmes potentially rendering benefits both for individuals and for communities (Ayala et al., 2007: 47). Therefore, the definition of intergenerational dementia programmes applied in this thesis is as follows:

The bringing together of people living with dementia with younger generations in purposeful, planned activities that are designed to promote inclusive, respectful interactions and be mutually beneficial to all participants.

# Participants

Intergenerational dementia programmes involve older participants living with dementia and younger participants. Within this thesis, the term 'living with dementia' is applied to uphold positive language when talking about dementia and to emphasise dignity (Alzheimer Society, 2022). Older participants may or may not have a formal diagnosis of dementia.

Younger participants may be of varying age depending on the programme with which they are involved. The age of younger participants, moreover, may impact the design and outcomes of programmes. Therefore, to seek clarity and avoid conflating evidence, this thesis makes reference to specific groups of younger participants insofar as possible. The term 'preschool children' is used to describe very young participants aged 0-5 years. The term 'school-aged children' is used to refer to children attending school aged between 6 - 15 years. The term 'young person' is used to describe children and young people aged 16 years or older.

# Background and Drivers

There are a number of drivers currently generating interest in intergenerational programmes to support both older and younger participant groups. One of the strongest drivers continues to be demographic change and ageing populations, particularly within developed economies. Scotland, for example, faces a projected 50% increase in over 60s by 2033. The dependency ratio<sup>1</sup> is projected to grow from 60 per 100 to 68 per 100 by 2033 (Scottish Government, 2010: 14). In 2020, the dependency ratio for Scotland as a whole was 56 per 100, however, the ratio exceeded 70 per 100 in several regions including Dumfries and Galloway, the Scottish Borders, South Ayrshire, and the Western Isles (Scottish Government Statistics, 2022*a*).

Combined with ageing societies, dementia has been identified by the World Health Organization as a global public health priority (World Health Organization, 2012). The World Health Organization estimates there are currently 55 million people worldwide living with dementia and that there are approximately 10 million new cases each year (World Health Organization, 2021). In Scotland alone, there is an estimated 90,000 people living with dementia (Alzheimer Scotland, 2020).

The growing population of older people and older people living with dementia is perceived to be at risk of potentially harmful loneliness and isolation (Clark et al., 2016: 301). Social exclusion and the related detrimental impact on wellbeing this can have, combined with an absence of an effective pharmacological treatment for dementia, has led to interest in promoting the quality of life for people living with dementia through non-pharmacological, psychosocial interventions (George and Singer, 2011: 392). Moreover, while the majority of older people are able to remain living at home in their communities, nevertheless, there is increased demand for flexible housing and care home capacity particularly for people living with dementia (Weeks et al., 2020: 1; Landi and Smith, 2019). Therefore, it is through the ability of care homes and organisations to provide meaningful activities and innovative care services that the quality of life for people living with dementia can be maintained (Weeks et al., 2020: 227).

However, the need for care and support is not limited to older populations, rather 'the demand for quality childcare' and education for young people coincides with 'the increasing need for creative older adult programs [creating] a receptive environment for intergenerational programs' (Weeks et al., 2016: 228). Both children and older people may increasingly find themselves in nonfamilial care settings, which traditionally may have been segregated by age (Jarrott and Bruno, 2007: 240). Family members may also live at a distance from each other. Given the increasing competition for scarce social funds, intergenerational

<sup>&</sup>lt;sup>1</sup> The Population of children (aged 0 to 15) and older people (aged 65 and over) expressed as a percentage of people aged 16 to 64 (Scottish Government Statistics, 2022).

programmes may be especially appealing because they 'provide the potential to address a range of community members' needs simultaneously and cost-effectively' (Gigliotti et al., 2005: 425). Intergenerational programmes, by sharing resources, may result in 'economies of scale in which more services could be made available to meet families' needs' across and between generations (Jarrott and Bruno, 2007: 243). The health benefits of programmes for both older and younger participants may relieve pressure on health services and unpaid carers (Jenkins et al., 2021: 124). Intergenerational practice, for example, was perceived by older participants in one study as promoting the active ageing agenda, helping them to stay healthy and relieving stress (Teater, 2016: 14-16).

In addition to efficiency in resource allocation, intergenerational programmes are also seen to be an effective vehicle to 'address negative stereotypes and biases associated with ageing and dementia' (Canning et al., 2020: 271), an endeavour in which children and young people are integral given the role they will have in forming the communities and workforces that will support the growing proportion of older people in years to come. Currently, research suggests that levels of dementia knowledge among younger age groups is lower than among older age groups (Wu et al., 2022), nevertheless, the health beliefs and attitudes of children may be more malleable (Smith et al., 2020: 2). By enabling inclusive interactions which hold the potential to not only consolidate tolerance, but actively promote kinship and enthusiasm, intergenerational programmes may 'lead to more activist forms of career and civic commitment to the wellbeing of older people' among younger generations (Lokon et al., 2018: 12).

# Theoretical Underpinnings

# Personhood and Citizenship

The theory of personhood has informed the view of dementia I have taken within this thesis (Kitwood, 1997). Kitwood's theory of personhood begins with the ethical precept of the value of each person, which consequently should lead to social relationships and social interconnectedness founded on respect. He defined 'personhood' as 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being' (Kitwood, 1997: 8). As each person is unique and has value, they should be accorded 'recognition, respect, and trust' within their social interactions with others (Kitwood, 1997: 8).

Personhood has been highly influential in the field of dementia studies and is relevant to intergenerational dementia programmes. Intergenerational dementia programmes evoke social interconnectedness in their very structure through being designed to first engender, and then strengthen, interactions between older and younger participant groups, in a sense aspiring to construct safe, enabling contexts in which the value of one participant can be recognised by the others, old and young, and so on for all those participating. Utilising the theory of personhood, in the first instance, positively reinforces the purport of intergenerational practice, which, as related above, is to 'promote greater understanding and respect between generations' and provide a setting for the exchange of 'resources that the young and old have to offer each other' (Beth Johnson Foundation, 2011: 4). Personhood- as a second, broader point- provides the motivation and explanation that underlies this practice and its definition, that is, understanding, respect, and mutually beneficial exchanges are possible and necessary because each participant in the programme is unique and has value. Personhood further advocates for practice, services, and programmes that acknowledge 'the enduring potential of persons living with dementia to experience meaningful interactions and relationships despite their losses' (Canning and Blakeborough, 2019: 167), including interactions and relationships with people of different ages.

However, within the context of intergenerational dementia programmes, it is important to avoid conceiving of the relationships that may develop over the course of programmes as being simply 'experienced' or 'received' by those older participants living with dementia, rather older participants can have the potential to be the active agents of teaching, mentoring, guiding, assisting, and inspiring younger participants depending on the context, resources, choices, and opportunities that programmes offer them. Therefore, combined with personhood, this thesis has additionally been informed by the citizenship view of dementia that focuses on the social agency of people living with dementia (Bartlett and O'Connor, 2010). Bartlett and O'Connor argued that a 'significant boundary to how personhood has been utilised to date is that while it is grounded in the idea that a person with dementia is someone who counts, this lens does not necessarily promote the vision of someone with agency' such that the 'implicit assumption [is] that individuals are necessarily passive in the face of external forces' (Bartlett and O'Connor, 2010: 21-22).

The citizenship lens builds on personhood by looking at concepts such as agency and power, recognising and examining 'the other social statuses and actions of people with dementia' beyond those connected to the condition alone (Bartlett and O'Connor, 2010: 21-22).

Without undermining or denying the importance or effect of dementia in people's lives, the citizenship lens seeks to reveal 'the myriad of ways in which people with dementia are maintaining and asserting personhood, forming coalitions, claiming rights, becoming politically active, exercising agency, taking control, risks and responsibilities, speaking up for themselves and others, and dealing with the demands of citizenship within the context of having dementia' (Bartlett and O'Connor, 2010: 5; Alzheimer Scotland, 2022). In terms of intergenerational dementia programmes, therefore, a citizenship approach is adopted in order to open up examination of the different roles that people living with dementia may assume throughout interactions with younger participants; the experiences, assets, and preferences they may bring to bear within programmes to the benefit of the younger groups; and even how programmes may be actively harnessed by people living with dementia towards advocacy and the overcoming of discrimination. Moreover, as many intergenerational dementia programmes unfold outside of care settings- and even within care settings can be a vehicle for forging connections to the community- they further provide an avenue for exploring some of the 'unseen' processes and problems that people living with dementia may experience in the community and society at large, including issues related to 'socioeconomic status, discriminatory attitudes, public transport and work' (Bartlett and O'Connor, 2010: 6).

# Intergroup Contact Theory

Intergroup contact theory has informed the analysis of the inclusive interactions between different age groups (and between people living with dementia and typically younger groups) that intergenerational dementia programmes aspire to facilitate. Intergroup contact theory, based in the work exploring prejudice and race developed by the psychologist Gordon Allport (1954) and extended by the psychologist Thomas Pettigrew (Pettigrew et al., 2011; Pettigrew, 1998), seeks to explore the conditions in which contacts and interactions between different groups can move beyond mere specific, dissociated, sporadic acceptance of the 'other' group towards achieving genuine, sustained, generalised solidarity with and liking of the 'other' group. Intergroup contact theory posits that the members of one group – the 'in-group' (Allport, 1954: 31-33)- will be more likely to identify with each other on the basis of their shared affiliation as well as ascribed, achieved, or perceived statuses and characteristics they possess, while at the same time perceiving members of other groups – the so-called 'out-groups' (Allport, 1954: 41-43)- as being different. Moreover, in-groups may- but not necessarily- hold negative views of and be hostile towards out-groups (Allport, 1954: 42).

Intergroup contact theory proposes several 'positive factors' that must be met in order to achieve positive changes in attitudes and acceptance between different groups, thereby reducing prejudice (Pettigrew et al., 2011: 273). These factors include (i) equal status for the members of the group in the situation (ii) common goals for the groups to work towards (iii) intergroup cooperation, for example, to achieve the goals, and (iv) the support of authorities, law or custom (Pettigrew et al., 2011: 273). Pettigrew further argued that the generation of affective ties and friendships across groups through time was an additional condition necessary for optimal intergroup contact (Pettigrew, 1998: 76). The reasoning behind the implementation of these positive factors is that more superficial forms of intergroup contact will likely be unable to meaningfully achieve changes in prejudices held between groups and may even exacerbate or reinforce prejudices: it is only by 'reaching below the surface', 'doing things together' and through 'cooperative striving' (Allport, 1954: 276) that solidarity can be consolidated.

Intergroup contact theory was initially developed in relation to race relations in the United States, however, Caspi was one of the first researchers to apply intergroup contact theory to the domain of cross-age contacts (1984), finding that children attending an age-integrated preschool with daily contacts with older people were more likely to hold positive attitudes towards older people in general (Caspi, 1984). Intergenerational research has since utilised intergroup contact theory as a foundation due to 'its application [that aims to foster] positive intergroup interaction', which coincides with the goal of intergenerational practice in relation to different generations and age groups specifically (Caspar et al., 2019: 152).

Intergroup contact theory has contended with several criticisms, particularly from political science. For example, McGarry and O'Leary claimed that reducing prejudice does not prevent intergroup conflict or lead to changes in structure, reasoning that prejudice reduction does not affect structural policy (Pettigrew, 2008: 195-196) (McGarry and O'Leary, 1995). Pettigrew refuted these claims and suggested a more valid shortcoming of intergroup contact theory has been a lack of 'emphasis on transforming intergroup contact theory into an easily applied remedy within specific institutional settings' (Pettigrew, 2008: 195 - 196). Hodson cautioned that 'increased contact and more positive contact is associated with decreased outgroup negativity among the highly prejudiced, [however] these individuals are detrimentally impacted by low levels of contact and by poor-quality contact', which makes achieving optimal contact conditions imperative to render positive change with such individuals (Hodson, 2011: 158). Dixon et al., moreover, claimed that the ideal conditions of

intergroup contact theory are rarely achieved within 'everyday contact between groups [bearing] little resemblance to [the] ideal world' (Dixon et al. 2005: 699). Dixon et al. further suggested that the methods of intergroup contact theory did not always 'capture group members' own ways of making sense of their social relations in particular social situations' (Dixon et al, 2005: 702), with researchers 'inadequately considering participants' meanings of contact' (Hodson, 2011: 158).

# Realist Evaluation and Realist Synthesis

The thesis as a whole is grounded in and informed by realist evaluation (Pawson, 2013; Pawson, 2006; Pawson and Tilley, 1997). Intergenerational dementia programmes- with their duality of participant groups old and young, and relational, reciprocal core mechanisms working in tandem with individual choices and behaviours- are inherently complex. Realist evaluation emerged as a method for approaching and tackling complexity within social interventions, for 'untangling the complexity of real-life implementation' (Rycroft-Malone et al., 2012: 9), and thus offers a suitable research strategy for unpicking the processes involved in this type of intergenerational programme.

Realist evaluation coheres around the core question of 'what works for whom in what circumstances', and moreover, as it is a realist approach, it is critical to further ask 'and why' (Pawson, 2013: 15). Realist evaluation uses a 'generative' approach to causation, that is to say, 'why' explanations and the theories of 'how' and 'why' programmes work are related to mechanisms and contiguous contexts (Pawson, 2002: 342). Pawson describes mechanisms as the 'agents of change' in a given type of programme as they demonstrate 'how the resources embedded in a programme influence the reasoning and ultimately the behaviour of programme subjects' (Pawson, 2013: 115). Therefore, it is wrong to perceive any type of programme, including intergenerational dementia programmes, as working in a fixed sense: within realist evaluation, the outcomes of a programme are variable and subject to change as they ultimately depend upon contextual circumstances, the choices and capacities on offer, and the nature and behaviour of participants in the face of circumstances and choices (Pawson, 2002: 342).

Within realist evaluation, analyses are structured according to the context-mechanismoutcome (CMO) configuration, whereby contexts (C) are associated with outcomes (O) of interest through programme mechanisms (M), with mechanisms exerting explanatory power. Mechanisms are not variables but 'an *account* of the make-up, behaviour, and interrelationships' of programme processes. A mechanism is thus 'a theory which spells out the potential of human resources and reasoning' (Pawson and Tilley, 1997: 68). Realist evaluation is, moreover, theory-driven in that it searches for and refines 'explanations of programme effectiveness' (Pawson, 2013: 15) through harnessing data according to the CMO-configuration; and it is thus rooted in a realist philosophy of science (Wong et al., 2013: 1012).

In terms of the data to be used within inquiries, realist evaluation advocates the use of 'evidence of all forms, quantitative and qualitative, outcome and process, measurement and gossip', advising researchers to be attendant to the 'reasoning in research reports rather than look only to the quality of the data' (Pawson, 2013: 11). Realist evaluation has been used within this thesis to develop the ontology, epistemology, and methodology as well as to structure the analysis and presentation of findings and will consequently be discussed further throughout several chapters.

# Research Problem and Gap

Intergenerational practice today denotes a substantial and yet under-theorised area of research that merits further investigation from a range of disciplines. For example, in 2004 Vanderven argued that intergenerational practice was unfolding 'without an adequate conceptual framework to guide the design and implementation of these efforts' (Vanderven, 2004: 76) and proposed a number of concepts and questions to guide theory construction in future. More recently, Kuehne and Melville identified two premises underlying the use of theory within intergenerational practice, the first premise involving the use of existing theories to guide intergenerational practice and the second premise 'grounded in a call for a uniquely intergenerational theory that is specific to intergenerational practice' (Kuehne and Melville, 2014: 332).

Combining the topic of intergenerational dementia programmes with a methodology informed by realist evaluation as undertaken with this thesis offers a potential avenue to contribute to intergenerational theory, specifically intergenerational theory in relation to people living with dementia. This is because within the realist evaluation approach a class of interventions- such as intergenerational dementia programmes- together constitute the programme theory, with the theory itself '[setting] out how and why a class of intervention is thought to 'work' to generate the outcome(s) of interest' (Wong et al., 2013: 1006). Therefore, while it is beyond the scope of this thesis to consolidate a unique

intergenerational theory, nevertheless the realist evaluation approach can achieve insight into what is or is not 'unique' about intergenerational dementia programmes by scrutinising the contextual circumstances and mechanisms that point to different outcomes, and by encapsulating how participants and stakeholders themselves think and reason during, and when implementing, programmes (Pawson, 2013)(Pawson and Tilley, 1997). By examining the 'common-sense theory', as it were, of intergenerational dementia programmes generated by the realist approach (Pawson, 2013: 6), this thesis may contribute towards clarifying between the two premises related above and provide a cogent position on whether a unique intergenerational theory is currently a realistic or desirable goal.

Further refinement of the research problem involves a focus specifically on people living with dementia in terms of the older participant group within intergenerational programmes. Dementia itself is a complex, multi-faceted, cross-disciplinary research area: while intergenerational programmes involving people living with dementia may represent a smaller proportion of total intergenerational programmes, nevertheless, this focus introduces additional variables and concepts from the field of dementia studies and dementia theory, arguably bringing additional complexity. At least three recent reviews of intergenerational dementia programmes have been undertaken, including a systematic review and meta-analysis from Lu et al. (2021), a scoping review from Gerritzen et al. (2020), and a scoping review from Galbraith et al. (2015). These reviews identified a need for further inquiries to better elicit learning and evaluation from intergenerational dementia programmes. Adopting a realist synthesis approach towards existing evidence, and thereby analysing relevant, robust data sources from around the world in terms of contexts, mechanisms, and outcomes, represents a novel method that compliments and adds to the reviews that have already been published in this area.

Thirdly, through this thesis and undertaking stakeholder interviews exploring intergenerational dementia programmes in Scotland, I am aiming to provide insight into the Scottish context in particular. Gerritzen et al. proposed that future research focused on intergenerational dementia programmes seek to 'explore the possible influence of the social-cultural setting by comparing programs that were conducted in different countries' (Gerritzen et al., 2020: 242). Gualano et al. similarly identified a need for experiences to be expanded into additional settings (Gualano et al., 2018: 467). By focusing on the Scottish context, this thesis can contribute to this need for more studies to inform a comparative analysis of intergenerational dementia programmes across different socio-cultural settings.

# **Research Questions**

Through this thesis I aim to explore intergenerational inclusion for people living with dementia internationally and nationally, deploying three research questions:

- 1. How is the concept of intergenerational inclusion for people living with dementia understood and operationalised internationally?
- 2. How is the concept of intergenerational inclusion for people living with dementia understood and operationalised in Scotland?
- 3. How can insights from exploring international and national practice further inform the development of intergenerational practice and policy in Scotland and internationally?

The research questions are predicated on a distinction between the Scottish/national level and the international level. The international level within this thesis is understood to refer to contexts external to Scotland, which can be compared and contrasted to the Scottish level and to Scottish practice in order to identify commonalities and differences.

# Thesis Structure

The thesis is structured around the following chapters. Chapter two presents a critical review of current literature towards (i) examining dementia as a social phenomenon with impacts across all age groups and (ii) providing a theoretical basis for understanding dementia through the lens of intergenerational inclusion and vice versa.

Chapter three describes the research methods used in this two-phase study, involving (i) a realist synthesis of data sources exploring intergenerational dementia programmes internationally and (ii) realist interviews with Scottish stakeholders exploring intergenerational dementia programmes nationally. The ontological and epistemological approach, grounded in realist evaluation, is justified, and aligned with the realist synthesis and realist interview methods adopted to collect data. The chapter then progresses with a practical, transparent overview of how the research methods were applied.

Chapter four presents an overview of how the data have been analysed for both the realist synthesis and the Scottish stakeholder interviews. Analysis has primarily been completed through an applied thematic analysis method. The thematic analysis approach is grounded in Braun and Clarke's six phases of thematic analysis, including (i) familiarising yourself with the data (ii) generating initial codes (iii) searching for themes (iv) reviewing themes (v) defining and naming themes and (vi) producing the report (Braun and Clarke, 2006: 87). Nowell et al's 'means for establishing trustworthiness' pertinent to each stage of analysis (Nowell et al., 2017: 4) have also been used towards ensuring a robust, credible analytical process.

Chapters five and six present the findings from the realist synthesis and realist stakeholder interviews respectively. These findings are structured according to the context-mechanismoutcome configuration propounded by realist evaluation as described above. Contextual findings include an examination of the different settings of intergenerational dementia programmes combined with information regarding the make-up of participants. Outcome findings include the benefits and detriments of intergenerational dementia programmes identified both through the practice and perspectives of researchers and stakeholders, whether wellbeing, behavioural, relational, developmental, or implementational outcomes. Bridging contextual and outcome findings, mechanism findings are presented, that is, thematic data that points to the inner working of intergenerational dementia programmes, and the resources and choice opportunities that programmes have presented to participants and organisers.

Chapter seven presents findings from the realist stakeholder interviews in regard to Scottish policymaking and Scottish partnerships in relation to the understanding and operationalisation of intergenerational inclusion in Scotland.

Chapter eight discusses intergenerational dementia programmes internationally and in Scotland in terms of implications for the academic literature and vice versa. The findings are discussed in relation to the three research questions of this thesis, concerning the understanding and operationalisation of intergenerational inclusion internationally; the understanding and operationalisation of intergenerational inclusion nationally; and insights that can be gained towards furthering the development of intergenerational practice both internationally and nationally. Similarities and differences between programmes nationally and internationally are presented along with recommendations to enhance the development of intergenerational dementia programmes. The chapter then goes on to critically appraise the application of the realist evaluation approach in the field of intergenerational inclusion. The chapter closes with some additional insights from this study relevant to intergenerational theory. Finally, chapter nine provides some conclusions including my reflections on undertaking this thesis throughout a period characterised by the unique challenges of the COVID-19 pandemic. Future research directions are also identified, particularly the potential for critical and constructivist approaches to further build on programme theory by exploring the lived experiences as well as the latent, symbolic meanings ascribed to intergenerational interactions by programme organisers, intergenerational practitioners, and participants themselves.

# Chapter 2: Literature Review

## Introduction

Dementia represents a complex issue for practitioners and policymakers not only in medical terms, but in social and ethical terms in addition. Dementia is closely related to demographics and the ageing society, and as such, generational dynamics provide a useful framework for approaching and understanding the issue. Post (2000), for example, observed that the gains in life expectancy rendered through medicine, sanitation and public health consequently raised the dual importance of adult children fulfilling their obligations to their parents and of society meeting the growing needs of older citizens. Tobio, similarly, described a 'generational exchange of resources between generations' that is 'mediated by the state, the market, and the voluntary sector' and that unfolds simultaneously on both the macro-level and the micro-level (Tobio, 2010: 431). Within society, there is 'a distribution between adults who pay taxes, buy services, or give their time and children, elderly, or disabled who receive care resources' and within the familial context 'generations give one another support along life-changing roles as time goes by' (Tobio, 2010: 431). The needs of people living with dementia must be met by society in ways that are both sensitive and strategic, however, the effects for younger generations must be fair, reasonable, and sustainable for the future insofar as possible.

One way of mediating generational compromise and the 'division of assets between old and young' in relation to dementia would undoubtedly be by way of a cure for dementia (Post, 2000: 8). However, despite significant gains in aetiological and pathological knowledge combined with therapeutic and practice-based progress, a cure for dementia to date has not been found. Zeisel et al. thus recommended a greater focus on 'ecopsychosocial' interventions for people living with dementia capable of producing positive psychosocial effects for individuals involved as well as positively impacting individuals' environments, from their families and health systems to their neighbourhoods and communities (Zeisel et al., 2016: 504-505). Ecopsychosocial interventions may include intergenerational programmes for people living with dementia, such as 'schools where elders with dementia look at and discuss works of art in normal settings' (Zeisel et al., 2016: 504). The World Health Organisation more generally identified intergenerational solidarity (involving two-way giving and receiving between individuals as well as older and younger generations) as a key tenet

of active ageing and recommended intergenerational programmes as one potential intervention that could help foster social networks for ageing people (World Health Organization, 2002).

This chapter begins by exploring the key 'intergenerational' facets of dementia as a social and relational issue that can have effects for all age groups. These facets include young-onset dementia, preclinical Alzheimer's disease, preventative health, informal and family caregiving, and formal caregiving. Intergenerational inclusion for people living with dementia is then explored with reference to key concepts including ageism, stigma, generational intelligence, and dementia friendliness. The chapter then provides an overview of the field of intergenerational practice in terms of recent intergenerational research, intergenerational theory, and operational definitions of 'intergenerational programmes' including programmes specifically for people living with dementia.

#### Intergenerational Facets of Dementia

#### Young-Onset Dementia

Age undoubtedly remains the biggest risk factor associated with dementia. In the UK context, prevalence rates rise from about two in 100 people in the age bracket of 65 to 69 years to one in five people in the age bracket of 85 to 89 years (Alzheimer's Research UK, 2018). Misconceptions can be commonplace, however, such as thinking that dementia is a disease of the 'elderly' or an inevitable part of ageing. Holstein recounts how for much of the twentieth century following on from the discovery of Alzheimer's disease by Alois Alzheimer in the early 1900s, the condition as a diagnostic label was only attached to its *presenile* form as it affected younger people. Senile dementia, on the other hand, was conflated with broader processes of senescence and was not seen as a disease condition in its own right (Holstein, 2000). From the 1970s, this view changed towards the situation as it is known today: dementia is understood to have no age boundaries and is perceived as being qualitatively different from normal ageing (Holstein, 2000: 158 – 159). The arguably rapid change that understandings of dementia subsequently underwent- 'from an obscure, rarely applied diagnosis' to a leading cause of death (Fox, 1989: 58)- has since led to late-onset dementia becoming far more common and politically visible than dementias affecting younger people.

Young-onset dementia, also called early-onset or working-age dementia, is caused by similar diseases to dementia in older people, however, there are some notable differences. Young-

onset dementia is caused by a wider range of diseases, is much more likely to be an atypical or rarer form of dementia, and more likely to be hereditary than is late-onset dementia (Alzheimer's Society, 2019). In addition, metabolic syndromes, treatable causes, and secondary dementias (due to alcohol misuse, HIV, Down's syndrome, or traumatic brain injury) are more common among younger people (van Vliet, 2012: 3).

Estimating the prevalence rates of young-onset dementia has typically been difficult, not least because the age distinction on which the diagnostic definition rests has been perceived as medically arbitrary (Woodburn, 1999: 37). By most accounts, young-onset dementia 'begins before the age of 65' and is 'a much rarer condition than the late onset (senile) form' (Woodburn, 1999: 37). It has been estimated that in the UK there are now approximately 42,300 people with young-onset dementia (Alzheimer's Society, 2014). In Scotland, moreover, it has been suggested there are approximately 3,200 people with dementia under the age of 65 (Alzheimer Scotland, 2022).

Consistently through the years, young-onset dementia has been found more difficult to diagnose than late-onset dementia, as well as producing high rates of misdiagnosis. Using multiple linear regression analysis to compare the differences in duration between symptom onset to dementia diagnosis between those with young-onset and late-onset dementia, van Vliet suggested that individuals with young-onset dementia experienced a mean duration of 4.4 years between symptom onset and diagnosis, compared to only 2.8 years duration for those with late-onset dementia (van Vliet, 2012: 52). Hoppe, undertaking qualitative interviews in the Netherlands with people diagnosed with young-onset dementia as well as their family members, found that families were often keen to accept and maintain uncertainty in order to allow their lives to continue as normal, which postponed the seeking of medical advice and delayed diagnosis (Hoppe, 2018).

The social and familial impacts of young-onset and late-onset dementia may differ also. Often people living with young-onset dementia may still be in employment, have dependent young children, be the main earner for their families, or be involved actively in social roles, with divorce and unemployment being potential adverse consequences that could arise (Hoppe, 2018; van Vliet, 2012; Woodburn, 1999). The stigma experienced by people with young-onset dementia may be more 'poignant', with the younger person more likely to be seen 'as stupid' on account of their condition due to a lack of awareness that dementia can and does affect numerous younger people (Baker et al., 2018: 680). Young-onset and late-onset dementia

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may require different policy responses, support services, and diagnostic processes. Younger people with dementia may benefit more from work-based interventions driven by the voluntary sector that allow for them to engage in meaningful activity for as long as possible (Greenwood and Smith, 2016: 110). Similarly, people with young-onset dementia may need financial and income support arising from loss of employment during working years and early retirement, necessitating that dementia service providers be prepared and knowledgeable in making such referrals (Sansoni et al., 2016: 698). If dementia policy is primarily driven by ageing demographics and evidence related to late-onset dementia, then there is the chance more broadly that people living with young-onset dementia will simply 'fall between the cracks of service systems' (Sansoni et al., 2016: 696), being 'too young' for healthcare primarily 'designed to help older adults' (Gibson et al., 2014: 597).

# Preclinical Alzheimer's Disease

The emergence from 2011 of preclinical Alzheimer's disease as a distinct category is another way in which dementia could become increasingly relevant to younger people in the near future. Genetic studies have made progress in identifying biomarkers in relation to both young and late-onset familial Alzheimer's disease, explaining a small percentage of total Alzheimer's disease cases (Lesuis et al., 2018). Preclinical Alzheimer's disease is based on the pathology of these biomarkers (brain, blood, genetic and cerebrospinal fluid-based) in asymptomatic individuals rather than observable symptoms (Johnson and Karlawish 2015; Johnson et al., 2015). The preclinical phase thus begins with the 'accumulation of amyloid beta in the brain' and ends with the first 'subtle signs of cognitive decline' (Johnson et al., 2015: 117-118).

Preclinical Alzheimer's disease has the potential to affect younger individuals to whom preclinical diagnoses are made, resulting in a significant shift in the 'boundaries' of Alzheimer's disease itself 'from the bedside of the patient with dementia, to the desktop of the person who learns her biomarker results' (Johnson and Karlawish 2015: 1636). While opening up potentially beneficial avenues of enquiry for the biomedical research agenda, preclinical Alzheimer's disease nevertheless poses a number of complex ethical and social questions.

Disclosure of positive biomarker results, in keeping with dementia diagnoses in general, could be 'psychologically harmful' to some individuals (Johnson and Karlawish, 2015: 1368). It has long been recognised that the diagnosis and prognosis of dementia can be both

'severely distressing' for the individuals receiving their diagnosis as well as problematic for clinicians, requiring significant planning and management to handle procedures appropriately and to safeguard individual autonomy (Fearnley, McLennan and Weaks, 1997). Preclinical disclosures, much like the diagnosis of young-onset dementia, have the potential to be more disruptive and surprising in the lifecourse, and could have an impact on the health behaviour of individuals for decades of their life.

Issues of ageism, discrimination, and stigma directed at people living with dementia are also integral to debates surrounding the preclinical Alzheimer's disease research agenda. As younger people come to be pre-diagnosed, they may 'face decades of discrimination' unless dementia policy as a whole can achieve positive shifts in socio-political understandings and the social positioning of all people living with dementia (McDonald, 2019: 31). Social stigma and its relationship to different aspects of dementia, however, is a complex, multidimensional issue that bears further analysis. Undertaking a vignette-based experiment with a general population in the USA context, Johnson et al. sought to examine which aspects of Alzheimer's disease provoked negative reactions of stigma, whether it was the symptoms and behaviours of cognitive decline, or simply the 'disease label' itself (Johnson et al., 2015). They projected that if the 'disease label' provoked spillover stigma for people with preclinical Alzheimer's disease who were otherwise seemingly well, it could be possible that the preclinical category could result in discrimination for younger people. However, if it was rather the more visible symptoms of cognitive decline that provoked stigma, then the Alzheimer's disease community might come to be 'split' between those with worse symptoms experiencing greater stigma, and those with preclinical AD (Johnson et al., 2015), a split that would likely divide older and younger people experiencing different aspects of dementia. Interestingly, the researchers found that the 'disease label' of Alzheimer's disease could actually be protective against some elements of harsh social judgement (Johnson et al., 2015: 124). Among their main conclusions was that disease prognosis- the perception that symptoms would get progressively worse- 'led to significantly higher levels of expected structural discrimination, pity, and social distance' (Johnson et al., 2015: 125).

# Preventative Health

A growing body of research investigates the social, psychological, environmental, and behavioural factors earlier in the lifecourse that may be associated with an increased risk of dementia later in life. This line of enquiry has been influenced by the 'deep' evidence base demonstrating that 'experiences in childhood can influence patterns of illness, aging, and mortality later in life' (Wise, 2016: 37). Dementia from a preventative perspective takes account of health and wellbeing throughout all stages of life and across different age groups, rather than limiting the focus to older age groups. If dementia can be latent in the circumstances and behaviours of a person's childhood or working years, then much of the dementia risk may in fact have already been accumulated by the time that person approaches older age. By understanding the 'lifelong time-course' of Alzheimer's disease and dementia, 'early life, causative' risk factors can be identified offering potential for the development of 'preventative interventions during critical life stages' that may together reduce global excess disability arising from dementia (Seifan et al., 2015: 252).

Transgenic rodent studies suggest that pregnancy and the first year of life are critical towards ensuring cognitive health (Lesuis et al., 2018: 5). Cognitive stimulation and enrichment during the years when the brain is still in development can contribute to 'cognitive reserve' (Lesuis et al., 2018: 7-8), which refers to an individual's capacity to maintain cognitive function despite brain pathology, including the brain's resistance to disease-causing agents, brain compensatory mechanisms when confronted with insult, and the capacity of the brain to functionally adapt (Lesuis et al., 2018: 3). Conversely, 'disturbances like stress and trauma' can impede the building of cognitive reserve (Lesuis et al., 2018: 7-8).

A number of studies have been produced that focus on the particular environmental and psychosocial factors earlier in life that may be associated with less cognitive reserve and greater dementia risk. Childhood stress (Donley et al., 2018), childhood food insecurity (Momtaz et al., 2015), and the death of a parent before the age of 16 (Persson and Skoog, 1996: 20) have been found to contribute to dementia risk later in life. An early study sought to investigate the risk of incident dementia associated with low educational and occupational attainment, concluding that dementia risk was highest for people with both low education *and* low occupation (Stern et al., 1994: 1006 – 1008). More recently, a study was undertaken to test a life-course model of cognitive reserve in dementia and examine if school grades at approximately age 10, formal educational attainment, and lifetime occupational complexity affected the risk of dementia in old age (Dekhtayr et al., 2015). The researchers concluded that childhood school grades and occupational complexity with data provided 'statistically significant protective effects' against dementia (Dekhtayr et al., 2015: 891), and that early-life school performance could potentially be an early indicator of the capacity of an individual

to functionally reorganise when presented with 'age-related physiological changes' (Dekhtayr et al., 2015: 892).

Evidence clarifying the early risk factors for dementia later in life can provide a rationale for developing preventative health policies allowing for timely and preventative interventions at critical moments. A dual focus on lifestyle interventions and pharmacological innovation; an awareness of both cognitive and physical health and the relationship between the two; and the importance of intergenerational relationships and families in mutually sustaining healthier lifestyle changes are some of the policy constructs that emerge from a focus on preventative, lifecourse health models (Cheng, 2014: 906 – 907). Public health awareness regarding dementia, similarly, can be targeted at all age groups and not just older people facing increased risk. Educating children and the public generally about both authentic dementia friendliness as well as dementia risk reduction via a healthy lifestyle can become mutually reinforcing aims (Baker et al., 2018: 680).

Young-onset dementia, preclinical Alzheimer's disease, and drives towards preventative health emphasise the importance of dementia and healthy ageing awareness among younger groups. There is a need for research across contexts to explore not only the general awareness of ageing issues among children and young people, but to further investigate whether intergenerational inclusion and intergenerational dementia programmes can be an effective way to enhance dementia and ageing knowledge among the younger participants who are involved in such initiatives. This research aims to explore whether awareness and knowledge outcomes have been found through the operationalisation of programmes internationally and nationally in Scotland.

# Informal and Family Caregiving

Caregiving across a range of disabilities and health conditions, including but not limited to dementia, constitutes a social phenomenon that brings different generations together. Carers are seen to be equal partners in the caring system and delivery of care alongside health and social care partners (Scottish Government, 2010: 3), support for people with dementia throughout the course of their condition is understood to include the 'support needs of carers' (Scottish Government, 2013: 3), carers are seen to be a key resource allowing people living with dementia to remain as long as possible in their homes and communities (Scottish Government 2013: 4), and legislation aimed at supporting carers more broadly,

namely The Carers (Scotland) Act 2016, is seen to be essential to achieving suitable care and outcomes for people living with dementia (Scottish Government, 2017: 8).

An examination of the reality of community care revealed that the provision of support to older people in the community largely fell on the family (Bond, 1992: 11). Bond further made a distinction between formal caregiving, involving a commitment to tasks within bureaucratically structured organisations, and informal caregiving, involving an attachment to and affection for the person to be cared for (Bond, 1992: 9-10). Intergenerational caregiving, particularly the care provided by adult children to their parental elders, has its basis in norms of reciprocity and filial obligation: adult children even 'the ethical score' by morally paying back care to their ageing parents in exchange for the care they received in kind from their parents during childhood (Barber and Lyness, 2001: 11). As such, the proper safeguarding of older people must involve efforts directed not only towards formal carers, but towards the family sphere where the majority of care is currently provided (Cooper et al., 2009).

Sustaining family caregiving can be understood as a critical component of policy efforts towards meeting the demands of the ageing society, and caregiving can indeed bring a sense of profound fulfilment to carers. However, it is important to realise that family caregiving capabilities are not limitless, and that people will experience caring differently (Post, 2000: 37-38). For example, one study found that spousal caregivers were more likely to be older, have worse physical health, and provide more hours of care than other groups of carers, usually because they co-resided with the person they were caring for (Pinquart and Sörensen, 2011). A study examining compassion fatigue among adult daughter caregivers of a parent living with dementia demonstrated that adult daughter caregivers often experienced uncertainty over how to respond in their caring situation along with doubt about their ability to provide adequate care to their parents. The participants in the study displayed a strong attachment to their parents and a willingness to care, however, they also had competing and varied life demands, factors taken together that may make compassion fatigue more likely (Day, Anderson and Davis, 2014: 799-801).

# Formal Caregiving

Formal caregiving by paid care workers is a primary domain in which intergenerational social relationships can impact the experience of people living with dementia. Addressing issues in the care sector such as poverty-pay (Hussein, 2017: 1818) and exploitation (Baines, 2004:

285-287) are critical towards ensuring enough care workers can be recruited in the near future to meet the growing demand for care generated by the ageing society. Moreover, there is a consensus in the care sector that high vacancy rates and turnover of staff impede the delivery of quality care (Moriarty, Manthorpe and Harris, 2018: 3).

Towards this end, there are positive approaches being developed that aim to improve the recruitment and working conditions of the care sector. For example, it has long been recognised that improving employment in the care sector would likely go hand in hand with improving the status bestowed on caring as a vocation through policy activities such as raising public awareness about the contribution of social work, encouraging career advisors and job centre staff to be more informed about social work as an employment option, and providing developmental opportunities for existing staff (Moriarty, Manthorpe and Harris, 2018: 14-15).

Similar issues have been investigated in regard to the recruitment and retention of nursing staff within dementia care. It has been posited that nursing students are socialised into preferring a cure approach of nursing, encapsulated through fields such as emergency nursing and the manipulation of technology, rather than the traditional caring roles of the profession (McKenzie and Brown, 2014: 621). Undertaking a survey of 135 undergraduate nursing students within an Australian university, McKenzie and Brown (2014) found that both a higher age and positive ageism among the nursing student participants were positively correlated with future intentions to work in dementia care. In terms of perceived barriers to working in aged care, younger nursing students were more likely to cite emotional demands as a potential barrier, whereas older students were more likely to report conditions within the profession of dementia care, such as pay, as potential barriers (McKenzie and Brown, 2014: 630). In terms of nursing staff retention within long-term care, Tummers et al. found that factors such as development and career opportunities, the working atmosphere, and high work pressure were all important in determining nurses' intentions to leave their organisation (Tummers et al., 2013: 2834-2835). This accords with additional research that suggests nurses from different fields and of different generations have different developmental requirements and career ambitions. For example, in a recent literature review exploring nurse turnover, Hayes et al. emphasised generational differences that were apparent in nurses' work attitudes, such as younger nurses wanting to pursue more

qualifications while being at greater risk of burnout, and with older nurses being more committed to their organisations (Hayes et al., 2012: 888-890).

Caregiving for older generations is a key facet of intergenerational interaction and therefore may have an impact on how effective intergenerational dementia programmes can be. Lived experiences of caregiving, whether positive or strained, delivered within families or professionally within services, may impact perceptions of intergenerational inclusion and intergenerational programmes among people living with dementia. Older people with negative experiences of intergenerational caregiving relationships may be less inclined to get involved in initiatives or may not benefit as much from such programmes. This research aims to explore the ways in which preferences and lived experiences have been considered by practitioners and researchers over the course of implementing intergenerational dementia programmes, and how upholding personhood in these ways may contribute towards particular outcomes. Moreover, family and professional caregivers are key stakeholders in the delivery of intergenerational dementia programmes and there is a need for evidence demonstrating how these stakeholders may affect programme delivery and outcomes. Perceptions of risk among families and the attitudes of staff towards organising programmes may be influential in terms of the types of activities that are organised, and whether or not programmes can successfully deliver the conditions for inclusion to flourish among different age groups. Risk perceptions and staff attitudes may also be instrumental in whether programmes are implemented in the first place. This research aims to address these operational components of intergenerational dementia programmes across different levels.

# Intergenerational Inclusion for People living with Dementia

Dementia can thus be framed as a social issue involving multiple intergenerational dynamics and as a result ensuring intergenerational inclusion for people living with dementia can be perceived as an important consideration for practitioners and policymakers. As Galbraith et al. relate, 'whether society promotes the ongoing inclusion of persons with dementia...in meaningful activities and social relationships will have a tremendous impact on communities and the well-being of [persons with dementia]' (Galbraith et al. 2015: 358). Intergenerational solidarity can be construed as 'bonding between and among individuals in multigenerational family networks and among different age cohorts in the larger community' and is closely related to social cohesiveness as 'more solidarity results in more cohesiveness...allowing conflicts and tensions to be minimized' (Cruz-Saco, 2010: 9-10). Intergenerational inclusion for people living with dementia relies on tackling negative perceptions of dementia that can culminate in ageism and stigma, while also promoting positive perceptions through generational intelligence and dementia friendliness. As Lokon et al. relate, while 'reduction of negative attitudes toward older adults is extremely important, it is equally important to build genuine liking of older adults that transcends mere tolerance or acceptance' (Lokon et al. 2018: 2).

#### Ageism

Ageism encapsulates the stereotypes, attitudes, and behaviours that underpin interactions between people belonging to different age groups and is an important area of enquiry when analysing intergenerational relationships and dementia. Palmore developed definitions of both positive and negative ageism in the 1990s as age-related research gained increased interest both within and beyond gerontology. He stipulated that 'ageism is prejudice or discrimination against or in favor of an age group' (Palmore, 1999: 17). Prejudice encompasses the negative stereotypes or negative attitudes towards a particular age group, in which stereotypes tend to be more cognitive and attitudes more affective (Palmore, 1999: 17-19).

Palmore identified nine major negative stereotypes that commonly are held towards older people, including illness, impotency, mental decline, mental illness, uselessness, isolation, poverty, and depression (Palmore, 1999: 20). However, Palmore recognised that ageism could also be positive, grounded in positive stereotypes and attitudes towards older people, evoking connotations (arguably equally distortive) such as kindness, wisdom, dependability, affluence, political power, freedom, eternal youth, and happiness (Palmore, 1999: 34). Ageism, moreover, can operate at the individual and institutional levels (Palmore, 1999: 44). Two primary theories of ageism have been developed and extended within academic research: social identity theory (SIT) (Tajfel, 1982: Brown, 2019) and terror Management theory (TMT) (Greenberg et al., 1992).

Social identity theory holds that people sometimes see themselves as belonging to a group, the 'interpersonal-intergroup' (Brown, 2019: 2) or 'ingroup' (O'Connor and McFadden, 2012: 629). Being part of a group engages the social identities of the members, and these identities have 'cognitive, evaluative and affective consequences' for people's 'self-concepts', with people preferring to see themselves in a positive light (Brown, 2019: 2) especially in regard to other groups or 'outgroups' (O'Connor and McFadden, 2012: 629). One of the core

applications of social identity theory has thus been to offer a general theory of intergroup conflict (Brown, 2019: 3). For example, younger people may perceive older people to belong to an external 'outgroup' distinct from their own 'ingroup' resulting in bias against and stereotypes towards older people held by younger people (O'Connor and McFadden, 2012: 629). Moreover, older people, perceiving themselves to belong to a 'lower status' group (being old), may adopt several strategies to cope and maintain a positive identity. Strategies may include focusing on the positive aspects of ageing, perceiving younger groups to be especially threatening, or disidentifying with their own 'ingroup' by detaching from other older people (Bodner, 2009: 1005-1006).

While undoubtedly influential and generating supportive empirical evidence throughout several decades (Hornsey, 2008), social identity theory has been critiqued on several counts. One longstanding critique is that the theory is more adept at explaining ingroup favouritism rather than 'genuine intergroup hostility' (Hornsey, 2006: 217, Brewer, 1979: 307). More recently, the theory has been criticised for failing to address 'the complexities and nature of many intergroup encounters' (Abrams and Hogg, 2004: 103-104), particularly 'subgroup identities, cross-cutting identities, relational identities, outgroup identification, and the complex intersection of personal and collective identity' (Hornsey, 2006: 217). The theory has been perceived to downplay the subjective experience of identity, for example, the 'differing concerns about their status and reputation within the group' that people may hold as well as how 'people [do] not simply conform to their role or the stereotype of their group but [are] actively involved in characterizing their place and purpose' (Abrams and Hogg, 2004: 104). From a political perspective, moreover, social identity theory has been critiqued for generating less evidence on the development of identity, retaining a 'deeply deterministic view of identity development that omits individual choice', largely ignoring 'the personality traits most likely to influence the adoption of group identity', and inadequately accounting for gradations in identity strength, particularly 'the transition from weak to strong identity' (Huddy, 2001: 136-147).

Terror management theory proposes a fundamental linkage between self-esteem and protection from anxiety: "people need self-esteem because it is the central psychological mechanism for protecting individuals from the anxiety that awareness of their vulnerability and mortality would otherwise create" (Greenberg et al., 1992: 913). Studies adopting a terror management theoretical basis thus often test the Mortality Salience (MS) hypothesis,

which is particularly relevant to dementia. This hypothesis proposes that 'reminding people of their own mortality increases their need for self-esteem and adherence to their cultural worldviews' (O'Connor and McFadden, 2012: 629). Older people may cause death anxiety among younger adults by reminding them of death and these anxieties may in turn influence ageism and may be further compounded by stigmas associated with cognitive conditions such as dementia (O'Connor and McFadden, 2012: 630). Terror management theory has been critiqued from an evolutionary perspective, which supposes that 'other novel thoughts that began to appear with the evolution of the modern *Homo sapiens* would be at least as disconcerting as those about death' and, even if death anxiety were warranted to such a degree, it is 'not obvious why defending one's worldview should be the expected evolved solution to the adaptive problems purportedly posed by death anxiety' (Kirkpatrick and Navarrete, 2006: 289 – 290).

#### Ageism, Stigma and Dementia

Reducing dementia-related stigma is considered important in order 'to support the uptake of early dementia diagnosis, facilitate cognitive health promotion, and optimize health care services to support people with dementia' (Bascu et al., 2021: 9). However, evidence points to ongoing stigma directed towards people living with dementia and dementia-related stigma continues to be of interest within dementia studies.

In a global survey incorporating 60,860 complete responses from 155 countries and territories published in 2019, evidence of continuing stigma and discrimination against people living with dementia was apparent. For example, 31.8 percent of people living with dementia in high-income countries reported unfair treatment by their children and their family members. 33.3 percent reported feeling avoided and shunned by others; 40.9 percent had experienced jokes about dementia symptoms; and 54.5 percent had been denied a choice to do something. Within upper-middle and lower-income countries, even higher proportions of people living with dementia were affected by these domains of unfair treatment (Alzheimer Disease International, 2019: 24). Further surveys from the UK context point to ongoing fear surrounding dementia, for example, 68 percent of people believing they 'would no longer be the same person' following a diagnosis of dementia (Alzheimer's Society, 2016).

Research studies have further been conducted to explore ageism and attitudes towards dementia using a range of methodologies. For example, O'Connor and McFadden examined

college students' (n=240) reactions toward hypothetical descriptions of target adults in which age and health status were manipulated. Target age was either 29 or 71, and targets were described as having normal health, unknown health, arthritis, or dementia. Participants were asked to rate the targets on stereotype content dimensions of competence and warmth, their emotions toward the targets, and were further asked to complete a measure of deaththought accessibility (O'Connor and McFadden, 2012). In terms of findings, the young participants rated the targets with dementia as both less competent and warmer (noncompetent and benevolent) than targets with normal health. In addition, targets with dementia received higher fear ratings than targets with unknown health; higher pity ratings than targets without health conditions; and higher empathy ratings than normal targets. Finally, participants were also more likely to generate death-related words when assessing dementia conditions (O'Connor and McFadden, 2012: 639-640).

A separate study provided further nuance within these attitudes of younger people towards dementia. Using a similar methodology involving 120 young people, the researchers were able to demonstrate that college students have different responses to the symptoms of people living with dementia depending on the type of dementia diagnosis and the causes associated with the diagnosis (Diekfuss, Larwelle and McFadden, 2018: 159). In particular, the participants in the study showed more empathy for a target with Alzheimer's Disease (biologically caused) than a target with Wernicke-Korsakoff Syndrome (primarily affecting those who chronically misuse alcohol) (Diekfuss, Larwelle and McFadden, 2018: 157).

Qualitative research undertaken in Australia, using in-depth interviews conducted with 29 self-selected people from a range of professions and age groups, has sought to explore how attitudes towards dementia vary by age group, analysing differences in dementia knowledge and perceptions between young people, middle-aged groups, and older people (Biggs, Haapala and Carr, 2019). Within their sample, they found that while younger people correctly identified that dementia was not something that was linked with normal ageing, nevertheless, younger people maintained 'a mixture of age-related distance or professional role-related distance' when giving their initial thoughts on dementia (Biggs, Haapala and Carr, 2019: 77). Participants from the two middle-aged groups were less certain about whether or not dementia was a normal part of ageing. They were more likely to have 'cognitive, neutral' first thoughts related to dementia, commenting on resource-driven issues such as the current state of care homes and the cost of care (Biggs, Haapala and Carr, 2019: 79). Older groups,

in contrast, were found to perceive dementia as being less distant, more personalised and tied to direct experience (Biggs, Haapala and Carr, 2019: 81). All of the age groups reported that they thought, in general, that the public perception of dementia was 'negative', and that knowledge of the condition was 'low' (Biggs, Haapala and Carr, 2019: 82). All of the age groups further concurred that young people were least likely to pay attention to dementia (Biggs, Haapala and Carr, 2019: 83).

Another factor to consider is the perceptions of older people and people living with dementia themselves in regard to how they think others perceive them. For example, if older people personally believe that their age group is 'seen as of lower social status and that others feel pity, contempt and envy toward them' then their reports of age discrimination may be higher (Vauclair et al., 2016: 707). Additionally, perceptions and fears regarding dementia among older age groups have also formed the basis of research. Using semi-structured interviews with community dwellers aged 65 years and over, Rosenberg et al. found that the participants in their study 'expressed general fear and concern over [cognitive] conditions' as well frequently mentioning 'having specific concerns over their own cognitive status or risk of cognitive disorders' (Rosenberg et al. 2020: 6). Moreover, cognitive conditions were 'commonly perceived as terrifying conditions, mainly due to their irreversible, progressive nature and lack of treatments' leading the researchers to conclude that 'cognitive disorders' seemed to be surrounded by a stigma' (Rosenberg et al., 2020: 6-7).

The need to combat negative perceptions of dementia and reduce stigma towards people living with dementia has informed research specifically into intergenerational dementia programmes. Lokon et al. explored whether arts-based intergenerational experiences increased 'allophilia' or 'liking of the other' (in the context of the study, positive attitudes towards people living with dementia) among college students (Lokon et al. 2018). Femia et al. analysed intergenerational preschool experiences among younger children and whether 'planned interactions between the generations' could increase children's 'acceptance of older adults into their lives' and enable them to 'become socially close' to older generations (Femia et al., 2008: 274).

## Generational Intelligence

Generational intelligence is a model that has emerged from the field of critical gerontology and aims at allowing people of different age groups to act 'knowingly' in intergenerational spaces by being able to reflect and negotiate in ways that allow them to put themselves in the position of their 'age-others' (people belonging to different generations) (Haapala, Tervo and Biggs, 2015; Biggs, Haapala and Lowenstein, 2011; Biggs, 2008).

A number of precepts are involved in the model of generational intelligence. Firstly, generational identity is posited as the meeting point of an individual's birth cohort, familial lineage, and progress through the lifecourse (Biggs, Haapala and Lowenstein, 2011: 1109). For example, while older people may be able to reflect upon earlier phases of life they have experienced, it may be harder for younger people to empathise with an 'old age' that has not yet been directly experienced (Biggs, Haapala and Lowenstein, 2011: 1110). Generational intelligence furthers attests to the differences that exist between generations: by acknowledging generational difference there is scope to reduce rivalry and promote partnership (Biggs, 2008: 118). Thirdly, ageing is conceived of as an intergenerational process unfolding in intergenerational spaces negotiated by different age groups (Biggs, 2008: 119). Fourthly, awareness of one's specific generational position becomes the springboard towards achieving greater awareness of the position of other generations (Biggs, 2008: 118-119). Finally, intergenerational solidarity is becoming more important 'under conditions of increasing scarcity and competition between groups, generated in part by environmental change' (Biggs, 2008: 119). Generational intelligence has been adopted as a model for examining community care work between younger and older adults (Haapala, Tervo and Biggs, 2015).

In essence, generational intelligence 'refers to the degree to which one becomes conscious of self as part of a generation, a relative ability to put one's self in the position of other generations and an ability to act with awareness of one's generational circumstances' (Biggs, 2008: 118). Generational intelligence, informed by critical gerontology, can be an important construct for understanding intergenerational inclusion as it endorses an 'attempt to discover the special properties of each [age group] and work toward a relationship of complementarity, rather than dominance, between groups who are at different points in the life course' (Biggs, 2008: 118). Such approaches further see 'value' and 'unique contributions' arising from adult ageing and later stages of the lifecourse (Biggs, 2008: 118).

## Dementia Friendliness

While generational intelligence offers a way to think about the behavioural, affective, and cultural processes of empathy and solidarity underlying intergenerational relationships, dementia friendliness offers scope to conceive of social and physical environments that

promote the inclusion of people living with dementia. Dementia-friendly communities enable people living with dementia to remain engaged in daily life for as long possible, while continuing to contribute as valued members and citizens. Dementia-friendly communities meet the needs of people living with dementia and their carers; and further focus on ensuring quality lived experiences (Shannon, Bail and Neville, 2019: 1). Harris and Caporella noted that there are no agreed upon 'gold standards' when it comes to developing dementia-friendly communities, however, the characteristics most commonly discussed involved instances where 'community members are: informed about dementia, respectful and inclusive of people with dementia and their families, provide support, promote empowerment, and foster quality of life' (Harris and Caporella, 2019: 2).

In broad terms, the principles of a dementia-friendly community include (i) the inclusion of people living with dementia, particularly in shaping initiatives designed to support them (ii) a focus on improving social accessibility for people living with dementia by tackling stigma and social isolation (iii) developing a physical environment that meets the needs of people living with dementia (iv) the development of organisations that are respectful and responsive to people living with dementia (v) access to appropriate health care for people living with dementia, particularly timely diagnosis and early treatment and (vi) the establishment of cross-sectoral partnerships towards achieving beneficial outcomes for people living with dementia and their carers (Alzheimer's Disease International, 2016). Dementia-friendly communities have been endorsed by Alzheimer's Disease International and a range of organisations in Scotland, including the Life Changes Trust and Alzheimer Scotland.

Moreover, intergenerational inclusion and dementia friendliness have been combined in a range of programmes to date. The 'Adopt a Care Home' initiative from the UK context arose out of a National Dementia Challenge encouraging dementia-friendly communities that would empower people living with dementia (Di Bona et al., 2019: 2). Harris and Caporella conducted research over several years investigating a university-based intergenerational choir bringing together people living with dementia and young college students in the USA (Harris and Caporella, 2019). A dementia-friendly innovation agenda was implemented at a university in Australia towards addressing 'a pressing need to engage professionals from diverse disciplines and workforces who provide services within these communities to ensure they can understand and respond to the challenges faced by people with dementia and their families' (Phillipson et al., 2019: 2).

However, the dementia-friendly agenda has come under criticism for involving too few people living with dementia in the community development process and for using inaccurate, even offensive, language within related literature (Swaffer, 2014). Moreover, the term 'dementia friendly' is contested, recognised as 'positive and laudable in its intentions' and yet culminating in the advocation of 'charitable kindness' towards people living with dementia rather than meaningful social change (Buckner et al., 2019: 1236). Dementia-friendly communities have been found to vary in terms of their sources of income, their priorities and organisation, and whether or not people living with dementia and their carers are explicitly involved in the design and monitoring (Buckner et al., 2019). The motivations underlying dementia-friendly initiatives may vary in addition, with the risk that initiatives are prompted by a need to 'better handle the symptoms and behaviours of people living with dementia' rather than genuine concerns with enhancing person-centred care (Hansen et al., 2021: 9) or increasing access to services and upholding rights for people living with dementia (Buckner et al., 2019: 1241).

Intergenerational formats have been used within stigma reduction interventions of dementia (Bascu et al. 2021). Reducing stigma and ageism while promoting intergenerational inclusion appear to be goals of intergenerational practice, however, there is a need to explore the outcomes of programmes and perspectives of practitioners in order to consolidate a programme theory that outlines how these processes unfold. Towards this end, this research uses a realist evaluation approach that links programme contexts to outcomes by way of explanatory mechanisms allowing for a programme theory to emerge through the consideration of multiple programmes implemented across a variety of different contexts.

#### Intergenerational Research

Increasing interest in and momentum for intergenerational programmes has been reflected in a number of research reviews exploring different factors related to intergenerational relations and programming. In 2013, Robertson explored the contribution of volunteering towards active ageing and intergenerational solidarity (Robertson, 2013). His review provided a number of brief case studies from across the world of projects aimed at facilitating intergenerational contact and dementia friendliness in sectors such as education and housing. In 2017, Blais et al. produced a literature review exploring the benefits of volunteering in long-term care homes, specifically focusing on intergenerational interactions between care home residents and high school/post-secondary college and university students. Their results were encouraging, noting that such exchanges were not only feasible but resulted in benefits for both groups as well as reciprocal relationships between the residents and students involved (Blais et al., 2017).

In 2018, Radford et al. completed a systematic literature review exploring intergenerational care models 'involving the caring of older and younger people in a shared setting under the supervision of a formally trained caregiver' (Radford et al., 2018: 303). Their review consolidated multiple models of co-located intergenerational care and discussed these in relation to the Australian policy context. In 2018, Gualano et al. produced a review exploring the impact of intergenerational programmes on children and older adults. They identified a wide variety of settings and heterogeneity of activities involved in intergenerational programmes, as well as specific findings such as the importance of training for the operators, the effectiveness of interactions that promoted conversation between older and younger participants, as well as the most investigated outcome of psychosocial wellbeing (Gualano et al., 2018).

O'Dare et al. provided a literature review exploring the intergenerational friendships of older adults in 2019. Their main finding was that intergenerational friendships continued to be an under-researched area on account of negative views of ageing, a bias towards homophily and age-peer friendships, as well as the general perception of older adults either as recipients or givers of care, help or support (O'Dare et al., 2019).

A systematic literature review in 2019 was authored by Giraudeau and Bailly exploring the theory, implementation, and findings of intergenerational programmes for school-aged children and older adults excluding older adults with dementia (Giraudeau and Bailly, 2019). They found that of the studies included in their review, some found differences in positive attitudes, behaviours, confidence, and competence for the children, and significant differences in mental and physical health, and quality of life for the older adults (Giraudeau and Bailly, 2019). However, the authors noted that these benefits were not systematic but instead relied on factors such as the meaningfulness of activities, the organisation of programmes, and participants' knowledge of the other generation (Giraudeau and Bailly, 2019).

Another recent systematic review and meta-synthesis of qualitative literature by Bagnasco et al. explored the experiences of participating in intergenerational interventions in older people's care settings with reference to both older and younger participants. They

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synthesised four experiential themes including recreating the family, building empathy and respect, energising and uplifting exchanges, and engagement risks and challenges (Bagnasco et al., 2020). Peters et al. undertook a systematic review investigating intergenerational programmes bringing together community dwelling non-familial older adults and children (Peters et al., 2021). The authors noted while there was 'a consensus that intergenerational programmes are likely to have positive outcomes for reducing social isolation and increasing cognitive functioning and health, [and] that they may also bring other benefits in psychological well-being, personal development, growth, meaningfulness, and empowerment' nevertheless there was 'not only a lack of detail around the empirical evidence of benefit (for individuals, for society) but there [was] a lack of best practice evidence for the delivery of such programmes' (Peters et al., 2021: 3-11).

Heins et al. undertook a systematic review examining the role of technology in improving social participation for community-dwelling older adults with and without dementia (Heins et al., 2021). They found that while quantitative and mixed methods studies showed limited effects on loneliness, social isolation, and social support, qualitative findings were able to identify various benefits such as the development of social connections and the improvement of social connectedness (Heins et al. 2021: 23).

Phang et al. undertook a realist review examining the effect of digital intergenerational programmes on social isolation and loneliness among older adults (Phang et al. 2023). A key finding that emerged from the review concerned the need to adopt different intervention strategies in order to optimise programmes for different groups of older adults, for example, older adults who are lonely, older adults who reside in long-term residential care facilities, and community-dwelling older adults (Phang et al. 2023: 15).

#### Intergenerational Dementia Programmes

A number of reviews have specifically addressed intergenerational dementia programmes. In 2011, Camp and Lee provided an aggregated review of results from multiple studies involving Montessori-based activities for people living with dementia and preschool children (Camp and Lee, 2011). They found that Montessori-based activities provided an effective interface, allowing for activities to be meaningful to both groups and facilitating high levels of constructive engagement.

In 2015, Galbraith et al. authored a scoping review investigating intergenerational programmes specifically for people with dementia. They identified a number of barriers to

intergenerational dementia programmes, such as the reluctance of older and younger participants to engage with each other and a lack of training among staff. However, the authors further identified several positive outcomes for both younger and older people participating in programmes and concluded that the literature they had reviewed was generally supportive of programme implementation (Galbraith et al.).

Gerritzen et al. examined the successful elements of intergenerational dementia programmes via a scoping review in 2020. They identified buddy systems, dementia education provision, Montessori-based activities, close consideration of activity set-up, student reflective journals, and reminiscence programmes as elements contributing to success when people living with dementia were engaged in intergenerational interactions (Gerritzen et al., 2020).

D'Cunha et al. undertook a systematic review examining activities outside of the care setting for people living with dementia, which included one study involving a 5-month intergenerational mentorship programme at an intergenerational school that supported the finding that 'intergenerational volunteering [could be] a meaningful activity to promote quality of life for people living with dementia, which may also help to reduce stigma of dementia through engagement with children' (D'Cunha et al. 2020: 9).

Matheson-Monnet provided an overview of reminiscence therapy for people living with dementia with a particular focus on intergenerational reminiscence interventions, concluding that while evidence was growing that pointed to the benefit of such interventions, nevertheless there remained 'gaps and tensions around thinking about societal generations and intergenerational issues which include: focusing on age only and ignoring cohort, treating generations as static and ignoring within-cohort diversity' (Matheson- Monnet, 2020: 704).

Bacsu et al. undertook a scoping review analysing stigma reduction interventions of dementia, which included findings drawn from multiple intergenerational initiatives (Bacsu et al. 2021). The authors emphasised the importance of 'local context and culture' in addressing 'stigmatizing beliefs surrounding dementia' and argued for 'more research...to develop culturally and geographically informed interventions to address the stigma of dementia' (Bacsu et al. 2021: 9), potentially entailing an important stigma-related finding for the development of intergenerational dementia programmes.

Lu et al. analysed the effectiveness of intergenerational participation on residents living with dementia, finding that 'participation significantly increased pleasure levels and reduced

behavioural disengagement among residents with dementia but did not significantly improve [quality of life] and depression' or other types of engagement (Lu et al., 2021: 9).

Thijssen et al. undertook a rapid realist review to explore how community-based dementia friendly initiatives work for people living with dementia and their carers (Thijssen et al. 2021). Their findings demonstrated that several dementia-friendly initiatives included in the study 'used the interdisciplinary organization of intergenerational activities in the community, together with people with dementia and their caregivers, to create an activating community' capable of producing beneficial outcomes for people living with dementia, such as maintaining interests and contacts with others, initiative to go out and engage with others, and the searching and receiving of support (Thijssen et al. 2021: 9-10).

This research adopts a methodology grounded in realist evaluation deployed towards investigating intergenerational inclusion and intergenerational dementia programmes specifically in order to provide additional insight and build on these recent reviews. Realist synthesis deploys 'theory-driven interpretative techniques' and combines heterogenous evidence (Greenhalgh et al., 2011: 2) in ways that can complement traditional systematic reviews.

#### Intergenerational Theory

In terms of intergenerational theory, Vanderven explored a number of concepts that were relevant to and offered promise in shaping intergenerational theory, such as 'relationship and activity theory, cultural transmission, life span theory and generativity, relating to the relationship, reciprocal transformation, matching through needs and assets, and multigenerational relationships' (Vanderven, 2004: 77). In 2014, Kuehne and Melville provided an in-depth review of the theories underpinning intergenerational programmes and related research finding that the most frequently cited theories were the theory of personhood (Kitwood, 1997), contact theory developed by Allport and Pettigrew (Pettigrew 1998; Allport 1954), and Erikson's theory of lifecourse development, particularly the concept of generativity involving a concern in establishing and guiding the next generation (McAdams et al. 1993; 221; Erikson, 1997: 67).

Kuehne and Melville further observed that examination of how theory was being used in intergenerational practice and research was often lacking (Kuehne and Melville, 2014: 318). They concluded that, while there was a promising trend of greater theoretical utilisation and grounding of programmes, nevertheless there was a need for researchers to be more diligent

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in 'circling back' and providing critical commentary on the theories they had used to better enhance theoretical development for the field of intergenerational studies going forwards. Clark et al. queried, furthermore, whether 'any one perspective [presented] an immediately compelling case for integrated working on intergenerational projects' and that enabling programme partnerships may 'require a subtle use of several of these theoretical perspectives' (Clark et al. 2016: 306).

This research considers theory from two angles, Firstly, it considers the use of theory within the literature identified within the realist synthesis. Secondly, it combines the findings from the realist synthesis with the findings from qualitative interviewing in order to develop programme theory. These theoretical considerations allow for a degree of 'circling back' in order to comment on what has been learnt about intergenerational theory throughout this study within Chapter 8 and the discussion (Kuehne and Melville, 2014: 336).

## Personhood and Intergenerational Practice

Personhood has informed the development of several studies investigating intergenerational dementia programmes. Jarrott and Bruno recognised that caregiving must uphold the individual's personhood and that a central way to support personhood was through 'the use of biographical information to meet clients' needs' (Jarrott and Bruno, 2007: 242). Lokon et al. related the potential for 'genuine, reciprocal relationships in intergenerational programs' to both personhood and person-centred care (Lokon et al., 2012: 342). Person-centred care emphasises the 'recognition, respect, and trust for people with dementia' while also recognising the ways in which people living with dementia can provide opportunities for authentic growth to those they interact with and thus 'in a person-centered context, [the concern is] not only with the maintenance of personhood of the people with dementia but also that of the staff/volunteers/caregivers, and these two phenomena affect one another' (Lokon et al., 2012: 342). In another study, Lokon et al. described how the failure to maintain personhood for people living with dementia resulted in 'the confidence and capacity for selfexpression of the person with dementia [being] undermined not only by the disease itself, but also by the way they are re-defined as mentally and physically incompetent by the very people caring for them' (Lokon et al., 2019: 473).

Therefore, where personhood is not maintained then the capacity for genuine intergenerational interactions can be limited. Lim et al. conducted a study within an intergenerational programme that adopted a person-centred care approach that supported

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older people 'by enabling them to build on their interests and strengths so that they can feel dignified and continually be active participants in society' (Lim et al. 2019: 370). Harris and Caporella, investigating the creation of a dementia-friendly community through a university choir, described how dementia friendliness was derived from Kitwood's theorising around person-centred care among other approaches, and how person-centred care emphasises the role of the environment and the community in determining a person's ability to live well with dementia and/or other conditions (Harris and Caporella, 2019: 2).

## Intergroup Contact Theory and Intergenerational Practice

Intergroup contact theory, analysing the conditions under which different groups can cooperate and achieve genuine solidarity, has also informed intergenerational dementia programmes. Gigliotti et al. (2005; 437) sought to implement an intergenerational summer programme that would optimise 'ongoing interactions between child and adult participants' providing opportunities for friendship development as recommended by Pettigrew (Pettigrew, 1998). Moreover, the summer programme also aimed to achieve authority support by 'seeking parent, administrator, and staff input' as well as provide participants with a 'common goal' through the 'facilitators' efforts to provide meaningful provocations requiring interdependence among child and senior participants' (Gigliotti et al. 2005; 437).

Jarrott and Bruno used a combined theoretical framework encompassing both personhood and intergroup contact theory, claiming that the utilisation of 'contact theory, under the umbrella theory of personhood, [provided] a framework for programs that promote personhood and well-being of participants through [intergenerational] contact' (Jarrott and Bruno, 2007: 242). Along with person-centred care, Harris and Caporella similarly applied intergroup contact theory in their study of an intergenerational choir project as bringing small groups of disparate people together could be a means of working towards the goal of lessening stigma on the micro-level and moreover the creative arts could be a means of 'accomplishing' this psychosocial process (Harris and Caporella, 2019; 4; Harris and Caporella, 2014; 271).

Isaki and Harmon observed that contact theory had been incorporated into intergenerational programmes as well as being adopted by speech-language pathologists, with speech and/or language group therapy commonly enabling 'cooperation between group members and opportunities for friendship' (Isaki and Harmon, 2014: 91). Janke et al. associated intergenerational programmes with intergroup contact theory, claiming that programmes

'might be well suited to provide a stimulating contact environment to adults with dementia that can promote positive engagement and [quality of life] for both generations by incorporating the tenets of contact theory' (Janke et al., 2019: 133). Caspar et al. used intergroup contact theory as the theoretical foundation for their exploration of an intergenerational programme bringing together care home residents and youth volunteers, finding that it was important to ensure activities were meaningful in order to fully uphold the tenets of the theory by providing for cooperation, common goals, and opportunities for friendship among the participants (Caspar et al. 2019: 159).

#### Generativity and Intergenerational Practice

Generativity, involving the concern in nurturing future generations, has also been utilised as a theoretical concept within the development of intergenerational programmes. Lim et al., investigating a co-located programme, found that the initiative 'provided the seniors with opportunities to express generativity, the passing down and recycling of human understanding, experiences and cultures to children' (Lim et al. 2019: 375). George et al. conceived of the concept of 'intergenerativity' to encapsulate learning taking place not only with one's peers but with 'students of all ages from various backgrounds who have different points of view'. The authors further described intergenerativity as 'the meaningful fusion of ideas and emotions that emerge from conversations and experiences shared between the generations and inspires actions that benefit individual minds, social lives, and the natural world that sustains and connects persons of all generations, past, present, and future' and provided findings from a study conducted at an intergenerational school based in the USA (George et al., 2011: 391).

# Intergenerational Programmes

Definitions of intergenerational programming throughout the literature are today variable, ranging from being fairly prescriptive about the age groups involved to being broad and general regarding participants. For example, Gigliotti et al. describe intergenerational programmes as '[uniting] older adults (65+) and children/youth under the age of 21 in mutually beneficial interactions fostered by a carefully planned program of activities' (Gigliotti et al., 2005: 425). Clark et al., in contrast, describe intergenerational work more loosely as 'activities that are specifically designed to bring people together from across generations' (Clark et al., 2016: 300). Similarly, Janke et al. state that intergenerational

programmes provide 'formal or informal interaction between two or more generations' (Janke et al., 2019: 133).

Ayala et al. summarised three broad characteristics of intergenerational programmes, including 'the purposeful bringing together of different generations in mutually beneficial, planned activities', with the activities themselves designed to increase 'cooperation, interaction or exchange' between the generations and, finally, with intergenerational programmes potentially rendering benefits both for individuals and for communities (Ayala et al., 2007: 47). Different models of intergenerational programmes have also been identified, including older adults serving children and youth; children and youth serving older adults; and the old and the young together serving the community (Hatton-Yeo and Ohsako, 2000: 5-6).

Building on these conceptualisations and characteristics, a definition of intergenerational dementia programmes for the purposes of this thesis is proposed as follows:

The bringing together of people living with dementia with younger generations in purposeful, planned activities that are designed to promote inclusive, respectful interactions and be mutually beneficial to all participants.

## Dementia and Intergenerational Policymaking in Scotland

Dementia has been on the Scottish policy agenda for a number of years and comprises several key initiatives and actors. In 2009, the Cross-Party Group in the Scottish Parliament on Alzheimer's published the Charter of Rights for People with Dementia and their Carers in Scotland (Alzheimer Scotland, 2009). This was closely followed by Scotland's first National Dementia Strategy in 2010 (Scottish Government, 2010) and the supporting Standards of Care for Dementia in Scotland (Scottish Government, 2011*b*). Two subsequent national dementia strategies were published by the Scottish government in 2013 (Scottish Government, 2017) respectively. An updated dementia strategy was postponed due to the COVID-19 pandemic, however, the Scottish Government specifically published a 'Coronavirus (COVID-19) – dementia and COVID-19: Action Plan' outlining a national response to support recovery for people living with dementia and their carers (Scottish Government, 2020). The Scottish Dementia Working Group is an active, national campaigning and awareness group funded by Alzheimer Scotland and the Scottish Government (Alzheimer Scotland, 2022).

Dementia policy and services for people living with dementia in Scotland have further been influenced by broader transitions that have taken place in health and social care in Scotland. The Scottish Government legislated to integrate health and social care with the passing of the Public Bodies (Joint Working) (Scotland) Act 2014, which established Health and Social Care Partnerships throughout Scotland (Health and Social Care Scotland, 2022). The delivery of adult social care, in particular, continues to be under review, with the undertaking of The Independent Review of Adult Social Care in Scotland (Scottish Government, 2021c). The National Care Service (Scotland) Bill introduced in 2022 may further impact the delivery of health and social care through the transfer of social care responsibility from local authorities to a new national service (Scottish Parliament, 2022). Additional legislation has emphasised rights-based approaches to service access and delivery, particularly the Social Care (Self-directed Support) (Scotland) Act 2013, which aims to give people more choice and self-determination in regard to services.

While Scotland does not yet have a specific intergenerational strategy, intergenerational issues, particularly in relation to older people, healthy ageing, and the needs of Scotland's ageing population, have nonetheless been implicitly addressed through several key policies. Demographic change, healthy ageing, and forging links between the generations were discussed in the Scottish Executive's planning document 'All our Futures: Planning for a Scotland with an Ageing Population' (Scottish Executive, 2007). A new demographic paper was more recently published exploring the challenges and opportunities of Scotland's changing population (Scottish Government, 2021*a*).

Legislation in Scotland has further recognised that demographic trends and the ageing population in Scotland necessitate advocacy and support for carers. The Carers (Scotland) Act 2016 granted carers of all ages new rights in Scotland and had a key focus on young carers. Social isolation and loneliness for all age groups formed the focus of the Scottish Government 2018 strategy to combat loneliness trends and build stronger social connections (Scottish Government, 2018). In regard to Education policy, Scotland's Curriculum for Excellence has emphasised learning for young people in regard to responsible citizenship (Education Scotland, 2022), which has been linked to intergenerational practice in Scotland.

Scottish policymaking can be critiqued on several counts. Systematic differences in health continue to exist between different population groups and an intersectionality approach can be useful towards explaining these differences, that is adopting a lens that can incorporate

the interacting influences of 'social location, identity and historical oppression' on how inequalities are experienced (Kapilashrami and Marsden, 2018: 4). However, policymaking processes in Scotland are not always equipped to address intersectionality and the complexity of multiple inequalities within lived experience, which can lead to groups, previously termed 'hard to reach', that are now increasingly recognised as 'easy to ignore' (Lightbody et al. 2017: 1). Groups that contend with multiple or complex inequalities 'are often easy to ignore due to the complexity of their situation, the difficulty of forming a solution and a lack of understanding from governments, organisations and programmes' (Lightbody et al. 2017: 1). Therefore, policymakers may find it easier to understand and focus on reducing socio-economic inequality rather than focusing on the complexities of exclusion and deprivation (Matthews et al. 2012: 3). Scottish policymaking has also been found to have an implementation gap that may be more profound than in the UK policy sphere, whereby there is a gap between 'expectations at the top and perceived policy outcomes at the bottom [involving the] problem of ensuring that policies made by elected governments are carried out by subordinate authorities such as local governments and delivery agencies' (Cairney, 2009: 356).

In relation to Scottish dementia policy, in particular, service users and communities have described a 'policy into practice gap' involving a discrepancy between 'Scotland's world leading commitments on dementia policy and people's experiences of receiving support' (Scottish Government, 2023: 2). Geographical inconsistencies in the availability and provision of support, including the 12-month minimum entitlement of post-diagnostic support, a lack of education and training about dementia within the health and social care workforce, and a one-size-fits-all service approach impeding person-centredness were additional challenges identified during Scotland's national conversation to inform the new dementia strategy (Scottish Government, 2023). Scotland's educational Curriculum for Excellence has been criticised for the narrowness of the four capacities it adopts (including successful learners, confident individuals, responsible citizens and effective contributors) and for a lack of theoretical rigour in its structure (Priestley and Minty, 2013: 40).

This research aims to provide policy findings related to the Scottish context, including the perspectives of stakeholders in regard to current Scottish intergenerational policy as well as the relationships between intergenerational policy, practice, and partnership working.

#### Conclusion

This chapter began by exploring the intergenerational facets of dementia as a social, relational issue with potential impacts for all age groups. Crucially, dementia is not just a condition that affects older people, but one that can affect younger people through young-onset dementia, often in different ways and necessitating a differing policy response. Preventative health, combined with the increasing use of preclinical Alzheimer's disease as a diagnostic category, emphasises the need for greater understanding and awareness of dementia and ageing among younger age groups. Caregiving, whether familial or professional, is a key domain in which intergenerational relationships can directly affect the quality of life and social environment for people living with dementia.

As dementia, like ageing, unfolds in an intergenerational space that is negotiated by different age groups (Biggs, 2008: 119), ensuring that intergenerational spaces are inclusionary for all and particularly for people living with dementia and their carers can be a beneficial line of inquiry and action. Intergenerational inclusion can be understood to involve intergenerational solidarity along with social cohesiveness, culminating in less conflict and tension between different age groups and generations (Cruz-Saco, 2010: 9-10). Achieving intergenerational inclusion relies, firstly, on tackling negative perceptions and negative forms of ageism that can exist between different age groups along with reducing dementia-related stigmas that can remain prevalent in society at large, whether this be distance from and a lack of attention to dementia among younger age groups (Biggs, Haapala and Carr, 2019: 83) or fears and aversions related to cognitive decline among older age groups (Rosenberg et al., 2020: 6-7). However, intergenerational inclusion further requires the promotion of positive attitudes, whether increasing individual capacity to act intelligently, respectfully, and imaginatively when interacting with other generations (Haapala, Tervo and Biggs, 2015; Biggs, Haapala and Lowenstein, 2011; Biggs, 2008) or focusing on social acceptance of dementia along with improvements to physical and social spaces that can benefit people living with dementia and enable them to contribute to and live well within their communities (Alzheimer's Disease International, 2016).

Interest in intergenerational relations and practice is growing as evidenced by a number of recent reviews, including several reviews that specifically analyse intergenerational dementia programmes (Lu et al., 2021; Gerritzen et al., 2020; Galbraith et al. 2015; Camp and Lee, 2011). Intergenerational theory is also gaining traction however there remains a lack of a

definitive theoretical approach. Two theories have been especially relevant to the development of intergenerational programmes specifically for people living with dementia, including personhood (Kitwood, 1997) and intergroup contact theory (Allport, 1954; Pettigrew, 1998). Finally, this chapter reiterated a specific definition of intergenerational dementia programmes to be used throughout this thesis focusing on elements such as purposeful, planned activities; inclusive, respectful interactions; and mutual benefits for all participants. This thesis will explore the topic of intergenerational inclusion for people living with dementia in relation to three research questions. Firstly, the thesis will explore how the concept of intergenerational inclusion has been understood and operationalised internationally. Secondly, the understanding and operationalisation of intergenerational inclusion in Scotland will be examined. Finally, the insights gained through these analyses will be used to further inform the development of intergenerational practice and policy in Scotland and internationally.

The chapter that follows will build on this critical literature review by outlining the ontology, epistemology, and methodology that has been adopted for this study.

# Chapter 3: Methodology

## Introduction

This chapter describes the ontology and epistemology for this study grounded in realist evaluation; and then relates these philosophical foundations to the qualitative, realistorientated methodology adopted to address the research questions of this thesis. Realist evaluation emerged as a strategy for approaching complexity and aims to structure inquiries into 'programme ontologies', that is, inquiries that seek to explore the explanatory 'causal laws' that account for different patterns of outcomes arising from programmes, interventions, and policies unfolding in different contexts (Pawson, 2002: 341). The ontology section will further explore realist philosophy in reference to three key guiding principles, namely structure, agency, and generative causation. Some discussion of the implications of this ontology for using a realist evaluation approach is interwoven throughout, and the chapter then moves on to an overview of the epistemology harnessed by realist evaluation.

The chapter concludes with the methodological section critically outlining the two-phase design I have adopted. The first phase of the study involves a realist synthesis method exploring intergenerational dementia programmes from around the world in order to analyse how the concept of intergenerational inclusion for people living with dementia has been understood and operationalised internationally. The second phase of the study involves semi-structured interviews with stakeholders involved in Scottish dementia support and intergenerational practice in order to explore how the concept of intergenerational inclusion for people living with dementia for people living with dementia support and intergenerational practice in order to explore how the concept of intergenerational inclusion for people living with dementia has been understood and operational inclusion for people living with dementia has been understood and operational inclusion for people living with dementia has been understood and operational inclusion for people living with dementia has been understood and operational inclusion for people living with dementia has been understood and operationalised in Scotland. Each of these methods are described in turn.

## Ontology

Ontology 'studies the nature of reality, especially problems concerning existence' (Niiniluoto, 2002: 1). Realist epistemology and methodology *ontologically* assume 'a real world external to the organism, with which the organism is in dialectical interaction' (Campbell, 1988: 319). In other words, realist ontology focuses on the nature of physical reality and the nature of social reality, and, crucially, the nature of the relationships between these physical and social worlds. Physical reality, sometimes simply referred to as nature, comprises the collection of entities that are ontologically independent of human minds (Niiniluoto, 2002: 27). As the existence of this physical reality does not depend on human minds, physical reality is characterised as 'self-subsistent' though people undoubtedly have an increasing ability to

intervene within and change the physical world (Archer, 1995: 1). In contrast, social reality has a 'human constitution' and is inseparable from its human components, thus society can be described as ontologically dependent on human activities (Archer, 1995: 1). In terms of characterising the differences between social and physical reality, Karl Popper's 'three worlds' doctrine has been influential in realist philosophy. Within this doctrine, the first world comprises physical processes and things (nature); the second world is the domain of consciousness, including human and animal consciousness; and the third world comprises the products of human social action, such as cultural products and social institutions (Niiniluoto, 2002).

#### Structure and Agency

This realist interplay of physical and social reality informs realist evaluation, which is an evaluation approach that has as its object 'treatments, interventions, programmes, schemes, services, legislation, policies and so on and so forth' wherein the common thread is implementation (Pawson, 2013: 35). The key to 'programme ontologies' within realist evaluation- that is the explanation underlying the patterning of programme outcomes, whether success or failure- concerns the 'choices' and 'behaviours' of participants, organisers, and other subjects involved in the programme. As Pawson relates, 'programmes seek to change the way that the subjects make choices' and 'are inserted into systems which are already fluid and changing' (Pawson, 2013: 5-6), particularly mutable social systems structuring social reality. Ontologically, when exploring programmes we are in effect exploring participants' choices in regard to the physical and social resources, options, and opportunities that have been generated through programme implementation:

"...it is not 'programmes' that work: rather it is the underlying reasons or resources that they offer subjects that generate change. Causation is also reckoned to be contingent. Whether the choices or capacities on offer in an initiative are acted upon depends on the nature of their subjects and the circumstances of the initiative." (Pawson, 2002: 342)

In philosophical terms and in relation to Popper's doctrine, this can be characterised as a conscious subject's interaction with physical things and processes on the one hand, and cultural products and social institutions on the other while participating in a programme.

However, it is this ontological basis of realist evaluation that accounts for much of the complexity of programme implementation and evaluation, whereby programmes are described as complex systems inserted into complex systems (wider social processes) (Pawson, 2013: 52). With ontological explanation pivoting on the individual, collective, and interactive choices of social agents within social and natural structures, predictability in evaluation research and in the social sciences in general becomes exceedingly complex because researchers must consider both the 'reasons' and 'causes' accounting for these choices (Porter, 2015; 69). Pawson identifies the competing and interweaving 'volitions' of programme subjects- whether they be participants, organisers, practitioners, policymakers, or any other stakeholder affected by the programme - as the first and imponderable 'root of complexity' (Pawson, 2013: 34):

"Programme subjects are active agents, not passive recipients. Evaluation research needs to discover, and thus may usually begin, with some expectations about the volitions of programme subjects. How will they respond to the policy? Interventions seek to open up new choices - but will they be chosen?" (Pawson, 2013: 34)

However, it is not only people's choices that exacerbate complexity: social reality is inherently transformable with no fixed state. Society at any given time 'depends upon human doings and their consequences', however, the characteristics and actions of social beings are also 'affected by the society in which [they] live and by [their] very efforts to transform it' (Archer, 1995: 1-2).

Society is erected through people's choices and collective decision making, but under the control of no individual social agent as within any sociohistorical moment the particular choices on offer 'are conditioned by pre-existing structures, institutions, and opportunities' (Pawson, 2013: 5). The relationship between the individual and society, structure and agency, is therefore integral to the realist ontology (Archer, 1995) and consequently to the evaluation of programmes. Pawson emphasises these social dimensions stating that for the realist 'programmes are carried out by human activity' and that 'intervention outcomes are realised through human interpretation' (Pawson, 2013: 49). Choices- individual and collective- are both constitutive of, and shaped by society via ontologically complicated, ceaseless linkages; and therefore reality, particularly social reality, is by nature taken to be complex within realist evaluation.

#### Generative Mechanisms

Realist evaluation accords explanatory power to the 'generative mechanism', which bears clarifying in view of the ontological discussion so far and before moving on to discuss the epistemology. Realism posits a physical and a social world that are further perceived to be 'patterned', that is, 'some physical properties are related uniformly, and some social events unfold in regular sequences' (Pawson, 2013: 63). As Pawson relates, these uniformities 'occur because of some underlying order in the world which is to be discovered at the level of the generative mechanism' (Pawson, 2013: 63). Causal explanations for programme outcomes cohere around the manner in which programmes present physical and social resources and opportunities to participants, thereby affecting programme participants' choices and behaviour. It is these effects of programmes on participants' choices that denote the explanatory generative mechanisms within realist evaluation:

"[Programmes] work by providing some resource that persuades the subject to change and this is the underlying generative mechanism around which inquiry is constructed." (Pawson, 2013: 63)

The centrality of the generative mechanism towards explanations of 'how' programmes essentially work further privileges and promotes the role of theory within realist evaluation. Pawson, for example, describes realist evaluation as 'avowedly theory driven' on account of its search for and refinement of explanations of programme effectiveness (Pawson, 2013: 15). However, as Pawson further relates, realist evaluation's 'theories are not the highfalutin' theories of sociology, psychology and political science' but rather good evaluations 'capture the manner in which an awful lot of participants think' and thus are concerned with 'common-sense theory' (Pawson, 2013: 6). Given the infinite number of properties within complex physical and social realities, it is theory that directs the gaze of scientific inquiry and tells researchers where to look and also what to look for (Pawson, 2013: 62). Theory helps to consolidate the explanations and generative mechanisms of programmes by directing researchers to the 'vital explanatory components within the world, their interrelationships and the things that bring about those interrelationships' (Pawson, 2013: 62), leading to the development of methods in order to interrogate the theory further.

## Epistemology

Epistemology concerns the 'possibility, sources, nature, and scope of human knowledge' (Niiniluoto, 2002: 1). The epistemology of realist evaluation aspires to follow the scientific method by focusing on explanation, generative mechanisms, and their elaboration and testing through theory, however, it is broadly postpositivist. The following section will discuss the epistemology of realist evaluation in relation to (i) historicism and context-dependency (ii) partial knowledge and theoretical gradualism and (iii) the necessity of incorporating both quantitative and qualitative evidence within comprehensive programme evaluations.

#### *Historicism and Context-Dependency*

Historical- and context-dependencies are crucial to the epistemological approach of realist evaluation: both programmes themselves, as well as the methods deployed to evaluate them and the researchers undertaking evaluations, belong to and are embedded within particular social, cultural, historical moments that affect implementation and related knowledge generation. For example, Pawson states that context is another source of programme complexity comprising factors such as the characteristics and capabilities of stakeholders; interpersonal relationships, such as the relationships between stakeholders and their respective organisations; institutional settings including but not limited to rules, norms, and customs; and the wider social, economic, and cultural infrastructure (Pawson, 2013: 36-37). Complexity arises because these contextual layers are 'infinitely complicated, intertwined and in motion' and so it is fair to say that a programme- even when it is a part of a broad family of programmes with the same 'common-sense' reasoning such as intergenerational practice- is 'never implemented in exactly the same circumstances' (Pawson, 2013: 37).

Realist evaluation is, moreover, grounded in Archer's mutable 'morphogenetic' approach to society: society has no pre-set form or preferred state (*morpho*) and is formed by people and the intended and unintended consequences of their actions (*genetic*) (Archer, 1995: 5). Knowledge subsequently is a product of changeable social contexts and the transformative, unfixed interplay between individuals and their social systems and structures. For related reasons, Pawson argues that programme evaluations must be seen as affected by the phenomenon of 'emergence' (Pawson, 2013: 42-44). Programmes can lead to outcomes that represent either continuities, changes, or unintended, even unwanted, changes within the context of what has gone before. Thus programmes 'not only work to change behaviour but they may also change the conditions that make the programme work in the first place'

(Pawson, 2013: 44). Programmes- and consequently the knowledge gained by evaluating them- may have a limited 'shelf life' for this reason (Pawson, 2013: 6).

It is necessary to go an epistemological step further and see research and researchers, similarly, in relation to and dependent on the context of their research:

"At any given time, even in the best of science (even in physics), we are in a historical context and our experiments and our theoretical arguments are historically imbedded. They have a historical provincialism; they are reactions to what has gone before; they are dated and uninterpretable outside of that context." (Campbell, 1988: 319)

As knowledge is context-dependent, this leads realists to accept knowledge itself as 'uncertain, incomplete, and truthlike, but...'directly' about reality' (Niiniluoto, 2002: 79). Pawson commits evaluators to being 'corrigible realists' due to this need to admit to 'a permanent state of partial knowledge' about society (Pawson, 2013: 84). The changeable, emergent nature of society precludes final answers and definitive understandings so that evaluation findings in turn are 'corrigible' (Pawson, 2013: 84).

#### Partial knowledge and theoretical gradualism

However, it does not follow from this admission of partial knowledge that evaluation research becomes nihilistic or pointless, rather it recommends a certain sceptical, gradual, and critically engaged approach to knowledge and evaluation. If all human knowledge is liable to error and if common sense and surest science alike have time and again been proven to be mistaken, then this reconfirms the necessity of being sceptical and of challenging absolute truth claims (Niiniluoto, 2002: 80-82). Pawson recommends that evaluation researchers embrace 'organised scepticism'. In terms of research goals, organised scepticism suggests foregoing absolute truth seeking in favour of the more modest goal of seeking to increase validity (Pawson, 2013: 107). Validity, crucially, does not hinge upon 'favouring or disfavouring particular research designs but assessing whether the evidence brought forth supports adequately the inferences made' (Pawson, 2013: 110-111). In terms of research and policy communities, they should be willing to expose all scientific claims to critical scrutiny as well as ensuring that studies 'cross-refer' and 'challenge, enlarge and refine the inferences' drawn in the corpus of previous studies (Pawson, 2013: 107). Processes of cross-reference

may support mixed method studies, as well as studies with multiple phases as adopted in this thesis.

Scepticism in the face of partial knowledge further has implications for theory building within realist evaluation. Activities to disprove and strengthen theories should not be seen as 'simple transactions' in which theories are either 'right or wrong', but rather 'a gradual, incremental process' in which theories can be understood to be 'better or worse' (Pawson, 2013: 100-101). Scepticism also implies a degree of trust in the strongest, most truth-like elements of a theory, with inquiry strategically targeted towards data that is 'fragile', 'weak', or 'contradictory' and towards points where 'doubt provides us with pressing rival theories to account for a particular finding' (Pawson, 2013: 106-107). Campbell expounded a somewhat optimistic theoretical 'trust-doubt ratio' of ninety-nine percent trust to one percent doubt, claiming that for 'the cumulative, evolutionary process of knowing, our only available tactic is to trust most of our current beliefs while we use that distributed fulcrum to revise a few of them' (Campbell, 1988: 318).

#### Heterogenous Evidence

As a third and final point, the epistemology of realist evaluation endorses the use of different types of evidence within evaluation research, recommending methodologies that are both qualitative and quantitative, or a combination of mixed methods. Crucially, realist evaluation rejects hierarchies of evidence because 'multiple methods are needed to illuminate the richer picture' (Pawson et al., 2005: 29). Moreover, the complexity of programme implementation can render strategies aiming at experimental closure, such as randomised control trials (RCTs), inappropriate as the programmes themselves involve 'complex social situations with their own stakeholders, histories, environments and polities' and thus 'are not open to closure' (Pawson, 2013: 50). Context is 'not unwelcome noise, not a confounding variable to be controlled for- but an integral part of a programme' (Pawson, 2013: 36).

However, different methodologies can be understood to work together and contribute towards different aspects of the context-mechanism-outcome configuration, with quantitative measurement being suited towards investigating outcomes and qualitative inquiry scrutinising the process explanations. Outcomes arguably cannot adequately be measured through 'anecdotal remarks' alone (Pawson, 2013: 21), however, nor can outcomes be fully explained without investigating the reasoning and beliefs of stakeholders involved in a programme. As Campbell relates, factors such as 'implementation history', 'sitespecific wisdom', and even 'gossip' are 'all essential to interpreting the *quantitative* data' (Campbell, 1988: 319).

## **Realist Evaluation Limitations**

Realist evaluation as an approach faces several criticisms, particularly from the field of critical realism (Hinds and Dickson, 2021; Porter, 2015). Realist evaluation, firstly, has been criticised for a contradictory treatment of context. Context is undoubtedly integral to realist evaluation and moreover is considered to be dynamic and complex to such a degree that programmes will rarely if ever work in the same way within different contexts (Rycroft-Malone et al. 2012: 2). Hinds and Dickson argue that this understanding of context as inherently complex is incompatible with realist evaluation's aim of finding a generalisable theory that can be tested in various contexts (Hinds and Dickson, 2021: 6). Treating context as complex while also trying to generalise across contexts, they argue, pushes researchers in 'two directions' – towards '[engaging] with context and [adding] it as a factor in their explanations' while also 'stripping out' context in the pursuit of generalisability (Hinds and Dickson, 2021: 6).

Structure and agency are key to the realist ontology and are perceived to be of crucial explanatory importance in terms of understanding how programmes work within realist evaluation. Within realist evaluation, programmes are deployed towards affecting agency, that is, seeking to 'change the way that...subjects make choices' (Pawson, 2013: 6). At the same time, choices (agency) 'are conditioned by pre-existing structures, institutions, and opportunities' – choices are contingent on structures (Pawson, 2013: 5). Programmes are also contingent on structures as they are 'complex interventions introduced into complex social systems' (Pawson, 2013: 33). However, Hinds and Dickson argue that realist evaluation conflates agency and structure within the explanatory mechanisms that denote how programmes work:

"[A mechanism] is described as an amalgam of resources and reasoning which implies that it is both structure and agency. This conflation makes it impossible to tell the contribution of agents or structures to change..." (Hinds and Dickson, 2021: 4-5)

While realist evaluation does not deny the importance of either structure or agency, nevertheless critics perceive the 'mechanism' to conflate structure and agency (Porter, 2015: 77), which in turn loses sight of the relation, interconnection, and interplay of these 'different

elements of social reality, which possess different properties and powers' (Archer, 1995: 6). For example, it has been proposed that the context-mechanism-outcome configuration should be extended with agency being 'included as a separate category alongside context and mechanism in the evaluation formula' (Porter, 2015: 78).

Related to this need to clarify and emphasise agency, realist evaluation has further been criticised for having a 'lack of robust critical values' and a 'focus [on] technical solutions' that overlooks ideological concerns (Porter, 2015: 76-77). This technocratic approach does not fully uphold the 'responsibility of [the] scientist to consider carefully which values to adopt to guide decision making, and to be transparent about those values' (Porter, 2015: 76). Realist evaluation consequently does not allow for more normative inquiries, such as examining lived experience towards 'establishing the degree to which an intervention supports the development of people's capacities and potentialities, and the degree to which it inhibits them' or evaluating programmes 'on the basis of whether [relevant] actors interpret it as promoting their human needs, or whether they regard it as alienating' (Porter, 2015: 78-79). I address these limitations of realist evaluation in the discussion chapter as well as the conclusion to the thesis.

#### Methodology

Having established the methodological foundations in relation to ontological complexity and an epistemology admitting of partial, context-dependent knowledge, this section will now critically outline the methods used to collect data. The study comprises two phases including, firstly, a realist synthesis review of intergenerational dementia programmes that have been implemented internationally and, secondly, realist, semi-structured interviews with stakeholders involved in dementia support and intergenerational practice in Scotland. A methodological justification for each method given the limitations is provided followed by a summary of the practicalities of how the research was conducted via the realist synthesis and stakeholder interviews.

A number of additional methods were considered for the research and are discussed in more depth in Chapter 9. In the first instance, I envisaged undertaking a comparative analysis of intergenerational policy responses between Scotland and Germany, followed by field work in Germany. Previous research, for example, has compared national dementia strategies between different contexts to ascertain how person-centred dementia services can be optimised (Fortinsky and Downs, 2014). However, in the absence of specific intergenerational policies in Scotland, I felt a different methodological approach would be more suited in order to explore intergenerational practice, including the perspectives of dementia and intergenerational policy held among Scottish practitioners. I also considered organising discussion groups directly with people living with dementia in Scotland in order to understand their lived experiences of interacting with younger age groups and participating in programmes. Involving the people of Scotland directly in the definition, design and delivery of interventions is a key component of the 'Scottish approach' to public services (Scottish Government, 2019). However, this method was impeded by the social restrictions of the COVID-19 pandemic.

#### Phase 1: Realist Synthesis

## Overview and Justification

Realist synthesis, also referred to as realist review, is a systematic review method that has developed in relation to realist evaluation. Realist synthesis emerged as a methodological approach 'for synthesising evidence and focuses on providing explanations for why interventions may or may not work, in what contexts, how and in what circumstances' (Rycroft-Malone et al. 2012: 2, see also Wong et al., 2013*a*; Wong et al., 2013*b*; Greenhalgh et al., 2011; Pawson et al., 2005; Pawson, 2002).

Realist synthesis, in keeping with realist evaluation, focuses on identifying and analysing context-mechanism-outcome configurations related to health and social care programmes. Context can refer to the broad social and geographical features of a programme; features affecting the implementation of a programme, such as specific settings, for example, community or care home settings; the make-up of the participants or the population profile of a location receiving a programme; and the conditions in which participants seek to enact their choices (Wong et al., 2013b: 7). Mechanisms relate to the way in which the programme's 'infrastructure and resources trigger particular decisions or behaviours in human participants' (Wong et al., 2013a: 1016). Mechanisms are identified 'by asking what it is about a program that generates change' and the realist synthesis approach 'looks for interactions among the opportunities or resources provided by the intervention and the reasoning or responses of the participants' (Wong et al., 2013b: 6). Mechanisms thus provide an understanding of the relationship between the contexts and the observed outcomes of interest related to a programme, bearing in mind that 'rarely would the same intervention work in the same way in different contexts' (Rycroft-Malone et al., 2012: 2). A further

defining feature of a realist synthesis 'is the nature of the theory(ies) it offers...[explaining] why a social programme/intervention generates particular outcomes in particular contexts' (Wong et al., 2013a: 1016).

Realist synthesis is a flexible review method capable of investigating complex health and social care interventions because it uses 'theory-driven interpretive techniques' and combines 'heterogenous evidence' (Greenhalgh et al., 2011: 2). Realist synthesis lends itself to the examination of the complexity of intergenerational programmes. Intergenerational programmes involve outcomes for disparate groups, including older and younger participant groups, and in the case of this thesis, outcomes for older participants living with dementia in particular. However, intergenerational programmes normally involve complex partnerships in addition, bringing together organisations and services aimed at older and younger people respectively, with their contingent work cultures, aims, and regulatory frameworks (Clark et al., 2016). As such, the evidence arising from programmes is similarly complex. The realist synthesis approach provides a structured yet flexible 'roadmap' to grapple with this complexity.

Realist synthesis is further beneficial in pooling together the theories, process explanations, and results from multiple studies exploring the same 'family' of programmes (such as intergenerational dementia programmes), in which the 'analytic task is basically to sum the fortunes of this same intervention across its different trials in order to come to a net estimate of its impact' (Pawson, 2013: 83). This does not mean losing sight of the context-specificity of each instance of the programme, but rather focusing on the family resemblance of similar programmes to allow for theory consolidation, meaningful and justified abstraction, as well as greater availability of evidence (Pawson, 2013: 83).

Another benefit of realist review is that it builds common ground between policymakers and social researchers by assisting policymakers in their decision-making processes (Greenhalgh et al., 2011: 2-3). Policymaking is a particular focus of this study and has been incorporated into the research questions alongside consideration of practice. The realist review further satisfied the need to prepare for the interview data collection by gaining a substantive understanding of the topic to be investigated through activities such as the retrieval, appraisal, and deployment of previous knowledge (Kallio et al., 2016: 2959). As a final point, the review informed a realist approach to the interviews in general and informed the development of the interview topic guide in particular as discussed below. A 'realist

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interviewing approach' involves probing of 'the assumptions and expectations of the program designers (folk theories)' (Mukumbang et al., 2020: 491).

#### Strengths and Limitations

The major limitation of realist synthesis review is that it differs from systematic review and may be perceived as less rigorous, with systematic review commonly described as the gold standard for summarising evidence and informing clinical guidelines (Munn et al., 2018: 1). However, realist synthesis developed out of a need for a more dynamic strategy to synthesise evidence in instances where traditional systematic review would prove too specific and inflexible (Malone et al., 2012: 2). Realist synthesis review differs from systematic review, firstly, in that 'the search and appraisal of evidence is purposive' rather than exhaustive (Rycroft-Malone et al., 2012: 2). This is because the aim of realist synthesis is not to conduct a statistical meta-analysis of evidence from all studies of a suitable standard, normally involving randomised control trials (RCTs) (Munn et al., 2018: 1-2). The aim is to instead refine a 'theory', that is, provide 'explanations for why interventions may or may not work, in what contexts, how and in what circumstances' (Rycroft-Malone et al., 2012: 2).

A second core difference is that realist synthesis review will integrate 'multiple types of information and evidence' (Rycroft-Malone et al., 2012: 2), including studies utilising quantitative, qualitative, and mixed method designs, as well as grey literature (Pawson et al., 2005: 29). Realist synthesis rejects a 'hierarchical approach' to research quality as described above and perceives multiple methods and mixed methods to enhance inquiries (Pawson et al., 2005: 29). This accords with the results of the realist synthesis conducted here. Few studies have been conducted on intergenerational dementia programmes that utilise a randomised control trial design, thus rendering systematic review a limited tool and meta-analysis by and large unfeasible. Nevertheless, taking a broader, inclusive approach to diverse evidence as prescribed through a realist synthesis approach allows for rich evidence predicated in qualitative, quantitative, and mixed method studies to be drawn upon, along with relevant grey literature, rendering theorisation feasible as presented in the discussion chapter of this thesis.

## Ethics

As a review method of secondary data sources, including journal articles and grey literature, it was not necessary to submit a research ethics application for this phase of the research. However, in recognition of the fact that the purpose of evidence reviews in large part resides in offering 'decision support' to policy makers and practitioners, the review was conducted to a robust, systematic standard in order to ensure sound findings could be synthesised. While the review did not culminate in 'authoritative arithmetic on what will work' for intergenerational dementia programmes, nevertheless it aspired to offer 'advice on the contingencies of programme-making' across several different contexts where suitable evidence was available (Pawson, 2013: 107). Moreover, I accurately reported on the data sources included in the synthesis through use of direct quotes and a comprehensive data extraction sheet, as described below.

#### *Review Purpose and Objectives*

Through the narrative literature review process, combined with a detailed analysis of existing reviews that investigated intergenerational dementia programmes (Lu et al., 2021; Bacsu et al., 2021; Matheson-Monet, 2020; D'Cunha et al., 2020; Gerritzen et al., 2020; Galbraith et al., 2015; Camp and Lee, 2011), a strong understanding of the field was developed and allowed for the sketching of an 'initial rough theory' regarding how intergenerational dementia programmes may work (Wong et al., 2013*b*: 11). The realist synthesis review of this thesis, moreover, built on the existing literature by applying a realist synthesis approach aimed at exploring the context, mechanisms, and outcomes of intergenerational dementia programme theories, similar to, but distinct from intergenerational programme theories, similar to, but distinct from intergenerational programme theory in general. In addition, this review provided a basis for the consideration of intergenerational dementia programmes in terms of their applicability to Scotland, as investigated further in the second phase of this study comprising semi-structured interviews.

The objectives of the realist synthesis were to:

- investigate how the concept of intergenerational inclusion for people living with dementia has been understood and operationalised internationally;
- gain an understanding of the contexts in which intergenerational dementia programmes have been implemented internationally;
- identify the outcomes that intergenerational dementia programmes have generated;
- identify and analyse the mechanisms that account for the observed outcomes arising in different international contexts; *and*

 identify the theoretical bases and programme hypotheses that have been developed by researchers and practitioners involved in intergenerational dementia programmes internationally and, by combining this with the CMO analysis, begin the process of refining a preliminary, explanatory theory accounting for how intergenerational dementia programmes work (or not) in different contexts.

## Search Procedure

In keeping with the realist synthesis methodology, the search procedure was driven by the objectives and focus of the review and aimed to be iterative rather than exhaustive (Wong et al., 2013*b*: 30). The primary search was conducted between June and August 2020 and was designed to identify literature regarding intergenerational dementia programmes specifically. The search combined the keyword terms of 'Dementia/Alzheimer's Disease' and 'Intergenerational/Multigenerational' with a third term concerning 'programmes/projects' in an attempt to limit the focus to non-pharmacological, ecopsychosocial interventions only. Searches were further limited to literature published between January 2005 and June 2020 to reduce duplication with existing intergenerational dementia programme reviews (Gerritzen et al., 2020: Galbraith et al., 2015) and to ensure a focus on the latest articles published in the field of interest to policymakers.

'NOFT/Anywhere but full text' and 'Title, Abstract, Keyword' limits were adapted for each database. The databases searched were: CINAHL, Cochrane Library, Medline, ProQuest ASSIA, ProQuest ERIC, ProQuest Psychology, ProQuest Public Health, ProQuest Social Science, PsychInfo, PubMed, and SCOPUS. Iterative searches adapted from the keyword terms above were then conducted via Google search engine with the aim of finding relevant grey literature. Iterative searches were also conducted via Google regarding programmes and projects of interest that had been identified through the literature appraisal and synthesis procedures, for example, combining the programme name and country with the keyword terms above. Additional articles were found through snowballing and searching the reference lists of highly relevant articles. A complete, repeat search procedure based on the parameters above was conducted at the start of 2022 in order to check for any new publications, either academic or grey literature, that may have been published on the topic during the intervening period. A document flow diagram outlining the search procedure is provided in Appendix 1.

## Inclusion and Exclusion Criteria

Although the focus of the review was to explore intergenerational dementia programmes, programmes that involved both older participants as well as older participants living with dementia were included, that is, programmes need not have been exclusively dementiabased for inclusion, however, they must have included at least one or more persons living with dementia. The justification for this broader inclusion criterion was that having a range of older participants with different physical and cognitive needs provided an accurate reflection of how such programmes actually are implemented in contexts governed by scarce resources and thus provides useful evidence for policymakers and practitioners. Programmes focused on exploring intergenerational interactions and dementia within families were excluded as were programmes focused on exploring intergenerational interactions and protein interactions between professional caregivers and people living with dementia.

#### Appraisal Procedure

The appraisal procedure was flexible in order to account for different types of evidence and to avoid the application of a methodological hierarchy favouring randomised control trials (RCTs) (Wong et al., 2013*b*: 34). Journal articles were appraised using the Critical Appraisal Skills Programme (CASP) checklists (Critical Appraisal Skills Programme, 2018). Qualitative studies were appraised using the CASP qualitative checklist and quantitative studies were appraised using the CASP Randomised Control Trial checklist, with mixed method articles appraised using both checklists. Articles of lower methodological quality and lower relevancy were excluded from the synthesis, however, articles of lower methodological quality that were highly relevant were included. Document characteristics and appraisal overviews, including an indication of methodological quality, are provided in Appendix 2.

#### Data Extraction

Once articles were appraised, they were read in full and then read again for the purposes of data extraction. Data extraction was undertaken using a data extraction sheet developed specifically for this phase of the research and included at Appendix 3. Data extraction served the purpose of extracting relevant data and information from the documents that were included in the realist synthesis (Wong et al. 2013*a*: 1008). Data of interest within documents reflected 'data that [supported] the use of realist logic to answer the review's question(s) – for example, data on context, mechanisms and outcome configurations, demi-regularities, middle-range, and/or programme theories' (Wong et al. 2013*a*: 1014). Once extraction for

each document was complete, each data extraction sheet was given a unique identifier and uploaded/classified within Nvivo. The quick characteristics were collected for programme documents, that is, primary studies investigating intergenerational dementia programmes internationally. These characteristics were built into a document classification table within Nvivo 12 Pro in order to facilitate comparative analysis of the research projects and programme contexts.

## Phase 2: Semi-structured Interviews

#### Overview and Justification

Interviews, one of the most commonly used data collection methods particularly in qualitative and healthcare research (Kallio et al., 2016: 2955), are aimed at inviting 'conversational encounters to create a space for intricacies and vicissitudes of respondents' lived experiences' (Poindexter, 2003: 384). The second phase of this study deployed a qualitative, semi-structured interview method. Pre-determined questions were included in a topic guide (Appendix 4) used to structure all interviews in a similar manner. However, interview participants were permitted and encouraged to focus on the questions, issues, and themes they perceived to be most important. Therefore, sufficient structure within the interviews retained a focus on the overall research questions yet left space for 'participants' to offer new meanings to the topic of study' (Galletta, 2013: 2). By being simultaneously structured and flexible in this way, semi-structured interviews generally 'allow for the exploration of lived experience as narrated...in relation to theoretical variables of interest' (Galletta, 2013: 9). This particular interview approach was deemed appropriate due to the strong theoretical basis of the thesis grounded in a realist methodology along with the variables emerging through the realist synthesis on the one hand, and the need for interview participants to offer new, extended meanings concerning intergenerational dementia programmes within the Scottish context on the other.

The interviews, moreover, adopted a 'realist interview approach' pursuing theory refinement and theory consolidation about how a programme works by teasing out the various components of 'intervention, context, actor, mechanism, and outcome' (Mukumbang et al., 2019: 487). The interview topic guide developed to structure the interviews thus explored the context, mechanisms, and outcomes of intergenerational dementia programmes in Scotland, with additional questions addressing the barriers to intergenerational dementia programmes, as well as policymaking and the COVID-19 pandemic in relation to intergenerational practice.

The realist interview approach involves 'presenting the respondent with a formal description of (part of) the parameters of the initial program theory for examination (teacher-learning function) and offers the respondent the opportunity to explain and clarify the thinking of the researcher based on their (respondents) ideas (conceptual focusing function)' (Mukumbang et al., 2020: 491). Therefore, intergenerational dementia programmes were described in the participant information sheet shared prior to interview, and the programme description was reiterated during questioning. However, it is important to note that the semi-structured interviews were informed by and adapted from this interview approach only as the aim was to have a flexible conversational process led by the participants' reasoning and experiences.

## Strengths and Limitations

Semi-structured interviews, while allowing for 'accommodation of a range of research goals', having 'unique flexibility' (Galletta, 2013: 45, 1), and often perceived to 'achieve deeper insights and richer understandings' (Poindexter, 2003: 384), nevertheless are problematic as a research technique. Semi-structured interviews, in particular, typically involve questions delivered in a time-restricted environment with researchers and respondents not normally being known to each other previously, thus invoking particular balances of power and introducing elements of unpredictability (Husband, 2020: pp 6-7). Being inherently interpretative, moreover, problems of communication, understanding, and interpretation may occur during interviews on the part of both researcher and interview participant. When approaching texts such as transcripts, for example, researchers may be 'heavily influenced by such factors as class, age, religious background, regional origin, ethnicity, and sexual orientation' and may be incapable of determining 'what is most important to the teller because of linguistic, experiential, theoretical, and cultural filters and disparate frames of reference' (Poindexter, 2003: 384).

Interview participants are vulnerable to similar influences that may 'spoil' the data received (Diefenbach, 2008: 880). Participants, likewise, will interact with researchers according to the 'internalised norms [and] cultural scripts deeply embedded in [their] personality and attitudes' (Diefenbach, 2008: 880). Participants may be unconsciously affected by the interview situation in which they are 'officially' asked about a particular topic (Diefenbach, 2009: 880). Data arising through interviews may further be affected by participants' ability

to recollect information and events related to the topic under investigation and, at the extreme end, participants may even deliberately seek to mislead researchers (Diefenbach, 2008: 881). An additional point to note is that, due to constraints imposed by the COVID-19 pandemic, it was necessary to conduct the interviews for this research project virtually. Conducting interviews within computer-mediated communication contexts may differ from face-to-face contexts and may even be more depleting for those involved (Nadler, 2020: 2).

While it was beyond the scope of the current study design to eliminate these issues that are inherent to the nature of interview techniques, nevertheless these limitations were taken into consideration and accounted for through the application of the two-phase study design. This design was capable of incorporating a broader range of data than that generated solely through the semi-structured interviews. Undertaking the realist synthesis exploring intergenerational dementia programmes as a first phase served to generate 'a comprehensive and adequate understanding of the subject', create 'a predetermined framework for the interview[s]', and marshal 'previous knowledge' towards 'a conceptual basis for the interview[s]' (Kallio et al., 2016: 2959).

However, the realist synthesis further allowed for the use of evidence regarding intergenerational dementia practice generated in different cultural contexts from around the world, as well as evidence generated via both qualitative and quantitative data collection methods. Firstly, this allowed for a degree of transcendence of the cultural limitations of the Scottish-bound context in which the interviews for this thesis took place. Secondly, this permitted some secondary analysis of quantitative data as part of the realist synthesis process, which gave additional insight within the overall qualitative paradigm adopted for this study, particularly in relation to outcome measurement.

A final point to note is that, due to the nature of the research questions focusing on the practice and policy of intergenerational dementia programmes in Scotland rather than issues of critical and constructivist theory, it was not considered necessary to dig deeper in order to reveal the hidden layers of a person's personality and his or her 'real and genuine experiences or ideas' when it came to interview participants (Diefenbach, 2008: 880). However, using a critical or constructivist orientation to explore the different meanings attributed to intergenerational inclusion by a range of actors, including participants themselves as well as the organisations and staff involved, could form the basis of a future study. Similarly, while a realist evaluation paradigm was adopted within my methodology, I do not see this as

precluding a future critical realist inquiry to explore more 'ideological' concerns such as whether 'the solutions [intergenerational dementia programmes posit] promote or inhibit non-alienating social forms' (Porter, 2015: 76).

# Ethics, Informed Consent and Data Management

#### Ethics

The interview phase of the study received approval from the Queen Margaret University Business, Enterprise and Management Ethical Approval Committee on 24<sup>th</sup> November 2020. The ethics submission included documents that would be used throughout the interview process, including the research protocol, the information sheet outlining the purpose of the research for participants, the participant consent form, and a finalised interview topic guide indicating the questions to be asked during interviews. The ethics form further outlined consent procedures, the safeguarding of participant welfare and confidentiality, and data management procedures.

#### Informed Consent

Ensuring that interview participants were informed about the research and consented to taking part was a critical step of the interview process. Participants were thus made aware of the terms on which they participated at several junctures, including a right to anonymity, a right to withdraw without having to give a reason, and a right to voluntary participation free from coercion (Husband, 2020: 3). Informed consent was also approached as 'an active and continuing aspect of the relationship between respondent and researcher' (Husband, 2020: 7). All potential participants were sent the participants mere additionally offered an opportunity to have a 'research chat' prior to interview if they so wished. This 'research chat' comprised a more informal conversation that allowed for introductions, a chance to find out more about the research and the researcher's prior to interview, all participants were given a consent form to complete (Appendix 6). At the start of each interview, moreover, the main points of consent and data protection were reviewed verbally by the researcher and participant.

Participant review post-interview formed a final step of the consent process. Each participant was given a document outlining the professional characteristics that had been collected about them and how these details would ultimately be presented within the research to

ensure that participants were confident their confidentiality and anonymity had been sufficiently protected. The review document also indicated the themes that had emerged from the combined interview data and participants were invited to raise any concerns they had about this brief thematic summary. Finally, participants were also offered further review in early 2022 closer to completion of the thesis if they wished, enabling them to see the quotations that had been taken from their interview data with an indication of the context in which they were being used.

#### Data Management

Interviews were conducted and recorded remotely via Zoom or Microsoft Office Teams depending on the preference of the participant and lasted sixty minutes on average. Remote interviewing was essential due to legal restraints and safety concerns restricting in-person social contact throughout the COVID-19 pandemic. Participants were informed of and consented to all recording processes taking place, which normally included video as well as audio recording on account of the internet video conferencing applications being used to conduct interviews. However, participants were allowed to indicate if they objected to video recording and had the option to turn off their web cameras if this was their preference. Back-up recordings were taken with a Dictaphone application, again with the consent of participants, but these recordings were deleted immediately once it was verified the core recordings were playing correctly.

Interview recordings were saved to the organisational QMU Microsoft OneDrive with access restricted to the researcher only on a temporary basis during transcription. Master recordings were saved to the QMU Server. Once transcription was complete, recordings saved to the cloud were permanently deleted and replaced with completed transcripts. Master transcripts were again saved to the QMU server in preparation for classification within the Nvivo software. All data documents, comprising recordings, transcripts as well as consent forms, were saved with a linked-anonymous format, that is to say, participant names did not appear in the naming conventions of documents. Instead, each participant was assigned a unique participant number and this anonymous identifier was used to track data and documents. Specific names occurring in interview data were also redacted within transcripts, for example, with an individual's name replaced with a bracketed generic job title.

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#### Sampling and Recruitment

Participants to be approached for interview were identified as part of the ethics process and included policymakers and practitioners involved in Scotland's dementia policy network and/or involved in Scottish intergenerational practice for people living with dementia. Figure 1 below outlines the interview participants recruited for this phase of the study. The exclusion criteria for interview participation included (i) insufficient or irrelevant professional experience and/or (ii) no affiliation to Scotland's dementia policy network/provision of dementia/intergenerational support services in Scotland. Recruitment was cross-sectoral encompassing the third sector, local government, health and social care partnerships (HSCPs), as well as policy and intergenerational networks. The sampling strategy was thus purposive and 'faithful to the research question', rather than random and probabilistic, in keeping with the qualitative research technique being adopted (Galletta, 2013: 33).

The sample size was kept small in order to allow for intensive study of each case and in anticipation of each interview generating a large amount of data (Curtis et al., 2000: 1002). However, in recognition of the cross-disciplinary, cross-sectoral, and diverse nature of intergenerational practice for people living with dementia in Scotland, involving many different partners and organisations to date, it was important to secure a sample that would further account for geographical variation across Scotland and incorporate different perspectives and views on the topic to be investigated. It was also important to ensure the sample would be 'likely to generate rich information', enhance the 'analytic generalizability' (rather than statistical power) of findings, and produce 'believable descriptions/explanations' of the processes and phenomena under investigation, namely intergenerational programmes and inclusion for people living with dementia (Curtis et al., 2000: 1003).

Initially the sampling process identified a need for eight participants to be included in the study, however this was revised to ten participants prior to commencing recruitment, with the aim of achieving data saturation. Data saturation is generally defined as 'information redundancy' or 'the point at which no new information, codes or themes are yielded from data' (Braun and Clarke, 2021: 202). While the notion of data saturation in qualitative research is contested (Braun and Clarke, 2021), the aim with the interview phase was to achieve a point in data collection and analysis 'when new information produces little or no change to the codebook' (Guest et al., 2006: 65). Thirteen interviews were undertaken in

total between January and May 2021 and by the final interview the research team agreed that data saturation had been met.

Recruitment was in large part guided by feasibility (Curtis et al., 2000: 1003), including time restraints and the period in which this phase of the study was being undertaken during the COVID-19 pandemic. Recruitment was initiated through internet research, including review of case studies documented through Scottish intergenerational networks and dementia supporting organisations. Suitable candidates were approached by email with an invitation to find out more about the PhD project and with the participant information sheet included as an attachment. Snowballing, whereby interviewees were asked to identify other individuals they felt may have expertise to offer, was also implemented, however, did not lead to additional interviews. Recruitment was enhanced by one network representative approaching multiple contacts on behalf of the researcher, several of whom then went on to participate in this phase of the study. Gender was not a factor which influenced or determined recruitment, however, it is interesting to note that the majority of interviewees were female. This may be related to general evidence indicating that both informal caregivers (Scottish Government, 2022*b*) and the adult social care workforce (Scottish Government, 2022*b*) and the adult social care workforce (Scottish Government, 2022*b*) and the adult social care workforce (Scottish Government, 2022*b*) and the adult social care workforce (Scottish Government, 2022*b*) and the adult social care workforce (Scottish Government, 2022*b*) and the adult social care workforce (Scottish Government, 2022*b*) and the adult social care workforce (Scottish Government, 2022*b*) and the adult social care workforce (Scottish Government, 2022*b*) and the adult social care workforce (Scottish Government, 2022*b*) and the adult social care workforce (Scottish Government, 2022*b*) and the adult social care workforce (Scottish Government, 2022*b*) and the adult social care workforce (Scottish Government, 2022*b*) and the adult social care workforce (Scottish Gover

Interview Participants		Number of Participants	
Gender			
٠	Female	11 (85 %)	
•	Male	2 (15 %)	
Job Leve	el		
٠	Manager	6 (46 %)	
•	Coordinator	2 (15 %)	
٠	Director	2 (15 %)	
٠	Organisational Officer	2 (15 %)	
•	Board Member/Trustee	1 (8 %)	
Organisa	ation		
•	Charity	10 (76 %)	
•	HSCP	2 (15 %)	
•	Local Authority	1 (8 %)	
Sector			
٠	Third Sector	10 (77 %)	
•	Local Government	3 (23 %)	
Practice	/work Setting		
٠	Community	10 (77 %)	
•	Care home/Unit	2 (15 %)	
•	Policy	1 (8 %)	
Region			
•	Scotland-wide	3 (23 %)	
•	Central Scotland	2 (15 %)	
•	Lothians	2 (15 %)	
•	Southern Scotland	2 (15 %)	
•	Strathclyde	2 (15 %)	
•	Highlands & Islands	1 (8 %)	
•	UK-wide	1 (8 %)	

Figure 1: Interview Participants – Characteristics

\*Due to rounding, not all percentages add up to 100 %.

#### Transcribing

Transcribing was completed verbatim in order to generate an accurate written reproduction of the conversation that had transpired during each interview. Transcripts, once complete, were reviewed to ensure that questioning and prompting had been undertaken consistently, though in keeping with the conversational, flexible approach of the semi-structured interview method and with the caveats that participants were not obliged to answer every question and that interviews were time-restricted (Guest et al., 2012: 22-24). Core findings identified during transcription were reviewed regularly by the research team to ensure that no 'significant gaps' were becoming apparent in the data that would impede 'a comprehensive plan for moving forward' with the research (Guest et al., 2012: 28).

## Conclusion

This chapter has explored the ontology, epistemology, and methodology of the research, along with providing a detailed account of the methods deployed in both phases of the study. The thesis is based in a realist ontology that admits the existence of both physical and social reality. Realist evaluation, the approach that has informed the development of the methodology, reflects these realist philosophical foundations. By seeking to scrutinise patterns of programme outcomes across different contexts, realist evaluation explores the choices and behaviours of those involved in programmes - whether as organisers or participants- as they use, respond, and react to the physical resources, social opportunities, and social structures that are created and harnessed during programme implementation. Realist evaluation was further discussed in relation to some core precepts including complexity, structure and agency, and generative mechanisms. The epistemology that underlies realist philosophy in general and realist evaluation in particular was outlined in regard to historicism and context-dependency, partial knowledge and theoretical gradualism, and the use of heterogenous evidence. This epistemology endorses the methodology developed for this thesis in two fundamental ways. Firstly, context is a key area of focus within the research questions and methodology, with methods subsequently designed to explore international and national contexts throughout each phase respectively. Secondly, while the paradigm of the study is broadly qualitative, the conducting of the realist synthesis allowed for consideration of both qualitative and quantitative evidence while assuming no methodological hierarchy. Some preliminary limitations of realist evaluation were also presented and will be drawn upon further in the discussion chapter. The chapter then presented a detailed overview of both phases of the study, comprising a realist synthesis review in the first phase and realist, semi-structured interviews in the second phase. Each method was described and justified with information regarding the strengths and limitations presented along with detailed descriptions of how the methods were deployed.

The next chapter will outline how data collected during each phase of the study were analysed.

## Chapter 4: Analysis

#### Introduction

Thematic analysis has been applied as a method towards approaching, organising, and interpreting the data gained throughout both phases of this study, including the realist synthesis review and the realist, semi-structured interviews with Scottish stakeholders. Despite its widespread use as a method, Braun and Clarke noted that there was a tendency to treat thematic analysis as a singular approach, in turn leading researchers to obfuscate their 'particular orientation' to thematic analysis (Braun and Clarke, 2021: 333). This chapter, in a bid to avoid this problem, begins by providing definitions of thematic analysis as a methodological framework and then describes the qualitative paradigm that has informed the thematic analysis of data regarding intergenerational dementia programmes and policy both internationally and nationally. The chapter continues with an outline of the orientation to thematic analysis that has been adopted for the study comprising both inductive and deductive elements. An account of the analytic steps that have been taken towards the realist synthesis data and the interview data is then provided (Braun and Clarke, 2006: 87).

The analytical steps taken for both data sets are interwoven throughout the chapter, however, the points of analytical difference are highlighted and recounted in separate sections where necessary to provide clarity and to accurately reflect the process. Each analytical step is further accompanied by an overview of how trustworthiness has been maintained throughout the process (Nowell et al., 2017).

## Defining Thematic Analysis

Thematic analysis has variously been characterised as a tool or process to complement other methods and analytic traditions, however, there are strong arguments for treating thematic analysis as a method in its own right in keeping with Braun and Clarke (Braun and Clarke, 2006: 78), for example, achieving more explicit and transparent insight into the manner in which the qualitative analysis has been conducted. Thematic analysis for the purposes of this thesis is treated as a specific methodological framework that necessitates detailed explanation, as will be provided in this chapter. Thematic analysis, at its most basic, invokes a 'process for encoding qualitative information' (Boyatzis, 1998: 4). Braun and Clarke built on this definition, describing 'thematic analysis [as] a method for identifying, analysing, and reporting patterns (themes) within data' (Braun and Clarke, 2006: 79). Minimally, therefore, thematic analysis can describe data sets in rich detail and maximally it can provide for the

theorisation and interpretation of a phenomenon (Braun and Clarke, 2006: 79) (Boyatzis, 1998: 4).

#### Qualitative Paradigm

Braun and Clarke referred to thematic analysis as a 'foundational method for qualitative analysis' that would equip researchers with core skills (Braun and Clarke, 2006: 78) and as such is an appropriate method for interpreting qualitative data gained through, for example, realist, semi-structured interviewing. However, thematic analysis can also be an appropriate tool for organising data gained through realist synthesis reviews. As Greenhalgh et al. relate, realist reviews are 'theory-driven interpretative techniques' (Greenhalgh et al., 2011: 2). Moreover, within realist philosophy more generally 'social reality is mainly an interpretative reality of social actors' (Rycroft-Malone et al., 2012: 2). The review process itself culminates in an analytical stage wherein findings need to be synthesised, that is, findings from different documents are compared and contrasted with a view to developing a narrative (Rycroft-Malone et al., 2012: 3). Therefore, thematic analysis was deemed a compatible methodological framework to guide analysis of both the realist synthesis data and the interview data within this thesis.

The thematic analysis of both data sets is grounded in what Braun and Clarke termed the 'Big Q qualitative' tradition, that is 'the use of qualitative techniques within a qualitative paradigm' rather than qualitative techniques deployed within a positivist paradigm (Braun and Clarke, 2021: 329). In analysing the data, therefore, word frequency analysis was not used to derive codes, themes, or interpretations, as it would have been inappropriate given the qualitative orientation (Cutliffe and McKenna, 2002: 614). Moreover, while some code checking was undertaken within the supervision team, formal intercoder agreement checks were not applied to either the first phase or second phase data. Within qualitative research unfolding in a positivist paradigm intercoder agreement is understood to be important towards achieving reliability and validity (Guest et al., 2012: 89-92), however, Braun and Clarke argue that demonstrating coding reliability and thus avoiding bias is 'illogical, incoherent and ultimately meaningless in a qualitative paradigm...because meaning and knowledge are understood as situated and contextual, and researcher subjectivity is conceptualised as a resource for knowledge production' (Braun and Clarke, 2021: 334-335).

Within both stages of the thematic analysis, there is the assumption that there has been a 'researcher effect on the data' (Guest et al., 2012: 50). In keeping with Braun and Clarke,

themes within the data have been actively developed and generated by the researcher and have not simply emerged from or been passively 'discovered' within the data (Braun and Clarke, 2006: 80). The researcher effect, moreover, is not a weakness of the analysis, but rather an integral element of the analytical interpretation 'undertaken by a researcher who is situated in various ways, and who reads data through the lenses of their particular social, cultural, historical, disciplinary, political and ideological positionings' (Braun and Clarke, 2021: 339). This awareness and acceptance of an active role for the researcher in organising the data is further coherent with the realist epistemology of the study, in which research processes fundamentally involve 'judgemental, discretionary components' that are unavoidable, such as 'the interpretation of results, and...the choice between competing theories' (Campbell, 1988: 317). The researcher effect is also presupposed in the active researcher-stakeholder interface involved in the realist synthesis approach (Wong et al., 2013*b*: 18).

The thematic analysis undertaken on each data set, while fully qualitative, further embraces qualitative pragmatism, 'with research driven by pragmatic demands around pre-determined information needs' (Braun and Clarke, 2021: 335). Within this thesis, pre-determined information needs included the context-mechanism-outcome configuration of the realist synthesis review that was extended to structure the interview topic guide. Applied thematic analysis has also influenced the overall analytic approach to the data sets, with a 'pragmatic focus on using whatever tools might be appropriate to get the analytic job done in a transparent, efficient, and ethical manner' (Guest et al., 2012: 18).

## An Inductive-Deductive Approach

Inductive and deductive analytical approaches to thematic analysis are not treated as oppositional within this study. The inductive approach involves coding 'from the raw data' in a 'data-driven' way (Boyatzis, 1998: 29), with analysis thereby seen to be 'grounded in the data' (Braun and Clarke, 2021: 331). In contrast, 'deductive analysis is driven by the researchers' theoretical or analytic interest' (Nowell et al., 2017: 8) with 'existing research and theory [providing] the lens' through which data are analysed and interpreted (Braun and Clarke, 2021: 331). Prior theoretical understanding, moreover, may relate to 'the characteristics of the phenomenon being studied; from already agreed on professional definitions found in literature reviews; from local, common-sense constructs; and from researchers' values, theoretical orientations, and personal experiences' (Ryan and Bernard,

2003: 88). Inductive and deductive approaches are often formulated as 'a continuum, rather than dichotomy' (Braun and Clarke, 2021: 331), or as Boyatzis claimed 'a continuum from theory-driven to data-driven approaches' (Boyatzis, 1998: 29). For example, Ryan and Bernard describe themes as coming 'both from the data (an inductive approach) and from the investigator's prior theoretical understanding of the phenomenon under study (an a priori approach)' (Ryan and Bernard, 2003: 88). The thematic analysis of both the realist synthesis data and of the interview data combined inductive and deductive elements and consequently the analytical approach overall can be positioned towards the middle of the inductive-deductive continuum.

#### Realist Synthesis Review

In terms of the realist synthesis review, data from the documents included in the review were extracted and organised according to the pre-determined structure of the data extraction sheet (Appendix 3). The data extraction sheet was designed to sort data in terms of contexts, mechanisms, and outcomes in order to facilitate CMO-configuration, and therefore there was an analytical assumption made that 'across the included documents, recurrent patterns of outcomes (or demi-regularities) and their associated mechanisms and contexts (CMO configurations) [were] likely to occur' (Wong et al., 2013a: 1015). The use of the context-mechanism-outcome structure was largely deductive as it assumed that this structure would be an effective means of evaluating intergenerational dementia programmes internationally and their related outcomes. Deductive approaches are, in this way, 'based on the assumption that there are "laws" or principles that can be applied to the phenomenon' under investigation (Boyatzis, 1998: 30). However, there were no additional structural, theoretical, or thematic limitations placed either on the data extraction or coding processes, and as such, the thematic analysis did not involve searching for evidence for pre-conceptualised themes, but rather strove for 'immersion in the data' (Braun and Clarke, 2021: 332).

#### Interview Data

As no pre-determined codebook was used when coding the data from the interviews, a broadly exploratory, inductive approach was taken (Guest et al., 2012: 7). However, it is important to acknowledge the ways in which the first phase of thematic analysis involving the realist synthesis review undoubtedly influenced this inductive approach towards the interview data.

Firstly, the undertaking of the realist synthesis during the initial phase of the study involved substantial, in-depth engagement with prior research. The realist synthesis process enhanced the analysis of the interview data by increasing 'sensitivity to subtle nuances in the data' (Braun and Clarke, 2006: 86; Tuckett, 2005: 79; Strauss and Corbin, 1998: 49) and by raising awareness around those variables that had been interpreted by other researchers that were likely to similarly occur in the interview data. However, it should be recognised that the realist synthesis may have simultaneously limited, or at least impacted, the inductive approach to the interview data. As Boyatzis notes, 'the use of prior data and research as the basis for development of a code means that the researcher accepts another researcher's assumptions, projections, and biases' (Boyatzis, 1998: 37), or short of accepting them, may well be influenced by them in implicit and explicit ways. Secondly, the CMO configuration of context, mechanism, and outcome that deductively influenced the analytic approach during the realist synthesis was similarly influential during the second phase of analysis and was utilised within the broadly inductive approach towards the interview data, particularly during thematic mapping.

## Manifest Level

The overall analysis, along with being fully qualitative and broadly inductive with some deductive elements, has moreover unfolded on the manifest or semantic, rather than latent, level. Boyatzis defined themes identified in the manifest level as being 'directly observable in the information' and further described 'manifest content-analysis' as 'the analysis of the visible or apparent content of something' (Boyatzis, 1998: 16). Braun and Clarke described 'a semantic approach' wherein 'the themes are identified within the explicit or surface meanings of the data, and the analyst is not looking for anything beyond what a participant has said or what has been written' (Braun and Clarke, 2006: 84). While themes in both sets of data have been generated on this manifest, semantic level, nevertheless an attempt is made to move from description and summarisation towards a more sophisticated interpretation and theorisation of intergenerational inclusion internationally and nationally (Braun and Clarke, 2006: 84). Moreover, a latent level analysis exploring 'underlying aspects of the phenomenon under observation' (Boyatzis, 1998: 16), or in other words, the more implicit, hidden meanings (Braun and Clarke, 2021: 332) underlying intergenerational inclusion, could form the basis of future research.

## Stages of Thematic Analysis

This chapter will now explain the different stages of thematic analysis that have been applied to the data generated through both phases of the study. These stages follow Braun and Clarke's six phases of thematic analysis, including (i) familiarising yourself with the data (ii) generating initial codes (iii) searching for themes (iv) reviewing themes (v) defining and naming themes and (vi) producing the report (Braun and Clarke, 2006: 87). The stages of analysis described below have further been integrated with Nowell et al.'s 'means for establishing trustworthiness' (Nowell et al., 2017: 4). Trustworthiness in thematic analysis involves a demonstration of 'how data analysis has been conducted through recording, systematizing, and disclosing the methods of analysis with enough detail to enable the reader to determine whether the process is credible' (Nowell et al., 2017: 2).

#### Familiarising Yourself with the Data

Braun and Clarke state the importance of researchers familiarising themselves with the data they are analysing as an initial phase of thematic analysis, involving actions such as transcribing data, reading, and re-reading data, and noting down initial ideas (Braun and Clarke, 2017: 87). For the realist synthesis review, I took responsibility for reading each document included in the review multiple times and took further responsibility for the data extraction process using the data extraction sheet (Appendix 3).

For the interview data, I similarly took responsibility for the transcribing process in recognition that this would enhance my familiarisation with the data. Transcription involved, firstly, ensuring the secure storage and archiving of interview data files, which comprised a combination of audio and video files produced during interview recording via Zoom and Microsoft Teams. Nowell et al. identify the storage of raw data in 'well-organized archives' to be a criterion of trustworthiness throughout analysis, beginning in this first phase (Nowell et al., 2017: 4). Master copies of interview recordings were immediately transferred to the QMU server once an interview was successfully completed. Back-up recordings were temporarily stored in the QMU OneDrive cloud storage while transcription was in progress. Both master copy and back-up files were assigned participant numbers that were used in file naming conventions to avoid the use of personal identifiers such as names. Once transcription of each interview was complete, back-up recordings in the cloud were deleted and replaced with back-up transcript files. Master transcripts for each interview were

additionally stored on the QMU server alongside master recordings. All other interview files were comprehensively deleted to avoid data duplication.

Transcribing, similarly, was undertaken in a consistent and robust manner in keeping with the protocol proposed by McLellan et al. (McLellan et al., 2003). Interview recordings were transcribed in their entirety in order to 'provide a verbatim account of the interview' (McLellan et al., 2003: 66). Elisions, nonverbal sounds such as sighs and laughs, and background noises were indicated on transcripts as they occurred (McLellan et al., 2003: 66). Transcripts were formatted identically to aid with computer-assisted coding in Nvivo (McLellan et al., 2003: 66), including a header with participant number, date and time of interview, and length of interview; and with tabulation to indicate the segments and questions corresponding to the interview topic guide. Source labelling was deployed throughout all transcripts in order to 'identify whether the text [was] associated with the interviewer or the interviewee' (McLellan et al., 2003: 67-68), and to avoid coding of interviewer text. Source labels included 'INT' to refer to text associated with the interviewer and 'PART' to refer to text associated with the participant. Finally, during interviews, it was common for participants to speak of other individuals specifically by name, workplace, job title and so on when answering questions, necessitating a method for handling such information (McLellan et al., 2003: 70-71). Personal identifiers were consistently omitted from transcripts and replaced with more generic descriptors, thus allowing for the anonymity of these individuals to be preserved while retaining the purport of the interview text.

Once transcripts were completed and stored, they were then read and re-read by the researcher to enhance familiarity with the raw data before coding commenced, and thereby 'prolong engagement with the data' (Nowell et al., 2017: 4). Additional prior steps taken to enhance the trustworthiness included setting up an audit trail to document the file management, data analysis, and relevant decisions, such as the method and rationale for generating codes and any changes made to codes thereafter (Guest et al., 2012: 93-94). A reflexive blog was also implemented in order to complement the audit trail and as a means of documenting reflexive and theoretical thoughts, as well as thoughts about potential themes (Nowell et al., 2017: 4).

## Generating Initial Codes

Braun and Clarke identified 'generating initial codes' as a second stage of thematic analysis, involving 'coding interesting features of the data in a systematic fashion across the data set,

collating data relevant to each code' (Braun and Clarke, 2006: 87). The coding process for this study was undertaken using the Nvivo software version 12.6.0.

#### *Realist Synthesis Review – Classification, Structural and Content Codes*

For the realist synthesis, data extraction sheets for each document included in the realist synthesis review were loaded into the Nvivo software and assigned a unique document number/file name. For programme documents (data sources involving primary research undertaken in relation to an intergenerational dementia programme internationally outside of Scotland), the relevant data extraction sheets were given file classification attributes including: research discipline, publication year, programme year, country, region, setting, programme activity overview, programme duration, session duration, programme frequency, dementia-only programme, dementia stage, older participants age, older participants number, younger participants age, younger participants number, younger participant groups, and outcomes simplified.

For theory and review documents, the relevant data extraction sheets were given file classification attributes including: research discipline, research focus, country, and publication year. Reviews were also classified by review type.

Before content coding was initiated, structural codes were implemented across the data extraction sheets. Structural coding often uses 'a hierarchical approach' with specific codes forming 'logical groupings based on questions that center on a particular focus of inquiry' (Guest et al., 2012: 55-63). Structural codes were thus derived from the categories of the data extraction sheet (Appendix 3) and focused on the context, mechanisms, and outcomes of intergenerational dementia programmes and related policy at the international level.

Following the structural codes, content codes were developed across the data extraction sheets and were intended to describe what could be observed in the data of relevance to the research design (Guest et al., 2012: 50). Content codes were documented comprehensively in order to aid the analysis, enable review by the supervision team, and ensure transparency. Moreover, an efficient codebook was developed through iterative readings that organised the extracted data into 'categories, types, and relationships' and was a necessary step towards 'moving beyond basic description to an explanatory analysis' (Guest et al., 2012: 52-53). Codes were comprehensively defined through a code label (a short word or phrase to allow the researcher to quickly distinguish between codes); a full definition (a paragraph summarising the assigned data features the code was intended to signify); and instructions

for use if required (when to use and not use the code, as well as relationships and triangulations with additional codes) (Guest et al., 2012: 53-54). Content codes were identified through systematic line-by-line readings of the extracted data.

### Interview Data – Classification, Structural and Content Codes

Transcripts were loaded into the software and assigned both a file and a participant case classification for tracking purposes. File classification attributes included the date, time, and length of the interview, and the number of pages. Participant case attributes included each participant's unique number, the broad geographical area and setting of their line of work, their broad job level, sector, and organisation type, and finally their involvement in dementia support and/or intergenerational practice in Scotland. All codes (both structural and content codes) were coded back to the participant via the participant case classification to ensure that coding was drawing upon data from each interview, that is to say, from each participant voice.

Before content coding was initiated, structural codes were implemented across the transcripts. These structural codes did not limit or inform content coding and so were not used as a preliminary codebook, rather they allowed for quick scanning to review whether questions had been consistently phrased and asked throughout the interviews; to identify any questions that may have been missed in particular interviews, for example, due to time restraints; and to briefly interrogate differences and similarities in participant responses, for example, questions that prompted long replies in some interviews, and short replies in others. The structural coding was modelled on the interview topic guide (Appendix 4), pertaining to the guide's segments and questions (see Figure 2 below).

As with the realist synthesis data, a comprehensive codebook was developed in which codes were defined through labels, descriptions, and instructions for use if required. Content codes were identified systematically through close, line-by-line readings of each transcript in its entirety. As each novel, interesting feature of the data was identified, a relevant code was created, and the data feature assigned accordingly. As analysis progressed, however, fewer 'novel' features were identified within transcripts as similar, corresponding ideas started to occur across multiple interviews, resulting in fewer new codes and the assigning of repeating data features to existing codes. By the thirteenth transcript, no new data features were identified, nor new codes generated, resulting in no additional changes to the codebook. This accords with Guest et al.'s conceptualisation of data saturation 'as the point in data collection

and analysis when new information produces little or no change to the codebook' (Guest et al., 2006: 65).

Within the codebook for the interview data, full definitions and instructions would often have to direct the breakdown and use of a key, broad code- for example 'enjoyment'- between the participant groups involved in intergenerational programmes, whether older participants living with dementia or younger participants. Multiple coding was permissible and frequently occurred throughout the thematic analysis due to the complexity of the phenomena under investigation: some features of the data were therefore coded multiple times to different codes in recognition of the fact that 'sections of the data...[would] typically include multiple themes' (Pope et al., 2000: 114). As an additional step to check the trustworthiness of the codes, a coding review was undertaken by the supervision team in summer 2021 incorporating several codes including 'enjoyment' (general, older participants, younger participants) and 'relationships' (community, outcome). Meetings of the supervision team involving discussion of initial codes were documented through minutes (Nowell et al., 2017: 4).

Figure 2: Structural Codes applied to the Phase Two Interview Data

•	Introduction Segment -Q1A Job Role and Stakeholder Involvement
•	Awareness and Definition Segment -Q2A Awareness -Q2B Definitions
•	Context and Actor Segment -Q3A Perceptions of Intergenerational Inclusion -Q3B Programme Need -Q3C Context -Q3D Groups
•	Programme Segment -Q4A Understanding of Working -Q4B Effectiveness -Q4C Ineffectiveness
•	Outcomes Segment -Q5A Outcomes -Q5B Drawbacks
•	Barriers Segment -Q6A Barriers
•	Policy Segment -Q7A Policy to Date -Q7B Policy Do More
•	-Q8A Pandemic
•	Final Remarks Segment -Q9A Final Remarks

## Searching for Themes

The third stage of thematic analysis described by Braun and Clarke is that of 'searching for themes', a process which involves 'collating codes into potential themes, gathering all data relevant to each potential theme' (Braun and Clarke, 2006: 87). Within the thematic analysis of both data sets, the scope of codes and themes was similar in keeping with the definitions proposed by Guest et al. (2012: 50). They defined a theme as a 'unit of meaning that is observed (noticed) in the data by a reader of the text', whereas a code in contrast was defined as 'a textual description of the semantic boundaries of a theme or a component of a theme' (Guest et al., 2012: 50). Therefore, in the analysis of this study, codes in some instances represented entire themes in their own right, however, in other instances codes represented theme components only, necessitating further synthesis with additional codes in order to complete a theme. However, sufficient time and consideration was built into the coding and theme development process to ensure that an analytical narrative was developed capable of illustrating 'the analytic points the researcher makes about the data' and further

making 'sense of the data' for the reader (Braun and Clarke, 2006: 94). For this reason, themes were complex, varied, and data-driven rather than simply overlapping with the data extraction sheet/interview topic guide (Braun and Clarke, 2006: 94) and concomitant structural codes. Themes were kept purposefully specific towards capturing discrete, complete units or patterns of meaning, recognising that different theme components could be synthesised to encompass broader meanings if required.

#### *Realist Synthesis Review – Theme Development*

Theme development for the realist synthesis data was explicitly driven by the contextmechanism-outcome configuration of realist evaluation. Themes related to context described aspects of 'the circumstances' in which intergenerational inclusion and intergenerational dementia programmes had played out internationally, including the characteristics and capacities of the various stakeholders involved in programmes, the stakeholder relationships that carried programmes, the rules, norms, and customs influencing programmes, and the wider social, economic and cultural settings of programmes, particularly drivers and barriers affecting programme implementation (Pawson, 2013: 36).

Themes related to outcomes were identified in two primary ways. Firstly, for programme documents involving primary research, outcomes were identified through the research designs, methodologies, and results that had been reported in the pertinent research studies. Where similar outcomes had been investigated by multiple research teams, moreover, strong outcome themes emerged (though the evidence arising from different studies supporting the outcome themes could be both confirmatory and contradictory).

For example, multiple studies used similar 'repeated measure' research designs based on the words that younger participants associated with dementia prior to and following programme participation as a means of evaluating the effect that intergenerational interactions could have on the perceptions of the younger people involved (Harris and Caporella, 2019; Chow et al., 2018; Harris and Caporella, 2014; Alant et al., 2015). Convergence on this research design and outcome measure contributed to the development of an outcome theme exploring 'reduced stereotyping and improved attitudes' among younger participants, as reported in chapter five.

Review documents further consolidated outcomes that had been repeatedly measured. For example, Lu et al. undertook a meta-analysis on programme outcomes including pleasure,

engagement/disengagement, depression, and quality of life, which further confirmed outcome themes that were arising from the realist synthesis as a whole (Lu et al., 2021). Secondly, additional documents including editorials, grey literature, and theoretical analyses were also used to probe the 'everyday reasonings' of stakeholders that could also contribute towards clarifying programme outcomes and the 'fates' of programmes (Pawson, 2013: 6). For example, in a perspective article, McGeorge et al. make multiple references to 'joy' and 'enjoyment' in relation to their overview of an intergenerational programme based in a hospital setting (McGeorge et al., 2021), which endorsed an outcome theme exploring enjoyment arising through intergenerational dementia programmes.

Mechanism themes were developed by identifying those codes and partial themes that appeared explanatory and that implied a 'chain of inference' (Rycroft-Malone et al., 2012: 8) bridging context and outcome data. For example, role provision for people living with dementia participating in programmes was identified as a mechanism theme within the realist synthesis. The importance of providing roles during programmes linked contextual and theoretical data concerning, for example, the maintenance of personhood for people living with dementia (Lokon et al., 2012: 342) with outcome measurement related to purpose, sense of usefulness, and engagement.

#### Interview Data – Theme Development

A number of techniques were deployed to identify themes within the interview data as guided by Ryan and Bernard (2003). Repetition was a key scrutiny technique for identifying themes as the 'more the same concept occurs in a text, the more likely it is a theme' (Ryan and Bernard, 2003: 89). One repeating data feature throughout multiple interviews related to the idea that intergenerational practice involving people living with dementia in Scotland represented only 'pockets of practice' rather than a general uptake across all areas. For example, 'pockets of excellence ', 'pockets of ideas of things beginning to happen' and 'very small pockets' are examples of this motif in the data describing intergenerational programme rollout.

Indigenous categories occurred on occasion in the interview data denoting 'local terms that may sound unfamiliar or are used in unfamiliar ways' (Ryan and Bernard, 2003: 89). For example, multiple participants spoke about the need for the partners involved in organising intergenerational dementia programmes to raise awareness and negotiate the practice beforehand; and one participant in particular referred to this aspect of partnership working with her own indigenous term of 'brokerage'. The manager elaborated on this term of partnership brokerage stating it involved the 'need to do presentations to schools, head teachers, to managers of care homes, to day centres and it's letting them believe that you are competent, or your organisation...can do this...it's also logistically...it's planned' (Participant 010).

Interview data was also scrutinised for metaphors and analogies, with analysis directed towards 'deducing the schemas or underlying themes that might produce those metaphors' (Ryan and Bernard, 2003: 90). Enjoyment through partaking in intergenerational dementia programmes was a top-level, common theme throughout the majority of interviews encompassing older participants, younger participants, and even on occasion the enjoyment of staff. Therefore, further analysis of the complexity of enjoyment for different participant groups was necessary; and particularly for enjoyment in relation to participants living with dementia was encapsulated profoundly through one interviewee's use of metaphor. The manager deployed the metaphor of an 'emotional hangover of being happy' to convey the meaningful yet perhaps inevitably ephemeral nature of the enjoyment experienced by older participants living with dementia participating in intergenerational activities [Participant 003]. This characterisation of the enjoyment for older participants was corroborated more practically by another manager who claimed that 'sometimes people that have dementia, they forget how the day went but the feeling of if they enjoyed a day stays with them for a lot longer' [Participant 002]. Undoubtedly this idea of ephemeral enjoyment developed into a theme throughout the data set, however, with extra insight achieved through this one participant's use of metaphor.

Comparative techniques were also deployed, for example, to analyse similarities and differences in the length of response and response content among participants towards particular questions. As Ryan and Bernard state, 'abstract similarities and differences that [a] question generates are themes' (Ryan and Bernard, 2003: 91). One area where similarity and difference keenly emerged was in relation to the role of Scottish policy in promoting intergenerational practice for people living with dementia, with some participants claiming Scottish policy needed to do more to promote practice and other participants perceiving Scottish policy to already be sufficiently supportive of practice. Therefore, comparisons across transcripts were utilised in identifying this thematic tension in relation to the role of policy, in turn feeding into broader debates concerning the respective roles of policy and practice in the health and social care sector in Scotland currently being shaped by legislative

developments such as health and social care integration, self-directed support, and the review of adult social care.

While reading the interview data, a final technique deployed was scrutiny for missing data. As Ryan and Bernard advise, 'Instead of asking, What is here? we can ask, What is missing?' adding that much can be gained from scrutinising qualitative data for 'what is not mentioned' (Ryan and Bernard, 2003: 92). Throughout the interview data, positive descriptions of intergenerational dementia programmes and their outcomes abounded, however, negative descriptions were much rarer. While negative aspects indeed became apparent throughout close analysis, synthesis, and cross-referencing of the details of the interviews, often explicit prompting to describe what made programmes ineffective, or what could generate negative programme outcomes, failed to elicit responses from participants. This potentially indicated missing data, with the reasoning and motivations for this lack of response among participants operating at a more latent conversational level. For example, when asked directly about what makes programmes ineffective, several participants choose positive language to frame their replies, similar to this manager recounting the stories they had heard from other practitioners during intergenerational training: '...everything has been very, very positive in the groups' [Participant 012].

## **Reviewing Themes**

Braun and Clarke advise that themes should be reviewed as a fourth step of thematic analysis, whereby themes are 'checked' to see if they 'work in relation to the coded extracts...and the entire data set' often through the use of thematic mapping (Braun and Clarke, 2006: 87). A similar review process was implemented for both the realist synthesis and interview data themes.

Firstly, themes were sorted into broad areas of findings. For the realist synthesis, the broad areas of findings included context themes, mechanism themes, and outcome themes, with additional thematic groups created for programme recommendations and programme theory.

For the interview data, the major area of findings concerned the working of Scottish intergenerational dementia programmes, with convergence on the findings that had emerged from the realist synthesis concerning programmes internationally. Two further findings areas were also identified in the data. The first area involved the role of Scottish policymaking towards intergenerational dementia programmes, derived from responses to

the questions on the interview topic guide addressing this aspect of the topic. The second area related to intergenerational partnerships in Scotland, which, although not addressed directly through an interview question, nevertheless emerged in the data particularly in relation to discussion about the effectiveness of intergenerational programmes.

Once these areas had been identified and the codes sorted for both data sets, codes were then reviewed in both a bottom-up and top-down fashion. In terms of bottom-up, all the data extracts assigned to a code were read closely to 'consider whether they [appeared] to form a coherent pattern' in terms of the code and its definition (Braun and Clarke, 2006: 91). In terms of top-down, codes were then considered in relation to the data set as a whole in order to ascertain 'the validity of individual themes' in relation to the entirety of the data (Braun and Clarke, 2006: 91). This ensured that the framework of codes was forming an accurate representation of each data set that would support further synthesis and narrative-building. Thirdly, diagramming was used to interrogate 'theme connections' and, moreover, be transparent about the connections that were being drawn (Nowell et al., 2017: 4). Thematic maps were shared with the supervision team in order to ensure a degree of 'vetting' of themes and sub-themes in a more holistic manner (Nowell et al., 2017: 4).

In addition to these maps, a table was produced in order to compare themes and their structuring across both data sets in order to identify convergence and divergence between the two sets of themes as is discussed further in chapter eight. This comparative-thematic table was also shared with the supervision team in addition to the separate thematic maps for each data set.

## Defining and Naming Themes

Braun and Clarke describe a fifth phase of thematic analysis involving ongoing theme refinement in terms of the 'overall story the analysis tells, generating clear definitions and names for each theme' (Braun and Clarke, 2006: 87). In order to explicate the theme definitions and connections towards producing an analytical narrative for both the realist synthesis and interview data, preliminary findings were written up. The production of written drafts of findings served a number of purposes. Firstly, it allowed for the supervision team to gain insight into the linkages between themes, representative data extracts, and my overall interpretation, which assisted with building team consensus on the themes (Nowell et al., 2017: 4), including identifying those that needed to be clarified.

Secondly, it ensured that data extracts were being used to generate a critical analysis and were not simply being described. As Braun and Clarke relate, it is 'vital' that a researcher 'not just paraphrase the content of the data extracts presented but identify what is of interest about them and why' (Braun and Clarke 2006: 92). Only by working towards capturing the 'complex story of the data' can a researcher convince 'the reader of the validity and merit of the analysis' (Nowell et al., 2017: 11).

Thirdly, it allowed for 'points of departure' to be identified, that is, interesting features of the data extracts that were extending the analysis into further critical discussion in terms of the study as a whole. Peer debriefing was also integrated into this phase of the thematic analysis through two formal seminars with assessors who could bring additional expertise to the analysis, thus helping to 'expose the researcher to aspects of the research that might otherwise [have remained] unspoken' (Nowell et al., 2017: 10).

## Producing the report

The final stage of thematic analysis proposed by Braun and Clarke is the production of a written report, also described as the 'final opportunity for analysis' in which 'vivid, compelling extract examples' are selected and subjected to final analysis, and the analysis as a whole is related back to the research question and positioned in relation to the literature with the end result of a scholarly report (Braun and Clarke, 2006: 87). Therefore, written drafts of thematic findings from the realist synthesis and from the interview data were edited and restructured, with regular feedback provided from the supervision team.

From the realist synthesis data, an analytical narrative was developed in order to explore how intergenerational inclusion had been understood and operationalised internationally. From the interview data, an analytical narrative was developed in order to explore how intergenerational inclusion had been operationalised nationally in Scotland. Themes relevant to intergenerational policymaking from both data sets were incorporated into a third analytical narrative. These analytical narratives were then synthesised and positioned in relation to the literature in a final discussion. A final step towards producing the report involved scrutiny of the data extracts selected to represent themes and the analytical narrative in keeping with Braun and Clarke who advise choosing 'particularly vivid examples, or extracts which capture the essence of the point you are demonstrating, without unnecessary complexity' with each extract epitomising the issue (Braun and Clarke, 2006: 93).

#### Interview Data – Participant Review

Participant review was undertaken towards establishing trustworthiness in relation to the interview data (Nowell et al., 2017: 4). Member checking- also termed respondent validation or, as within this study, participant review- 'entails participants themselves, or members of the participants' community, reviewing the summarized data to see if they accurately reflect their intents and meanings' (Guest et al., 2012: 93). Member checking is seen to be problematic in that 'study results have been synthesized, decontextualized, and abstracted from (and across) individual participants, so there is no reason for individuals to be able to recognize themselves or their particular experiences' (Morse et al., 2002: 16). Moreover, 'members are not always the best judge of what a valid research account is' because they may 'forget what they have said, regret what they have said, feel compelled to agree with researchers, or, as we all do, have the need to present themselves in different ways at different times' (Sandelowski, 2002: 108). For this reason, Sandelowski characterised member checking less an exercise in enhancing trustworthiness and validity in the current study, and more 'an opportunity to collect additional data about members' responses to a new phenomenon, namely, the researcher's account' (Sandelowski, 2002: 108).

However, for the purposes of the second phase of this study, member checking was undertaken and viewed as an important step, in large part guided by the realist synthesis approach that recommends close collaboration between researchers and stakeholders, and further perceives the roles and perspectives of stakeholders to be critical to the theorybuilding process. Therefore, during the member checking that was implemented with interview participants throughout autumn 2021 it was important that 'participants [could] recognise something of themselves, some of their world in the product' and that the initial themes 'should have some special meaning for them' (Cutliffe and McKenna, 2002: 615). Moreover, had the interview participants been unable to 'recognise the fundamental concepts in the theory' as presented in the themes then this would have indicated that the researcher had 'missed the meaning' (Cutliffe and McKenna, 2002: 615).

In order to complete member checking, therefore, every interview participant was contacted with a document (i) outlining how they would themselves be referred to in the write-up in the report (i.e. using either a participant number or generic job title) to check that confidentiality was being fully preserved; and (ii) offering an overview of the coded themes as sorted into the three top-level areas of programmes, policy, and partnerships. Participants were given sufficient opportunity to raise concerns about confidentiality and comment on the thematic framework if they felt compelled to do so and were offered further member checking in early 2022 in order to review the specific data extracts (quotations) that had been selected from their transcript and used in the final presentation of findings. Member checking resulted in no analytical conflicts between the researcher and participants.

#### Conclusion

Thematic analysis, a technique for describing data in rich detail towards developing explanatory narratives, was deployed as a methodological approach to analyse data collected during both phases of this study. Thematic analysis is a foundational qualitative analytical method and represented an appropriate methodological choice for analysing the qualitative interview data collected during the second phase of the study. However, as realist synthesis review is essentially an interpretivist review approach, thematic analysis was further deemed appropriate for data collected during the first phase. Both phases of the analysis utilised a broadly inductive, exploratory approach to the data with no pre-determined content frameworks. However, there were strong deductive elements whereby the realist synthesis analysis was structured around the context-mechanism-outcome configuration upon which realist evaluation is based; and with the analysis of the interview data impacted by the variables, theories, and themes developed through the first phase of the study. Moreover, the analysis was undertaken on the 'manifest level' in that it explored the explicit, rather than the latent, meanings of the data that had been collected.

The thematic analysis was guided by Braun and Clarke's six phases of thematic analysis (Braun and Clarke, 2006: 87). Reading combined with data extraction/transcribing processes served as a means to familiarise myself with each data set in turn. Using the Nvivo software, systematic document classifications combined with both structural and content codes served as the basis for theme development. Themes for the realist synthesis were refined by grouping data patterns according to the context-mechanism-outcome configuration. Themes for the interview data were refined through the application of several techniques including repetition, indigenous categories, metaphor and analogy, comparisons, and scrutiny of missing data. Themes were reviewed through developing major areas of findings for each phase of the study respectively, along with mapping and diagramming of themes and relationships. Moreover, top-down reviews of all extracts assigned to codes combined with top-up reviews of each code in respect of the entire data set were completed. Themes were

progressively named and refined during a comprehensive drafting and editing process supported by discussion and input from the supervision team. Finally, the report was produced through final write-up and the considered selection of exemplar quotes to represent core themes. Trustworthiness was established throughout the analytic process via systematic audit trails, a reflexive blog, meetings with the supervision team, assessed seminars that provided opportunities for peer debriefings, and a robust participant review process with all interviewees involved in the second phase of the study.

The following three chapters will present the findings of the research. Chapter five presents findings in regard to intergenerational inclusion internationally. Chapter six presents findings in regard to intergenerational inclusion in Scotland and chapter seven presents findings regarding intergenerational inclusion, Scottish policymaking, and Scottish Partnerships.

## Chapter 5: Findings - Intergenerational Inclusion Internationally Introduction

This chapter presents findings from the first phase of this study comprising the realist synthesis. The findings explore how the concept of intergenerational inclusion for people living with dementia has been understood and operationalised internationally. The chapter begins by exploring the different contexts in which intergenerational dementia programmes have been enacted globally. Data on the geographical scope and research disciplines of the different studies are presented, followed by information regarding older and younger participant groups that have participated in programmes globally. Contextual barriers are then summarised. These barriers are related to the institutional 'rules, norms and customs' as well as the 'wider social, economic and cultural' infrastructures that can vary by location (Pawson, 2013: 36) and subsequently affect programme implementation. The section on context concludes with an exploration of the means by which suitable contexts can be developed through, firstly, the provision of training and support to younger participants and, secondly, the overcoming of barriers through partnerships and staffing.

Following this contextual exploration, the programme mechanisms identified within the realist synthesis are presented, including role provision, matching and preferences, and meaningful and structured activities. These mechanisms explain the process by which a family of programmes (in this case intergenerational dementia programmes) generate outcomes in specific contexts by way of the infrastructure and resources they provide that 'trigger particular decisions or behaviours in human participants' (Wong et al., 2013: 1016). Finally, outcomes arising from intergenerational dementia programmes internationally are presented. Within realist evaluation, outcomes relate to the measurement of change arising through programme implementation and thus form the first objective of the evaluation project (Pawson, 2013: 40).

### Context

#### Context: Definitions

A key difference is apparent in how the term 'intergenerational' has been defined across data sources, with some authors using definitions that are more prescriptive than others in terms of the age groups that intergenerational practice definitionally involves. For example, Gigliotti et al. defined intergenerational programming as uniting 'older adults (65+) and children/youth under the age of 21 in mutually beneficial interactions fostered by a carefully planned program of activities' (Gigliotti et al., 2005: 425). Low et al. defined intergenerational programmes as '[bringing] together older adults and children or adolescents to participate in a shared activity' (Low et al., 2015: 228). Baker et al., similarly, described programmes as involving 'older people and youths [participating] in a shared activity' (Baker et al., 2017: 213). Therefore, within these definitions of 'intergenerational' exists an implicit understanding that the younger participants involved will be children, youths and most likely 'younger' than a specific age.

However, other data sources deployed definitions that were more flexible and gradated in terms of their treatment of age groups, referring more broadly to 'generations' in a way that could encompass a greater range of ages, especially in terms of younger participants. For example, Clark et al. described intergenerational work as 'activities that are specifically designed to bring together people from across generations' (Clark et al., 2016: 300). Caspar et al. cited an earlier definition from Cohen-Mansfield and Jensen that described 'engagement between younger and older generations' (Caspar et al., 2019: 151; Cohen-Mansfield and Jensen, 2017: 255). Janke et al. defined intergenerational programmes as involving 'two or more generations' (Janke et al. 2019: 133). Definitions of 'intergenerational' as simply involving 'multiple' generations that can be drawn from a variety of ages may suggest that 'multigenerational' is a more accurate and accommodating term to apply, that is, relating to several generations (Collins Dictionary, 2022).

Some definitions used in data sources, moreover, allude to a need to define the nature of the interaction between age groups more specifically when describing intergenerational programmes. Janke et al. suggest programmes can involve either 'formal or informal interaction between two or more generations' (Janke et al., 2019: 133). However, the distinction between 'formal' and 'informal' programmes could be explicated further, for example, whether programmes become 'formal' on account of the structure and planning of activities, the setting in which activities unfold, the content of activities themselves, the nature of the organising partnerships, or even the degree to which younger and older participants are known to each other prior to the programme. Arguably there could be a need to be clearer that intergenerational programmes involve non-familial interactions between the generations, in keeping with Peters et al. who define intergenerational practice as the 'bringing together of older adults and children to support active non-familial intergenerational intergenerational interaction' (Peters et al., 2021: 2). Jarrott and Bruno, in a similar vein,

described intergenerational programmes as a means to 'decrease social distance between generations' predicating the definition in an awareness that not only does such social distance exist, but it should be acted upon (Jarrott and Bruno, 2007: 240).

A final point is that intergenerational programmes across data sources are most often defined without specific reference to dementia, even in instances where the older participants involved in an intervention may be living with dementia. Greater clarity regarding dementia and how this may influence intergenerational programme design or 'working' could be beneficial. Thus definitions could be linked to the specific aim or potentiality of intergenerational dementia programmes to '[inspire] positive views of persons living with dementia' among children and younger people (Canning et al., 2020: 279). However, when linking definitions of 'intergenerational' to 'dementia' caution should be taken due to the potential to heighten 'benevolent othering' whereby people living with dementia are portrayed as belonging to an exceptional group in need of special treatment, which can exacerbate felt stigma (Fletcher, 2021: 422).

## Context: Geographical Scope

The majority of data sources explored programmes that had been enacted in North America, including nineteen studies from the USA (Reel et al., 2021; Harris and Caporella, 2019; Janke et al., 2019; Lokon et al., 2019; Janke et al., 2019; Lokon et al., 2019; Lokon et al., 2012; Yamashita et al., 2013; Guerrero et al., 2017; Biggs and Knox, 2014; George et al., 2011; George and Singer, 2011; George, 2011; Femia et al., 2008; Lee et al., 2007; Jarrott and Bruno, 2007; Gigliotti et al., 2005) and eight studies from Canada (Weeks et al., 2020; Canning et al., 2020; Canning and Blakeborough, 2019; Caspar et al., 2019; Hannan et al., 2019; Raber et al., 2019; Chow et al., 2018; Weeks et al., 2016). Five studies were Australian-based (Smith et al., 2020; Hernandez et al., 2022; Baker et al., 2021; Zamir et al., 2021; Lyndon and Moss, 2021; Di Bona et al., 2019; Collins et al., 2017). Other geographical locations included Brazil (Brandão et al., 2021), China (Chung, 2009), the Netherlands (Landi and Smith, 2019), Singapore (Lim et al., 2019), and South Africa (Alant et al., 2015).<sup>2</sup>

<sup>&</sup>lt;sup>2</sup> Several data sources present studies in which data has been collected within the same enacted intergenerational programme, such as the 'Opening Minds through Art' (OMA) initiative and The Intergenerational School, both of which are based in the USA. Two data sources from Canada

#### Context: Research Disciplines

Data sources were authored by researchers from a wide array of disciplines, with many studies produced by interdisciplinary health and social science teams. Health studies and public health, psychology, nursing, geriatrics, gerontology, occupational therapy, sociology, social work, education, and child studies were frequent disciplines involved in intergenerational programme research. However, art, design, music, media, performance, recreation, and informatics were additional disciplines incorporated in certain studies depending on the nature of the intergenerational programme under investigation.

#### *Context: Older Participants – Key Settings and Diversity*

Based on data available in articles, the age range of older participants across the studies was 60 - 101 years old.<sup>3</sup> Early stage, mild, moderate as well as generic descriptors of dementia predominated throughout the programmes. However, there were multiple studies referencing participants living with more advanced (Zamir et al., 2021: 2, Canning et al., 2020: 271, Canning and Blakeborough, 2019: 169) severe (Di Bona et al., 2019: 1682, Janke et al., 2019: 136, Lokon et al., 2019: 477, Skropeta et al., 2014: 4, Lee et al., 2007: 478, Jarrott and Bruno, 2007: 248) and late stage (Lokon et al., 2017: 412, Lokon et al., 2012: 343) dementias.

The majority of studies focused on intergenerational programmes involving older participants living with dementia only, however, thirteen studies investigated programmes where only some, or even a minority, of the older participants were living with dementia<sup>4</sup>. This indicates some flexibility in practice regarding the targeting of programmes and that people living with dementia can be included in programmes alongside older participants living with other conditions and physical needs.

investigated a proposed co-located intergenerational programme. Full details are presented in Appendix 2: Document Characteristics. A breakdown of programme, theory and review data sources included in the synthesis are presented in Appendix 1: Document Flow Diagram.

<sup>&</sup>lt;sup>3</sup> In a study investigating an arts-based programme, two of the 'older' participants were aged in their twenties and diagnosed with traumatic brain injuries accounting for their attendance at the adult day service primarily aimed at people living with dementia in the community (Reel et al., 2021: 5). This demonstrates the flexibility and age-inclusiveness that can be achieved when programming for people living with dementia, however, may pose challenges in providing suitable adult day services capable of catering for people of different ages facing different life needs and challenges (Sansoni et al., 2016; Gibson et al., 2014).

<sup>&</sup>lt;sup>4</sup> Weeks et al. (2016) is a study conducted with nursing home staff only regarding their views on a proposed shared site childcare facility. Hannan et al. (2019) do not specify whether the programme was dementia only, however, Raber et al., exploring the same intergenerational design project, clarify that 'some of the residents live with mild to moderate dementia, others with profound physical challenges, while some live with both' (Raber et al., 2019: 64).

Finally, studies investigated programmes involving older participants from a range of different settings including the community (Brandão et al., 2021; Jenkins et al., 2021; Reel et al., 2021; Smith et al., 2020; Collins et al., 2017; Guerrero et al., 2017; Harris and Caporella, 2019; Harris and Caporella, 2014; George et al., 2011; George and Singer, 2011; George, 2011; Chung, 2009; ), co-location (Janke et al., 2019; Landi and Smith, 2019; Lim et al., 2019; Low et al., 2015; Biggs and Knox, 2014; Femia et al., 2008; Jarrott and Bruno, 2007; Lee et al., 2007; Gigliotti et al., 2005) with two studies focusing on the same proposed co-location programme (Weeks et al., 2020; Weeks et al., 2016), care homes (Lyndon and Moss, 2021; Zamir et al., 2019; Chow et al., 2019; Martet al., 2019; Caspar et al., 2019; Di Bona et al., 2019; Chow et al., 2019; Baker et al., 2017; Alant et al., 2015; Isaki and Harmon, 2014; Skropeta et al., 2014), retirement communities (Yamashita et al., 2013; Lokon et al., 2012), and mixed and other settings (Lokon et al., 2019; Lokon et al., 2018; Lokon et al., 2017).

#### Context: Older Participants – Barriers to Participation

There was some evidence that implementing intergenerational programmes for older adults could be difficult due to scheduling and attendance. In a review article analysing several Montessori-based intergenerational activities, Camp and Lee described 'logistical difficulties' affecting older adults' attendance including 'illness, [and] unexpected or unscheduled visits from relatives, physicians or therapists' (Camp and Lee, 2011: 367).

There was more evidence across data sources regarding the potentiality for older participants to experience negative reactions when participating in intergenerational programmes, and how this potentiality could affect the perceptions of staff and carers when considering intergenerational programmes specifically for people living with dementia. For example, Camp et al. noted that caregivers 'have expressed anxiety regarding provision of intergenerational activities to persons with dementia, especially those activities involving young children' with concerns involving 'agitation, frustration, or aggressiveness potentially being demonstrated by older adults' when in the intergenerational context (Camp et al., 2007: 477). Jarrott and Bruno, in contrast, found that only 2 out of 50 adult caregivers responding to a survey 'specified concerns for their family member participating in [intergenerational] programs, including noise, disagreements between the participant and a child, and feeling that their relatives' talents were not used' (Jarrott and Bruno, 2007: 250).

Staff within older adult services may also hold views regarding the potential for negative reactions among older participants, further limiting the initiation and/or continuity of programmes. Within a study examining the use of Skype within care home settings, Zamir et al. reported that 'care home staff felt long video-call conversations (more than 30 min) per resident, especially for those with dementia, could be quite tiring and stressful' due to the length (Zamir et al., 2021: 4)<sup>5</sup>. Weeks et al. analysed the perceptions of nursing staff in regard to a proposed co-located childcare centre within the nursing home at which they were employed. They found that staff were concerned about the preferences of residents, particularly those who would not 'enjoy the presence of children' and would not 'want to participate in activities' with children (Weeks et al., 2016: 294). Staff also expressed concerns regarding safety, both that children may pose a risk of infection to older residents (Weeks et al., 2016: 294) and that 'residents with cognitive challenges might cause harm to the children' (Weeks et al., 2016: 294).

Moreover, there was evidence to suggest that older participants living with dementia themselves could perceive intergenerational programmes with concern. These perceptions, especially when reinforced with empirically bad experiences, could also form a contextual factor limiting participation because of the potential for perceptions to subsequently affect how older participants behave during programmes. Weeks et al. found that, when asked to consider a proposed co-located intergenerational programme, some nursing home residents expressed uncertainty regarding 'the role that they would have in implementing the intergenerational program' and being hesitant 'around being responsible for the children on some level' and not being supported when interacting with the children (Weeks et al., 2020: 9). The authors stressed that all of the male participants in the study 'expressed concerns' about interacting with children, indicating some older male participants may need additional preparation (Weeks et al., 2020: 12), or ultimately their choices to not participate should be upheld. The authors also found that nursing home residents exhibited concern regarding their health and not being able to fulfil their commitments to their children 'due to their physical limitations' (Weeks et al., 2020: 10). Another concern reported by Weeks et al. was the perception among residents that the children would cause too much commotion and noise (Weeks et al., 2020: 9). Noisiness and busyness during intergenerational programmes were reported in a number of studies (Hernandez et al., 2022: Smith et al., 2020: Biggs and

<sup>&</sup>lt;sup>5</sup> The study was initiated before the COVID-19 pandemic, however, undoubtedly has new implications in the current public health context in the UK and elsewhere (Zamir et al., 2021).

Knox, 2014: Jarrott and Bruno, 2007) and thus may contribute to a general perception of intergenerational practice involving 'noisy' environments.

Other negative reactions among older participants during programmes were reported, including impatience, frustration, and communication difficulties (Gigliotti et al., 2005: 434); recollection difficulties resulting in older participants being unable to recognise younger participants from session to session (Chow et al., 2018: 191); and unpredictability in mood (Lokon et al., 2012: 349). While such evidence is important towards understanding programme outcomes, it may reinforce perceptions among stakeholders that intergenerational programmes are unsuitable for people living with dementia, thus restricting implementation and participation.

## Context: Younger Participants – Key Settings and Diversity

Younger participants' ages across studies ranged from 0 - 58 years<sup>6</sup>. Younger participants were not explicitly targeted for participation in intergenerational dementia programmes on the basis of needs or conditions with the exception of Isaki and Harmon's study that purposefully included school-aged children identified with language and reading concerns (Isaki and Harmon, 2014).

Younger participants were recruited from a range of different settings across the studies, including colleges/universities (Brandão et al., 2021; Reel et al., 2021; Hannan et al., 2019; Harris and Caporella, 2019; Raber et al., 2019; Collins et al., 2017; Guerrero et al., 2017; Lokon et al., 2018; Lokon et al., 2017; Harris and Caporella, 2014; Yamashita et al., 2013; Lokon et al., 2012), schools (Zamir et al., 2021; Canning et al., 2020; Smith et al., 2020; Canning and Blakeborough, 2019; Caspar et al., 2019; Di Bona et al., 2019; Isaki and Harmon, 2014; George et al., 2011; George and Singer, 2011; George, 2011), co-locations (Janke et al., 2019; Landi and Smith, 2019; Lim et al., 2019; Low et al., 2015; Femia et al., 2008; Jarrott and Bruno, 2007; Lee et al., 2007; Gigliotti et al., 2005), high schools (Chow et al., 2018; Baker et al., 2017; Alant et al., 2015), volunteering/youth groups (Jenkins et al., 2021; Lokon et al., 2019;

<sup>&</sup>lt;sup>6</sup> Collins et al. (2017) investigated a one-off intergenerational festive event based at a university involving staff and student volunteers with an age range of 23-58 years.

Biggs and Knox, 2014), nursery/playgroups (Hernandez et al., 2022; Lyndon and Moss, 2021; Skropeta et al., 2014), and mixed settings (Chung, 2009).<sup>7</sup>

#### Context: Younger Participants – Barriers to Participation

There was some evidence in data sources that the participation of younger people within intergenerational dementia programmes could be limited by the busy schedules of children and young people, particularly during summer (Gigliotti et al., 2005: 434). The activities of younger participants may conflict with the scheduled activities of older participants, particularly within care home or assisted living settings, requiring flexibility to work around (Biggs and Knox, 2014: 65). Transporting younger participants to the venue for an intergenerational dementia programme may also be challenging (Zamir et al., 2021: 2; Smith et al., 2020: 7).

Parents and caregivers may have concerns about younger people participating in intergenerational dementia programmes which similarly could restrict participation if left unaddressed (Lee et al., 2007: 477; Jarrott and Bruno, 2007; 245, Biggs and Knox, 2014: 64). Concerns may focus on how children and young people may react to dementia and serious illness, or death should it occur (Biggs and Knox 2014: 64), with potential reactions among younger participants being confusion or apprehension (Lee et al., 2007: 477).

Younger people may experience apprehension and worry prior to participating in intergenerational dementia programmes (Di Bona et al., 2019: 1685; Lokon et al., 2012: 346; Canning et al., 2020: 272). Di Bona et al., for example, described how worries among younger people may focus around 'the potential of people living with dementia becoming angry and frightening' (Di Bona et al., 2019: 1685). While participation in programmes may be a vehicle for alleviating such anxiety among younger participants (Lokon et al., 2012: 346), nevertheless, it may represent a barrier if anxieties are not addressed as part of the programme implementation.

There is some evidence across data sources of children and young people demonstrating negative or disengaged behaviours during programmes, particularly if younger participants are not supported during programme implementation. Examples of suboptimal behaviours include preschool children refusing to stop playing in order to join in intergenerational

<sup>&</sup>lt;sup>7</sup> Weeks et al. (2020) and Weeks et al. (2016) were not applicable to younger participant involvement as the studies investigated a proposed co-location programme only and data collection did not involve younger participants.

activities (Jarrott and Bruno, 2007: 250), ambivalence among college students in judging between assistance and autonomy when interacting with and supporting participants living with dementia (Yamashita et al., 2013: 156; Lokon et al., 2012: 349) and college students communicating in inappropriate ways when interacting with participants living with dementia (Reel et al., 2021: 9). These suboptimal behaviours may give evidence to organisers that some children and young people, depending on their age, may lack the ability to interact successfully with people living with dementia or may require too much support to reach a point where successful participation becomes more likely.

#### *Context: Policy Drivers*

Ageing populations and dementia prevalence around the world and in different contexts were the most frequently cited contextual drivers across the majority of studies. However, a number of additional factors were also identified. Care provision, firstly, is a major driver of intergenerational dementia programmes. There are increasing needs for both informal caregiving and formal services (Lokon et al., 2018: 1), good quality living environments for people living with dementia (Landi and Smith, 2019: 2) particularly nursing home capacity (Weeks et al., 2020: 1), and further needs for psychosocial interventions (George and Singer, 2011: 392), meaningful activities (Low et al., 2015: 227), and rich social opportunities (Hannan et al., 2019: 50) within both care and community settings. Intergenerational practice, through its focus on addressing simultaneous needs, is further driven by competition for funds (Gigliotti et al., 2005: 425), the ambition to achieve economies of scale (Jarrott and Bruno, 2007: 243), and the potential to relieve pressure on services (Jenkins et al., 2021: 124). Intergenerational practice is also associated with the loneliness agenda and promoting social inclusion (Zamir et al., 2021: 1), as well as the need to reduce stigma and negative attitudes towards people living with dementia (Canning et al., 2020: 281, Harris and Caporella, 2014: 270-271).

# Context: Policy Barriers

Organisations may contend with scarce resources that prevent consideration of intergenerational dementia programmes. Long-term care typically needs to be designed around staffing and care routines, and this can result in a focus on 'prioritizing care tasks and meeting basic care needs' rather than exploring innovative practice (Canning and Blakeborough, 2019: 171). Scarce resources, particularly in terms of staffing, may limit the implementation of different types of activities for people living with dementia, or result in a

reliance on trained volunteers to realise implementation (Chung, 2009: 260). A reliance on volunteers to implement public services has been related to a neo-liberal idea of 'self-contained communities and the privatization of the service sector' in which the state aims to pass on state responsibilities to civil society (Rosol, 2011: 240). Such trends have been perceived to culminate in community as a means of government and the 'responsibilization' of voluntary agencies, wherein voluntary agencies 'train their numerous volunteers to become responsible citizens' such that ultimately citizens themselves are 'responsible for service provision to their individual clients and their communities' (Ilcan and Basok, 2004: 137).

Funding for intergenerational practice can be difficult to come by for organisations wishing to pursue such programmes (Clark et al., 2016: 309), and funding issues may further threaten programme sustainability (Isaki and Harmon, 2014: 97). Smith et al. conducted a cost-benefit analysis of a dementia education programme undertaken in a primary school with embedded intergenerational excursions, estimating a 'per unit of student benefit [of] \$600 [Australian dollars] per student who demonstrated an increase in dementia knowledge and attitudes at post program when compared to baseline' (Smith et al., 2020: 7). Although in-kind support throughout the programme meant that this estimation represented an upper bound (Smith et al., 2020: 7), nevertheless, such costs may be prohibitive for some educational partners, particularly if dementia friendliness or age awareness is not a curriculum priority for a particular age group.

Different studies have identified regulatory issues that may affect the implementation of intergenerational dementia programmes, including a need for constant safeguarding of younger and older people during interactions, the need for younger people to be covered by insurance when entering certain care environments (Zamir et al., 2021: 2), infection control and instructions for emergencies when bringing young people into a hospital care setting (McGeorge et al., 2021: 1877), and multiple property regulations being required to meet the needs of older and younger populations when planning co-location programmes (Weeks et al., 2020: 12). These regulatory issues can require lengthy risk assessment processes which may deter some organisations from pursuing intergenerational programmes, or may lead them to implement limited, passive forms of intergenerational interaction that are considered 'safe' such as 'having older adults observe a group of children sing or perform,

without one-on-one interaction between members of different generations' (Lee et al., 2007: 477).

Staff turnover can affect the implementation of intergenerational dementia programmes (Zamir et al., 2021: 7) (Gigliotti et al., 2005: 428). Staff may also lack the training, knowledge, and skills required to effectively support intergenerational dementia programmes (Lim et al., 2019; Canning and Blakeborough, 2019), or they may perceive people living with dementia to be incapable of meaningful engagement (Canning and Blakeborough, 2019: 171). Different expectations and approaches may further arise between staff from the different organisations involved, whether educational or youth organisations, or older adult services (Low et al., 2015: 236; Gigliotti et al., 2005: 435). Issues of recruitment, retention, and service reach can also affect the participant groups involved in intergenerational dementia programmes (Brandão et al., 2021: 10; Collins et al., 2017: 1605; Guerrero et al., 2017: 293).

#### Context: Overcoming Barriers - Training and Support

Providing training and support was an important contextual factor that could equip children and young people with the skills, knowledge, and confidence they needed to successfully manage the opportunities provided by programmes and thereby enhance their interactions with older participants. There was less of a focus on training and support being provided to older participants living with dementia across the studies, however Weeks et al., in reference to a nursing home setting, advised that time be 'devoted to explain to the residents their role and expectations related to the intergenerational program' (Weeks et al., 2020: 12).

For the Zeitgeist storytelling programme, student participants attended a session led by a nursing professor in which they were presented with information about 'how to communicate respectfully and effectively with people living with dementia' (Raber et al., 2019: 65). For the Avondale Intergenerational Design (AVID) challenge, younger participants attended an orientation seminar delivered by a diversional therapist from a partner residential aged care facility which addressed the ageing process, communication, and what to expect (Baker et al., 2017: 214). As part of a programme based in residential care homes in Canada, younger participants received intergenerational sensitivity training at their school (Caspar et al., 2019: 154). In relation to an intergenerational co-living programme, students selected for residency within the nursing home underwent training in 'first aid, fire security, and other applicable courses' (Landi and Smith, 2019: 6). For the Opening Minds through Art programme, student volunteers received '3- to 5-hour training on ways to facilitate the

elders' creative expression without doing the art for them' including a dementia simulation experience, a scientific lecture, orientation to the programme including video clips, and roleplays (Lokon et al., 2017: 411-412). For a university-based choir programme, younger participants 'attended a mandatory 1 hour orientation/information session' on dementia and the experience of living with dementia (Harris and Caporella, 2014: 273). Other aspects of support included debriefing sessions following programme sessions and the opportunity to ask questions of a geriatric psychiatrist by email (Chow et al., 2018: 191), providing briefs and prompts (Zamir et al., 2021: 3, Hannan et al., 2019: 56), and the opportunity to buddy-up with a fellow student to increase comfort (Zamir et al., 2021: 4).

Training and support given to younger participants prior to and during programmes is perceived to contribute to positive outcomes by dispelling negative misconceptions (Raber et al., 2019: 65) and promoting positive attitudes (Lokon et al., 2017: 420, Lokon et al., 2012: 159), providing an optimal basis for interactions to subsequently take place. Moreover, with adequate support interactions between younger participants and older participants living with dementia are both possible and beneficial (Lokon et al., 2012: 349-350). Training and support can address worries, increase comfort, and reassure younger participants (McGeorge et al., 2021: 1877, Raber et al., 2019: 65). Caspar et al. further relate the provision of training to ensuring the conditions of intergroup contact theory are met within programmes by building equality between the participant groups and signifying the support of the organisers (Caspar et al., 2019: 154). Skills-based training can also help younger participants be confident in communicating appropriately and effectively with people living with dementia (Reel et al., 2021: 9).

# Context: Overcoming Barriers – Partnerships and Staffing

The findings suggest that in order to ensure programme implementation unfolds within an appropriate context within which barriers have been recognised and addressed requires strong partnerships and organisations that adopt a suitable approach. Clark et al. recognised that partnership development represented one of the key challenges of intergenerational working involving consideration of 'which organisations need to be involved, what (leadership) roles they need to take and the degree to which they need integrated working to deliver the desired outcomes' (Clark et al., 2016: 303 – 304).

A number of studies attributed successes to the organisations involved and their partnership working. During an intergenerational summer school initiative, Gigliotti et al. described staff

from children and adult services building relationships to deliver the initiative with success contingent on 'staff from various programs and backgrounds communicat[ing], cooperat[ing], and work[ing] together' (Gigliotti et al., 2005: 433). Biggs and Knox, on the basis of their study, found 'institutional support from both the facility and the sponsoring volunteer organization' to be critical particularly towards securing 'sustainability...when changes in organizational staff and leaders occur' (Biggs and Knox, 2014: 65). In regard to an intergenerational dementia education programme, Smith et al. described how the 'combined efforts and shared vision of all partner organizations' involved were critical to success (Smith et al., 2020: 8). In particular, the collaboration allowed 'each partner [to provide] their own lens in design, implementation, and program support' (Smith et al., 2020: 7). McGeorge et al., in addition, accredited the 'passion and flexibility of the multidisciplinary organisations' involved in allowing the creation of an 'explorative' intergenerational initiative in a hospital setting (McGeorge et al., 2021: 1877).

It is up to organisations to ensure that different groups and stakeholders have a say in the design of intergenerational dementia programmes towards ensuring they are suitable and meet needs. Within a shared-site intergenerational day care service, Jarrott and Bruno described how organisers had focused on increasing 'efforts to inform caregivers/parents about their family member's...interactions' using, for example, a section in the monthly newsletter (Jarrott and Bruno, 2007: 252). The intergenerational summer school, in a similar vein, sought the 'perspectives of various stakeholders, including parents, administrators, facilitators, and program staff' in order to organise and implement the initiative (Gigliotti et al., 2005: 426). Weeks et al. recommended the inclusion of staff within programme development, particularly the need for organisations to address staff concerns surrounding intergenerational working (Weeks et al., 2016: 296). Similarly, in their study exploring residents' views of a proposed shared-site initiative, Weeks et al. noted that 'though older adults are key to any intergenerational program, their thoughts on programming are rarely solicited' (Weeks et al., 2020: 10).

Organisations are also instrumental in ensuring that staff and volunteers receive adequate training. Within the summer school initiative, high turnover among staff at the adult daycare facilities combined with student involvement tied to the academic year resulted in a need for ongoing training to equip 'program representatives with appropriate skills and knowledge' (Gigliotti et al., 2005: 436). A suggestion which emerged from their study was for the creation

of an intergenerational coordinator representing both services that would 'enhance continuity, staff training, and issues related to buy in' (Gigliotti et al., 2005: 436). Within the shared-site ONEgeneration initiative, two dedicated joint members of staff contributed to the intergenerational programming, including 'an intergenerational daycare director and an intergenerational coordinator' (Jarrott and Bruno, 2007: 246). The ONEgeneration programme also had a strong focus on training and cross-training for 'all levels of staff at both the child day care center and the adult day program' (Femia et al., 2008: 274; Jarrott and Bruno, 2007: 247). McGeorge reported that a hospital-based intergenerational programme offered staff professional development opportunities as well as the opportunity to interact with and see their patients in a different light and without being clinical (McGeorge et al., 2021: 1877).

Organisations must also provide suitable locations and venues for intergenerational dementia programmes. Biggs and Knox related institutional support to the 'provision of available meeting space', whereas the provision of funding may or may not be required (Biggs and Knox, 2014: 65). McGeorge et al. recognised that hospital settings and complex care environments in particular may require risk assessments and emergency planning for intergenerational activities to take place (McGeorge et al., 2021: 1877). The physical space and room layout for intergenerational activities was important in order to create opportunities for children to come together with older participants, enable 'appreciative moments' between participants (Hernandez et al., 2022: 493), increase interactions, enhance enjoyment, and encourage participant movement (Lyndon and Moss, 2021: 10). There was some conflicting evidence regarding the optimal size of space. One study found that a smaller space increased focus on the activity whereas a larger space resulted in the younger participants 'running around' (Lim et al., 2019: 374-375). Another study found that the 'limited size of the room' used for some activities 'made it difficult for the children and older adults to move' resulting in activities that 'were more static, structured and adult led' (Lyndon and Moss, 2021: 10). The use of technologies such as Skype within programmes may overcome the need for physical spaces and associated risk assessments, however, virtual communications in a study conducted by Zamir et al. appeared to work better when visual environments were incorporated into interactions (Zamir et al., 2021: 6).

Organisers must also consider the frequency and duration of programmed activities. For example, a number of studies found that a higher frequency and duration contributed to

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beneficial outcomes (Canning et al., 2020: 280; Femia et al., 2008: 275). Janke et al., however, found that 'higher frequency of participation' was predictive of poorer quality of life and fewer demonstrations of pleasure among older participants (Janke et al., 2019: 142). This was contrasted with Baker et al.'s suggestion that a lack of face-to-face time involved in one intergenerational design project may have accounted for student perceptions remaining static (Baker et al., 2017: 219). Other suggestions included focusing on the 'quality' of visits rather than the amount of contact (Chow et al., 2018: 192) and ascertaining the optimal duration on the basis of the activity itself (Lim et al., 2019: 374).

# Mechanisms

# Mechanism: Role provision

The provision of roles for people living with dementia engaging in intergenerational programmes has been identified as an important mechanism across data sources, whereby a clear and suitable role has been perceived to contribute to positive outcomes. Within data sources, role development for people living with dementia was emphasised whereas roles for younger people were discussed less frequently.

Across the different intergenerational dementia programmes, roles for older participants have been conceived in different ways. In their interactive reading project, Isaki and Harmon identify 'multiple roles' that were undertaken by the people living with dementia participating, such as providing spontaneous, unassisted guidance with reading, making comments, asking questions related to the stories and pictures, discussing vocabulary, and giving positive feedback to younger participants (Isaki and Harmon, 2014: 95-96). The Opening Minds through Art (OMA) initiative is based on enabling people with dementia to take on the core role of artist, with younger students as 'supporters' of this artist role (Lokon et al., 2018: 12). As the artistic experience is founded on autonomy, choice and friendship, it results in 'recasting the roles of older adults, with and without dementia, from custodial care recipients to still active and important participants in society with an important part to play in the transformative learning experiences of young adults' (Lokon et al., 2018: 12). Further research from the OMA project based in the USA suggests that the creation of the artist role for people with dementia encouraged the recognition of additional roles, such as 'teacher' and 'friend' (Lokon et al., 2012: 350).

Lee et al. used Montessori-based activities as a means of developing 'mentor-type' roles for older participants within their activity 'dyads' with younger participants, where '[h]igher

functioning older adults typically demonstrated and explained the activities to their child, and then assisted the younger child...in completing the activities' (Lee et al., 2007: 479). Through narrative and story techniques, the Zeitgeist publication project allowed older participants to assume a central role by possessing the 'knowledge' on which project outputs would be based, with younger participants facilitating the activities that would communicate this knowledge (Hannan et al., 2019: 50). Jarrott and Bruno, exploring a shared site programme, perceived mentorship roles as being more fluid between younger and older participants with both participant groups enabled to 'engage as mentors' and 'collaborate equally on an activity' (Jarrott and Bruno, 2007: 245). In relation to The Intergenerational School (TIS), researchers claimed that the school was the 'first known educational institution in the world to create a formal mentorship role for persons with dementia' (Whitehouse, 2017: 70; George, 2011: 988; George and Singer, 2011: 393; George et al., 2011: 393).

Studies further presented perceptions of how role development for older participants 'worked' as a mechanism within programmes, that is, how role development could affect the choices and reactions of older participants. Weeks et al. presented evidence that clear roles enabling older participants to make contributions accorded with the aspirations and preferences of older participants themselves. In their study, nursing home residents 'identified various ways they could contribute to the [children's] development including teaching the children music and reading to them' (Weeks et al., 2020: 8-9). Weeks et al. further noted that this finding indicated the importance that older adults living in care facilities placed on being able to continue in societal roles, and further demonstrated the value of intergenerational programmes towards animating opportunities (Weeks et al., 2020: 11). Enabling social usefulness has been described as 'one of the key aims of reminiscence and other intergenerational interventions' (Matheson-Monnet, 2020: 704) and the provision of social roles for people living with dementia has in particular been associated with Montessori-based practice (Camp and Lee, 2011: 367). In terms of enhancing practice, it is important to develop roles that are suitable, both enabling people living with dementia to 'succeed' while also 'preventing infantilization from taking place' (Lee et al., 2007: 482). Taking sufficient time to explain roles to older participants in a non-coercive way that takes account of preferences is also important (Weeks et al., 2020: 11-12).

## Mechanism: Matching and Preferences

Matching and pairing of older participants with younger participants emerged as a common feature of multiple intergenerational dementia programmes. The process of pairing has been grounded in knowledge of participants' backgrounds and shared interests (Guerrero et al., 2017: 291), assessed needs and preferences of the participants (Caspar et al., 2019: 154), and the use of specific Montessori-based assessments as a means of determining activities and matching older participants with children in 'dyads' (Lee et al., 2007: 479). Pairing between older and younger participants has been used within practice in order to 'strengthen interactions' (Lim et al., 2019: 375) and allow participants to 'complement each other's abilities' (Gigliotti et al., 2005: 429).

Programmes in general have frequently sought to use information about individual participants towards enhancing practice. In relation to an intergenerational dementia programme at a long-term care facility, Janke et al. recommended practitioners 'use assessments with residents as well as observations during programmed activities and interventions to ensure that individuals with dementia are benefitting from their involvement' and have a continued desire to participate, with the option to leave activities depending on observed reactions (Janke et al., 2019: 143). In relation to a shared-site programme, Jarrott and Bruno described how staff would use 'information from the individuals and their families about clients' interests, skills, and social history to develop programme, the choices of children were prioritised along with those of older participants to secure voluntary participation for all (Femia et al., 2008: 275).

The implementation of pairing along with the use of information and preferences was perceived to enhance intergenerational dementia programmes in several ways. Personcentred care upholds choice and individualisation, particularly in long-term care environments (Weeks et al., 2020: 11). Emphasising choice, moreover, further upholds selfdetermination and respect for privacy (Biggs and Knox, 2014: 55). Biographical information can be used as the basis for programme development ensuring a good fit between participants and activity, such as a gardening project for those with experience working with plants or who have enjoyment in being outside (Jarrott and Bruno, 2007: 242). Ongoing data gathering regarding participants can allow longer-term programmes to accommodate 'changes in cognitive and physical functioning in both older adults and children' (Lee et al., 2007: 482). Suggestions for practice included time to prepare matches between participants and activities (Lee et al., 2007: 482), consistency in the matching between participants (Caspar et al., 2019: 154, Lokon et al., 2017: 420), and an awareness of and allowance for the fact that intergenerational dementia programmes will not suit everyone (Hernandez et al., 2022: 495).

#### Mechanism: Meaningful and structured activities

Ensuring effective activity development as the basis of intergenerational dementia programmes was a frequent theme throughout data sources. Lee et al., in their study of Montessori-based activities, perceived the structuring of interactions as a 'key issue' in the development of successful intergenerational programmes (Lee et al., 2007: 478). In relation to the choir-based programme in the USA, Harris and Caporella observed that the activities of the choir enabled 'change to take place' through allowing 'structured meaningful interactions and [the] interweaving of melodic voices [to make] beautiful music' (Harris and Caporella, 2014: 279). Chung described how an intergenerational reminiscence programme in Hong Kong was structured to focus on 'three reminiscence functions' including promoting interaction, teaching and informing, and reinforcing self-image (Chung, 2009: 260).

In relation to an intergenerational 'grandfriends' project, Low et al. concluded there was a 'requirement for structured interactions between generations to maximize participation by older adults with symptoms of dementia' (Low et al., 2015: 237). For the Opening Minds through Art project, Yamashita et al. described the initiative as a 'highly structured service-learning program' (Yamashita et al., 2013: 157). Canning et al. perceived the 'highly-structured and relational nature' of an intergenerational dance programme to be instrumental in the programme's success, with the partnering between participants additionally being 'highly structured and purposeful, involving touch, communication and working towards common goals' (Canning et al., 2020: 279). Femia et al., with their study examining intergenerational preschooling, cautioned against 'mixing' generations together, arguing that 'well-conceived' programmes would instead aim to 'planfully [bring] the generations together' (Femia et al., 2008: 285). In their study of an intergenerational playgroup, in contrast, Hernandez et al. described interactions between children and older participants occurring 'organically', with structure relating to the 'environment and occupations' (Hernandez et al., 2022: 492 – 495).

Activity development was seen to be important in order to create meaning for both older and younger participants and particularly for people living with dementia (Camp and Lee, 2011: 1), with a number of implications for programme implementation and outcome optimisation. Baker et al. noted that structured visits with a clear purpose could help promote positive responses among younger participants (Baker et al., 2017: 213). The authors further saw 'guided' interactions as being beneficial in allowing longer engagement among people living with dementia (Baker et al., 2017: 217). Caspar et al. suggested that the focus should not be on the activity type per se, but rather on 'ensuring the activities were meaningful to the older adults and that they fostered shared growth and relationship building' (Caspar et al., 2019: 159). Gigliotti et al., similarly, found efficacy in activities 'that emphasized cooperation between the generations to achieve a common goal and optimize interactions' requiring ongoing flexibility (Gigliotti et al., 2005: 438).

Lim et al. described a process of initial learning within one intergenerational pilot programme in order to address the 'uncertainty [of] whether the activities designed would appeal to both the seniors and children' (Lim et al., 2019: 372). Femia et al. described ongoing planning and evaluation towards developing activities in terms of their 'feasibility and acceptability to child and adult participants and center staff' (Femia et al., 2008: 274). A key consideration for effective activity development was ensuring that activities would be developmentally appropriate for younger and older participants, as well as older participants living with dementia. For example, in regard to the LINKages programme, activities were implemented in a way that was 'appropriate to the functioning level of the residents and ... thus, failure free' (Caspar et al., 2019: 158). However, given diverse needs and abilities among the different participant groups, appropriate activity development can be complex and challenging. Jarrott and Bruno described curriculum development harnessed towards creating 'developmentally appropriate motor, language, social, and creative provocations' addressing children's needs whilst also promoting 'rehabilitative or maintenance goals for each adult' (Jarrott and Bruno, 2007: 245). Effective activities are required to enhance intergenerational interactions, however, ensuring appropriate activities for all participants may require substantial planning.

## Outcomes

#### Outcome: Community and Relationship Building

A number of studies described the benefit of intergenerational programmes in terms of building and replicating community dynamics. Skropeta et al. found that the

intergenerational exchange via a playgroup programme produced 'an environment which could be representative of the mix of generations associated with community life' (Skropeta et al., 2014: 6). Another study focused on a playgroup programme found that the programme was more than a social activity provided in a care setting as it 'enabled clients to be treated 'like family' by members of the community' (Hernandez et al., 2022: 494). During a summer school initiative, Gigliotti et al. concluded that the programme had 'fostered community capacity by linking the children and adults in mutually supportive interactions' (Gigliotti et al., 2005: 437). Although a remote programme, Zamir et al. perceived a Skyping programme to result in increased non-familial social contacts and social networks for the older participants by establishing new friendships (Zamir et al., 2021: 6). Harris and Caporella described the goal of the intergenerational choir as 'making a college community more dementia friendly through building connections between groups of people and increasing students' understanding about dementia' (Harris and Caporella, 2019: 8).

Programmes were also strongly associated with relationships. Programmes were described in terms of synergy, strong bonds, and special relationships (Gigliotti et al., 2005: 433), shared growth and relationship building in keeping with the conditions of intergroup contact theory (Caspar et al., 2019: 159), relationship building through dance interactions, name learning, and eye contact (Canning et al., 2020: 280), feelings of belonging, connecting, and learning (Brandão et al., 2021: 8), and supportive, positive relationships and making new connections (Jenkins et al., 2021: 123).

Subsequently, reciprocity and mutuality between participant groups arises from the communal and relational character of intergenerational dementia programmes. Studies described how the relationships that were formed between older and younger participant groups were mutually beneficial (Jenkins et al., 2021: 124, Canning and Blakeborough, 2019: 174, Hannan et al., 2019: 61, George, 2011: 993), mutually respectful (Hernandez et al., 2022: 495, Jenkins et al., 2021: 123, Skropeta et al., 2014: 7), and involved mutual learning and enjoyment (Jenkins et al., 2021: 124). The mutual and respectful nature that has been observed and described within intergenerational dementia programmes can be linked to the provision of person-centred care for older people (Hernandez et al., 2022: 495) and to theories of personhood (Kitwood, 1997). However, further studies may benefit from formal frameworks and methodologies to more rigorously evaluate the strength and longevity of community and relationship building.

# Outcome: Successful Participation – Older Participants

A number of studies explicitly described how people living with dementia had successfully participated in intergenerational programmes. Canning et al. found in their study that people 'living with more advanced stages of dementia in long-term residential care' could beneficially be included in an intergenerational dance programme (Canning et al., 2020: 280), with their own 'study findings [demonstrating] the residents' abilities to participate in meaningful social engagement in the face of their multiple deficits and losses' (Canning and Blakeborough, 2019: 170). Reflecting on a care home-based programme, staff interviewed for one study 'were keen to highlight that participants' ability to engage in the session had not related to severity of dementia' (Di Bona et al., 2019: 1686). Skropeta et al. described how their study of an intergenerational playgroup corroborated other practitioners' findings that people living with dementia's 'experiences interacting with and caring for children [remain] so ingrained that they remain able to interact appropriately and positively with children until late in the progress of a dementia illness' (Skropeta et al., 2014: 8).

Zamir et al. concluded that care home residents living with dementia were 'capable of using and benefiting from video-call conversations...with new social contacts such as school students' if the support of a facilitator was available (Zamir et al., 2021: 7). Brandão et al., however, described the difficulties that could be encountered through using digital platforms such as Zoom to facilitate remote intergenerational interactions in the community without direct support (Brandão et al., 2021: 7). Despite these difficulties, Brandão et al. similarly concluded that the 'Playful Living' programme was 'feasible' for vulnerable older adults with and without stroke and dementia-induced cognitive impairments (Brandão et al., 2021: 9).

Low et al., however, suggested that dementia could preclude some benefits, noting that a 'grandfriends' programme, while promoting engagement and enjoyment, did not appear to 'improve longer term outcomes in comparison to usual care' suggesting this could be because of insufficient time built into sessions, the preschool age of the children, or 'that the moderate level of dementia in many of [the] older participants meant that most did not derive the extended benefits' (Low et al., 2015: 236-237).

# *Outcome: Cognition and communication – older participants*

Evidence across studies indicating an impact on cognition and communication for older participants living with dementia was mixed and merits further empirical examination. Using the Mini Mental State Exam (MMSE) during a reading-based intervention, Isaki and Harmon found that 'there was no change in cognitive status during [the older adults'] participation in the study' and similarly 'the older adults did not feel that their personal mood and communication skills changed because of participation' (Isaki and Harmon, 2014: 96). In a study focused on volunteering at The Intergenerational School (TIS) in the USA, the researchers similarly found that the intervention group engaged in volunteering 'showed no significant difference in decline relative to the control group' on measures of cognitive functioning (George et al., 2011: 398, George and Singer, 2011: 394). However, there was a medium effect size for cognitive functioning suggesting the 'lack of statistical significance for these outcomes may [have been] due to the small sample' (George et al., 2011: 398). Similarly, when taking account of mixed methods to analyse the study including interviews with older participants and participant-observation ethnography, a number of participants 'acknowledged that the process of learning new facts as well as thinking and responding to students helped them stay cognitively stimulated' during the programme (George, 2011: 991).

In terms of communication outcomes for older participants living with dementia, Di Bona et al. found that among those 'who spoke with the children, there were occasions when they struggled to answer the children's questions, finding it difficult to understand what or why they were being asked, or being unable to recall the detail', however, such situations were handled with spontaneity and staff facilitation (Di Bona et al., 2019: 1686). Canning and Blakeborough, moreover, found evidence of nonverbal communication between older and younger participants during a dance-based programme (Canning and Blakeborough, 2019: 176). Brandão et al. found in their remote play study that participants living with dementia had 'mild linguistic impairments and needed greater attention and memory remote and inperson support during communication' (Brandão et al., 2021: 6).

# *Outcome: Purpose and Personhood – older participants*

Role provision and providing opportunities for older participants to feel purposeful and useful was identified as a key mechanism of intergenerational dementia programmes, yet evidence regarding the degree to which programmes actually achieve increases in purposefulness is again mixed. Similar to cognitive functioning, George et al. found no significant increase in sense of purpose for the participating group relative to the control group arising from an intergenerational volunteering programme, and no significant increase in sense of usefulness (George et al., 2011: 398, George and Singer, 2011: 394-395). However,

the participating group engaged in volunteering experienced no mean decline in either sense of purpose or sense of usefulness, whereas the control group's mean scores declined for these measures, but not significantly (George et al., 2011: 398, George and Singer, 2011: 394-395). Moreover, a medium effect size was found for sense of purpose for the participants suggesting the lack of statistical significance could have, again, been due to the small sample (George et al., 2011: 398). Qualitatively, the intergenerational volunteering experience 'strongly suggested that serving as ''mentors'' to younger students imbued participants with a sense of purpose and sense of usefulness that enhanced their [quality of life]' and 'provided an opportunity for participants to reprise meaningful professional roles in their late-life course' (George, 2011: 992).

In regard to a shared site study in which 39 older participants were interviewed, 86 percent of respondents answered positively that being around the children in the programme made them feel 'needed' (Jarrott and Bruno, 2007: 251). Jenkins et al. found programme participation, particularly for older participants, gave them purpose and something to look forward to that would get them out of the house (Jenkins et al., 2021: 124). Zamir et al., with their study examining intergenerational interactions via Skype, found that the 'visual aspect of the communication seemed to encourage residents to "put on clothes" and fix their appearance' (Zamir et al., 2021: 6).

Other findings included intergenerational dementia programmes providing older participants with the opportunity to feel 'productive' and get purposefully involved (Janke et al., 2019: 142), and demonstrate a 'stronger sense of purpose through their mentoring role to the children' (Lim et al., 2019: 375). Additional facets of purpose included imparting knowledge and advice (Zamir et al., 2021: 6), sharing life histories and thus inspiring younger participants with knowledge about career options (Biggs and Knox, 2014: 61), and becoming role models to younger participants (Harris and Caporella, 2019: 13).

# *Outcome: Engagement – older participants*

Engagement outcomes for older participants have been a major focus of several studies. Janke et al., for example, conducted a study at a shared site intergenerational programme using instruments to measure engagement and quality of life. Their findings indicated a significant, positive correlation ( $p \le .01$ ) between constructive engagement and pleasure for older participants, indicating that adults who engaged more constructively, or actively, also exhibited more pleasure (Janke et al., 2019: 140). Similarly, non-engagement was

significantly correlated with less pleasure exhibited amongst older participants ( $p \le .001$ ); and non-engagement also impacted quality of life scores (Janke et al., 2019: 140-141). The authors also found a significant correlation between constructive engagement and helping behaviours ( $p \le .001$ ) (Janke et al., 2019: 140). The authors additionally found that a higher frequency of participation resulted in lower quality of life and fewer demonstrations of pleasure, constructive engagement among older participants could be of brief duration, and that older participants were more responsive to active games and the infant younger participants (Janke et al., 2019: 141 – 145).

Lee et al. investigated engagement outcomes in relation to the application of intergenerational Montessori methods compared to regular programmed activities. They found that constructive engagement predominated during Montessori-based activities compared to regular activities (p < 0.001) (Lee et al., 2007: 480). In addition, more negative forms of engagement predominated during the regular activities (Lee et al., 2007: 480). Montessori-based activities also resulted in less non-engagement compared to regular activities (p < 0.001) (Lee et al., 2007: 481). The authors noted that 'on average, [residents] were constructively engaged for almost 5 times longer during intergenerational Montessoribased activities compared to regular unit activities programming' (Lee et al., 2007: 482). Moreover, the study involved observations conducted '2 days a week, at three different times of day' over the course of six months, which gives some indication that the engagement patterns they found were durable (Low et al., 2007: 480) and accords with Janke et al.'s recommendation for longer study periods when assessing engagement during intergenerational activities (Janke et al., 2019: 143).

Baker et al. reported similar findings in regard to an intergenerational design programme whereby 'a significant main effect of activity [was present], in that resident engagement was higher during the...student visits compared to usual...activities averaged across all 4 time points' (Baker et al., 2017: 216). They further found that there 'was a significant interaction effect between activity and resident cognition', with greater cognitive impairment being associated with increased resident engagement during visits, whereas greater cognitive impairment was associated with decreased resident engagement during usual activities (Baker et al., 2017: 216). Low et al. found higher passive engagement and less self-engagement during intergenerational befriending sessions (Low et al., 2015: 234).

In a comparative assessment of activity types including intergenerational sessions, Lokon et al. found that activities of any type resulted in more frequent engagement and less frequent disengagement than when there were no activities at all, with pleasure showed more frequently during the intergenerational arts sessions (Lokon et al., 2019: 481-482). Reel et al., similarly conducting a study of an arts-based intergenerational programme, found that engagement did not increase across sessions for participants (Reel et al., 2021: 6). The authors also found that there were significantly more social (verbal and nonverbal) engagements per participant than activity engagements per participant in each session (p < 0.01) (Reel et al., 2021: 5).

Qualitative studies indicated some evidence regarding engagement for older participants. Jenkins et al. related how participants in a performance-based arts project described their feelings of 'engagement and absorption in artistic activities' (Jenkins et al., 2021: 123). Canning and Blakeborough observed positive engagement among participants living with dementia during an intergenerational dance initiative (Canning and Blakeborough, 2019: 172). During an intergenerational volunteering initiative involving girl scouts, staff in the assisted living facility found that 'residents [were] more interactive and [came] out of their rooms to do activities with the girls and their parents on meeting days' (Biggs and Knox, 2014: 63). Similarly, in regard to a university-based programme, a survey of caregivers revealed 'socialization and stimulation were the overwhelming benefits, as perceived by the caregivers' (n = 15, 56%) (Guerrero et al., 2017: 293). Lyndon and Moss observed that 'singing was a time when both the older adults and the children were more engaged' (Lydon and Moss, 2021: 9).

#### *Outcome: Depression and stress – older participants*

Regarding depression, George et al. found that the intervention group in their intergenerational volunteering study experienced 'no significant difference in decline in depression relative to the control group' (George et al., 2011: 398, George and Singer, 2011: 394). During a study of a reminiscence-based programme, however, Chung reported a significant pre- and post-programme difference for older participants using the Chinese version of the Geriatric Depression Scale (CGDS) (Chung, 2009:261).

In regard to stress impact, George et al. observed a statistically significant mean decline in stress from baseline to posttesting within the intervention group of their study (p = 0.0485)

(George et al., 2011: 397-398, George and Singer, 2011: 394). The authors concluded that intergenerational volunteering could thus contribute to the quality of life of intervention group participants through this demonstrable decrease in stress (George and Singer, 2011: 395). In contrast Low et al., using the Cohen-Mansfield Agitation Inventory (CMAI) to assess agitation among older participants engaged in intergenerational sessions compared to a control group receiving usual care found 'no differences between Grandfriends and control groups' for agitation (Low et al., 2015: 234).

# Outcome: Positive affect and quality of life - older participants

Positive affect and quality of life outcomes for older participants were investigated across a number of studies. In a study investigating a design programme, Baker et al. found a significant main effect of activity whereby residents felt more positive and less negative from pre- and post-design sessions relative to pre- and post-usual activities (P < .001) (Baker et al., 2017: 217). Using an observational measure, Caspar et al. noted through descriptive statistics that 'pleasure and general alertness were the two visible emotions observed most often (62% and 87% respectively) during the observation periods' for older participants engaged in a care home intergenerational initiative (Caspar et al., 2019: 158). The authors concluded that this finding '[indicated] that the residents tended to experience a positive affect while participating in the intergenerational programs' (Caspar et al., 2019: 158). They further noted that negative emotions were rare during the observation periods, with 'anger (.2%), anxiety/ fear (0%), and sadness (.3%) ...rarely observed and never for more than 16 seconds at a time' (Caspar et al., 2019: 158). Qualitative methods also suggested some evidence for positive affect among older participants as identified by staff, caregivers, or by participants themselves (George, 2011: 991, Jarrott and Bruno, 2007: 251). Through interviews with older participants engaged in a shared site programme, for example, Jarrott and Bruno found that participants most commonly reported positive affect as a benefit they had experienced as a result of their participation (Jarrott and Bruno, 2007: 251).

Weeks et al. found that staff working at a nursing home perceived that intergenerational programming in the form of a proposed shared-site childcare centre would 'improve the quality of life of the residents' (Weeks et al., 2016: 293). Nursing home residents themselves perceived factors such as relationships and participation in various activities to be important to their quality of life (Weeks et al., 2020: 6). In an intergenerational reminiscence programme in which the Quality of life-Alzheimer Disease (QoL-AD) measure was used,

Chung found significant pre- and post-programme differences for QoL-AD (Chung, 2009: 261). However, Low et al. in their study of the 'grandfriends' programme found no differences in quality of life between the participating and control groups through using the Long Term Care Quality of Life Scale (LTC-QoL) (Low et al., 2015: 234). As related above, Janke et al. deployed the Quality of Life in Dementia Scale (QUALID) to report findings that non-engagement during intergenerational sessions resulted in lower quality of life among older participants, whereas increased pleasure during sessions was associated with higher quality of life (Janke et al., 2019: 141).

#### *Outcome: Enjoyment – Older Participants*

Multiple data sources provided evidence that older participants had found intergenerational dementia programmes to be enjoyable. Using feedback forms to evaluate a co-location programme, Lim et al. found that '97.4 [percent of] seniors stated they enjoyed [the] activity with children and would like to participate again' (Lim et al., 2019: 373). In their observational study comparing a friendship programme to usual activities in a care home environment, Low et al. found that 'enjoyment was significantly higher during the Grandfriends sessions compared to usual activities averaged across time' (Low et al., 2015: 234). Through focus groups with participants and caregivers participating in an intergenerational choir, Harris and Caporella found a strong theme of enjoyment, whereby every focus group member 'expressed the enjoyment they were having participating in the choir' and how it was a 'positive experience for them' (Harris and Caporella, 2014: 278). In a study involving dementia education combined with embedded intergenerational visits, Smith et al. reported that older participants and their carers found the programme to overall be positive generating 'positive emotions, as a direct result of interacting with the children, and positive self-changes' (Smith et al., 2020: 5). McGeorge et al. described that a hospital-based intergenerational project allowed for the older patients to be 'absorbed in an environment whose sole purpose [was] creating joy' (McGeorge et al., 2021: 1877).

Older participants were also observed as exhibiting, and reported having, physical signs of enjoyment, such as leaning in and smiling in the presence of children along with other positive behavioural changes (Di Bona et al., 2019: 1686), and enjoyment in being able to laugh and have fun with the children who did not judge older participants on the basis of their cognitive incapacities (George, 2011: 991).

A number of studies described particular aspects of programmes that older participants had enjoyed. Jarrott and Bruno found that of those older participants who said they had enjoyed the intergenerational programme, 87 percent of the interviewees went on to say they had particularly enjoyed the children's playfulness and affection (Jarrott and Bruno, 2007: 251). In relation to an intergenerational volunteering programme with girl scouts, older participants who were resident in the assisted living facility 'said that they [liked] to hear the young people and know that they [were] using the place' and further 'mentioned enjoying going to their meetings, doing things with the girls, and visiting with the girls and their participants in particular 'appreciated when they witnessed a child in a moment of learning' and found watching the children to develop and learn to be significant (Hernandez et al., 2022: 493). Zamir et al. found through feedback forms that all care home residents involved in an intergenerational Skyping programme had 'enjoyed using video calls to communicate with students' (Zamir et al., 2021: 5).

## *Outcome: Wellbeing – Older Participants*

There was some evidence in studies that intergenerational dementia programmes could have a beneficial impact on the wellbeing of older participants. Using a wellbeing profiling observational tool to investigate a co-located programme, Lim et al. found that 'all the seniors maintained their wellbeing scores throughout the [programme] and none showed decline' (Lim et al., 2019: 373). Chung reported a similar maintenance function through the Cantonese version of the Mini-Mental State Examination, finding that although 'the global mental state of the elderly participants did not show significant improvement at postintervention, it was kept relatively stable throughout the whole reminiscence programme' and that overall 'the elderly participants experienced better psychological functioning after participating in the reminiscence programme' (Chung, 2009: 262).

In regard to their hospital-based intergenerational programme, McGeorge et al. observed that the intergenerational 'workshops...[facilitated] physical movement on occasion, providing encouragement for patients get out of bed and mobilise' (McGeorge et al., 2021: 1876). Jenkins et al. found that participants reported a perceived impact on overall health resulting from participation in an arts programme, including 'the emotionally and mentally stimulating effect of engaging artistically and socially' as well as 'some physical benefits too, such as the opportunity to expand range of movement and exercise vocal chords' (Jenkins et al., 2021: 124). In contrast to this, Skropeta et al. found 'a significant difference between the pre-test and post-test results' for energy/fatigue among older participants engaged in a playgroup programme using the SF36 instrument (Skropeta et al., 2014: 5). They proposed this change may have occurred due to the general age of the older participants where the mean age was 85 and, while suggestive of deterioration, the sample size was too small to confirm this (Skropeta et al., 2014: 9).

Finally, Lokon et al. reported findings relating staffing to overall wellbeing intensity. They found that 'both creative and non-creative activities regardless of who conducted the activity contributed significantly to the overall intensity of well-being for PWD when compared to no activity at all' (Lokon et al., 2019: 480). Creative activities conducted by art and music therapists had a greater impact on the overall wellbeing of people living with dementia than creative activities conducted by regular staff members, however, this difference was not significant (Lokon et al., 2019: 480). Moreover, Lokon et al. found that higher staffing ratios 'resulted in higher overall intensity and frequency of well-being' for people living with dementia (Lokon et al., 2019: 482-483).

#### *Outcome: Reduced Stereotyping and Improved Attitudes – Younger Participants*

One of the key outcomes for younger participants was reduced stereotyping and improved attitudes towards older people and people living with dementia, with both quantitative and qualitative evidence supporting this outcome.

Quantitative measures suggest that intergenerational participation can improve attitudes towards dementia among younger groups of different ages. In a study deploying multiple measures to explore the effect of intergenerational preschool experiences on young children's attitudes and behaviours towards older people, Femia et al. found significant group effects in several areas. Young children attending an intergenerational preschool were significantly more likely to express empathy toward older adults (p = .05), demonstrated marginally greater social acceptance of an old woman (p = .06), and expressed greater willingness to be close to an old woman (p = .03) than children attending a standard, non-intergenerational preschool (Femia et al., 2008: 282 – 283). Using a measure exploring children's views on ageing, Isaki and Harmon found significant findings for younger participants' pre- and post-test scores following participation in an intergenerational reading programme involving people living with dementia (p = .009) (Isaki and Harmon, 2014: 96). They concluded that the programme had made the children's perceptions 'more positive

even though many of the older adults exhibited physical impairments' (Isaki and Harmon, 2014: 97).

Caspar et al. deployed a pre- and post-test method exploring youth perceptions of ageing among young volunteers of high-school age participating in an intergenerational programme involving four residential care homes. They found statistically significant differences in 20 of the 24 items measuring youths' perception of aging, with students' impressions of older adults becoming more positive (Caspar et al., 2019: 156). Some of the strongest findings related to 'younger participants perceptions of older adults as being more hopeful than despairing, more friendly than unfriendly, more fair than unfair, and more positive than negative' (Caspar et al., 2019: 156).

In a study exploring allophilia<sup>8</sup> and college students' 'liking' of older adults following participation in an arts-based intergenerational dementia programme, Lokon et al. found that college students' participation in the programme 'showed significant positive association with affection, comfort and kinship, engagement and enthusiasm, as well as the overall Allophilia scores' and that participating students showed greater improvements in these domains of allophilia than students in the non-participating control group (Lokon et al., 2018: 10). In a university-based study deploying pre- and post-test evaluations among students participating in a befriending community-based intergenerational dementia programme, Guerrero et al. found that while young participants tended 'to have highly positive perceptions of working with seniors at baseline' nevertheless positivity was maintained throughout participation in the programme (Guerrero et al., 2017: 292).

However, there was quantitative evidence suggesting weaker findings regarding changes in attitudes among young participants. Using a repeated-measures within-subject design, Baker et al. found 'no significant change in students' attitudes to older adults, self-esteem, or empathy, at any time point' and suggested this may be related to the limited face-to-face time (3.5 hours) that younger participants had with older participants (Baker et al., 2017: 217 -219).

Qualitative evidence also suggested that participation in intergenerational dementia programmes could reduce stereotyping and result in more positive attitudes. Di Bona et al.

<sup>&</sup>lt;sup>8</sup> Allophilia denotes liking of and positive attitudes towards other groups. The Allophilia Scale was first developed and validated by Pittinsky et al. (Lokon et al., 2018: 4; Pittinsky et al., 2011).

conducted a focus group with children who had participated in a pilot programme involving visits to a care home, finding that 'those children who had visited the care home exhibited sympathetic attitudes and increased confidence in relation to dementia' (Di Bona et al., 2019: 1689). Biggs and Knox similarly conducted focus groups with girl scouts volunteering in an assisted living facility along with content analysis of essays written by the young volunteers, finding that the girl scouts 'mentioned learning about getting along with others no matter their age and learning about respect' (Biggs and Knox, 2014: 60).

Lokon et al. conducted a study analysing the content of reflective journals written by university students participating in an intergenerational art-based initiative for people living with dementia, finding that students reported their 'attitudes toward elders with dementia became more positive' and they felt 'more knowledgeable, more comfortable, and more confident in their interactions with elders who have dementia' (Lokon et al., 2012: 344).

Using participant observation and interviews conducted with children involved in an intergenerational ballet programme, Canning et al. found that the children began 'to see the ways that they were alike [with their partners living with dementia] in the dance classes, rather than the differences' (Canning et al., 2020: 278). The authors concluded that intergenerational programming had a role to play in 'dispelling negative stereotypes of ageing, and inspiring positive views of persons living with dementia among children' (Canning et al., 2020: 279, Canning and Blakeborough, 2019: 177).

Harris and Caporella conducted two phenomenological studies that sought to explore the meanings behind younger participants' experiences when participating in a university-based intergenerational choir involving people living with dementia, with the latter study collating data from four cohorts of younger participants over the course of four years (Harris and Caporella, 2014, Harris and Caporella, 2019). Using a repeated measure design involving a pre-test, mid-point test, and post-test, they asked the students to relate the images that came to mind when they heard the word 'Alzheimer's disease or dementia' by writing down ten words. At the end of participation in the choir, younger participants were more likely to associate positive words with dementia with only 15 percent of words being negative (a percentage decrease from pre-test of 49 percent) and 71 percent of words being positive (a percentage increase of 55 percent) (Harris and Caporella, 2019: 11).

Analysis of student responses to open-ended questions corroborated these findings, with students reporting that participation in the choir reduced their perception of the 'differences'

they thought they had with people with [dementia]' and 'lessened their feelings of discomfort' (Harris and Caporella, 2014: 275). A number of additional studies used similar pre- and post-test repeated measures built around the word associations generated by younger participants in reference to 'dementia'. For example, Chow et al. found that younger participants' perspectives 'completely changed' by post-assessment to focus on similarities, personhood, and individuality when describing someone living with dementia, with younger participants evincing 'more positive attitudes' and 'more complex responses' (Chow et al., 2018: 192). Alant et al. similarly found that after exposure via an intergenerational intervention 'all participants described older persons as positive, while mixed terms were used before exposure to the programme' (Alant et al., 2015: 153).

Reduced stereotyping and improvement in attitudes were also perceived by other stakeholders as an outcome, actual or potential, for younger participants. For example, in their survey of nursing staff asked to consider a shared-site intergenerational initiative, Weeks et al. reported that staff saw a potential benefit in younger participants' attitudes becoming more respectful and aware of ageing as a result of intergenerational interactions (Weeks et al., 2016: 295-296). Jenkins et al., using focus groups, found that the adults involved in an intergenerational arts initiative- including older participants, carers, and facilitators- felt that participation in intergenerational programmes 'enhanced levels of understanding and sensitivity towards working with the older participants' among the younger participants involved (Jenkins et al., 2021: 124).

## *Outcome: Dementia Knowledge – Younger Participants*

There was some evidence to suggest that participation in intergenerational dementia programmes could improve the levels of dementia knowledge and awareness among younger participants. In a mixed methods study with children aged 9 and 10 years undertaking visits in a care home context, Di Bona et al. implemented a 12-item dementia awareness questionnaire (Di Bona et al., 2019). Their results indicated that dementia knowledge and awareness 'was very low amongst children before their participation in the scheme (mean 2/11) and still low (mean 4/11) but statistically significantly higher (p<0.01) post-curriculum' (Di Bona et al., 2019: 1685).

In a dementia education initiative involving children aged on average 9 years, Smith et al. implemented the Kids Insight into Dementia Survey (KIDS). They found that 'KIDS scores increased from baseline to post-program' and improvements were sustained at the 6-month

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follow up, suggesting a moderate maintenance effect (Smith et al., 2020: 5). The authors concluded that the study 'provided strong evidence that dementia education improved children's knowledge and attitudes toward dementia, for at least 6 months' (Smith et al., 2020: 8). However, the education initiative involved embedded intergenerational excursions for a smaller group of the children enrolled in the programme and the authors did note that 'there were no between group differences in dementia knowledge or attitudes in the children who did or did not interact with older adults through the intergenerational experience' (Smith et al., 2020: 8).

In a study exploring an intergenerational reminiscence programme involving youth volunteers aged 15 or over, moreover, Chow implemented an adapted 'Dementia Quiz' measure and found 'significant pre- and post-programme differences' in dementia knowledge (Chow, 2009: 261). The younger participants further reported 'gains in the knowledge of dementia' (Chow, 2009: 262). In a study with college students participating in an arts-based intergenerational initiative, Lokon et al. implemented the Dementia Awareness Scale (DAS) finding a significant association between participation in the programme and improved overall DAS scores and knowledge about people living with dementia (Lokon et al., 2017: 420).

Qualitatively, Biggs and Knox found that girl scouts with an age range of 5-12 years volunteering in an assisted living facility reported 'learning about Alzheimer's disease and other health problems and disabilities of aging and how these impact on elders' within their reflective essays following programme completion, with eight out of twelve essays themed for learning (Biggs and Knox, 2014: 61). In their study of a care home visitation scheme involving school children aged 9 - 10, Di Bona et al. conducted a focus group with the children involved and found that they had acquired 'factual knowledge' as a result of their experiences corroborating the moderate gains on the dementia awareness questionnaire (Di Bona et al., 2019: 1687). For example, many of the children 'were able to describe signs and symptoms of dementia, knew there were many types of dementia and that there is no cure' (Di Bona et al., 2019: 1687).

In a dementia awareness programme with four participating high school students, Chow et al. reported that students 'shared that they learned a lot about both themselves and dementia' in the post-programme assessment, including better listening skills and how to be compassionate (Chow et al., 2018: 191-192). Harris and Caporella found that nine college

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students out of thirteen self-reported that their experiences participating in an intergenerational choir involving people living with dementia had 'increased their awareness and understanding about living with dementia' (Harris and Caporella, 2014: 275). Students, in particular, described becoming 'more aware of the role of the family members in assisting their diagnosed member' suggesting greater appreciation of the importance of caregiving (Harris and Caporella, 2014: 276). Collating student cohort experiences, the authors concluded that this increase in dementia awareness remained consistent for the different students participating in the choir throughout the four years of the programme (Harris and Caporella, 2019: 11-12).

#### *Outcome: Enjoyment – Younger Participants*

There was some evidence across data sources that younger participants found intergenerational dementia programmes engaging and enjoyable. Di Bona et al. reported non-participant observations during the 'Adopt a Care Home' initiative involving 'both adults and children with smiling faces, making eye contact and engaging in lively conversations and laughter' (Di Bona et al., 2019: 1686). However, they also reported a number of children who required encouragement from staff to engage in interactions or 'looked bored, confused or frustrated' during activities (Di Bona et al., 2019: 1686). Harris and Caporella related how student participants were motivated to join their choir-based intervention out of an enjoyment of singing, however, 'by the end of the rehearsals, their pleasure from participating in the choir far exceeded their reasons for joining' (Harris and Caporella, 2014: 276). In their analysis of college students' reflective journals during participation in the Opening Minds Through Art (OMA) programme, Lokon et al. found that 'students' sheer enjoyment of interacting with their partners and facilitating their partners' creative expressions' was the most commonly reported theme (Lokon et al., 2012: 348).

# Conclusion

This chapter has presented findings related to the context, mechanisms, and outcomes of intergenerational dementia programmes as identified within the realist synthesis and provided an overview of the understanding and operationalisation of intergenerational inclusion internationally. In terms of geography, settings, and research disciplines, intergenerational practice involving people living with dementia has a broad international scope. Moreover, there is evidence that people living with more advanced dementias have successfully participated within programmes internationally. Nevertheless, a review of the

programme context reveals continuing participation barriers along with barriers to programme implementation. Older participants, particularly in care settings, may be vulnerable to illness and scheduling issues beyond their control. There can be a perception among carers, care staff, and service providers that people living with dementia have the potential to react negatively within intergenerational situations. Older participants themselves may be apprehensive about their participation, which can further be compounded by their views not being solicited prior to programme development and/or a lack of training among facilitators. Younger participants, similarly, may find their participation restricted due to additional commitments and pursuits. Anxiety about ageing and dementia may be prevalent among younger participants, and misconceptions about dementia may be common. Barriers to participation for all participants groups can be reinforced by organisational barriers, such as implementation complexity, scarce resources, and staffing and regulatory issues.

However, mechanisms and outcomes were also apparent. The provision of roles for older participants living with dementia was perceived to be important as it allowed older participants to contribute and reinforced their broader, ongoing societal roles. Using knowledge about the interests and backgrounds of all participants was perceived to enhance programme effectiveness, allowing for participants to be matched up and contributing to the development of meaningful, structured activities. A range of outcomes had been measured throughout the studies using a variety of methods. Cognition and communication, purpose and personhood, engagement, depression and stress, positive affect and quality of life, enjoyment and wellbeing were outcomes discussed in relation to older participants. Reduced stereotyping and improved attitudes, dementia knowledge, and enjoyment were outcomes investigated for younger participants. Community and relationship building was an outcome that pertained to all participants.

# Chapter 6: Findings - Intergenerational Inclusion in Scotland

# Introduction

This chapter presents findings from the second phase of this study comprising qualitative interviews and addresses how the concept of intergenerational inclusion has been understood and operationalised in Scotland via intergenerational dementia programmes. The next chapter presents distinct findings concerning intergenerational inclusion and Scottish policymaking.

This chapter begins by exploring the contextual factors that have affected the implementation of intergenerational dementia programmes in Scotland. Information regarding the make-up of older and younger participants groups is presented along with an indication of the settings from which participants have commonly been recruited in Scotland. Following this, barriers to participation for people living with dementia and for children and younger people are presented. The section on the Scottish context concludes with findings related to the primary ways in which implementation barriers have been overcome, including programme development, training and facilitation, and resources.

The next section provides an overview of the programme mechanisms that were identified within the interview data. Preparation and planning formed a theme that bridged context and explanatory mechanism due to the emphasis that interviewees placed on continuous, iterative, and flexible planning throughout the duration of programmes. Additional core mechanisms included purpose and roles; preferences, lived experience and personhood; and sharing and learning between participant groups.

The final section explores the outcomes that were described by the interviewees including relationships, gains in knowledge and understanding, reduced stigma, enjoyment, resultant behaviour and feelings, confidence and wellbeing, and engagement.

# Context

# Context: Definitions

Interviewees described 'intergenerational' as a term that remained novel in Scotland. One manager suggested that intergenerational practice in general was both 'broad' and 'new' (Participant 002). Another manager felt that while intergenerational practice was established in Scotland, it was rather 'dementia' in intergenerational work that could be perceived as new (Participant 010). A trustee felt that intergenerational as a term was now being used

more often, however, they were sceptical if people's understanding of the word was becoming clearer (Participant 007). An officer, along similar lines, perceived that the term 'intergenerational' was still likely to cause surprise and confusion in general (Participant 006). A coordinator noted that some groups delivering programmes that involved intergenerational elements may be engaged in intergenerational practice without realising or without labelling their practice as such (Participant 008).

Several interviewees were of the view that intergenerational practice could be flexible in terms of the age groups involved, for example, that practice 'should include everyone' (Participant 006) and that the ages of those involved should not be the focus but rather that practice should seek to '[challenge] the siloing of ages' (Participant 007). A director, similarly, suggested intergenerational practice should not be perceived as a duality of age groups:

"...it's not just about those two age groups specifically, it's about the different layers of those generations and the impact that can have." (Participant 005)

A coordinator felt there were not necessarily 'rules' about the age groups that ought to be involved in intergenerational practice, however, they did perceive that intergenerational dementia programmes in particular would result in the 'older people involved... [being] quite relatively older' due to the fact of age being a risk factor for dementia (Participant 008).

The coordinator additionally pointed out that intergenerational practice could be defined as programmes that were purposefully implemented and organised:

"...one of the definitions of it or used to be, that it's something that's brought about by an agency or group or somebody, it's something that is incepted or developed or done." (Participant 008)

This was in contrast to a trustee who felt that the term 'intergenerational' could best describe more 'natural' processes of inclusion that unfolded within communities (Participant 007).

The two key components that interviewees used to define intergenerational dementia programmes included relationships and getting involved with other people (Participant 002; Participant 005; Participant 010) and reciprocity (Participant 0007), that was variously encapsulated as mutually beneficial (Participant 006), interdependency (Participant 007), an exchange (Participant 009), and a two-way practice (Participant 012).

Therefore, while there was strong consensus that intergenerational dementia programmes could be defined in terms of the reciprocal relationships they could engender, some ambiguity remained in regard to the degree of popular understanding of the term 'intergenerational' in Scotland, a preference to be non-prescriptive in terms of the specific age groups to be involved, and a key distinction drawn between 'intergenerational practice' that is done on purpose through programme implementation and more organic intergenerational processes within communities in general.

# *Context: Older Participants – Key Settings and Diversity*

Interviewees described the settings and older people's services involved in intergenerational programmes, including care homes, day care centres and services, and sheltered housing/housing associations. However, a number of interviewees were keen to emphasise that intergenerational work involving people living with dementia should not just be limited to care homes and older people's services (Participant 008), but rather should involve the whole community:

"...(it) involves the whole community, whether it's the local school, whether it's the youth club down the road, whether it's the church you know, or the walking group, you know, it's about a whole community approach." (Participant 005)

Interviewees, moreover, perceived that people living with dementia could successfully participate in intergenerational programmes. For example, one officer described that there was a need for intergenerational programmes involving participants with 'early onset right through to end stage dementia' (Participant 006). Similarly, one coordinator stressed the need to consider the personhood of people living with dementia and their own particular journey rather than make blanket assumptions based on their condition alone:

"But I mean there's no reason why someone who lives with dementia can't do mentoring. It depends on the person, it depends on the type of person, the type of dementia a person has, what stage they're at, their personalities, their background." (Participant 008)

Some interviewees described people living with fairly advanced dementia being involved in intergenerational initiatives, suggesting this was both possible and could have perceived

beneficial outcomes. For example, one officer described a party-based intergenerational activity in which the older participants had 'quite late-stage dementia'. Another manager described an initiative she had heard of involving a woman with advanced dementia volunteering in a nursery in Scotland:

"...they had a nursery, and they had a lady with really advanced dementia that really was struggling in the community, and she started going there and she was very mobile..." (Participant 012)

However, another manager described fewer services and opportunities being available for those people living with more advanced dementia:

"...there's not a lot of things out there for people whose dementia is further on, you know, so when people go through their journey, and they go a little bit further there isn't a lot out there." (Participant 002)

Within some intergenerational programmes aimed at people living with dementia, furthermore, it was not necessary for older participants to have an actual dementia diagnosis to get involved:

"We were allowed to be very loose in our definition, we didn't have to be targeting people with a diagnosis of dementia. So we tended to work with older people who might have early memory issues but who didn't necessarily have a clinical diagnosis." (Participant 004)

Often interviewees cited programme examples, particularly those based in care homes, and could not say exactly whether they were targeted at people living with dementia or not, again suggesting fairly loose, informal criteria for older participants to get involved in the Scottish context:

"I can't specifically say that's dementia, but there are many people in the care homes who are living with dementia." (Participant 006)

# Context: Older Participants – Barriers to Participation

The interviewees described a number of restrictions and barriers to participation in intergenerational dementia programmes that may affect older people. Firstly, familiarity and

continuity within a service was described by one manager as important for enabling the participation of older people living with dementia:

"...if they have been with us a year or so they're comfortable, so even if they're maybe not quite as chatty or even if they're finding it a little bit difficult, it is easier for them because they have been coming along and they know the service and they know us... What's really hard is somebody whose cognitive skills aren't as good coming into the service and feeling a little bit outside because they can't contribute" (Participant 002)

Another restriction on participation for people living with dementia may be a lack of support from carers, although it appears that where carers have had misgivings about activities involving children in the Scottish context these concerns have been overcome:

> "...lots of the carers who didn't know that we did this would say, have you got children in the unit...? And I would be like, yeah, we get them, they come twice a week. And they were like, oh and how does that go? Is that alright? (Worried expression). Because a few people were maybe a bit unsure about it, you know, and I would have to reassure them that, no, no, it goes okay and nobody is upset by it, everybody really enjoys it, and you can see a benefit of it." (Participant 003)

Beyond the concerns of carers, there may be more generalised perceptions of people living with dementia as being uniquely at risk within their social interactions, and this perception may make it more difficult for some older people to get involved in intergenerational programmes:

> "I think there is a bit of a perception of we must treat them with kid gloves and wrap them in cotton wool. And that's maybe to the detriment of the older people who have dementia, or any older people... what am I trying to say, the benefits outweigh the risks, maybe? Or you should maybe balance it up and say, well, if you shut them away for months on end with no social connections, what's going to happen to them then?" (Participant 004)

A manager corroborated this view, perceiving older people's services in Scotland to be on occasion 'quite risk-averse in...care planning'.

Risk may be emphasised by environmental factors such as the venue for activities to take place in, and the need for transport to deliver participants to the venue safely. For example, one officer linked programme ineffectiveness to a failure to adequately plan the venue for intergenerational dementia programmes:

"...the big one that I would think for ineffectiveness would be the venue, so planning where the activity takes place is really important. And the seating and everything for older people has to be appropriate. Because one of the nurseries invited the older people to the nursery and they had these wee stupid chairs that you can (laughing) hardly sit on." (Participant 006)

Another manager described how organisers may struggle to find venues that are entirely inclusive, particularly in rural communities where choice is more limited:

"I think, certainly for our groups, venues is a big one because a lot of the time there is maybe not a lot of choice, especially some of the more rural communities. They don't have a lot of choice of where they can hire to hold that activity. And sometimes it's maybe not ideal in terms of its layout or accessibility and there're things they can do to help that but maybe not sort of make it completely inclusive." (Participant 008)

Transport can also compound venue issues. For example, one officer observed that transport was an issue 'that comes up all time' when planning intergenerational programmes in Scotland (Participant 006). Another manager similarly described transport as a big problem:

"...transport is a big problem as well with a lot of things that were going on, you know, how do you get people to these places to meet up, you know, where's the best place for everybody." (Participant 012)

Therefore, the perception of older people living with dementia as being vulnerable and at risk may make it harder for them to participate in intergenerational programmes, and issues

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with transport and venues may increase the risk perceived by potential organisers when contemplating this type of practice.

# Context: Younger Participants – Key Settings and Diversity

In terms of younger participants, they were most often associated with educational settings and youth service providers. Nursery schools, primary schools, secondary schools (described by the majority of participants), early years centres, primary school children's councils, modern apprenticeships, work experience opportunities, colleges and further education, youth clubs, and volunteering initiatives like the Duke of Edinburgh Award were typical groups and social spaces from where younger participants had been drawn in the experience of the interviewees.

An interesting finding within the Scottish context of intergenerational dementia programmes was the degree to which younger participants with additional needs had been included. For example, one manager worked with a number of intergenerational volunteers from a secondary school, and they described the volunteers as 'some students that (were) not academic' (Participant 002). An officer described how one intergenerational project provided a space for some younger participants where they were 'not being judged as the sort of...the pupils who (weren't) making it at school sort of thing' (Participant 004). A director, moreover, perceived intergenerational dementia programmes to provide a good 'opportunity' and 'route' for 'people who might be less academic' and 'perhaps even less engaged' (Participant 011). The director described some of the groundwork they had undertaken with educational partners towards building intergenerational programmes targeted at particular younger people:

"What we have done...with some schools...because some schools have got teachers who are responsible for those who are more disruptive or less academic and were harder to engage, and about targeting them for this kind of programme...I think there's a really strong argument for doing that, but again, you know, it depends what particular schools, if they've got that focus..." (Participant 011)

Another manager described how their intergenerational dementia programme included younger participants 'who were looked after and who had a lot of special needs' (Participant

003). The manager alluded to the extra planning this required in collaboration with a colleague from the educational sector:

"...(teacher) would look at what children were coming, did they have special needs, that type of thing, what we had to put in place for that, the extra help that we would maybe need, kind of dietary issues." (Participant 003)

One manager described how some of their initial intergenerational working was in fact inspired by a younger person with autism who had stated they wanted to work with older people during an evaluation for a prior project (Participant 010). The manager further described the younger person as a 'very, very, very bright boy but a lot of problems...(t)hat wasn't just the autism, there was family background as well which was...bad' (Participant 010). Other groups of younger participants described as getting involved in different intergenerational dementia programmes included a college class of people with learning disabilities (Participant 006) and pupils with 'behavioural problems' (Participant 010). Two participants further suggested that intergenerational dementia programmes could be a route for engaging excluded groups, for example, people who are recovering from drug use (Participant 008; Participant 010).

In contrast to this, a number of participants also described typical younger participants within intergenerational dementia programmes as being 'high-fliers' (Participant 010) and the 'usual suspects' of very active young people engaged in lots of activities (Participant 011). For example, a coordinator described the younger participants involved in one project, saying 'the quality of the young pupils who participated...they were of rather a high calibre' and further stating they 'were really, really impressive' with some of them even aiming for medical and surgical careers (Participant 008). A director further saw a tendency for programmes to rely on active, engaged young people getting involved:

"...the younger people tend to be those really self-motivated, bright, young volunteers. It's not those younger people who would never, you know, wouldn't volunteer...I think, yeah, there's a good argument for those programmes to be structured in such a way that you bring them in. Otherwise, what happens out in the world is, I think, it's always the same young people do, do the Duke of Edinburgh, work with older people...attending all the sports clubs. The usual suspects, that's what it is." (Participant 011)

Some participants also suggested there was a need to be flexible and broad when considering the types of younger participant that could potentially be involved in intergenerational dementia programmes, moving beyond notions of younger participation limited to education or dementia being simply a condition of much older people. For example, one officer stated:

> "...I think any age, that's what I believe, I just think that if it was somebody over thirty and they were going to do a befriend with someone of an older age, and you get younger people with dementia, too, so whatever fits I think across the generations." (Participant 006)

Similarly, a director suggested flexible definitions were necessary including, for example, younger people of working age:

"I think in terms of how we define it, I think we just see so many different opportunities across all age groups so if you did start looking at particular age groups of younger people and moving into young adults, and adults before old age...I think there are different opportunities for different age groups." (Participant 011)

The director preferred the term 'multigenerational' as it encapsulated how inclusion was 'far more of a gradation' (Participant 011). Finally, there was some evidence that achieving parity among genders could be difficult when it came to involving younger participants. For example, one officer noted in a relation to a project that, 'It happened to be boys' (Participant 004). A coordinator in relation to a separate project observed, 'it was a few boys as well, but it was mainly girls, strangely enough' (Participant 008).

# Context: Younger Participants – Barriers to Participation

The interviewees described a number of barriers to participation in intergenerational dementia programmes affecting younger people. The participation of younger people in programmes in most instances relies on the support of the adults and leaders engaged with the younger people:

"It varies on- on different communities and different areas, on how children are supported to be included with older people. I think they need leadership, you know, from...groups like ours, you know, to get the meetings between generations to actually happen." (Participant 013)

The coordinator further described 'the people who are the adults that are engaged with these children, so that's whether it's teachers like we said, group leaders, after school club leaders...' as being among the key stakeholders of intergenerational dementia programmes for this reason (Participant 013). The support of parents towards their children participating, moreover, was also seen to be key. One manager described how a lack of parental support resulted in some children being excluded from participating in an intergenerational dementia programme:

"We had the same with...some of the children's parents, they didn't like the idea, you know, about children coming into a unit like this, they thought it was dangerous. And those children, we either...(teacher) worked her magic and got the parents to come round or those children were excluded from the visits, which was very hard on the children because they did want to come, obviously, with all their friends." (Participant 003)

Along with parents, educational and youth leaders, the support of organisations to enable younger people to get involved was also perceived by interviewees to be important. For example, one manager described how, especially in the past, some volunteering organisations did not facilitate volunteering for younger people:

> "...there were very few volunteering opportunities for young people under the age of sixteen because of insurance, various things, a bit of bias on the part of volunteer-involving organisations who felt that young people just weren't up to it." (Participant 010)

Similarly, a coordinator described an organisation that preferred young volunteers to be at least sixteen years of age:

"So I recruited (four) fifteen-year-olds who were coming up to their sixteenth birthday. And that was sort of viewed in that organisation as quite a low, young age to be able to volunteer." (Participant 008)

Therefore, particularly where participation in intergenerational dementia programmes is of a voluntary nature rather than school-led, then there may be a preference for young volunteers to be above a certain age, resulting in a barrier to younger volunteers. A literature review undertaken by the Scottish Government to inform the development of Scotland's volunteering outcomes framework noted that the promotion of volunteering among younger people had been a focus of the programme for government in 2017-18. However, the review further suggested that younger people may experience unequal opportunities when it came to volunteering, for example, with grammar schools supporting volunteering to a greater degree than comprehensive schools and with grammar schools thus acting as "volunteering brokerage workers' that [benefit] their students and [provide] routes to volunteering not available through other schools' (Rutherford et al., 2019: 39).

In addition to age restrictions, some organisations may also be risk averse whereby perceptions of risk may militate against participation for younger people more generally. This can involve the perceived risk that people with dementia may pose to younger people, resulting in the groups being kept apart:

"They're often not in touch with children or people are fearful of having children be around them because of the unpredictable nature of dementia." (Participant 003)

It can involve, secondly, services for older people who are not amenable to giving access to children:

"...we found quite a lot of people didn't want us to come to their sheltered housing, you know, like to the big room that they all have in these sheltered housings. So we were fine with the one they have in (area), but other places were very kind of like, oh no, we don't want children here." (Participant 003)

A third type of risk can involve wider partners and stakeholders who are unaccustomed with intergenerational practice and who perceive bringing older and younger groups together as posing a risk:

"You say that you want to bring, you know, six people with dementia and ten children, three year olds, and they look at you with absolute horror (laughing)." (Participant 003)

Another major barrier several interviewees described involved the commitments and competing priorities that younger people have. Competing priorities could involve part-time work for young people, with big employers being more inflexible now regarding issues such as overtime:

"...there are so much demands on young people, whether it's study, whether it's working part-time...it's not necessarily that they want the extra money for working these extra hours, but they haven't got a choice because they're told, if you're out, don't come in, cheerio." (Participant 007)

The trustee went on to describe how young people may face difficult choices between earning money, sports clubs, and other extracurricular activities. Exam pressures were also recognised as a barrier to participation for younger people (Participant 008; Participant 010; Participant 011). However, one trustee suggested that younger children also faced competing commitments and that lack of time did not only affect teenagers:

> "...the younger kids, you know, are they going to lots of things that they don't have the time either?...Is there Brownies on a Tuesday, is there swimming on a Wednesday?" (Participant 007)

Competing pressures, moreover, may negatively impact the experience young people have during the programme. For example, one coordinator described a young participant who was unable to fully engage with a training session:

"And one of the girls, I know that she worked at (fast food restaurant) part-time, she fell asleep. She just, it wasn't her fault, she just fell asleep, you know." (Participant 008)

# *Context: Older Participants – Fear*

A number of interviewees described aspects of fear that may be felt by older people when considering whether or not to get involved in intergenerational dementia programmes. One aspect of fear related to a deep-seated fear among older generations of dementia itself. Such fears could make older people in general eschew programmes aimed at people living with dementia, or it could result in older people prior to a formal dementia diagnosis avoiding such programmes even though they may be best placed to benefit. One officer alluded to such issues:

"It's still got such a big stigma even among that age group, or maybe even especially among that age group there's a fear or there's something...yeah, where people want to avoid being in among people with dementia- you know, it's not logical and maybe it is a fear of the unknown or fear that that'll be them one day soon." (Participant 004)

A manager similarly felt that fear of dementia could lead families and individuals to attempt to cope alone making it difficult to implement early interventions:

"...patterns of behaviour have been established that are quite destructive and so we need to get people out and about just that wee bit, you know, sooner." (Participant 001)

The same manager felt that older people continued to 'live in such fear' of dementia to the point where a generation in Scotland 'had been lost' when it comes to dementia (Participant 001).

Some older people were also perceived to experience fear of younger people:

"There still seems to be quite a lot of fear, older people seem to think that youngsters are just a bunch of hooligans, you know, and are going to rob them or stab them or you know (laughing) take their drugs off them or something." (Participant 001)

Therefore, fear of dementia and fear of younger people may be experienced by some older potential participants of intergenerational dementia programmes, and if left unaddressed, such fears may affect participation and outcomes.

### Context: Younger Participants - Fear

Interviewees further recognised that younger participants may also have fearful perceptions about dementia prior to getting involved in intergenerational dementia programmes. One manager described a popular myth about ageing that abounded in their particular region: "The kind of, the myth (here) is if you get diagnosed with dementia, you end up locked up in the mental hospital...So then, you know, you have to unpick that, that perception, a lot of time." (Participant 001)

Another manager felt that, in general, fear is a common response to dementia:

"And I think that, you know, in general- and I am generalising now – you know, people are scared of dementia. You know, people are like 'Ahhhhh!' (breathing in with fright) and it's a scare for them." (Participant 002)

Finally, a trustee perceived a danger that the COVID-19 pandemic may emphasise fears among younger people that they may pose harm to older people:

"...I think there's a danger that we've gone back to that kind of like, oh, be a bit scared of older people because we might hurt them and that's a shame." (Participant 007)

#### Context: Programme Barriers – Stigma and Misconceptions

Interviewees perceived that age-based stigma and misconceptions were still apparent in the Scottish context and could be a barrier to intergenerational programmes. For example, one coordinator felt there was still 'a lot of ageism around' (Participant 008). An officer perceived there to be 'a lot of mistrust and blame and misunderstanding between the generations' (Participant 004). One manager described how different age groups could persist in labelling each other, which could result in the labels coming to bear on actual behaviours:

"I mean I suppose you know there's ageism so old people think young people, young people think old people, middle-aged people, you know, we all seem to sort of sit in a label and actually we kind of, sometimes our behaviour sort of acts out the label." {Participant 001)

All age groups, whether older or younger, were perceived to still be liable to stereotypes and misconceptions about other age groups. Young people were described as seeing older people as 'old fogies' (Participant 001) and 'slow, (with) walking sticks, deaf, smelly, bossy'

(Participant 010) on the one hand, while at the same time viewing older people as 'super vulnerable' and 'to be protected at all costs' on the other hand (Participant 004).

Particularly in relation to dementia, one officer described how misconceptions about dementia could lead to changes in behaviour among other groups:

"They were all early onset dementia, and they came once a month to a group, and I worked with them for three years. And I learned a lot about what happened to them in the community when they had been diagnosed, and how they felt, and how people treated them differently. Even although, the people thought they weren't aware of them treating them differently, but they were very aware..." (Participant 006)

Younger people were also perceived by one officer to be vulnerable to negative attitudes arising from their own peer group. The officer noted a lack of confidence in some young people participating in one intergenerational programme:

> "Some of them had no confidence and you know probably aren't treated well by their peers and don't fit in with their age group." (Participant 004)

Older people, similarly, were described by interviewees as holding stereotypes about younger people. For example, older people were described as viewing younger people and children as 'pests' (Participant 001), as 'selfish, loud, always on the telephones' (Participant 010), as 'noisy, horrible, swearing all the time' (Participant 012), and as antisocial or threatening based on fashions such as baggy jeans and hoodies (Participant 010, Participant 012). One manager noted a tendency for different groups to judge each other by appearances and the often false connotations drawn from the appearance, speech, and actions of others:

"...people judge people by what they're wearing as well, or how they act, or how they think they're acting, when a lot of the time they're just standing there in hoodies because it's cold and they're having a chat. Older people can maybe feel a bit frightened..." (Participant 012)

#### Context: Programme Barriers – Resources

A strong debate emerged regarding monetary resources and the degree to which funding was required to enable effective practice, as well as monetary resources relative to resources of staffing and time. Funding was recognised to be a potential barrier to intergenerational dementia programmes by several interviewees (Participant 2, Participant 004, Participant 006, Participant 007, Participant 008, Participant 009, Participant 011, Participant 012). One interviewee noted that funding cuts were affecting the health and social care sector in general, resulting in less funding available in the Scottish context than before (Participant 012). Third sector groups, typically a major partner in dementia support services and intergenerational practice, were perceived to be particularly vulnerable to funding issues, such as continually having to seek out new funding (Participant 002), having short-term funding only (Participant 004, Participant 011), and having less funding and influence than statutory partners (Participant 008). Activity/leisure coordination in care homes could also be limited in monetary terms (Participant 008) and in terms of coordinators themselves frequently having to provide cover for absenteeism among care staff (Participant 010). In terms of realising programmes, interviewees described how 'resources and funding could be an issue' (Participant 007), 'financially...a lot needs to be invested' in practice (Participant 010), and that at least some resources would be required for activity set-up (Participant 013).

One officer, however, suggested that funding as a barrier may be a perception not necessarily rooted in actual experience:

"People are always looking for funding, right? And I always say, well, what do you need funding for?" (Participant 006)

Other interviewees described a more positive, supportive funding landscape in Scotland (Participant 012), suggesting money is available for different types of practice but may vary in terms of access (Participant 007). Several interviewees described intergenerational dementia programmes they were considering or had run in the past that had not cost anything or had cost very little (Participant 001, Participant 010, Participant 012). For example, a coordinator stated:

"You can actually put on activities on a shoestring. And you just manage your resources to the best of your ability." (Participant 013) Another manager, similarly, described how they had completed 'good' programmes on 'shoestrings', suggesting funding was not an essential criterion of effective practice.

Some interviewees described resources in addition to funding that may be more critical to effective programmes. One manager felt that attitudes, values, and time were the biggest issues affecting effective programme implementation (Participant 001). An officer, similarly, felt a key requirement was a 'general acceptance that this sort of project is appropriate and acceptable' (Participant 004).

Time was similarly described as a 'big enemy' (Participant 008) and as a 'factor' (Participant 006). Staff resources were recognised to be important to implementation (Participant 008), with in-person programmes affected by sickness and absence (Participant 002) and online sessions not having capacity to provide the one-to-one tech support that may be necessary to assist people living with dementia to participate virtually (Participant 009). The success of programmes was also perceived to rely on how organisers managed their pre-existing resources and assets, including the participant groups they worked with and their buildings (Participant 006). A coordinator felt that 'people can change their practice to include people with dementia, without spending money' (Participant 008).

### Context: Overcoming Barriers – Programme Development

Interviewees described several ways in which programmes could be initiated effectively. The frequency and duration of programmes were considered to be important programme factors. One officer noted that setting the frequency and duration of intergenerational contact was up to the groups and participants themselves 'to decide if they want to meet four times a year, once a week, a six-month project, once a week forever' depending on their own preferences (Participant 006). Interviewees described programmes ranging from one-off sessions to programmes occurring on a weekly, fortnightly, or monthly basis. A manager described a special intergenerational session that had lasted all day and that provided important learning for planning sessions in terms of length:

"The length, I think they came up in the morning and they were right near to the end, and I think that was an awful long day...because this group...hadn't had the children or the interaction with the children as much, it was probably a little too much for them." (Participant 002) During an online intergenerational event, a manager found differences in preferences for how long the session should last:

> "People were saying they wanted longer, we thought that was plenty for people living with dementia, but I think that came from maybe some of the younger people who are not living with dementia, could have had it go on a bit longer." (Participant 009)

There was a recognition that many programmes continued to be 'small scale and short term' (Participant 008). One manager stated that interactions '(need) to be a regular thing so that people can see an actual benefit from it' (Participant 003). A director, similarly, perceived programmes would be 'more effective the longer they can go on' and should ensure 'regular, ongoing connections' (Participant 011). Similarly, without longevity the director felt intergenerational practice may not be the best option available to organisers:

"...unless you've got programmes where you can, longer term...really demonstrate deeper impact then there are other things that you could spend money on that are more effective." (Participant 011)

Participant numbers was a minor theme. Especially when involving people living with dementia, smaller numbers appeared to be more effective:

"I think as well as the, the...informing both parties of who will be attending so...we know how many children are going to be there, so it's not overwhelming, you know, so that it can be sensitive to the needs of both parties." (Participant 013)

However, the need to keep numbers small to ensure effective practice was recognised by one manager as being incompatible with some larger service providers that needed to reach 'big numbers' (Participant 010). Managing participant numbers also caused additional planning for one programme as the attendance of children had to be rotated to ensure they all had the chance to participate equally (Participant 003).

Evaluation was considered by some interviewees to be important to programme development, however, implementing evaluation could be difficult where resources were not reserved for the purpose (Participant 013), measures were incapable of capturing some

of the subtler aspects of intergenerational practice (Participant 008), or outcomes themselves, such as an increase in social networks for people living with dementia, were inherently difficult to measure (Participant 011). Aspects of effective evaluation described by interviewees included using intergenerational networks to assist with setting up evaluations (Participant 003), ensuring the evaluated outcomes actually measured 'the intergenerational aspect of the project' (Participant 006), building in regular evaluation throughout a project and involving different stakeholders including participants (Participant 010), and ensuring self-evaluation along with independent evaluation (Participant 005).

Interviewees further gave examples of and recommendations for recording programmes, including producing books from photographs and drawings (Participant 002), written resources for others to use towards similar projects (Participant 004), creative recordings using 'music, art, film and animation' (Participant 005), capturing oral history (Participant 007), qualitative feedback from all involved (Participant 008), and the use of quotes, photographs, and films (Participant 010). Recording programmes was perceived to contribute towards the legacy of practice and consolidating meaning for participants who would continue to talk about what they had done (Participant 010). Recording could also facilitate learning and adoption of practice for others:

"Because often the real success of work is then the legacy of it and how others can utilise it going forwards." (Participant 005)

Incentives and recognition were also described as an additional element of programme development, including certificates and badges, often associated with dementia awareness training (Participant 001, Participant 004, Participant 010), as well as special celebrations at the end of programmes (Participant 010). One officer queried whether recognition had any impact on younger participants' motivations in particular:

"...maybe they got a wee certificate saying they had volunteering hours, but I don't think that was so important to them." (Participant 004)

#### Context: Overcoming barriers - Training and facilitation

There was some agreement among interviewees that having the right facilitators to lead programme activities contributed to positive programme implementation. One manager, for example, stated that programmes were 'ineffective' where facilitators were 'definitely not skilled in intergenerational practice' and further recommended it was 'crucial' to get the right facilitator (Participant 010). In terms of skills and qualities that made facilitators effective, enthusiasm was perceived to be important towards overcoming the uncertainties and inhibitions of participants:

"...if people haven't got that kind of enthusiasm, then children and people with dementia pick up on it very, very quickly that you're not bothered about that so they're not going to make the effort...they already have a hindrance to them joining in with things so you have to be super enthusiastic." (Participant 003)

The manager further felt that programmes required 'personality to drive that kind of thing forward' (Participant 003). Another manager similarly felt that all programmes needed was 'enthusiasm' to get started (Participant 012). Other qualities that were perceived to be important included 'patience and empathy' on the part of organisers (Participant 009), experience in practice (participant 012) and the ability to 'read a room' and to read the people participating (Participant 003). A number of interviewees described how facilitators needed to have a wide range of skills and good knowledge relevant to working with both older and younger groups, with the result that 'not everyone can do it' (Participant 010):

"...that's where it goes wrong because you can tell when someone's not comfortable with a group, whether it's older or younger...you need to understand both, the ages across the board." (Participant 010)

Another officer similarly described how 'if people understand dementia, they need to maybe understand intergenerational practice, too, you know, and vice versa' in order to deliver a project (Participant 006).

Interviewees also suggested several ways in which good facilitators could enhance practice, including 'pitching' programmes (Participant 001) and bringing promotional skills (Participant 013), providing leadership, structure, and organisation through skills and knowledge (Participant 008), and bringing particular skills to make programmes genuinely intergenerational rather than just like any other activity (Participant 007).

The training of participant groups was also perceived to be important. Examples of training included intergenerational training (Participant 006, Participant 012), practitioners

specialising in dementia providing younger participants with training on meaningful activity development (Participant 008), dementia awareness training (Participant 001, Participant 010), training in body language and non-verbal communication (Participant 010), and preparatory sessions with participants to address misconceptions they may have about other age groups (Participant 010). Where programmes relied on volunteers, it was important that volunteers were provided opportunities to train (Participant 008) and upskill (Participant 009).

### Mechanisms

#### Mechanism: Preparation and Planning

The majority of interviewees spoke of preparation and planning as an important element contributing to the 'success' of intergenerational dementia programmes. Two interviewees expressed the importance of planning via common sayings, highlighting this importance further. For example, one manager stated:

> "Well, you know what they say, ninety nine (percent) preparation, one percent project. It's very true." (Participant 010)

Other descriptions of planning abounded in the interview data, for example, that intergenerational practice takes 'as much preparation as possible' (Participant 009), 'takes organisation' (Participant 012), and requires 'people do their research and their planning properly' (Participant 006). Planning and preparation were further perceived to allow for efficient handling should anything go 'amiss' (Participant 013) and to ensure 'no surprises in the middle of or halfway through the project' insofar as possible (Participant 010). A director, similarly, felt that getting the logistics organised was the central aspect of programme development:

"...but then the nuts and bolts really is- so even if you had all the money in the world (laughing)- to go away and do it...It's the logistics...are the biggest encumbrances, I'd say." (Participant 011)

However, multiple interviewees further stressed the importance of flexible, adaptable planning in order to ensure that intergenerational dementia programmes were manageable and achieved desired outcomes. Flexible planning was described as necessary for several reasons. Firstly, flexibility was seen to be required to account for the feelings and needs of participants on the day: "We did plan a lot of things out and change things around, and you know, just depending on the children on the day." (Participant 002)

Secondly, flexibility was required if an activity was started but then did not go as planned. One manager described an experience with a planned arts and craft activity:

> "It was more about, like, you would plan ahead and say, right, this is what we are going to do but then you'd be starting it and you'd be thinking, *oh no, this isn't going well at all*. Say it was an arts and crafts or that, and the children and the people with dementia were just not into it at all and it was just, glitter was going everywhere, and people were having issues with scissors, and things like that, so you would just have to say, right, timeout, let's have a tea break." (Participant 003)

Thirdly, planning programmes over the long term may require flexibility due to the changing circumstances of people living with dementia and their carers:

"I think the barriers can be often that, you know, people with dementia and unpaid carers' circumstances can change and can change very quickly. So what you intended to do might not be able to happen or might change, so there's a barrier to, you know, how long that intervention can take place for..." (Participant 005)

A fourth justification for flexibility related to the need to not be so strict as to limit spontaneity among participants:

"It wasn't really rehearsed or planned, it was just something really random they would do...So a lot of it was spontaneous but generally there was that pattern..." (Participant 004)

Another manager, similarly, felt that activities that were 'really strictly planned' or didn't 'have any flexibility or choice involved' did not work so well (Participant 009). A coordinator advised 'not (having) too many rules and regulations around what's happening, but just cautiously observing the interactions' (Participant 013).

A final reason for flexibility in planning related to the recognition that all organisational partnerships and participants would be different, meaning that programmes would need to be tailored in each circumstance:

"I think...everyone is an individual, whether they are a young volunteer or a person living with dementia, or manager or member of staff working at the care home. Everyone is an individual with different views, okay, and one size doesn't fit all." (Participant 008)

Interviewees also spoke about the difficulties involved in planning intergenerational dementia programmes as a complex intervention. For example, one manager spoke of the need for advance planning and variety when it came to activities, with the implication that planning could be fairly intensive:

"Things like activities, so we wanted to always make sure there was something that was stimulating the children and stimulating the adults, so we always had to be thinking, what are we going to next week?... But I wouldn't say that's a negative, it's just that we had to think about different options of what we could do with them." (Participant 002)

Another manager suggested that programmes with younger children 'take a lot more preparation', and also that incorporating celebrations such as Christmas and Easter could also increase planning requirements (Participant 003). Other interviewees commented on scheduling difficulties:

But it's also logistically, it's very difficult when you have got snow, you've got children, you've got exams, you got people being ill. The hairdresser turns up at the care home (laughing) on the wrong day...my most important thing that I always go on about is intergenerational work is a planned process. It's planned." (Participant 010)

Despite these difficulties, some interviewees were optimistic that programme planning could prevail to develop successful intergenerational dementia programmes. For example, a manager noted that planning became easier over time: "...it's a lot that goes into it but...it becomes second nature the more you do it. You know, the first year was hard for (teacher) and I, but as time went on, we got a lot better at it." (Participant 003)

A director similarly emphasised that while logistics could be difficult, the interactions between participants thereafter were often much easier to realise:

"Everything else is easy, (logistics) that's the hard thing and it's difficult to get over that." (Participant 011)

Interviewees also suggested ways in which preparation and planning could be enhanced to better ensure optimal outcomes. For example, some interviewees spoke of the importance of consultation during programme design and set-up, essentially 'talking to who the beneficiaries of that support might be, what is it they want, what do they want it to look like" (Participant 005). An officer made a similar recommendation for participatory planning:

"...it's about having equal decision-making from the beginning for the people living with dementia and their family carers and having them involved in planning the programme, deciding what they will do." (Participant 004)

Another early element of planning was the preparation prior to introducing participant groups:

"Often it has to be planned and preparations made to prepare each group for meeting each other. And there's a lot in the background that actually goes on before you would introduce younger people to older people." (Participant 006)

For example, this could involve training, addressing concerns among participants, or addressing the negative perceptions each age-based group may hold about their 'age others'. One manager likened this to information gathering to ensure that no participant would feel vulnerable in the moment:

> "And I think if you plan it and you do your research like you're doing, you should have enough information to know that nobody's going to feel vulnerable, you know." (Participant 012)

The manager suggested consideration of which participants may get on well together was another related aspect of planning that could enhance programmes:

> "You know, you wouldn't do that with everybody with dementia, you had to make sure that someone- the right person was there for the right setting so it's almost you got to tie up people that are going to get on together. Because not everybody gets on, so it's really important I think to plan, plan these things, yeah." (Participant 012)

### Mechanism: Purpose and Roles

Providing purpose and roles for participants emerged as a strong theme and was perceived to be another important factor towards achieving effective practice. One officer described a programme that 'worked because there were these people who didn't have a place or a role and they found a mutual place and role together' (Participant 004). A manager related how the projects they organised were always 'very person-centred...helping people to find their own niche within a group' (Participant 010).

For older participants, a trustee explained that intergenerational practice should be predicated on the idea that 'people with dementia can contribute' (Participant 007). A coordinator similarly felt that intergenerational practice was a 'a great way to make a useful contribution', particularly for participants living with dementia (Participant 008). One manager described older participants involved in delivering awareness training in schools observing that this new voluntary role was 'like a wee job to them...(when) they're not working anymore' and satisfied their need to have 'purpose' and 'meaning in life' (Participant 001). In relation to one volunteer, the manager related:

"And her husband said that doing the session with the kids, it was just like, she became herself again." (Participant 001)

The past careers of older participants were described by several interviewees as a good mechanism towards providing purpose and defining roles for older groups:

"So (the children) can learn about careers these people had, whether they worked, what did they work as, it's just fascinating." (Participant 013) Examples of past careers among older participants used within programme activities in Scotland included policeman (Participant 002), teachers (Participant 001, Participant 003), farmers (Participant 004), war pilots (Participant 008, Participant 010), and footballer (participant 008). Industries historically embedded in Scottish regions, such as coal mining, were also described as a potential focus for future programmes (Participant 008). One manager, however, did point out that some older people may not want to engage in activities that provided continuity with their past careers once they had retired (Participant 003). In terms of how past careers could inform programme development, one manager stated:

> "He brought pictures of him when he was a policeman, and he had a dog and so you know he did a little presentation and he brought these pictures in for the kids and so that was something just from sitting chatting and how excited they were about what he did, you know?" (Participant 002)

A manager suggested how past careers could work as a programme mechanism as people living with dementia would retain knowledge, lived experience, and abilities related to roles that had been dominant in their lives:

> "We had a lady who had been a teacher all her days and she had severe Parkinson's, but when the children were in, she just went straight back into teacher mode, and she would get up and she would tell them off and she would do all the dancing with them." (Participant 003)

Equally important was giving due consideration to the roles that younger participants could take during programmes. One director felt that intergenerational practice could be defined by its 'inclusive approach for young people being involved in the delivery of work' (Participant 005). A manager similarly described how:

"The young people are just as responsible for...leading the project, taking decisions, taking responsibility, what should we do, is this working..." (Participant 010)

Purpose and roles for younger people described by interviewees included being given a sense of helping people living with dementia and further knowing what they could do to help (Participant 001), older children buddying younger children during programmes as well as developing and leading programme sessions (Participant 003), taking a supportive role to assist participants living with dementia (Participant 011), and taking a role in managing funds and petty cash as well as facilitating evaluations (Participant 010). One coordinator cautioned against being 'too prescriptive' with roles for older and younger participants (Participant 013).

#### Mechanism: Preferences, Lived Experience and Personhood

Programmes were perceived to be more effective when the preferences of older and younger participants were taken into consideration, particularly as this enabled practice to be grounded in the lived experiences of those participating as well in their personhood. For example, allowing participants choice (Participant 009, Participant 012) and control over their participation was described as important. One manager described deliberation with participants in order to incorporate their suggestions into a programme (Participant 010). Another manager described proactive programme development to make use of each older participant's skills:

> "I would look at the guests that we had coming in and what type of things they had, like what type of skills, had they been a teacher, could they play a musical instrument, did they like football? Were they extroverted, was there something that they might actually want to teach the children?" (Participant 003)

The preferences of older participants in relation to participation in intergenerational programmes were perceived to be critical in several additional ways. A number of interviewees, firstly, were keen to emphasise that some people may not like children (Participant 003) or may not want to join in (Participant 010). They may also have delivery preferences such as preferring in-person interactions rather than online (Participant 008). Organisers had to therefore recognise that programmes were 'not for everyone' and implement 'rigorous recruitment' as a result (Participant 010).

A director, secondly, described how certain traumatic experiences in people's lives could make intergenerational programmes inherently inappropriate or potentially harmful:

"...we need to be mindful that some people in their earlier lives might have experienced a degree of trauma, too, so that maybe

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work around an intergenerational practice and approach could stir up memories around that as well." (Participant 005)

Thirdly, dementia as a progressive condition could also result in people's preferences changing over time. One manager described the potential for participants to be in a 'darker place or...in a different timeline regarding where they thought they were' as programmes progressed (Participant 003). A director further observed the potential for positive experiences to become negative over time 'depending on how things progress for (older participants) ... in their own health but also external factors as well' (Participant 005).

The preferences of younger participants were mentioned less frequently by interviewees but nevertheless were similarly considered to be important towards enabling programmes to work. A coordinator noted that:

"Some young people will be into it, and some won't." (Participant 008)

The coordinator further elaborated that in their experience of organising programmes, working intergenerationally with older participants 'wasn't the right volunteering role' for some pupils (Participant 008). A director, similarly, pointed out that some young people may prefer going home or playing sports to volunteering (Participant 011). A manager stressed the importance of ensuring younger participants engaged voluntarily:

"Some schools...wanted to push certain pupils in and I said to them, I would say at the very first meeting with them, you do not have to do this, this is voluntary. Because there's no point in doing it if you don't want to, so I would say that." (Participant 010)

Interviewees also described how preferences could be used to enhance practice. One manager felt that where organisers knew the 'backgrounds' of the participants to be involved there was a greater chance for success (Participant 012). In regard to programmes within care homes, a coordinator similarly felt that activities worked better where staff utilised 'prior information' and had knowledge about what would work with individuals (Participant 008). Grouping participants according to their interests (Participant 010) as well as allowing participants to share their interests, likes, and hobbies were additional techniques (Participant 013). A coordinator described this in practice:

"...particularly the high school girls and what not, they love to do manicures and hand massages and they just sit and it's lovely watching them giving a hand massage, just chatting away naturally to the older person." (Participant 013)

Practice, particularly dementia awareness elements, was understood to be further enhanced by embracing and exploring the lived experience of dementia among older participants. A coordinator described how dementia awareness was enhanced through sharing lived experience:

> "And normally I am escorted by a person with dementia...so they can explain what life is for them in the 'lived world' of having the disease." (Participant 013)

Another manager similarly described sharing lived experience through awareness raising:

"...so what (the volunteers) bring to it is they can embellish all the different exercises with their own experience...The memories, they talk about forgetting people's names, being quite disorientated in relation to time, all that kind of stuff. So that's where the lived experience comes in really well." (Participant 001)

Using preferences and lived experiences further was perceived to endorse the personhood of all involved, particularly older participants. It allowed organisers to 'see people as people' (Participant 004), consider the whole individual and what would be best for their quality of life (Participant 005), consider the whole individual and not just meet basic needs (Participant 012), give agency back to people (Participant 011), and 'enable people to have their independence and give them a wee bit of freedom' (Participant 012). Avoiding presumptions was seen to be important:

"Even with people with dementia, they can still make everyday decisions, you know. We shouldn't presume...that they don't have capacity." (Participant 012)

### Mechanism: Sharing and Learning

Intergenerational programmes were perceived by interviewees to work better when they enabled sharing and learning processes between participants. One manager pointed out that 'there is such a lot we can learn from each other' particularly across generations (Participant 001). Another manager noted that linking different generations together is important 'because they've all got so much to give' (Participant 012). Without intergenerational programmes to enable sharing, a manager felt there could be a risk of losing knowledge (Participant 012). In contrast, intergenerational programmes were a way to recognise that 'elderly people have got such a wealth of information and knowledge', a way to pass something on to the next generation (Participant 007), and a way to enable different age groups to 'impart' something to the other group (Participant 009). One manager described how knitting had been incorporated into a programme serving the purpose of conserving this skill:

"...that's a great way of handing on the skills, or like people who can teach the children how to knit or crochet, because that's a thing a lot of us have lost...we were taught it at school but you know a lot of children now don't know how to do things like that and they would be fascinated that you could actually make a small thing, you know, even if it was just a square and we put wee googly eyes on it..." (Participant 003)

Passing on skills and memories could heighten inclusiveness and community:

"So I think that to be involved and to feel part of the community through meeting young people and passing on memories of working in shipyards, or bowling, or playing golf, or playing football, or- it doesn't have to be reminiscence, it could be skills, it could be art or painting, or writing." (Participant 006)

Sharing and learning processes were understood to be effective when they were mutual, reciprocal, and inclusive rather than one-sided with one group being dominant within these processes. One manager described how both 'giving something' and 'getting something' were necessary to strengthen activities (Participant 009). A director described reciprocal reminiscence between age groups in terms of 'comparing and contrasting':

"And then it's a compare-and-contrast. And the young person's memories can be just as meaningful in those conversations as the older person's with dementia. And they can both learn from each other." (Participant 011)

The director further related how contributions from the different age groups could differ but were equally important and integral:

"You know, it's that wisdom that [people living with dementia] can still have around physical activity, while the younger people can run around, retrieve the ball or you know." (Participant 011)

A trustee described a similar exchange:

"...where you might have thought it's just the older people teaching the younger people to knit, well, no, the young people do different things with wool now, so that's interesting..." (Participant 007)

A manager observed during one programme that young participants loved 'showing people how to do things' (Participant 002). Assisting older participants with digital skills and the use of technology was a frequent example cited by interviewees of where younger participants could take on the teaching and mentoring (Participant 001, Participant 002, Participant 005, Participant 010).

Communication was described frequently by interviewees and underpinned the sharing and learning processes that programmes enacted. A coordinator felt that communication was crucial to defining intergenerational practice, which revolved around 'how younger generations communicate and interact with older members of the community' (Participant 013). A manager further felt that 'communication between the different groups' was necessary to allow programmes to work (Participant 012). Often in connection to sharing, interviewees mentioned different aspects of communication between participants including 'a lot of communication', 'banter and talk', 'chat' (Participant 002), 'speaking' (Participant 006), 'talking about art' (Participant 007), conversing (Participant 008), 'meeting new people and talking' (Participant 009), 'talking about your own experiences about the same things' (Participant 011), 'storytelling' (Participant 002, Participant 012), and 'getting to know each other' (Participant 013). A coordinator felt that programmes could improve young participants' communication skills (Participant 013).

Reciprocity was another factor that related to sharing and learning. A coordinator described some activities that fell short of being intergenerational because they were not predicated on communication and reciprocity:

"...so people would say that children singing Christmas carols to older people in a care home is intergenerational. And it is not...You know, because it is not reciprocated. There's no communication." (Participant 006)

Reciprocity throughout programmes was described in a number of ways, including 'working both ways' (Participant 002), 'respectful and reciprocal', 'reciprocal arrangement' (Participant 005), 'reciprocally or mutually beneficial' (Participant 005, Participant 006, Participant 008, Participant 009, Participant 010), 'some sort of exchange' (Participant 009), and 'a two-way practice and enjoyment' (Participant 012). Therefore, although communication and reciprocity appear to be indirect or latent aspects of the sharing and learning processes involved in programmes, it is nevertheless interesting to note the similarities with which interviewees described these aspects.

# Outcomes

## Outcome: Relationship Building

Relationships were perceived by interviewees as an important outcome arising from intergenerational dementia programmes. An officer reflected that 'relationship building' would be a big outcome throughout practice (Participant 006). Another officer thought that 'the relationships it built up between the boys and the older people' was a particular strength of one programme (Participant 004). One manager who had been involved in multiple programmes with children and young people of different ages observed 'real friendships' growing throughout the programmes (Participant 002). These close relationships were often revealed through physical and social behaviours, particularly on the part of younger participants. The manager described how nursery-aged children throughout one programme 'would have favourites that they would like to sit beside' (Participant 002) and further observed relationships forming between younger and older participants during one visit to the nursery school:

"To the extent that when we visited them at the nursery school...they waited outside to hold hands and bring into their class...so they had their favourites..." (Participant 002)

In a programme involving younger participants who were of an older age, a director observed similar indications of relationships forming with the older participants with dementia:

"...from the beginning, the guys are at one end and the young lads at another. That's exactly what it was like. It was like, how are these two factions going to come together? But by the end, it's warm handshakes, it's cheering, it's genuine coming together and, and through that what you're seeing is the young people intuitively helping (to be) supportive, you know, you see arms going out supporting an elbow, or, you know, mind your step, helping them, being supportive." (Participant 011)

Relationships were also revealed through the behaviours of older participants:

"And I know from my members part, they loved seeing the children, they really loved every single one of them, from the ladies to the gentlemen, you know, it didn't matter, from the seventy year old to the ninety nine year old." (Participant 002)

Interviewees also expressed ideas about how it was necessary to organise programmes in order to generate strong, positive relationships, as one director stated:

"I think there is a degree of safety as well for people, and security, in that when it is done well and when it's done in a way where they have felt inclusive of what is happening, that they are safe in the knowledge that this is a really good relationship for them to be in, and it's one that is going to be respectful and reciprocal." (Participant 005)

In order to do intergenerational work 'well', interviewees reflected upon the role of programme organisers, the importance of creating the right atmosphere, and the way in which organisers should approach activity development in order for beneficial relationships

to arise from practice. For example, an officer emphasised the role of the organiser and their responsibility to engage in planning in order for relationships to form:

"The relationships form naturally as a result of the middle person bringing them together...so it's important that the staff involved that they understand..." (Participant 006)

Another officer stressed the importance of the right atmosphere in allowing relationships to flourish:

"So I think if you have a common, safe place for that sort of encounter to happen, then it just happens naturally, it's not forced..." (Participant 004)

Several interviewees, moreover, felt it was important to ensure activities were designed in a way to facilitate relationship building between older and younger participants. This could involve planning time to socialise within activities that were largely performative, as described by one manager in relation to a musical activity involving secondary school students:

"...I think it was also for them, you know, to sort of mix with the elderly group as well because I think after the playing it was also very important that they sat and had conversations and got to know and build up relationships." (Participant 002)

An officer, moreover, likened programme activities to 'props' that should initiate relationships, such that the focus should not be on the actual activity as and of itself, but rather the degree to which the activity would be capable of fostering relationship building:

"...one of the things that comes up a lot is that the activities are actually second place to what happens in the relationships that are built. So the activities are props to start and get things going." (Participant 006)

This conceptualisation of activity development was closely corroborated by another manager:

"...it is about focusing obviously on something that's interesting like reminiscence work, films, artwork, but the, well as far as I am

concerned, the overall aim, the outcome, is to improve relationships and give people a chance to come together to (do) mutually beneficial, interesting things that makes their lives better." (Participant 010)

Relationship outcomes were also perceived by interviewees to signify a significant part of the 'unique' purport and contribution of intergenerational programmes, with intergenerational practice arguably more able to produce relationship outcomes due to the inherent 'relationality' of such practice. Intergenerational programmes were described by one director as more holistic in that they promoted multiple benefits for different people simultaneously, rather than focusing on the individual:

"...it's reciprocal, it's not just about delivering that benefit to one person, it's the benefit that each individual gets from each other. So I think intergenerational for me is very much about the relationship between individuals and that mutual respect and understanding and then just appreciating the advantage of that relationship from both sides or from both representatives if you like that are involved in that exchange." (Participant 005)

Intergenerational programmes were also perceived to be important in producing relationships that otherwise would not have space to take place:

"...they're forming relationships and friendships with people that are maybe something that wouldn't happen, they might not come into contact with an older person and the older people probably may not come into contact with many younger people..." (Participant 006)

A manager, along similar lines, credited intergenerational dementia programmes with allowing young people to realise that relationships with people living with dementia are both possible and can be meaningful:

> "And so a chance for younger people to actually be around people who are older or living with dementia and realise that they can enjoy their company and learn things from them and have this build those relationships..." (Participant 009)

One interviewee, moreover, suggested that intergenerational dementia programmes can make a further contribution through allowing people living with dementia to enjoy relationships with younger people and children, which may for some older participants have a more profound effect than activities without an intergenerational component:

> "...at Christmas time the year before last when they came along to do a nativity play, our members were going 'Oh, there's little (nursery child), oh there's little (nursery child)' because they all dressed up...They all knew the individual children that came along, so they had built up such a rapport that they actually knew, and this is people with dementia, but they knew all the kids that came along." (Participant 002)

A final sub-theme that occurred in a minority of interviews, but nevertheless is important to note, is the concern that some groups may have regarding relationships between older and younger participants arising from issues such as death and grief, which may be difficult for younger participants to contend with:

> "...they were going to do some work on bereavement, so I think it was 'Good life, good death, good grief'. And they were looking at how do we approach that because we can't...well, we can't let the children go in case they form relationships, and someone dies." (Participant 006)

### Outcome: Older Participants – Knowledge and Understanding

Evidence for enhanced knowledge and understanding among older participants was apparent across interviews, however, interviewees spoke most compellingly about increased knowledge for younger participants. One officer suggested that older participants could gain a better understanding of the lives of young people and children today, learning that there can be a lot of pressure in today's society:

> "But the older people learning about younger people, learning about changes in their society, exploring the days of their youth and the differences. And breaking down the myths that young people are having an easy time...we're in information overload, good grief!" (Participant 006)

A director suggested that knowledge of younger participants gained through the interactions instigated by programmes could enable older people to feel more connected to younger people in their communities in general:

"...you know, being happy to go out your door and walk down to the shops and not seeing younger people as another threat...but actually being able to say, oh hi, mister whatever, because actually they know you from the work they do with them every week and suddenly it's a completely different feeling when you go out into the community because you feel connected with younger people." (Participant 011)

## *Outcome: Younger Participants – Knowledge and Understanding*

Several interviewees spoke of the knowledge and understanding of dementia younger people had in general prior to participation in intergenerational programmes. One manager, for example, expressed surprise at how many children during one session both knew and understood the word 'dementia':

> "...the kids were great, I mean, they brought all sorts of stories like about their neighbours, about people in their families, and it was amazing how many of the kids actually knew the word." (Participant 001)

However, beyond general knowledge, the opportunities to improve knowledge and understanding about dementia were seen to be fairly limited for younger people. One manager thought that awareness raising tended to be targeted at people living with dementia themselves as well as their carers and peers, rather than younger people:

> "But quite a lot of it seems to be focused on that sort of target...age group and I don't see a lot of that...awareness raising in communities or groups with predominantly younger people, which I think would be something that would really...help for communities becoming more dementia-inclusive in general." (Participant 009)

The majority of interviewees saw intergenerational dementia programmes as a route towards increasing the knowledge and understanding younger people had about dementia.

One trustee described the importance of even one direct experience in which younger people were able to interact directly with people living with dementia:

"One experience of being young and meeting a group of people with dementia is better than no experience of being young and meeting people with dementia." (Participant 007)

Interviewees further described how intergenerational dementia programmes could help younger people and children 'understand dementia' thereby 'not being frightened of it in the way that the older adults tend to be' (Participant 001). Aspects of knowledge and understanding that had been enhanced through practice in Scotland included better awareness of the 'lived experience' of dementia (Participant 001, Participant 013), increased knowledge of illness in regard to dementia and generally (Participant 001, Participant 002, Participant 006), increased knowledge about ageing including lifting aids and other equipment (Participant 006), awareness of body language and non-verbal communication (Participant 010), and greater understanding of and empathy with the older participants within the programmes (Participant 012).

Several interviewees described how children and young people participating in programmes would begin to appreciate the personhood of people living with dementia to a greater degree, recognising that they are people and not just their condition, and that there is potential to live well with dementia:

> "...it's very good for the children to understand that dementia, there's nothing to be afraid of, that it's an illness like any other illness, that the people are still people, that you can do so much even though you have dementia." (Participant 003)

Another outcome described by interviewees was the potential for the enhanced knowledge and understanding of younger people to translate into better knowledge and understanding within communities and other groups. A manager described their ambition for younger people to be advocates for more acceptance of and less fear about dementia within their family circles:

> "So we hope that the young people will be a sort of encourage[ment] for older people, to say look, actually, you know it is just an illness like any other. If you had cancer, you would go to

the doctor, so why not if it is dementia? So use them as a sort of, you know, influencer for want of a better word within their own family." (Participant 001)

### Outcome: Reduced Stigma

Closely related to the outcome of enhanced knowledge and understanding, interviewees further described how intergenerational dementia programmes could be an effective means of tackling stigma, with greater tolerance combined with reductions in stigmatising attitudes and behaviours resulting through programmes. One coordinator stated that stigma reduction naturally would have to encompass younger people and their attitudes:

> "Particularly around people with dementia, because really what you are trying to do is remove the stigma associated with dementia. And my view is the best way to do that is through the next generation." (Participant 013)

A coordinator echoed this idea suggesting it was valuable for children from a young age to understand how to see people rather than illnesses, conditions, or age (Participant 008). A director, similarly, perceived intergenerational practice as being aligned with preventative approaches aimed at reducing stigma:

> "...quite a lot of the work will talk about preventative approaches, will talk about raising awareness, reducing stigma, but there's multiple ways that that could be done and the intergenerational work...can often be a good starting point to that." (Participant 005)

Intergenerational dementia programmes, moreover, were associated with 'tolerance' as an output (Participant 006), 'challenging stigma about ageing or living with dementia' (Participant 009), 'totally changed attitudes' (Participant 010), creating a 'failure-free' and 'stigma-free' environment (Participant 011), dispelling age-based misconceptions (Participant 011), and resulting in less alienation felt by older people (Participant 011).

However, similar to relationship building, reducing stigma and stereotyping was not perceived by interviewees to be an automatic outcome per se, but rather that achieving this outcome relied on designing and implementing programmes in an effective way. For example, one officer stated it was ineffective to just 'plop together' participants of different age groups within a programme without first trying to understand and approach the 'stories'- often negative- participants had formed about age others based on their own experiences (Participant 006). A manager similarly described how addressing stereotypes should be part of the initiation of an intergenerational dementia programme:

"So it was the kind of thing that I start off when I set up on intergenerational projects is the bias, the stereotyping. And we always start of by saying to the young people...when you think of older people, what do you think?" (Participant 010)

The officer and the manager both recommended drawing exercises- younger people drawing images of older people and vice versa based on common stereotypes and internet searchesas a place to start addressing and overcoming common stereotypes. One manager further described how they had designed and implemented programme activities themed around addressing intolerance and stigma, for example, roleplay, quizzes, and creative projects (Participant 010). The language used during activities to address the different participants was also perceived to be important by one officer towards ensuring equality:

> "I think just as well something about the language used and people and the roles... well, if people are called 'patients' or something like that, it's obviously going to put a label and a stigma on them, whereas if everyone is just a volunteer or a buddy or something neutral, you know, where people don't have a label assigned to them because of whatever diagnosis they might have or any other background thing, so people are just people and they are all at the same level." (Participant 004)

#### Outcome: Older Participants – Enjoyment

Several interviewees observed enjoyment among older participants during intergenerational dementia programmes. For example, one manager described the enjoyment among older participants as follows:

"And the elderly, their eyes just sparkled by just sitting talking to them, you know...It's an amazing thing to see, it's an amazing thing to watch and I think everybody gets so much out of it." (Participant 002) Other descriptions of enjoyment shared by interviewees included the older participants 'coming alive' (Participant 001), older participants displaying 'lots of smiles' and looking 'happier' after interactions with children (Participant 006) and being around younger participants having the potential to be a 'joyous experience' for people living with dementia (Participant 009).

Moreover, interviewees shared insights into intergenerational practice for people living with dementia specifically, and how their enjoyment of programmes may be unique and can inform programme development. Firstly, intergenerational interactions for people living with dementia can ensure 'a new, positive experience' (Participant 010). Such interactions can be a moment of enjoyment within otherwise daily, repetitive routines for people living with dementia:

"I think a good outcome from some of the work that we have seen is that it just brightens someone's day to have something different happen that moves away from that mundane day-to-day structure." (Participant 005)

Programme organisers in Scotland, following on from this, have often tried to heighten this enjoyment in novelty by ensuring programmes take older participants into new environments and out into the community. One manager described the enjoyment experienced by older participants when they went to visit a nursery throughout the course of one programme:

> "And we did, so the nursery invited us to visit them as well at the nursery school, so they provided an afternoon tea for the elderly and they got all these lovely plates and cakes and they dressed up and did a little play for us and they loved it, the elderly, our guys, they absolutely adored that, they enjoyed the visit..." (Participant 002)

Another manager, similarly, described their aim of creating a 'holiday atmosphere' for their service users, which came to inspire 'bringing the children in and going out into the community' as the programme progressed (Participant 003).

Moreover, given the nature of dementia, interviewees spoke of how the intergenerational structure of programmes and the involvement of children could heighten a sense of

enjoyment for participants that would last longer than the memory of the actual activity. For example, one manager stated:

"Dementia, you know sometimes people that have dementia, they forget how the day went but the feeling of if they enjoyed a day stays with them for a lot longer, so I guess our outcomes are always about making sure that people enjoy and have a nice feeling of the day." (Participant 002)

Another manager likened lingering feelings of enjoyment for people living with dementia as representing a positive 'emotional hangover':

"So it's about finding something that does make them happy so that they have, they may not remember the task, like so if I had said to a guest the following day what we did the day before, they might not remember the actual task but they will remember the feeling, so they will have the emotional hangover of being happy, you know, that they had a nice time and that there were children involved. And that's really all you can ask for." (Participant 003)

However, the manager also noted how the experience of dementia could result in changeable patterns of enjoyment among older participants and this would be important for programme organisers to take on board and prepare for:

"Because even people you thought you knew well and who...had really enjoyed doing a certain activity – because of the progression of their dementia this time they didn't. You know, they were maybe in a darker place, or they were in a different timeline regarding where they thought they were. And it's just about changing it all the time..." (Participant 003)

Interviewees also indicated ways in which the presence of children and young people, in particular, could further enhance the enjoyment experienced by people living with dementia. One manager suggested that the involvement of children could heighten stimulation and be 'part of that...story of keeping everyone excited and happy and stimulated' (Participant 002). The manager further described how older participants involved in the programme had

reported that the presence of the children 'made them feel young again...just to sit with them and listen to their banter and talk' (Participant 002).

A coordinator, moreover, felt that certain children could be capable of animating people living with dementia in unique ways:

"And then you may have the very enthusiastic child who actually will be the one that presses the button in the older person with dementia and makes the sparks happen." (Participant 013)

A director, in a similar vein, suggested that if the focus of the activities was pitched correctly between younger and older participants, then a 'natural common enjoyment and affinity' would emerge (Participant 011).

### Outcome: Younger Participants - Enjoyment

Interviewees also described the enjoyment experienced by younger participants throughout intergenerational dementia programmes, though this enjoyment tended to be connected to the actual content of activities, especially for preschool children. For example, one manager described the enjoyment of very young participants during an exercise class in which the children enjoyed being able to demonstrate the different moves:

"So we had a lady who came in and did a 'Move it or Lose it' class for us. And the kids loved it, they loved doing the exercise classes, sitting beside somebody doing the stretches and showing people how to do things." (Participant 002)

Activities attached to vivid descriptions of enjoyment for younger participants included additional exercise-based activities (Participant 010); parachute games (Participant 003); and activities involving animals (Participant 002). The manager noted that younger children in general found chatting easy within the context of intergenerational dementia programmes:

"Children have got no inhibitions that way though, you know, they'll quite happily tell you what they've done and it's lovely to see." (Participant 002)

For younger participants in secondary school or further education, it was more common that they simply enjoyed being able to communicate with and learn about the older participants:

"And so we have had two students that volunteer once a week and they came out and just supported us in our services and you know really enjoyed chatting with the members..." (Participant 002)

One officer observed that some younger participants may discover in intergenerational programmes an environment where they can 'fit in' better than other peer-based contexts such as classes at school:

"...they fitted in so well there, it was just...they could've spent the whole week there, they loved it." (Participant 004)

#### *Outcome: Older Participants – Behaviour and Feelings*

A number of interviewees spoke about their motivations for initiating intergenerational dementia programmes in terms of the types of behaviours and feelings they were aiming to engender for participants, particularly older participants living with dementia. For example a manager described aiming to ensure stimulation and excitement within their service provision:

"...we always tried to look outside the box of what's out there and what can we bring into our service to energise our members and to excite them and to give them things to think about..." (Participant 002)

A director, moreover, felt that intergenerational practice was one of the most effective ways to trigger a succession of positive feelings, such as confidence and self-value, that would benefit people living with dementia and allow them to successfully 'open up' in an interactive environment:

> "Because without (confidence) you can't do anything else. You know, without (people living with dementia) coming out of their shell, becoming emotionally more confident so that they can open up and feel relaxed, feel self-worth, and valued, and able to join in and do more things. And that's the process I do through all of our work, but I think with intergenerational work...it's almost the easiest way of helping to develop that." (Participant 011)

In terms of observed differences in behaviour, one manager noticed increased mobility and responsiveness to others throughout the duration of an intergenerational dementia programme:

"...we saw an improvement in their mobility because as soon as the children came in there was a great deal of energy and they were more likely to get up and do things. They would be more likely to fetch things for the children, to help the children with their snack." (Participant 003)

The manager further noted a positive influence on eating habits:

"...we found that even people ate better because the children were there, and they were all eating." (Participant 003)

Another manager felt while it would be wrong to claim intergenerational practice could prevent the worsening of dementia, nevertheless, it could be an effective way to regulate mood and alleviate depression among some older participants:

> "And I am not saying it prevents them getting worse, but their moods, you know, it might stop medication a wee bit, you know. They won't get so depressed. So it actually affects their health and wellbeing, and makes them feel better..." (Participant 012)

One manager related that, following intergenerational sessions, older participants may feel calmer and even sleep afterwards:

"...what I used to do was get the pupils ready to leave and then I would go in, one last time, into the room that I had been working in, and say bye...but they'd all be sleeping. And the care home workers said that it was like a wind-up toy, when the children left...they'd calm." (Participant 010)

Interviewees further observed that older participants would themselves communicate their feelings about their participation and interactions with younger participants, for example, to their carers and families:

"You know, everybody commented, her family when she went home, because she still remembered it, she still spoke about it, and we had loads of photographs that she could relate to everyday, and she would always ask, *when are the children coming back in?* So it did, it made a big difference." (Participant 003)

However, interviewees also reported how the behaviour and feelings of older participants could also be variable during programmes giving rise to the need for organisers to be sensitive to how different people were feeling. For example, one manager noted that during some intergenerational sessions, some older participants would 'feel a little bit off' (Participant 002). Another manager related how some people living with dementia could feel 'agitated', for example, when they did not want to sit to do something in particular (Participant 003). The manager further explained that people living with dementia can feel their emotions very acutely and staff should be prepared to intervene if required:

"...we just always had to be aware of you know how people were reacting all the time, so if there was something that was making them upset or if they looked uncomfortable, obviously you got staff to intervene so that you know it didn't become a problem." (Participant 003)

Some interviewees spoke of how it was important to allow older participants to find their own behaviours and preferences within the programmes, whether this be through alternative activities or being allowed to simply watch and listen rather than speak. One officer emphasised the importance of avoiding coercion:

> "So it's important to have other options I think for people, so they don't feel coerced into taking part in a group activity if they don't feel like it that day." (Participant 004)

Another manager explained the importance of ensuring younger participants knew to respect the behaviours of the older participants even if unexpected:

"It's also trying to find a niche for each person if they want it. If they don't want it, like for example there was a lady that we had, she hardly spoke two words, but she used to smile and nod her head a little bit. She was comfortable and of course you prepare the children for that by saying silence is a message, if that person does not want to speak, they don't want to speak." (Participant 010)

## Outcome: Younger Participants – Behaviour and Feelings

Interviewees also spoke of the behaviour and feelings they observed among younger participants during intergenerational dementia programmes. For example, one manager observed that younger participants could be patient and understanding with people living with dementia:

"...an example of it was, there was a lady who was brought up on a farm...And she would constantly, constantly repeat during the session, I have to go and get the cows, I have to go and bring the cows in now, I have to go and...And you know the children never once, never said, *Oh, you've said that a thousand times*. They were just, they said, *Oh right, that's okay, that's fine*. Whereas with other people from within the group in the care home would shout at the person and say, shut up..." (Participant 010)

A director, similarly, felt that younger participants were capable of demonstrating patience and being less expectant in negative ways:

> "Whereas with younger people, there are not those expectations you know to be a certain way and younger people aren't expecting the older people to, you know, they're not demanding in that situation of you know come on let's do (it) quickly..." (Participant 011)

The director further noted the potential for nurturing behaviours among the younger participants:

"But again, you just see naturally that nurturing...You know, they're not (laughing) going to try kick the ball as hard as they can with somebody, they learn how to actually enjoy the physical activity with an older frail person. And it's a natural thing to do when they're put in that context." (Participant 011)

The director felt, moreover, that younger participants who were not 'displaying great behaviour at school' would be more than capable of 'intuitively working with somebody' in the intergenerational context (Participant 011). A manager similarly perceived behavioural improvements among younger participants during their own projects: "I mean, behaviour improved, teachers were happier, families, the mothers coming and saying, so glad you got that boy involved, he's much better now, he can control his anger, things like that." (Participant 010)

The manager observed that particularly the younger participants became 'less aggressive' (Participant 010). Such changes in behaviour may stem from different power dynamics during intergenerational dementia programmes, which create less intimidation among certain younger participants:

"...I think the part of younger people, who could perhaps be intimidated by older people, you know, in terms of where they are, you know, in terms of teachers or as they perhaps are looking at work, in terms of older people as authority figures. I think that barriers disappear as soon as they start to meet and talk with older people with dementia and their carers." (Participant 011)

Younger children were also observed to be intuitively interactive with older participants during programmes:

"And the older people, they were just sitting...But then, maybe within about twenty minutes, this little boy goes up to an older man and says, *can you open this for me*? And then this little girl sat with this woman, and they were both eating cakes together. And another older man was chatting to a little boy. But they all just happened, nobody put the children there..." (Participant 006)

Other interviewees perceived that the behaviours and feelings of younger participants could vary depending on the person involved. For example, one coordinator observed that some younger participants seemed 'more natural' during intergenerational programmes than others:

> "Some people were just natural, walked in, confident, and...they just knew what to do. And some people needed a bit more support...perhaps didn't have the social, natural social skills or confidence to do it perhaps." (Participant 008)

Another coordinator similarly observed that some children may not engage in an activity and be 'shy or quiet' whereas other children will be 'very enthusiastic' (Participant 013).

Interviewees also commented on overly energetic or less engaged behaviours of younger participants, such as being 'restless', 'quite wild', 'not feeling well', 'having a bad day' (Participant 002), 'noisy', 'very energetic' (Participant 003), or creating 'chaos' as they arrived (Participant 006). One coordinator felt that noisy distracted behaviours among younger participants could stem from a lack of activity planning:

"I just think if it's too noisy or there are distractions...and there hasn't been thought, thoughtfulness put into the activity, it can end up being ineffective." (Participant 013)

Another manager described the importance of catering for the needs of different children and ensuring they had places to calm down with the support they required, especially when working with younger participants with additional needs:

> "If there were children who were very upset, because we did have children who were looked after and who had a lot of special needs, we would just take them into a separate part of the building or up to the fish tank or up to the pond or to a different garden and they would be there with their helper." (Participant 003)

## *Outcome: Confidence*

Interviewees felt that programmes could successfully promote confidence in general by promoting 'exchange' between age groups that allowed each group to be empowered by the other (Participant 009), creating a 'failure-free environment' for engagement to take place and build up the confidence of all involved (Participant 011), providing a context where everyone could be 'valued' and have their value recognised (Participant 001, Participant 004), enhancing confidence through everyone playing a part and being useful (Participant 004), and making people feel 'worthwhile' and improving their self-worth (Participant 005, Participant 012).

A manager perceived intergenerational activities as promoting the independence of older participants:

"They took on more of an adult role whereas previously it would be more of a 'looked after' role. You know, so they became much more kind of independent." (Participant 003)

In terms of younger participants, one manager observed the tendency of younger children to be initially shy during intergenerational sessions before quickly becoming more sociable and interactive with older participants (Participant 002).

#### *Outcome: Engagement*

Some interviewees perceived programmes could provide opportunities for enhanced engagement. One coordinator described how intergenerational activities could provide engagement for both younger and older participants:

"You know, they're...getting to engage with another human being, whereas if they were just sat at home all day, they wouldn't be talking, laughing, you know joking." (Participant 013)

Moreover, interviewees did provide some descriptions of intergenerational programmes encouraging engagement among older participants living with dementia. One manager described a change from passive to more active engagement related to assuming a teaching role towards the children:

> "Yeah, you know, we really found there was a huge difference in their engagement, you know, people that would normally maybe just sit with a paper or something like that were actually getting up and doing games or playing musical instruments and that was all coming back to them because they were trying to teach the children something that they knew." (Participant 003)

A coordinator, moreover, felt that people living with dementia may be uniquely responsive to engaging with children:

"Because for the person with dementia, as their dementia progresses and they lose their reality of the present moment, what can usually help them engage and rekindle some memories is younger children." (Participant 013)

#### Conclusion

This chapter has provided findings from interview data collected among Scottish stakeholders involved in intergenerational inclusion. Similar to the international level, intergenerational inclusion in Scotland has been understood and operationalised through programmes that bring older participants living with dementia together with younger participants. Key settings for programmes in Scotland included both care homes and adult day services provided in the community. Educational and youth services were perceived to be a central partner in the Scottish context in terms of encouraging the participation of younger people. Younger participants, moreover, were perceived to be diverse in Scotland, encompassing both those with additional needs who may be uniquely placed to both contribute to and benefit from programmes as well as proactive young people who may seek out opportunities and be involved with multiple initiatives. The Scottish context was perceived to present several barriers to the development of intergenerational programmes. Barriers for older participants included the concerns of carers as well as the risk perceptions of organisations, often compounded by perceived venue and transportation issues. Barriers for younger participants were perceived to be equally apparent, including participation being dependent on parents, schools, and youth organisations, volunteering restrictions, perceived risk in young people interacting with older vulnerable people, and competing commitments such as work, exams, and extracurricular activities. Moreover, fears and age-based misconceptions were described by interviewees with the potential to impede programmes. Other contextual factors included the resources required to develop programmes, elements of programme design, and training for both facilitators as well as participants.

Several programme mechanisms were synthesised from the interview data. Preparation and planning processes were perceived to be important, particularly the need for flexible planning that could accommodate participants' preferences, needs and behaviours as they changed between sessions and through time. Purpose and roles were a key mechanism allowing older participants to contribute in diverse ways that often related to their unique life experiences, while simultaneously allowing younger participants to take responsibility for different aspects of programmes. Sharing and learning were also important processes allowing for skills to be handed down between generations as well as allowing for older participants to engage with changes that were happening in Scottish society, such as digital transformation. Moreover, upholding preferences was understood to make programmes more effective by emphasising personhood and self-determination, and by taking into account information and life experiences that could affect each participant's receptivity and willingness to engage in intergenerational practice.

Multiple outcomes were described as arising from intergenerational dementia programmes in the Scottish context, including relationship building, enhanced knowledge and understanding, reduced stigma, enjoyment for both older and younger participants, different behaviours and feelings that interviewees observed among participants of all ages, confidence, and engagement.

# Chapter 7: Findings - Intergenerational Inclusion, Scottish Policymaking & Scottish Partnerships

## Introduction

This chapter presents findings from the interview data in regard to how intergenerational inclusion for people living with dementia has been understood and operationalised in Scotland, with particular reference to the role of Scottish policymaking in relation to practice. It therefore approaches the context of intergenerational inclusion and the aims and potential outcomes of intergenerational practice from a higher, policy-driven level. The chapter begins with contextual findings regarding both the need and potential for intergenerational practice in Scotland aimed at enhancing inclusion for people living with dementia. Findings regarding variation between Scottish communities, and between Scotland and other countries around the world, are presented with indications of how this could further affect the implementation of programmes in Scotland. Following this contextual overview, the chapter then moves on to outline three themes related to the interplay of policy and practice in regard to intergenerational inclusion for people living with dementia in Scotland. Firstly, findings regarding the specific role of policy towards enabling and promoting intergenerational inclusion in Scotland are presented. Secondly, findings indicating a policy-practice gap are presented and this is followed by, thirdly, an overview of how intergenerational practice to date has often been perceived to be linked up to different aspects of Scottish policy, particularly educational policy.

Intergenerational inclusion in the Scottish context is then linked to three high-level policy aims, including the preventative health agenda, the ambition of people living with dementia to remain living in their own homes and communities, and workforce development to support the ageing population. The chapter concludes with some key findings linking intergenerational inclusion to Scottish partnership working, including processes of setting up and 'brokering' intergenerational partnerships, developing shared responsibilities between partners to enhance implementation, and coordinating staff and organisational attitudes.

## A Need for Intergenerational Inclusion

A number of participants described how intergenerational inclusion could often be lacking in communities, mostly concentrated within families and therefore difficult to realise within non-familial settings and further affected by changes in society impacting on family dynamics. An officer, for example, observed that intergenerational contact was 'novel' due to a lack of regular family contact across generations:

"...some of the young people weren't in touch with their grandparents at all and it was quite a novelty for them to be around older people and the same with the older people, some of their grandchildren or great grandchildren were in England or whatever so it was a complete novelty for them..." (Participant 004)

Family was seen by interviewees as a key location for intergenerational inclusion, yet under pressure in Scotland due to family dispersion and societal changes culminating in a need to generate intergenerational contact through other social means.

Intergenerational contacts in the wider community beyond families, moreover, were perceived to be difficult to realise and quite rare. One trustee commented that 'outwith the family, there's very little connection' (Participant 007). A coordinator stated that intergenerational inclusion '[is] probably slightly more difficult in community-based setting[s]' and that there's 'probably still quite a long way to go before people just naturally mix with each other' (Participant 001), concluding that 'there's a lot of work to do to embed it as a way of living in a more natural setting'. Another manager thought that intergenerational inclusion is 'something that doesn't probably happen as much as it should do' (Participant 002). Furthermore, a trustee pointed out that beyond family and volunteering visits, institutions like care homes could be quite isolated from community dynamics:

"But I don't think people just rock up to the door and say *hi, I live two doors down and I've never been into the care home – can I come in and chat to the folk?* That doesn't happen. You know, they might have a relative and they come in and speak to that relative, but they don't come in and speak to everybody." (Participant 7)

Interviewees further saw that the lack of and need for intergenerational inclusion within communities could have negative impacts across different groups. For example, as one interview participant pointed out: "...loneliness...is maybe a commonality that we can build on for intergenerational, you know, because lonely is lonely, isn't it? So it's not owned by people with dementia." (Participant 007)

This was corroborated by another interviewee who felt that 'a lot of kids feel really isolated in their homes as well, because their parents are out to work' (Participant 012). The unmet need for intergenerational inclusion was perceived by some participants to be related to a separation between generations and between service providers focused on different groups. One manager claimed that there was 'a real disconnect' between schools and services for older people (Participant 002). Another manager similarly stated that:

> "You know, I think we keep everything so separate, whether it be schools or units like myself, there's not a lot of interaction and I think it's been (made) a hundred times worse by the pandemic now." (Participant 003)

An officer stated that such separateness between sectors and organisations had ramifications for different age groups, which provided an impetus for intergenerational work:

"[The] generations were fairly separated in a lot of ways so maybe there is a need to have these actual programmes running where people reconnect with people..." (Participant 004)

Combined with the separateness of age-specific services, intergenerational work could potentially be limited by a tendency for services to only work in their own localities and not further afield, with the result that some older people living with dementia with greatest need may actually miss out. As one director pointed out in relation to care homes collaborating with nearby schools:

> "So...that doesn't necessarily reach the older people with dementia who could really benefit from it. Because if they're not in that care home next door to the school, how does that school engage with those people?" (Participant 011)

The majority of participants did specify a need for intergenerational inclusion and activities to enhance inclusion, however, a number of participants expressed their views with caveats. A trustee, for example, felt that the 'need' for intergenerational inclusion could be linked to

the present inability of Scottish communities to organically generate relationships across different age groups:

"So I think it's sad that there has to be an emphasis on intergenerational anything, but the sad reality is that it is prompting relationships and I think it's that bit about relationships naturally forming, which are enhanced by that exposure to people of a different age from us" (Participant 007)

Two participants were keen to express intergenerational practice for people living with dementia as one approach among many that policy potentially could focus on. For example, a director stated that rather than a 'need' for intergenerational programmes per se, there was a 'need' for 'a level of awareness and acceptance that (intergenerational practice) is something that should be considered' (Participant 005). Another participant preferred to focus on the 'needs' of younger and older participants to which intergenerational practice could be a solution, however, that alone would not necessarily translate into policy attention or prioritisation:

"...younger people have needs, older people, people living with dementia have particular needs which need to be addressed...I think the intergenerational work is one solution to those needs, but I think...that in itself doesn't put it at the top of the agenda as this is the main thing that needs to be done" (Participant 011)

Therefore, interviewees felt that intergenerational relationships were mostly concentrated in the family sphere, with intergenerational contact more difficult to realise in communities more broadly. Services for different age groups could operate separately from each other and have tendencies to work locally rather than further afield. In terms of a need for Scottish policymakers to focus on intergenerational practice for people living with dementia, it was felt that policymakers should consider such practice as a potential solution while recognising other approaches that may be available.

## Potential for Intergenerational Inclusion

A number of participants saw a trend towards a more central role for communities within policy and the provision of services in Scotland, which could provide momentum for intergenerational work. For example, a director stated that the pandemic had highlighted the importance of communities in supporting people living with dementia in Scotland:

"(W)hat we have seen up until to this point (and) I think the pandemic has really shone a light on this, is that the community is actually the driving force and is what people are responding to." (Participant 005)

Moreover, an officer perceived Scottish communities as being capable of generating diverse types of intergenerational interaction between age groups despite media perceptions of intergenerational work being limited to small children and very old people:

> "...it kind of sells us as intergenerational work being very small children and very old people. And that's not the case, it's our whole community, it's across generations, so it could be a twenty-yearold working with a forty-year-old." (Participant 006)

Multiple participants spoke positively in general terms about Scotland's capacity for intergenerational programmes particularly in relation to people living with dementia, stating with intergenerational practice and dementia 'there's a lot of potential' (Participant 008), certain to 'snowball' during this interesting time (Participant 010), and with a huge amount of untapped opportunity (Participant 011).

Participants spoke of intergenerational practice in terms of the potential it had to generate better outcomes not just for older people, but for all age groups:

"...if we have...intergenerational communities, we will have communities built that are safe. And I quite like this, so it's safe to grow up and grow old in. So safe spaces for people to just be." (Participant 006)

Another manager stated that knowledge and skill sharing among generations 'makes for a good sign for building better infrastructure in communities long-term to be more inclusive...places.' (Participant 009).

Some participants, however, saw limitations to the potential for intergenerational practice in Scotland for people living with dementia. One officer commended the work that had been done but thought Scotland could do more: "I think that we have a long way to go. I think that we like to think that Scotland is, we're great, we do everything, but we have a long way to go in many areas." (Participant 006)

The officer further stated that involvement in intergenerational practice remained variable: '[s]o just for as many that are involved there are just as many who aren't involved' (Participant 006). Along similar lines, one coordinator thought that only some practitioners currently understood intergenerational practice:

> "...there are people who understand the value of it, but they're only in certain places." (Participant 008)

In addition, interview participants were keen to see a broad range of partners and organisations involved in intergenerational practice involving people living with dementia, however, views were mixed on how well projects could reach those who would benefit most. One participant perceived 'doors being opened to groups and people who [are] excluded or were already excluded in the community' (Participant 010), whereas another participant felt that finding older participants outside of service provision and referral systems could still be a 'long-winded approach' (Participant 004).

The short length and lack of continuity of programmes in Scotland was mentioned by a director as a limitation on the potential for intergenerational dementia programmes:

"And it's nice stuff when it happens and older people do enjoy it, but it's just like a...it's a moment, you know, and it's not, you know, it's not a deep societal change or you know, an ongoing impact, it's just a nice thing. It's a nice moment." (Participant 011)

Therefore, interview participants perceived a strong context of community characterised by needs for intergenerational inclusion and some potential for intergenerational practice.

## National and International Variation

#### National Variation

In regard to community variation within Scotland, one director noted that different areas of Scotland may vary geographically or have different participant groups to potentially involve in programmes, resulting in different forms of intergenerational practice: "It might be the case depending on the area or the group or you know geographically or of interest what that looks like, it might be different..." (Participant 005)

Along similar lines, another interviewee perceived widespread poverty in Scotland on the one hand and affluent communities on the other, with it often being the case that wealthier areas of Scotland will have greater resources to tackle social issues, such as total numbers of community volunteers:

"...we've got lots of poverty, we've got pockets of poverty and we've got pockets of deprivation, so therefore, you'll probably see from Volunteer Scotland, the strategy for Scotland, in affluent areas we get more volunteers, and you get more kind of input from volunteers and communities. But if you go to more deprived areas there's less of that happening...and there's still our people living with dementia in deprived areas too, so I think it is just about getting that message trickling down to all communities. And that's a big job, isn't it?" (Participant 006)

In the face of differing social challenges across communities, this may lead local authorities to deviate from national policy and pursue their own approaches resulting in further variation. As one coordinator stated, 'local government or whatever are going to do what they want to do, not what the Scottish government wants them to do' (Participant 008).

Interviewees perceived further variation in the extent to which intergenerational practice had or could take hold within differing communities:

"It varies on- on different communities and different areas, on how children are supported to be included with older people." (Participant 013)

A number of participants perceived that the rollout of intergenerational practice was confined to pockets rather than spreading across all communities at pace. For example, one trustee felt that there 'are pockets of excellence' across Scotland (Participant 007). An officer described how 'we have pockets of ideas of things beginning to happen, but it's early days' (Participant 006). A director, similarly, spoke of his awareness of intergenerational practice in these terms:

"...all I am really aware of are just individual projects here and there, you know, just case studies you hear of, you know, through the media, social media, and my perception is they tend to be very small pockets." (Participant 011)

## International Variation

In addition to national variation, a number of participants alluded to the fact that other countries engaged with intergenerational practice more and to a higher standard than Scotland, explaining this difference in terms of the culture of Scotland and Scottish family dynamics. For example, one manager stated, 'I know I looked at research in other countries and I know Denmark do a lot more than we do'. They elaborated that in Scotland, family members of different generations living together was not so common in the present day, whereas traditions of grandparents living with core families persisted in other countries:

"...you know, I have friends from other countries, and I think that a lot of other countries, grandparents live with daughters and sons, and I think we used to do that an awful lot more, and we do that a lot less now." (Participant 002)

An officer, moreover, described a care home in Japan that had been designed to be embedded in the community, rather than isolated like many of the care homes in Scotland were perceived to be:

> "Looking further afield to many studies in Japan, they have a care home there where they took the walls down round it and encouraged the community to make a kind of wander path all the way through...and it meant that older people could be part of the community. And even if they weren't involved physically, they could look out their window and see life happening." (Participant 006)

The officer felt that countries like Japan and the United States were ahead of Scotland in terms of intergenerational practice, but that Scotland was progressing within the bounds of its own culture:

"...if we look across the world, if we look at Japan and we look at America, and we see the work that's being done, we've got a long

way to go but we're getting there. But our culture is different, you know. We've got a different culture from Japan." (Participant 006)

Therefore, some variation was described by interviewees internally between different Scottish communities as well as externally between different countries, with Scotland progressing with intergenerational practice but arguably lagging behind certain other countries where practice was perceived to be more culturally embedded.

## Intergenerational Inclusion and Scottish Policymaking

## Role of Policy

A number of participants described how intergenerational practice and inclusion was currently not explicitly addressed through Scottish policy, especially national dementia policy. For example, a director stated:

> "So no, the Scottish Dementia Strategy does not mention it specifically. Even the COVID-19 action plan doesn't mention it..." (Participant 005)

A manager corroborated this:

"It is nothing I have ever seen on a...I mean the Scottish Dementia Strategy doesn't mention intergenerational work at all." (Participant 001)

One coordinator went further, claiming that they did not think Scottish policy took intergenerational practice 'seriously':

"I don't think any Scottish government policy document to do with health and social care has ever taken it really seriously. Certainly either in terms of mentioning it in the document- and they might have done- but certainly as a result of that document, something happening..." (Participant 008)

However, some participants were more willing to see Scottish policy as currently supportive and conducive of intergenerational work. One manager felt that Scottish policy 'had slightly' addressed intergenerational practice for people living with dementia. An officer, moreover, felt that 'linking in' with policy for intergenerational practice was fairly easy to achieve, putting the onus on organisations and practitioners themselves to be strategic: "I think that we always kind of link in with strategy and policy for older people and for younger people. And it's always helpful for us to know what the strategy is." (Participant 006)

Similarly, one manager felt the Scottish Government had developed a high degree and high level of policy, particularly in relation to dementia, that it endorsed an intergenerational approach without a need for more policy first:

> "I think the standards you could use them any way you want, really because there are so many standards and the Scottish government have done so much work, really good work on it, with the Charters and actually changed, changed the way people think about dementia." (Participant 012)

Participants also had different perspectives on the extent to which policy should more proactively and explicitly pursue intergenerational practice. For example, one director felt that Scottish policy should focus on tackling 'overarching themes' that sit above intergenerational practice, such as community development and support:

> "...what [policy] should be is you know the kind of arm that goes around the community and supports the community to deliver that." (Participant 005)

The director also felt that there was a risk Scottish policy would become incoherent if it tried to actively promote all possible approaches to dementia support and community development:

> "I think there would be arguments, I suppose, to say that, well, but we also need to include that element and we also need to include that - there are so many, many things that are part of people's lives and people's experiences." (Participant 005)

However, along with ensuring overarching themes, such as community and lifecourse approaches, that naturally synchronised with intergenerational practice at an operational and practice level, the director felt that assumptions could be questioned more within policy circles and that conversations around policy and practice could be clearer: "I think we need to be drawing more on intergenerational work and maybe what shouldn't be happening is...that there are assumptions that that is happening. I think we need to be moving away from just assuming that's the case, and maybe asking more questions around well, what does that look like, who's involved, is there an intergenerational aspect to this work, because that is not really the questions that are being asked...in my experience, it is not often mentioned or asked about, it is just assumed." (Participant 005)

A trustee similarly felt that dementia policy could be clearer when it came to intergenerational inclusion:

"I think the Dementia Strategy could do more in terms of being more explicit." (Participant 007)

The trustee described that, in the absence of explicitly pursuing an intergenerational policy, then greater clarity around key concepts such as 'community' would be required to make clear that these concepts organically involved intergenerational interactions and structures:

> "So I suppose there could be more defining that in the Dementia Strategy. You know, I have got the right to be involved in my community. Well, what does that mean? Everybody who has got dementia, is that your community...And I think that's maybe something in the strategy documents that needs to be more explicit? That when we're talking about a community, we're talking about the newest member of that community to the oldest member of that community." (Participant 007)

However, a number of interviewees envisaged a more proactive role for Scottish policy towards encouraging intergenerational practice involving people living with dementia. For example, an officer perceived funding and regional empowerment to be crucial:

"I think the wording of [policy] tries to address [intergenerational practice], but I think they have to put their money where their mouths are really and bring it down to regional level and provide funding for third sector groups to continue with these activities and projects." (Participant 004)

A director felt that policymakers may benefit from extending their understanding of intergenerational practice from something small and localised to programmes that could be holistic and reciprocal across different age groups:

"I think it would need that different mindset of where they are coming from, that it's not just an additional, nice-to-have... And I think that, I think it's too easy for policymakers, programme makers to have a concept of what intergenerational work is and can do, and I think it would perhaps help to look at it in a different way from the beginning...Or have a different starting point." (Participant 011)

Therefore, a degree of tension emerges from the data concerning the extent to which Scottish policy should actively vocalise and pursue intergenerational inclusion and practice, especially in relation to older people. Having greater clarity around key concepts such as community and inclusion appears to be a consensual starting point. However, it would appear that in order to build longevity into intergenerational practice, and fully enable organisations and partnerships in their intergenerational endeavours, may necessitate more deliberate steps on the part of Scottish policymakers, particularly in terms of funding and regional uptake.

## Policy-Practice Gap

Interviewees vocalised a 'gap' between Scottish policy and intergenerational and dementia support practice underway in Scotland, with this gap apparent in several different ways. Firstly, practice was felt to fall short of policy specifically in the area of dementia support in Scotland. For example, one coordinator felt that the monitoring of the implementation of the National Dementia Strategies in Scotland had to date been insufficient:

> "None of the previous three strategies were ever evaluated, so how can the policymakers and the people who have written what they said and committed to what they said they were doing know it's working if they've not evaluated it?" (Participant 013)

In particular, statutory post-diagnostic support for people living with dementia in Scotland was felt to be time-limited and insufficiently clear. An officer pointed out that post-diagnostic support could often end abruptly after one year:

"There's only statutory provision for one year post-diagnosis. So I think that once people are in that stage of being past that one year, they somehow get- I don't know- left, just abandoned or what I don't know." (Participant 004)

Several interviewees, similarly, spoke of policy in terms of being rhetorical and incapable of generating beneficial programmes or results 'on the ground' through practice, despite the nature of the policy itself being theoretically sound and positive.

For example, one manager stated:

"So often it is theory, it's all the theory stuff, it's all up there. So we know in practice we should be doing it, but the reality is that it doesn't happen on the ground...so the theory-practice gap is quite wide...So it's the same with intergenerational work, we all know it should happen, but you know getting people to actually do it on the ground..." (Participant 001)

A project officer further described the difficulty of getting policy to translate into regional practice consistently, claiming while the National Dementia Strategies were ultimately 'hopeful' it would nevertheless '...take a long time for that to filter down to local level and for that to become part of local and regional policy or practice' (Participant 004). A coordinator, moreover, saw policy as limited when confined solely to documents rather than an active policy-practice interface:

"Mentioning something in a document is one thing, things changing on the ground as result of policy, or a Scottish government document or policy document, is a complete other thing." (Participant 008)

Related to the perception of policy as rhetorical was a recognition of intergenerational practice for people living with dementia taking place in Scotland in the absence of clear guidance or support from policymakers. A director described the initiative demonstrated by local Scottish communities in the area of intergenerational practice, for example:

"What is being developed and borne out of a lot of this work has just been local communities and organisations alike just developing work off their own back." (Participant 005)

A coordinator similarly felt the link between intergenerational practice and governmental policy was not apparent:

"...if you look at [intergenerational practice] and what there's been...where's the link between that and government policy documents? Or government policy? Where is the link?" (Participant 008)

Along with a lack of links between intergenerational practice and government policy, the coordinator further saw potential for local authorities to pursue their own approaches irrespective of the national approach:

"So yeah, so really there's a disconnect between government policy and the next level of local government or health authorities that need to bring something into being, okay?" (Participant 008)

Therefore, a practice-policy gap was perceived to be apparent in Scotland, particularly in relation to dementia support whereby aspirational policies were not always matched by services or evaluation processes. Implementation gaps have been characterised as those 'gaps' that can exist between 'expectations at the top and perceived policy outcomes at the bottom' and have been associated with the Scottish context within research (Cairney, 2009: 356). Intergenerational practice was further perceived as too often taking place without clear policy guidance and thus relied on communities to generate their own initiatives.

#### Policy Linkage

In the absence of a formalised intergenerational policy approach or strategy for Scotland, practitioners were perceived to rely on linking their intergenerational practice to the existing policy of other sectors. This policy linkage and promotion has allowed practitioners to, for example, validate and structure programmes, or pursue funding. In particular, intergenerational programmes involving people living with dementia and school-age children were perceived by interviewees to be strongly embedded within educational policy, particularly the Curriculum for Excellence aimed at fostering different capacities in young people including responsible citizenship (Scottish Government, 2010).

For example, a director commented that intergenerational work could be harnessed towards awareness raising and reducing stigma, with educational policy providing a good foundation for such work to take place:

> "I think there's a real role in terms of intergenerational work around that raising awareness, that education, and reducing stigma, which I think can really be built on particularly when educational programmes, frameworks, are looking for, you know, good leadership qualities in our young people, good skills, good, you know, opportunities to develop their citizenship and being good people." (Participant 005)

A coordinator noted the potential for schools to host older participants during intergenerational dementia programmes rather than younger people always going to visit older people, stating:

"...it's the other way as well, for the schools to invite the elderly people into the schools and have it part of their citizenship agenda." (Participant 013)

Another coordinator recounted an intergenerational dementia programme that had been held in Scotland involving a nursery and school visiting a dementia respite organisation where the children would regularly walk to visit with the older participants, with 'even the walk' being 'part of their curriculum' (Participant 006). A trustee, similarly, stipulated that the 'Curriculum for Excellence Outcomes' were 'just so intergenerational' (Participant 007). A director stated that within the Curriculum for Excellence, moreover, there were 'possibilities' around creating time and opportunities for younger people to become involved in intergenerational work (Participant 011).

However, older people's services may face a number of barriers to working with educational partners including the lack of time of teaching staff, along with intermittent changes to curriculum. A director noted that priorities could vary within education over time and for different age groups, presenting a potential barrier:

"...so it might be that's it is a priority for one element of coursework or for one particular age group, but it might not be a priority for a long period of time or for all age groups, so it's about how those priorities are managed form both ends as well." (Participant 005)

Another director, in contrast, noted the potential for different organisations to converge around the same priorities given time:

"It almost becomes either part of a curriculum or you know, part of (a) development where both sides, whether it's older people and younger people, and their institutions, see benefits in it." (Participant 011)

The director did acknowledge that bringing different sectors together could be challenging initially due to complexity and disparity (Participant 011).

Intergenerational practice was perceived to be linked to a number of different policy areas in addition. For example, one manager saw potential for intergenerational work to be linked to the reform of adult social care:

> "I know there is going to be a huge overhaul of social care and so I am hoping the Scottish Government will look at that and see how they can put intergenerational activities at the heart of it..." (Participant 003)

One officer felt that intergenerational practice could effectively be linked to local outcome and improvements plans:

"...if we link in with local networks and groups, (we) would say, well, look at what the local outcome and improvement plan is for your local authority area. So we would build up like knowledge of what that is." (Participant 006)

A trustee perceived Scotland's loneliness agenda, 'A Connected Scotland', to represent a good vehicle for intergenerational work (Scottish Government, 2018):

"I think the Loneliness Strategy is important...It doesn't necessarily name intergenerational, but it does, it's that catchphrase of community, and unpicking that, that a community does not exist unless you've got from babies to a hundred-year-olds." (Participant 007) In some instances, interviewees were less specific about the policy grounding of current intergenerational practice, suggesting there exists some ambiguity over the exact nature of the policy-practice link in relation to intergenerational issues in Scotland. For example, one trustee felt intergenerational work was 'part of government drive' in Scotland and that 'intergenerational' was a word that could be seen in various reports (Participant 007). Similarly, a director related how practice could sometimes take place detached from specific policy, for example, work undertaken in care homes:

"Another strand of it is care homes, so again you know there's pieces of work going on. But again there's nothing specifically in there that has a focus on intergenerational work as a specific recommendation or a specific outcome..." (Participant 005)

Some interviewees noted that this policy ambiguity towards intergenerational programmes could be problematic. For example, one coordinator felt that intergenerational practice was 'not promoted properly in Scotland or promoted in the right way', that it was therefore not 'represented in policy' and thus was resulting in a need for government across all levels to 'buy into' intergenerational practice to a greater degree (Participant 008). Moreover, a director perceived their own projects to take place outside of any given policy framework or intergenerational network:

> "I think we're very much working in isolation away from any...any given sort of policy framework or network, of intergenerational networks." (Participant 011)

The director also noted that intergenerational programmes could often be 'short' and 'sharp' in nature and consequently face barriers to funding, and this again could be linked to a lack of policy drive behind the work meaning intergenerational practice still remained tangential in some respects:

> "I think in terms of difficulties, can be around funding, you know, in a lot of funding programmes tend to just be short, sharp programmes, and I think intergenerational tends to be almost, not an addition or nice to have, but it's not necessarily core, I don't think, to many organisations' work." (Participant 011)

Therefore, interviewees perceived that intergenerational inclusion for people living with dementia could be linked to some aspects of Scottish policy, particularly educational policy. However, there were instances where policy linkages were less clear or less relevant.

#### Intergenerational Inclusion and Policy Aims

Intergenerational dementia programmes were perceived by interviewees to reinforce policy aims including the preventative health agenda in Scotland, allowing people living with dementia to remain living at home in their communities, as well as workforce development across the care, health, and social care sectors.

#### Preventative Health

A number of participants perceived intergenerational programmes to feed into prevention and early intervention agendas, as well as enhancing lifecourse approaches to health and wellbeing among all age groups. A manager, for example, perceived intergenerational dementia programmes to be a way to raise awareness around lifestyle risk factors for dementia among younger participants:

> "I mean, I don't know that you can completely prevent dementia from starting with your behaviour, but there's a lot of stuff around, particularly about the consumption of sugar...and obviously the messages around alcohol and cigarettes are quite profound. So what we kind of hoped was if we could talk to younger people, we could help them to understand the illness and grow up with a different level of anxiety about it." [Participant 001]

The manager also felt that, through exposure to intergenerational dementia programmes at an early age, normalisation and knowledge could improve dementia diagnoses seeking among younger age groups as they themselves aged:

> "But in general I think people are much more alert...and that's the thing that we are trying to do, get people to come forward as early as possible, so the more people who know about dementia and understand it, the more chance you have got of achieving that...So it is about really encouraging people to be aware of their health and do something about it at an early stage." [Participant 001]

An officer further expressed greater awareness of lifecourse health in terms of more responsive, health-aware communities and linked this to the inclusionary approach of intergenerational practice:

"So for me intergenerational should involve everyone, it should be awareness for dementia in our communities, we should be aware of everyone, you know, that someone might be struggling with mental health, or someone might be lost in the moment of dementia, or the early onset dementia..." [Participant 006]

Another interviewee cited an example from their own intergenerational dementia practice where health and wellbeing formed the focus of the intergenerational activities undertaken:

"It was an eat well, age well project, so about malnutrition and dehydration in older people...So what we did was we approached a school [and] we gave them the idea..." [Participant 010]

#### Remain at Home

Another theme identified by interviewees was the preference for many older people living with dementia to remain living in their own homes in the communities they were familiar with, undoubtedly an influential aim within Scottish policymaking in regard to services for older people. For example, a manager described how older people living with dementia in general were reluctant to go into care homes:

> "...people with dementia can live in their own communities, live in their own houses, go to their local shops, all that kind of stuff. Because that is what people want to do, people don't want to go into nursing homes..." (Participant 001)

Moreover, another manager saw a role for different organisations in providing the support to enable people to remain at home:

"We have to really support people to stay in their own homes and feel they can do it, they can stay at home. And try keep them out of care homes as well to be honest as long as possible, too." (Participant 012) However, the manager did recognise that some older people, along with their caregivers, may favour an approach involving a care home as it could generate better outcomes or better accord with personal choice:

> "I mean, some people thrive in care homes. I have got a gentleman last week who just wouldn't eat, he just wouldn't comply with the carers at home but away he went into the care home and he's eating everything in sight, you know. So it's just making sure it's what the person wants." (Participant 012)

A trustee, moreover, recognised that old age has in effect extended and that the preferences and risks attached to remaining at home for people living with dementia may change throughout the lifecourse and depending on circumstances:

> "You know, we keep hearing that well, the people say that they want to live in their own...Well, you might ask me when I am seventy-four and quite mobile and going out to this, that and the other, but when I am eighty four and I am not seeing anybody, would I still have the same answer to your question about living at home as long as possible?" (Participant 007)

Therefore, there is a perception among practitioners that most older people want to remain at home, however, there is also a recognition that care homes will continue to be necessary, and in some instances or for some individuals may well be the preference. The consequence for policymaking in Scotland aimed at enhancing inclusion for people living with dementia is that it is not contextually-bound to only one type of setting and therefore programmes are needed to foster intergenerational inclusion both within communities and within care homes and other units.

## Workforce Development

Intergenerational practice was also perceived to have a potential impact on workforce development and the career choices of younger people. For example, a manager described how secondary students undertaking work experience with a dementia daycare service benefited from the experience: "...they learned a little bit about how our service works as well. And you know, that's always good as well, to find out about how different services work." [Participant 002]

Another manager described how in their unit, they were facing issues with staff succession, and how they felt through intergenerational practice, young people could be encouraged to think about opportunities in the caring professions:

> "And it also gets the children to maybe start thinking about a career in a caring role, whether it be in the social sector or the nursing sector or whatever, and in this country we are going to hit a huge deficit of care...like for instance in my unit, we are a very elderly staffing group and there isn't people coming in to take our place so the succession of staff is very important and I think it starts with intergenerational activities...And I think that's a really important aspect of intergenerational activities that a lot of people don't understand." [Participant 003]

An officer similarly felt that young people could acquire valuable skills in addition to helping shape their career choices and provide them with service knowledge:

"...there are young people who went along and did some work with care homes and people with dementia and then they went to decide that they're going to do, follow a career in that kind of work...So you can learn about what kind of skills are required in health and social care..." [Participant 006]

Therefore, interviewees perceived that intergenerational practice could be a means to encourage younger people to think about preventative health and be more proactive about their health and information seeking. In addition, intergenerational opportunities could be a means of both encouraging younger people to think about careers in health and caring professions, along with providing them with skills that could equip them to enter these professions in future.

## Intergenerational Inclusion and Scottish Partnerships

In addition to these policy perspectives, interviewees also described aspects of partnership working in the Scottish context that they felt were important in order to allow for intergenerational dementia programmes to be as effective as possible. Collaboration and coordination between service providers and partner organisations is a key facet of the 'Scottish approach' to service design (Scottish Government, 2019).

#### Brokerage

Firstly, interviewees thought it was important that all partners involved in developing programmes saw value in intergenerational work and were willing to get involved:

"So the people that you are working with have got to believe that it's worth it." (Participant 001)

A coordinator similarly observed that initiating a programme may involve getting partners 'to sign up to it in their minds' (Participant 006). Ensuring willingness and understanding among partners may require a degree of partnership building, which one manager described as a process of brokerage:

"...there's the brokerage part, for example, if you want to get two groups, so you...need to do presentations to schools, head teachers, to managers of care homes, to day centres and it's letting them believe that you are competent...and can do this." (Participant 010)

Such 'brokerage' was not perceived to be necessarily a straightforward process, but rather may require greater understanding among partners so that intergenerational is not a 'brand new' concept (Participant 007), resources and time to 'convince organisations that something can be done without much cost' (Participant 008), a 'long lead-time' to build partnerships with, for example, schools (Participant 011), and a process of 'selling' programmes to others you wish to be involved (Participant 013).

Partnership building may also involve clarifying a number of questions with partners, for example, related to outcomes:

"I think you really need to look at your outcomes, what are your outcomes? Why are you doing this? Why is it...needed?" (Participant 010).

Questions regarding partnership capacity may also be important:

"It's just finding, you know, what is it that they're willing to do, or what is it that they can do?" (Participant 013)

Different priorities may also need to be aligned in order to enable partnerships to deliver intergenerational dementia programmes, with a particular onus on linking in with the priorities of educational partners:

"You know, so both groupings so to speak, they will have sort of an output that they want from it, so they'll want, like, you know, younger people are socially active with older people, they're learning about what age is, they're learning about dementia maybe as well." (Participant 006)

#### Shared Responsibilities

Establishing shared responsibility between the different partners involved in intergenerational dementia programmes was also perceived to be important. Shared responsibility was understood to involve taking turns to initiate programme activities (Participant 002), trust between partners (Participant 010), good communication (Participant 012), and good collaboration and networking, including providing information in advance where necessary (Participant 013). Some responsibilities would naturally fall to particular partners, for example, schools seeking parental/guardian consent for children and young people to participate in programmes (Participant 010).

Some partners may also need to make more allowances than others:

"I think the care homes did have to tweak a few things to make it happen. You know, they're allowing me and young people into their home, where they couldn't really supervise them all the time. So it was quite a big ask..." (Participant 008)

A lack of shared responsibility, moreover, was perceived by one manager to be detrimental:

"...if it's the wrong partnership that's formed and the groups that are working together, there isn't a good structure there or they're not sort of gelling, if...the idea of the programme and why they are doing it isn't clear, if that's muddled, then I suppose that would have a detrimental effect" (Participant 009) Shared responsibility could be established by means of a written agreement setting our roles, responsibilities and boundaries and could further be maintained through regular stakeholder evaluations (Participant 010). This emphasis on shared responsibility between partners involved in programme delivery resonates with findings from the Christie Commission on the future delivery of public services in Scotland, which repeatedly advocated for joint working between Scottish stakeholders (Scottish Government, 2011*a*).

#### Staff and Organisational Attitudes

The attitudes of staff were also important towards ensuring that partnerships worked effectively. One manager observed that it was important to have staff 'on board' with intergenerational practice in order to have them involved in activities (Participant 003). The manager further noted that some staff would not see a benefit in intergenerational practice:

"...it only happened with one or two, but I was very disappointed in that attitude that they felt that it was too much like hard work and there wasn't a good outcome, when we could clearly see that there was a good outcome." (Participant 003)

Some staff members, on the other hand, could be 'enthusiastic champions' of intergenerational practice (Participant 007). A manager alluded to how staff could have apprehensions prior to getting involved in intergenerational programmes and may require time to build confidence and learn:

"...she said to me, oh, I can't believe I have known you so long now, I remember the first day you came in and...She said, I was absolutely terrified, I have never had anything to do with young people. All her...career life has been working in geriatric or whatever they call it etcetera. And she said, I can't believe how much I have learned." (Participant 010)

Organisational attitudes were perceived to militate against programme development in some instances, for example, there being too much 'red tape' (Participant 004), a negativity to trying new things (Participant 007), entrenched in their own 'habitats' (Participant 010), a tendency to go for 'low-hanging fruits' (Participant 011), risk averse (Participant 012), and prone to some old-fashioned ideas, for example, regarding what children should be allowed to do (Participant 013).

Therefore, effective partnerships were perceived to rely on robust partnership building combined with an understanding and willingness among partners to pursue intergenerational programmes. Shared responsibilities and trust were crucial to partnerships, and attitudes among staff and organisations could further have an effect on how partnerships functioned.

#### Conclusion

This chapter has explored intergenerational inclusion in more depth and in relation to Scottish policymaking and Scottish partnership working. Interviewees described a clear need for intergenerational inclusion related to trends of decreasing regular intergenerational contact among Scottish families combined with a lack of organic intergenerational relationships within Scottish communities. A lack of intergenerational inclusion was also perceived to be related to a risk of heightened loneliness and isolation among all age groups. However, some interviewees were keen to emphasise that intergenerational practice was only one approach among many and not necessarily at the top of Scotland's dementia policy agenda. Interviewees further saw potential for Scottish communities to deliver intergenerational initiatives that would build inclusive community infrastructure and safety for all groups. However, some interviewees expressed that Scotland did have a long way to go towards becoming socially intergenerational with practice happening only in some areas but not others. Scottish communities could also vary in terms of the degree to which they were currently delivering intergenerational programmes, and the degree to which they were able to equip programmes. Moreover, Scotland was perceived to be not as advanced in terms of intergenerational practice as some other countries.

In terms of Scottish policymaking, interviewees held differing perspectives regarding the exact role for policymakers towards enhancing intergenerational inclusion. Some interviewees preferred a role for policy operating on an overarching level, promoting community development approaches that would endorse intergenerational practice among many other types of programmes. However, other interviewees saw a stronger role for policy in initiating intergenerational work. Policy in Scotland was also perceived to be disconnected from intergenerational practice on the ground in Scotland, resulting in a policy-practice gap whereby policy was rhetorical and not sufficiently clear to guide programme development. However, some practitioners felt that intergenerational practice could be linked to some lateral aspects of policy, particularly Scottish educational policy and the Curriculum for

Excellence. Intergenerational inclusion was also perceived to relate to several broad, highlevel policy aims such as preventative health approaches, the right to remain at home for people living with dementia, and workforce development.

In terms of partnership working in the Scottish context, interviewees described the importance of establishing effective, coherent partnerships capable of navigating the complexity and cross-sectoral working that intergenerational practice often involved. Ensuring shared responsibilities among partners was also important, with the understanding that some partners may need to make allowances and take on responsibility for particular tasks. Staff and organisational attitudes were understood to be important to building and sustaining partnerships, however, interviewees indicated that some staff and organisational attitudes held in Scotland may impede intergenerational partnerships and programmes.

## Chapter 8: Discussion

#### Introduction

This thesis sought to explore how the concept of intergenerational inclusion for people living with dementia has been understood and operationalised internationally and nationally in Scotland. Moreover, the thesis sought to explore how insights from exploring international and national practice could further inform the development of intergenerational practice and policy across both the national and international levels. This chapter will discuss the findings that have emerged from both phases of the study in relation to these three research questions. By aggregating findings from a realist analysis of intergenerational literature with empirical findings generated through qualitative interviewing with Scottish stakeholders, this chapter is able to provide some new insights into the understanding and operationalisation of intergenerational inclusion across a variety of settings.

The first section of the chapter explores intergenerational inclusion internationally and nationally, emphasising findings that agree and findings that diverge across the different levels of analysis, and thus addresses the first two research questions. Both internationally and nationally, intergenerational inclusion has been operationalised through intergenerational dementia programmes involving activities designed to bring older participants together with younger participants of varying ages. There is strong evidence that people living with dementia can successfully participate in such programmes, however, a number of barriers to participation may also be present. The second section of this chapter then explores insights into intergenerational practice through the development of context-mechanism-outcome propositions, that is, propositions that connect contextual factors, explanatory mechanisms, and outcomes for each of the main groups involved in intergenerational dementia programmes (older participants living with dementia, younger participants involved in intergenerational programmes, and programme organisers).

Insights into intergenerational policy are also explored with particular reference to the Scottish context, followed by a number of recommendations for the future development of intergenerational practice and policy. The chapter then concludes with some further remarks on, firstly, the application of the realist evaluation approach to the field of intergenerational inclusion for people living with dementia and, secondly, the implications of these findings within intergenerational theory (figure 6).

## Intergenerational Inclusion Nationally and Internationally

This thesis aimed to address how the concept of intergenerational inclusion for people living with dementia has been understood and operationalised internationally and in Scotland. The following section will address these research questions by presenting similarities in understandings and operationalisation across the international and national levels that were apparent in the findings, as well as highlighting some key areas of difference. The factors explored in this section include the settings of intergenerational dementia programmes, the make-up of participant groups, barriers to participation, programme implementation, programme activities and mechanisms, and programme outcomes.

The findings indicate, firstly, that definitions of intergenerational practice across different settings can be variable. Some definitions in the literature were prescriptive, such as that described by Gigliotti et al. whereby programmes brought together 'older adults (65+) and children/youth under the age of 21 in mutually beneficial interactions fostered by a carefully planned program of activities' ((Gigliotti et al., 2005: 425). However, particularly within the interview findings, interviewees perceived intergenerational inclusion to be much more fluid, involving different age groups in different ways and at different stages of the life course, with one interviewee recommending the use of 'multigenerational' to encapsulate the gradation and diversity that is possible.

Intergenerational programmes were often but not always defined in terms of being either 'formal or informal', 'non-familial', and as interventions that were undertaken 'on purpose' by agencies and partners in contrast to non-organised intergenerational inclusion that may or may not occur organically in communities. Greater attention may therefore be required in order to fully define intergenerational programmes and practice in contrast to other familial or community forms of intergenerational interaction.

Moreover, while this research proposed a definition that made specific reference to dementia, the findings demonstrated that intergenerational programmes involving people living with dementia were often defined using definitions of intergenerational practice in general. Subsuming intergenerational dementia programmes within intergenerational practice more broadly may risk obfuscating aspects of practice- including contextual barriers and assets, mechanisms, and specific outcomes- that are particularly relevant when involving older participants living with dementia. This may further have consequences for adequate theorising and optimal implementation of intergenerational dementia programmes.

However, it was noted that definitions that were overtly dementia-specific may result in the 'othering' of people living with dementia and the exacerbation of felt stigma (Fletcher, 2021: 422).

The findings demonstrate that internationally and in Scotland intergenerational dementia programmes have been operationalised across a range of settings, including care homes and assisted living facilities as well as within communities. In Scotland in particular, the interview findings linked an increasing lack of intergenerational family contact combined with an inability of communities to organically generate intergenerational inclusion with a perceived need for intergenerational programmes for people living with dementia. These findings suggest that needs for intergenerational inclusion and dementia friendliness are not necessarily limited to communities, but rather can be extended to care homes in addition whereby services are connected with and open to the community. For example, Di Bona et al. explored one intergenerational initiative that sought to enhance dementia friendliness within care homes by increasing connections to the community for people living with dementia residing in care homes (Di Bona et al. 2019: 1680).

Intergenerational inclusion has been associated with drives to reduce loneliness and social isolation (Phang et al. 2023, Zamir et al. 2021, Heins et al. 2021). The loneliness agenda in Scotland, for example, envisions individuals and communities across the country that are more connected, with 'everyone [having] the opportunity to develop meaningful relationships regardless of age, stage, circumstances or identity' (Scottish Government, 2018: 3). The qualitative findings indicated that stakeholders in Scotland perceived loneliness to be a current issue in Scotland that did not exclusively affect older age groups or people living with dementia. Young people in Scotland, in particular, were perceived to be at risk of loneliness due to isolation at home while their parents worked. One interviewee expressed the view that Scotland's loneliness strategy, while not explicitly intergenerational, nevertheless could be a good vehicle for intergenerational practice across the country. Findings from both phases of the study demonstrated that strengthened relationships and communities were perceived to be key outcomes arising from intergenerational dementia programmes. Future research programmes could more specifically focus on the subjective experiences of all participant groups regarding whether or not intergenerational interactions positively impact their feelings of loneliness and/or social isolation in order to further consolidate the evidence base.

In terms of the makeup of participants, the findings across the international and national levels further demonstrate that people living with dementia were able to successfully participate within and contribute to intergenerational programmes, including older participants with more advanced dementia in some instances. Within the interview data, moreover, there were frequent references to particular groups of younger participants who had benefited from intergenerational participation in the Scottish context. For example, there was some evidence that children with autism of school-age and younger had successfully participated in intergenerational activities with people living with dementia. One interviewee described achieving beneficial results from intergenerational programmes involving young people with behavioural problems, while another interviewee specified that an intergenerational programme increased self-worth for school-aged participants who lacked confidence and did not fit in well with their age group. Another interviewee further advocated working with Scottish schools to include young people who may be less academic or are engaging less with academia.

One study incorporated in the realist synthesis described specifically targeting children aged 8-11 years with language and/or reading concerns within an intergenerational reading initiative in the American context (Isaki and Harmon, 2014). However, the perspective that groups of children and younger people with particular needs may uniquely benefit from intergenerational participation appeared to be stronger and more common among practitioners in Scotland; and may consequently be an area for further research in the Scottish context.

In terms of barriers to participation for older participants, both internationally and in Scotland the perceptions of caregivers were identified as a potential barrier, for example, where such perceptions were not supportive of intergenerational programmes. However, there was evidence to suggest that concerns may only be held by a minority of carers (Jarrott and Bruno, 2007: 250), or could be surmountable as in the interview findings. Internationally, logistical difficulties such as illness and scheduling were found to potentially affect participation for older participants (Camp and Lee, 2011: 367), along with some evidence of the potential for negative reactions (Gigliotti et al., 2005: 434) and concerns (Weeks et al., 2020) among older participants. Nationally In Scotland, the interview findings indicated that barriers to participation in Scotland were framed primarily in terms of risk, such as the vulnerability of people living with dementia, risk-aversion among services, and risk compounded by programme venue and transport. Weeks et al. provided support for this finding in their study examining the perspectives of nursing home staff in Canada, where intergenerational interaction was perceived to pose safety risks such as increased illness among older participants and issues of infection control (Weeks et al., 2016: 294).

The findings showed large agreement around participatory barriers for younger participants in intergenerational dementia programmes internationally and nationally. The busy schedules of younger participants affected participation during one intergenerational summer school programme (Gigliotti et al., 2005: 434). In the Scottish context, the interview findings suggested that exams and job commitments in particular were perceived to curtail participation for young participants in high school and higher education. The support of parents and guardians towards intergenerational programmes was instrumental in securing the participation of children and young people internationally and in Scotland. Some parents may have concerns around exposing younger participants to issues such as ageing, illness and dementia, and death (Biggs and Knox 2014: 64). The interview data similarly demonstrated that some parents had prevented their children from participating in programmes due to perceptions intergenerational practice could be 'dangerous'. In the Scottish context the findings demonstrated that some organisations may be restrictive towards allowing children to access areas where services are provided for people living with dementia, such as sheltered housing. The potential for apprehensions and worry among younger participants was also recognised internationally (Di Bona et al., 2019: 1685; Lokon et al., 2012: 346; Canning et al., 2020: 272), and in Scotland in particular centred on fears in relation to dementia in general and a renewed sense of posing harm to older people resulting from the COVID-19 pandemic. Some negative behaviours among younger participants were found internationally and could be connected to the age of the younger participants, however, there was not much evidence in the Scottish context of negative behaviours.

Internationally, attitudes between different age groups informed the development of a number of intergenerational dementia programmes and related studies, particularly Lokon et al.'s study of allophilia and Femia et al.'s study of the impact of intergenerational preschool experiences on the behaviours and attitudes of young children (Femia et al. 2008). In the Scottish context, the findings indicated that ageism was perceived by interviewees to persist, with younger people associating older people with bad temperedness, physical disability and vulnerability, and older people viewing younger people as loud and potentially threatening. Therefore, issues of ageism and stigma, and developing suitable services to alleviate negative

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perceptions between age groups, may continue to lend momentum to intergenerational practice and research across different levels.

Both internationally and nationally, moreover, the operationalisation of intergenerational inclusion for people living with dementia was understood and discussed in terms of programmes involving activities that purposefully brought younger people together with older people living with dementia. There was strong agreement between the international and national levels regarding how programmes can be developed in beneficial ways. Providing training and support to both participants and staff was found to be important. The findings demonstrated how programme organisers would be responsible for ensuring suitable venues and transport for programmes, though in Scotland venues and transport were related to risk management and debates around the inclusivity of the physical environment for people living with dementia. Programme organisers were also perceived to be responsible for determining the frequency and duration of programmes, however, there was great variety in how different programmes had been organised. Ensuring programmes were not too tiring for people living with dementia was a finding in the Scottish context.

The resources required to organise and implement intergenerational dementia programmes were frequently discussed in the interview data suggesting high relevancy and concern with resources in the Scottish context. Resources were also a factor in the findings emerging from the international level, with Smith et al. in particular addressing resources within their study of an intergenerational dementia education programme that included a detailed cost-benefit analysis of the programme (Smith et al. 2020: 6).

In terms of activities, in the findings from the realist synthesis and the international level ensuring that activities were meaningful and structured emerged as an important mechanism. In Scotland, interviewees provided frequent descriptions of the types of activities that had been undertaken within intergenerational dementia programmes. Moreover, activities in Scotland were discussed in terms of the sharing and learning processes they enabled between participants of different age groups allowing for bonding and relationship building.

References to Scottish culture and heritage were frequent throughout the interview data and were often implicitly linked to activity development. For example, in the Scottish context the past careers of older participants often provided the focus for reminiscence activities and careers particularly of interest to younger participants included fighter pilots (Participant 008, Participant 010) and footballers (Participant 008), linked to the World War heritage and sporting culture of Scotland respectively. Artistic activities developed or considered within intergenerational practice often utilised strong cultural elements, for example, the poetry of Robert Burns (Participant 003) or felt making (Participant 007). One interviewee, moreover, queried funding incentives for intergenerational activities based around war reminiscence because younger participants are not able to share their own lived experiences (Participant 011). Geographical history was also perceived to be contextually important in some cases, for example, in relation to particular misconceptions held locally in regard to ageing and dementia (Participant 001) or particular industries, such as mining, that had been prominent in certain areas and could provide the focus of conversations between different generations (Participant 008).

Internationally and nationally, incorporating the preferences of participants into programmes and activities was perceived to be effective and a way to enhance programme outcomes, for example, by facilitating matching between participants of different ages. Providing roles particularly for people living with dementia similarly was found to be important across both levels. In the Scottish context, moreover, the findings indicated that ongoing, continuous preparation and planning could further contribute to beneficial outcomes. These mechanisms of programme efficacy will be discussed further in the section below that presents insights into practice and policy towards generating intergenerational inclusion for people living with dementia.

Finally, there was strong convergence on the outcomes that could arise through intergenerational dementia programmes internationally and nationally across all groups, whether older or younger participants. However, it is important to note that engagement has been a key outcome measured through a number of international studies (Reel et al., 2021; Janke et al., 2019; Lokon et al., 2019; Baker et al., 2017; Low et al., 2015; Lee et al., 2007), however, engagement among participants was mentioned less frequently in the interview data.

# Insights into the development of intergenerational practice and policy

The following section explores how insights from international and national practice can further inform the development of intergenerational practice and policy in Scotland and internationally as per the third research question posed in this thesis. The section opens with distinct context-mechanism-outcome propositions regarding the development of intergenerational practice that have been developed in relation to the findings from both phases of the study as well as the methodology based in realist evaluation (figures 3, 4 and 5 below). Within realist evaluation, programme explanations need to move beyond an arbitrary exercise of 'identifying, labelling, and enumerating disconnected aspects of an intervention' according to context, mechanisms, and outcomes as isolated categories (Pawson, 2013: 26-27). Programme explanations, in contrast, are achieved through configuring contexts, mechanisms, and outcomes into 'specific propositions that tie specific Cs and specific Ms and specific Os together' whereby '(one) item leads to another and...defines the others' (Pawson, 2013: 26-27).

However, the context-mechanism-outcome approach has been criticised for analytic reductionism. For example, it has been observed that 'strong associations may exist between a defined context, the mechanisms selected and outcomes achieved in a particular domain' such that 'path-dependent effects could collapse context into mechanism, or mechanism into outcome' rendering complex systems 'simplified and inflexible' (Davis, 2005: 292). Moreover, attempting to develop a 'generalizable theory' for a family of interventions across different contexts runs the risk of 'stripping out context' as an explanatory factor (Hinds and Dickson, 2021: 6). These criticisms will be discussed in relation to this research and in more depth further on in this chapter.

This section proposes three specific CMO configurations in relation to the main groups involved in intergenerational dementia programmes, that is, older participants living with dementia participating in intergenerational programmes, younger participants participating in intergenerational programmes, and programme organisers and practitioners that are involved in intergenerational practice specifically for people living with dementia. Each CMO is explained and evaluated in turn, accompanied by a discussion of the implications for intergenerational practice. The section concludes with insights into the development of intergenerational policy in Scotland and internationally.

## Context-Mechanism-Outcome Propositions

Intergenerational Dementia Programmes and Older Participants Living with Dementia

*Figure 3: CMO*<sub>1</sub> – Older Participants Living with Dementia Participating in Intergenerational Programmes

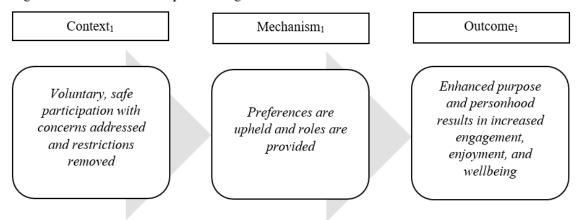


Figure: CMO<sub>1</sub> – Older Participants Living with Dementia

## Adapted from Pawson and Tilly (1997) p. 121

The findings demonstrate that, contextually, it is important to ensure voluntary, safe participation in programmes for older participants living with dementia. Optimal participation could be sought through addressing the concerns older participants may have as well as addressing restrictions that may affect their participation. The findings further suggest that achieving beneficial outcomes may be more likely where the preferences of older participants are taken into account, for example, in terms of the manner they may wish to participate in programmes as well as the types of activities they wish to get involved in. Providing suitable roles that allow for older participants to make contributions within programmes was also found to be important. The findings suggest that key outcomes that can arise for older participants include enhanced purpose and personhood along with increased engagement, enjoyment, and wellbeing.

The findings of this study indicate that older participants living with dementia should be able to participate in intergenerational programmes on a voluntary basis and free from coercion. As was apparent in the interview findings, organisers can consider, for example, that some older people do not like children. Moreover, some older people may wish to spend their time in different ways, and they should not lose out on the basis of their preferences and interests. This could necessitate the provision of other activities and options that can work in parallel to intergenerational activities, and/or the provision of quiet places for older participants to use during intergenerational activities (Gerritzen et al., 2020: 241). The qualitative findings highlighted the changeable nature of dementia through time during programme implementation, and so programme organisers may wish to consider ongoing consent monitoring with older participants and their carers whereby 'initial consent is revisited and re-established on every occasion or even within the same occasion' (Dewing, 2007: 19).

While ensuring voluntary, informed participation, the findings suggest that the concerns of older participants also need to be addressed as part of this process. Weeks et al. highlighted that men, in particular, may not initially be comfortable interacting with children possibly arising from 'fewer older men having experience working or caring directly for children in a formal or informal setting' (Weeks et al., 2020: 12). This again reinforces the importance of upholding personal choice and personhood as was emphasised in the findings across both phases of the study. Particularly within assisted living and care home contexts, it is important to ensure that intergenerational dementia programmes do not infringe on the privacy and preferred routines of older participants (Biggs and Knox, 2014: 55).

The findings also show that people living with dementia are more likely to experience barriers to participating in intergenerational dementia programmes. Organisers could address this by seeking support from family, carers, and other stakeholders by regularly informing them of the initiation, progress, and outcomes of programmes (Jarrott and Bruno, 2007: 252; Gigliotti et al., 2005: 426). Securing accessibility through venues and transportation can alleviate the risk that programmes may pose. Crucially, as was indicated in the qualitative findings, it is important to build a consensus among organisers and partners themselves that programme implementation is both feasible and worthwhile thus allowing a general acceptance of and consensus around intergenerational practice to be adopted.

In terms of the efficacy of programmes, the findings demonstrate that programmes are more likely to be effective where they take account of the preferences of older participants. Knowledge about preferences can be sought through a variety of ways such as assessments (Janke et al., 2019: 143), information gathering among participants and their families (Jarrott and Bruno, 2007: 246), and observations (Janke et al., 2019: 143). Use of preferences can ensure a robust person-centred approach (Weeks et al., 2020: 11) and can further enhance programme design in two primary ways. Firstly, preferences can feed into activity development ensuring a good fit between participant and activity, with the content of activities more likely to be meaningful, resonant, and engaging (Jarrott and Bruno, 2007: 242).

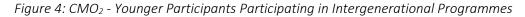
Using the preferences of older participants can mitigate the chances of programmed activities becoming child-orientated and infantilising for older participants (Lee et al., 2007: 477). Gerritzen et al. recommended that activities 'balance...the skills and preferences of both the younger and the older participants' (Gerritzen, 2020: 241).

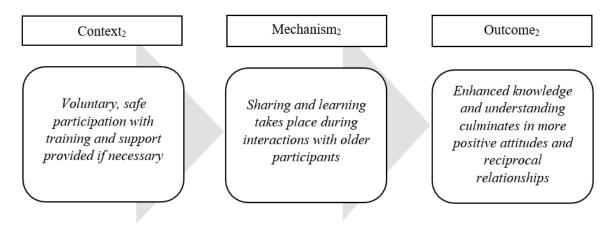
Secondly, the findings suggest that preferences can help structure interactions by providing the basis for matching and grouping between older and younger participants (Caspar et al., 2019; Lim et al.; 2019; Guerrero et al., 2017; Lee et al., 2007; Gigliotti et al., 2005) and thus complementing sharing, learning, and relationship building. Galbraith et al. suggested that further research should explore the 'participant characteristics' considered when forming dyads and groups of participants with the aim of identifying factors that 'increase the likelihood of a good match' (Galbraith et al., 2015: 374). Matching on the basis of such characteristics would likely 'support the selfhood of those involved and increase the likelihood of a positive experience in the intergenerational program' (Galbraith et al., 2015: 374).

The provision of suitable roles for older participants also appears to enhance intergenerational dementia programmes. A wide range of roles have been developed within programmes to date, including guide, mentor, teacher, artist, and friend. Particularly in the Scottish context, roles were often related to the past careers of older participants. Moreover, a failure to provide or clarify suitable roles may result in 'role ambiguity' capable of causing stress and anxiety among older participants (Weeks et al., 2020: 10-12).

Preferences and roles can work together to ensure the opportunities afforded to older participants throughout programmes elicit positive choices, reactions, and behaviours. The findings demonstrate that consideration of preferences ensures roles and activities are appropriate and meaningful, while role provision supplies the means for older participants to make a contribution within the programme context. Upholding preferences may subsequently lead to improved patterns of engagement (Lee et al., 2007) and greater levels of enjoyment (Lim et al., 2019, Low et al., 2015, Harris and Caporella, 2014). Role provision may subsequently lead to renewed purpose (Jenkins et al., 2021, Jarrott and Bruno, 2007).

#### Intergenerational Dementia Programmes and Younger Participants





## Adapted from Pawson and Tilly (1997) p. 121

Ensuring voluntary, safe participation was also important within the findings when recruiting younger participants to intergenerational dementia programmes, as was the provision of training and support to maximise skills and confidence. The consent process and training may vary depending on the age of younger participants. Moreover, the findings demonstrated that programmes 'worked' by allowing younger participants to engage in sharing and learning processes with the older participants. Beneficial outcomes among younger participants that were apparent in the findings included enhanced knowledge and understanding, reduced stigmatising attitudes and behaviours, and reciprocal relationships.

The findings indicate that the process for enabling voluntary, safe participation may vary depending on the age of the younger participants to be involved in the intergenerational dementia programme. For preschool children, participation hinges on caregiver support and therefore engaging with caregivers so they are aware of the purpose of programmes is important. Jarrott and Bruno described the process of caregiver engagement at the ONEgeneration daycare programme involving preschool children whereby staff addressed concerns that parents and caregivers may have had, for example, in regard to illness and death, while also emphasising the voluntary participation, beneficial outcomes, and supervision arrangements in place (Jarrott and Bruno, 2007: 245).

The interview findings demonstrated that similar caregiver engagement has also been implemented in the Scottish context, though resulting in the exclusion of a minority of young children where child caregiver support was not forthcoming. Programmes may also be designed to involve caregivers as additional participants, such as with intergenerational playgroup programmes (Hernandez et al., 2022, Skropeta et al., 2014). With school-aged children and young adults, ensuring younger participants can provide their own consent and engage voluntarily with programmes becomes increasingly important. There was an example in the interview data of ensuring voluntary participation for the younger participants engaged in a programme despite the school wanting to 'push' certain students.

Gerritzen et al. identified the provision of dementia education as a successful element of intergenerational dementia programmes that was typically aimed at younger participants (Gerritzen et al., 2020: 234). The training and support younger participants require prior to and during programmes may also vary by age, as was apparent in the findings. Within the interview findings it was suggested that for nursery and preschool children, formal training may not be necessary as participants of this age may have no inhibitions and may therefore comfortably converse with older participants naturally. However, older children and young adults may need training to address misconceptions they may have about older people as well as concerns they may have about dementia and ageing. Negative media representations, lack of exposure, and current institutional practice can drive misconceptions about older adults in general, and people living with dementia in particular (Galbraith et al., 2015: 358-359).

Findings from the interview phase of the study showed there is a need to address stereotypes and the negative views different age groups may hold about each other early on during programme initiation. This is congruent with the findings from the realist synthesis that showed providing support to younger participants in the form of orientations, information sessions, debriefings, and ongoing opportunities to ask questions were cited frequently across studies (Caspar et al., 2019: 154; Raber et al., 2019: 65; Chow et al., 2018: 191; Baker et al., 2017: 214; Lokon et al., 2017: 411-412; Harris and Caporella, 2014: 273). Therefore, training and support for school-aged children and young adults can build the knowledge, confidence and skills that will enhance their participation. Galbraith et al., similarly, stated that 'knowledge-building and training' for participants and organisers should be a necessary precursor to intergenerational dementia programmes (Galbraith et al., 2015: 372).

Activities during programmes can subsequently function to reinforce positive views among age groups and to harness the knowledge and skills gained by younger participants through training and support sessions, providing a strong basis for sharing and learning between participants. Within the interview data, sharing and learning was described as a reciprocal,

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relational process whereby all participants, older and younger, could share their skills and experiences with the others and thus could both 'give' and 'receive' something over the course of programmes. Two-way sharing and learning processes were strongly linked to communication between the participant groups. As Jenkins et al. relate, within one arts and health programme 'exchanges often involved mutual learning' and 'mutually beneficial interactions' led to '[opportunities] for perspectives of others to shift' (Jenkins et al. 2021: 124). Programmes can thus be understood to provide younger participants with resources, namely new social relationships, along with opportunities to both share with and learn from older participants. Additional opportunities may involve enacting aspects of their training and new skills acquired, and challenging negative views and misconceptions through positive interactions.

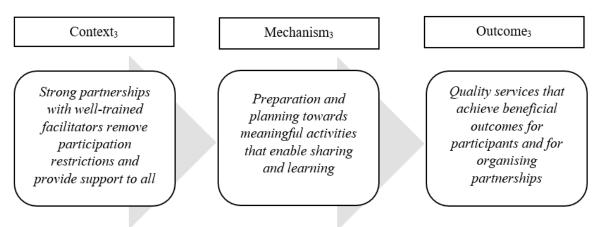
The findings from this study show that addressing misconceptions and providing support through training followed by the provision of suitable activities that allow for sharing and learning can thus lead to optimal outcomes for younger participants. Beneficial outcomes that can arise for younger participants described within the data included improved knowledge and understanding about ageing and dementia, and reduced stigmatising behaviours and attitudes. Multiple studies included in the realist synthesis were congruent with the above qualitative findings, demonstrating that younger participants could acquire greater dementia knowledge over the course of intergenerational programmes (Smith et al., 2020, Di Bona et al., 2019, Harris and Caporella, 2019, Chow et al., 2018, Lokon et al., 2017, Biggs and Knox, 2014, Harris and Caporella, 2014, Chung, 2009).

Furthermore, the qualitative findings demonstrated that practitioners perceived that younger people could potentially gain a better appreciation of the personhood of people living with dementia through participation in intergenerational dementia programmes, an effect already noted in the literature. A reduction in negative attitudes and perceptions, combined with increased positive attitudes, among younger participants was additionally perceived to be a potential programme outcome (Caspar et al., 2019: 156; Lokon et al., 2018: 10; Isaki and Harmon, 2014: 97; Femia et al., 2008: 282 – 283). Interviewees stressed, however, that this was not an automatic process but rather required the right approach to be adopted by organisers beginning with the identification and dispelling of negative attitudes among all the participants' outcomes in their scoping review, with 'more positive

attitudes and empathy toward older adults and people living with dementia' and 'increased knowledge about dementia' among the most commonly researched beneficial outcomes for younger groups (Gerritzen et al., 2020: 235).

The findings further indicated that activity development is effective where it engenders relationships between participants and creates sharing and learning experiences. Within the qualitative interviews, activities were likened to props that were secondary to relationships, but crucial in order to instigate relationships. Researchers explored in detail how one intergenerational programme utilised dance activities to emphasise the ongoing agency and capabilities of people living with dementia, and the effect this subsequently had on younger participants as they began to focus on partnerships with the older participants and likenesses over differences (Canning et al., 2020: 278, Canning and Blakeborough, 2019).

# Intergenerational Dementia Programmes and Programme Organisers Figure 5: CMO<sub>3</sub> – Organisers of Intergenerational Dementia Programmes



Adapted from Pawson and Tilly (1997) p. 121

The findings demonstrated how the role of programme organisers, similarly, was critical towards ensuring suitable contexts, mechanisms, and outcomes were developed throughout programme implementation. Organisers are responsible for securing consent and voluntary participation, addressing participant concerns, and providing training and support if required either for participants or for staff. Organisers, moreover, can enhance programme effectiveness through flexible and continuous programme planning along with the development of meaningful, suitable activities. Organisers, through their programme implementation, can achieve outcomes for older and younger participants as related above.

They may also increase their ability to uphold personhood for all participants, contribute to dementia friendliness, and make their services more competitive.

Organisers of intergenerational dementia programmes have a strong role to play in ensuring safe, voluntary participation for all participants. The findings indicate organisers can work with participants and their families/caregivers to secure informed consent and gather information about preferences. Organisers can also be key in addressing the concerns and apprehensions that participants may have regarding programmes whether centring on fears in relation to dementia, or misconceptions about people of different ages, fears that were apparent in the interview findings in particular.

Organisers also have a role in organising the provision of training and support, which can be particularly important towards equipping school-aged children and young people with skills and knowledge to participate successfully (McGeorge et al., 2021: 1877; Caspar et al., 2019: 154; Raber et al., 2019: 65). The interview findings demonstrated that while addressing concerns, organisers should uphold personal decisions, which may result in some individuals not participating and requiring quality alternative activities. Organisers can seek to adopt an appropriate approach towards risk management that finds a balance between risk mitigation in relation to the venue for and transportation to programmes, without being so restrictive that it limits implementation, hinders interactions, and/or prevents engaging activity design.

The findings additionally indicate that organisers may wish to ensure comprehensive training for staff, including intergenerational specific training (Participant 006) and even the development of specific intergenerational staff roles (Jarrott and Bruno, 2007: 246). All partners involved in the delivery should contribute and communicate with each other (Gigliotti et al., 2005: 433). The qualitative findings indicated that resources should be managed effectively within programme implementation and should not focus exclusively on monetary resources, but rather should prioritise resources such as time, availability of staff, as well as values and attitudes.

In terms of the role of organisers in determining how programmes work, organisers are able to optimise the likelihood of beneficial outcomes by ensuring comprehensive preparation and planning that is, crucially, flexible and continuous throughout the course of the programme. The interview findings emphasised the importance of flexible planning in order to accommodate the fluctuating needs and feelings of participants, to pivot between activities if they do not work on certain days, and to take account of the nature of dementia as a progressive condition affecting people's lives in different ways at different times.

Related to preparation and planning, the findings demonstrated how organisers are instrumental in developing activities that are the 'props' to relationship-building, learning, and sharing between participants. Organisers should ensure activities are meaningful (Camp and Lee, 2011: 1; Caspar et al., 2019: 159), which can be achieved by gathering information about participants and building in their preferences within activity design. Activities should be developmentally appropriate for all participants (Caspar et al., 2019: 158). Lim et al., for example, described how activities based around 'bingo' were typically popular with older participants, however, were 'discouraged in the childcare setting as [they were] associated with the notion of gambling' (Lim et al. 2019: 372). Lee et al. emphasised that intergenerational activities have been associated with the 'infantilization' of older participants and thus explored Montessori-based methods towards developing suitable activities within intergenerational programming (Lee et al. 2007: 477). Activities can also be designed in ways that may foster cooperation between the different participant groups (Gigliotti et al., 2005: 438). Caspar et al. related how questionnaires were used to ascertain participant preferences and form pairings for activities, with partnerships remaining consistent, thus reinforcing opportunities for cooperation and friendship (Caspar et al. 2019: 154).

Outcomes that can emerge for organisers, as related above, include those that may be experienced by older and younger participants, namely an increased sense of purpose and enjoyment for older participants, and increased knowledge and understanding among younger participants. Organisers can thus emphasise the personhood of people living with dementia and can contribute towards dementia friendliness by ensuring that more people are informed about dementia and are inclusive of people living with dementia as well as their carers (Harris and Caporella, 2019: 2). In addition, organisers may increase their own competitivity by offering a quality service as was suggested in the interview data.

#### Insights into the Development of Intergenerational Policy

The findings from the realist synthesis demonstrated a number of policy drivers that could potentially contribute to intergenerational dementia programmes including ageing populations, dementia prevalence, the need to develop quality services for people living with dementia, economic factors such as achieving economies of scale by working with multiple groups at once and easing pressure on services, and the need to promote social inclusion concomitantly to reducing stigma related to dementia and ageing.

The interview findings demonstrated insight into the role of policy in relation to intergenerational inclusion in the Scottish context specifically. The key policy finding apparent in the interview data was that interviewees perceived that there was no explicit policy to guide the understanding and operationalisation of intergenerational inclusion in Scotland, nor was intergenerational inclusion currently an explicit goal of the National Dementia Strategies. However, some interviewees felt that the policy landscape in Scotland was broadly supportive of intergenerational inclusion and that practice could therefore feasibly link in with higher-level policy goals.

The absence of explicit intergenerational policy gave rise to debate among the interviewees regarding the role of policy towards encouraging intergenerational inclusion. One perception of the role of policy was that policy should aim to promote wider goals such as community development, within which intergenerational inclusion could be subsumed if it was identified as a need in specific areas and populations. Several interviewees nevertheless expressed the view, firstly, that policymakers should not make assumptions that intergenerational practice would automatically happen even without policy encouragement and, secondly, that policy would benefit from being clearer in its treatment of concepts such as 'community' and 'community development', as intergenerational inclusion may actually be integral to how such concepts are understood and defined.

There was some evidence provided by interviewees that there was a policy-practice gap in Scotland that could affect intergenerational practice for people living with dementia, whereby policy could be theoretical and rhetorical without being sufficiently embedded within practice and service design. The policy-practice gap was perceived to be apparent in relation to dementia policy in particular. Some Scottish practitioners, potentially when confronting this policy-practice gap, had found that it was more beneficial to link with other elements of policy, particularly education and the Curriculum for Excellence (Education Scotland, 2022), as well as Scotland's loneliness agenda (Scottish Government, 2018).

A final insight into policymaking and intergenerational inclusion that emerged in the interview data was the perception that intergenerational inclusion, especially if implemented in meaningful and longer-term ways, could support a number of policy aims. Such aims included the preventative health agenda, whereby greater knowledge about and acceptance

of dementia among younger people in general would promote more openness around early diagnosis as well as awareness raising in regard to lifestyle risk factors. Intergenerational inclusion was understood by some interviewees to resonate with strong, responsive communities that could support people living with dementia to remain in their own homes for longer. A final aim that was discussed among the interviewees was the potential for participation in intergenerational programmes to have a positive influence on younger people, for example, equipping with them with the knowledge and skills they would need to enter the caring, health and social care professions.

Therefore, while there are strong drivers behind intergenerational policy both internationally and nationally, within Scotland the role of policy towards facilitating intergenerational inclusion was found to be ambivalent. The policy landscape generally was perceived to be compatible with intergenerational inclusion if not necessarily explicit in prioritising intergenerational approaches; and in some instances intergenerational practice had been successfully linked with aspects of policy, particularly the Curriculum of Excellence. Intergenerational inclusion was perceived to support goals related to preventative health, the ambition towards allowing people living with dementia to remain living safely at home in inclusive communities, and workforce development in the care, health, and social care sectors.

More broadly, Scottish dementia and intergenerational policymaking may benefit from greater emphasis on the 'social location' of people living with dementia within society in terms of gender, race, disability, socioeconomic status, access to social resources/supports among other factors to better enhance person-centred care and to avoid treating the lived experience of dementia as monolithic. Bartlett and O'Connor observed that there continued to be 'very little gendered or socioeconomic analysis of people's experience of dementia' and that this was 'surprising given that different groups of people will undoubtedly have very different experiences of dementia' (Bartlett and O'Connor, 2010: 6). More recently, the Scottish Government's national conversation to inform the new dementia strategy for Scotland found that there continued to be negative experiences of services among ethnically diverse, deaf, and LGBT+ communities in relation to living with and caring for someone with dementia' impeding person-centred care and resulting in some people feeling invisible to services and supports. The publication recommended 'greater societal understanding of the

range of people who make up our dementia communities, and for workforce training to reflect this diversity' (Scottish Government, 2023: 15).

# Recommendations

Based on this discussion, a number of recommendations can be proposed towards the optimisation of intergenerational dementia programmes.

- Greater clarity in regard to the definition of intergenerational practice and intergenerational dementia programmes in order to guide practice that aims to achieve inclusion and beneficial outcomes for people living with dementia.
- Voluntary, safe participation ensured for all participants with robust, sensitive consent procedures that uphold personhood and self-determination.
- Removal of barriers to participation for older participants living with dementia, for example, challenging restrictive perceptions of risk among services, using safe, appropriate venues and transport, and ensuring training for organisers, staff, and volunteers.
- Removal of barriers to participation for younger participants to allow them to participate in intergenerational programmes, for example, encouragement and enablement of intergenerational opportunities within youth and educational services, linking intergenerational practice into curricula, and consideration of those young people who may be uniquely placed to benefit from intergenerational interactions.
- Training and support for all participants, particularly younger participants in order to alleviate apprehension they may have in relation to ageing and dementia and to provide them with the confidence and skills to engage with people living with dementia in respectful, reciprocal ways.
- Positive steps to acknowledge, address and challenge age-based misconceptions that may be held among participants of all ages during programme initiation to ensure that interactions are founded in equality and uphold the value of each individual.
- Information gathering among participants regarding their preferences and using preferences to inform activity development as well as matching between participants of different ages.
- The provision of suitable, achievable roles for all participants that allow them to make a contribution within the interactive context.

- The development of purposeful, planned activities that are meaningful to participants through incorporating their preferences, providing them with roles, and enabling sharing and learning processes to take place between participants of different ages.
- Flexible, continuous planning throughout programme implementation that allows organisers to be responsive and adaptable given the complexity of working with different age groups with different needs, and in order to accommodate changing circumstances, which can be particularly acute for people living with dementia.
- More explicitly define 'intergenerational inclusion' within the policy-practice interface and in regard to key concepts such as community development.

## Realist Evaluation and Intergenerational Dementia Programmes

Realist evaluation has been a valuable approach for examining intergenerational dementia programmes. It has, firstly, provided a means of tackling and analysing the complexity involved in this type of intervention and, secondly, it has permitted the incorporation of heterogenous evidence in order to build a multifaceted understanding of how programmes work. However, the realist evaluation of intergenerational dementia programmes presented in this study raises a number of conceptual and analytical problems. These conceptual and analytical problems become apparent through a critical realist critique of realist evaluation (Hinds and Dickson, 2021; Porter, 2015).

Hinds and Dickson argue that realist evaluation pushes researchers in 'two directions' that are incompatible as they 'are encouraged to engage with context and add it as a factor in their explanations, but at the same time they are asked to strip out context as they identify a generalizable theory that can be tested in various contexts' (Hinds and Dickson, 2021: 6). The findings of this thesis suggest several problems in relation to the generalisability of context within intergenerational dementia programmes, that is, in terms of building an explanatory understanding of contexts where programmes work and those contexts where they do not.

Firstly, respecting and utilising the *individual* preferences of participants within programmes, whether older or younger, emerged as a key theme in both the realist synthesis and the interview data, and was found to be a strong mechanism contributing to programme effectiveness. The use of individualised information, assessments, and observations to ensure that older participants were comfortable with and benefitting from intergenerational

engagement was described in several research studies (Janke et al., 2019: 143; Jarrott and Bruno, 2007: 246). Similarly, interviewees were keen to emphasise that some older participants simply do not like children, and that some people living with dementia may have had previous trauma in their lives that would render intergenerational approaches inherently unsuitable. Trauma-informed interventions within dementia care are of growing interest (Flannery, 2002) and there is evidence to suggest that some interventions, such as reminiscence activities which often provide the focus of intergenerational practice, may be unsuitable for some people living with dementia for trauma-related reasons (Martinez-Clavera et al., 2017: 27).

Younger participants, in addition, may vary widely depending on their age, their ability to consent, their development needs, their preferences, and their competing educational, work, and extracurricular commitments, all of which can affect the participation context of programmes. Therefore, the importance of individual preferences combined with pronounced in-group differences within intergenerational dementia programmes make it difficult to generalise across contexts in terms of 'the make-up of the participants' (Wong et al., 2013: 7). Gerritzen et al., similarly, found it difficult to 'generalize and compare the successful elements' of different intergenerational dementia programmes, noting that 'successful (programme) elements (were) likely to depend on the target population and the developmental age of the younger participants' (Gerritzen et al., 2020: 241).

Some interviewees further perceived the lived experience of dementia to be changeable as programmes progressed, with the circumstances and health of people living with dementia and their carers capable of transforming within a short space of time. This factor again relates to the difficulty of generalising older participants living with dementia as a specific group due to the different types of dementia that can be experienced, the stage and progression of dementia, as well as the social, economic, and other resources that each individual has to hand within their particular situation (Bartlett and O'Connor, 2010: 6). As pointed out within one interview, these changeable circumstances could mean that a successful intergenerational dementia programme had the potential to become negative for some older participants through time, without any major changes in focus or practice having occurred within programmes themselves. The volitions of individual older participants and the choices that they make in response to the opportunities and resources offered by programmes (Pawson, 2013: 34) may fluctuate as the 'conditions in which they seek to enact (these)

choices' (Wong et al., 2013: 7) likewise fluctuate as a result of the progression of their dementia. Dementia thus presents an inherently changeable aspect of programme context and characterises 'the pre-existing complex system' (Pawson, 2013: 52) within which intergenerational dementia programmes are implemented, from the progression of dementia as a chronic condition to the broader social structures which may exacerbate disability for some people living with dementia more than others (Thomas and Milligan, 2018). Dementia can thus be related to ideas of emergence whereby the systems under investigation are continually changing (Pawson, 2013: 42) such that programme mechanisms become contingent and time-limited.

Developing programme theory within the realist evaluation approach, however, does not involve reviewing individual programmes, but rather reviewing a set of programmes bearing 'a family resemblance', with researchers summing 'the fortunes of this same intervention across its different trials in order to come to a net estimate of its impact' (Pawson, 2013: 83). The difficulties encountered in generalising the programme context within this thesis could relate to an analytical need to generalise on a more specific level of programme 'family resemblance', for example, by focusing on older participants with a particular type and stage of dementia combined with a focus on younger participants of a particular age group. Gerritzen et al. recommended that further research into intergenerational dementia programmes could seek to address 'whether the age of the younger participants may influence the success of the intergenerational dementia program and whether the effects differ for older adults with different levels of cognitive impairment', necessitating a narrowing of study focus (Gerritzen et al., 2020: 242).

Hinds and Dickson further argue that the notion of 'mechanism' within realist evaluation is problematic as it appears to be the 'key explanatory part of the (CMO) configuration' and yet, as an 'amalgam of resources and reasoning', it conflates agency and structure (Hinds and Dickson, 2021: 4-5). Porter further recommended that 'agency should be included as a separate category alongside context and mechanism in the evaluation formula' (Porter, 2015: 78). The complex context of dementia related above can be examined in terms of agency and structure by utilising person-centred approaches (Kitwood, 1997) alongside models that emphasise the social structures that affect people living with dementia, including the social model of disability applied to dementia (Thomas and Milligan, 2018) and the citizenship lens of dementia (Bartlett and O'Connor, 2010; Bartlett and O'Connor, 2007).

Boyle examined the agency of people living with dementia, finding that agency even for people living with advanced dementia continued to be expressed and embodied through emotions, intersubjective awareness, relational engagement, the exercise of subtle influence, and imagination among other factors (Boyle, 2014). Bartlett and O'Connor, moreover, argued for citizenship approaches in order to uncover how people living with dementia could be discriminated against in terms of structure, such as environments that exacerbated disability, systems that compounded economic losses, obstacles to accessing services, inadequate care provision, and communities that curtailed the contributions of people living with dementia (Bartlett and O'Connor, 2007: 108).

The agency of people living with dementia combined with the social structures they contend with together provide insight into which contexts and mechanisms enable intergenerational dementia programmes and those which do not. Upholding agency and ensuring voluntary, non-coercive participation for all participants was perceived to be paramount within the findings of this thesis.

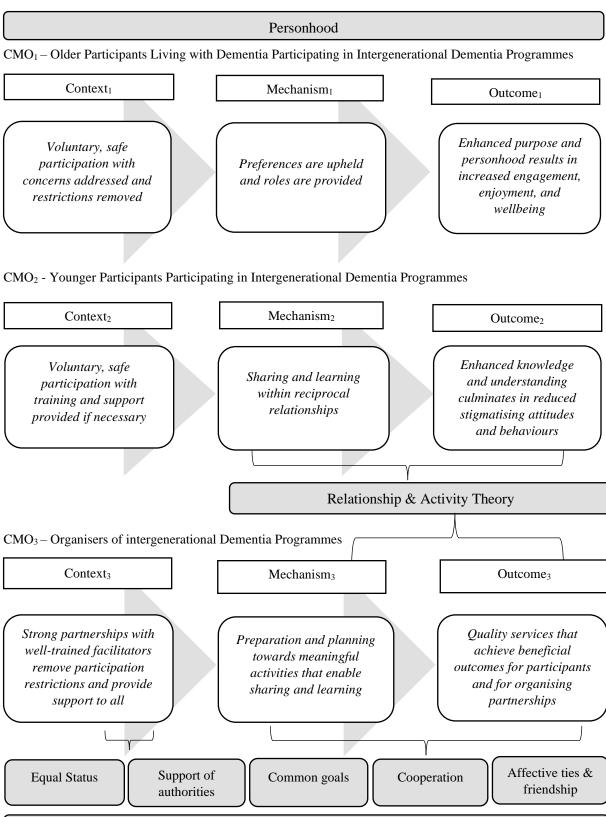
However, the findings further demonstrated the potential for social structures, in terms of organisational processes and policies combined with the behaviours and attitudes of carers and staff, to affect both the agency of older participants as well as the mechanisms of intergenerational dementia programmes. Within the interview data, it was found that a minority of staff felt that the intergenerational dementia programme was too much hard work and incapable of producing benefits, indicative of broader social attitudes towards dementia that can impede programme implementation. Moreover, risk emerged as a theme across data from both phases of the study whereby programmes can be affected by the approach towards and perception of risk among the organisations responsible for programmes. A risk perception cited in the realist synthesis included the notion that older people living with dementia may pose a risk to children due to the unpredictable nature of dementia (Weeks et al., 2016: 296). Risk perceptions emerging from the interviews included the idea that older people living with dementia were uniquely at risk and needed protecting and organisations perceived as being generally 'risk-averse' in their care approaches.

Discriminatory attitudes and risk perceptions among organisations and staff are important because they may lead to social barriers that in turn lead to mechanisms not being fully realised within intergenerational dementia programmes, such as a failure to provide roles to older participants and/or a lack of meaningful activities. This not only jeopardises the agency of older participants as their abilities and preferences may not be fully considered, but can further culminate in passive, observational intergenerational encounters that do not involve 'one-on-one interaction between members of different generations' (Lee et al., 2007: 477) and thus do not facilitate the sharing, learning, and reciprocity that is required to prompt enjoyment and relationship-building.

Agency and structure are particularly critical to the dementia debate; however, they also provide analytical insight into other aspects of intergenerational dementia programmes. Social relationships, for example, can be approached in terms of individuals and their place within broader social structures and social networks as emphasised in social epidemiology. Social epidemiological evidence suggests that 'ongoing network participation is essential for the maintenance of self-efficacy beliefs in late life' (Berkman and Glass, 2000: 145 – 150), with an individual's health outcomes tied to their ability, actual or perceived, to access social networks and supports, particularly in their later years. This resonates strongly with the findings of this thesis where social patterns of isolation among all age groups were of concern to practitioners culminating in a need to create inclusionary and participatory opportunities for individuals at risk. Similarly, intergenerational solidarity can be approached as a 'cultural idea' (Hinds and Dickson, 2021: 5) involving 'shared expectations and obligations regarding the ageing of individuals and the succession of generations' (Bengston and Oyama, 2007: 5). Moreover, this generational contract between age groups 'represents the norms operating at the micro- and macro-levels of social structure in a given socio-historical context' (Bengston and Oyama, 2007: 5). Therefore, intergenerational solidarity has structural properties and yet affects individual expectations, obligations, and behaviours when interacting with members of other age groups.

The application of the realist evaluation approach has been valuable towards approaching the complexity of intergenerational dementia programmes; however, conceptual and analytical problems remain, particularly in regard to difficulties generalising across programme contexts. Greater attentiveness to agency and structure across programme contexts and mechanisms offers the potential to yield additional insight into how intergenerational dementia programmes work.

# Implications for Intergenerational Theory



Intergoup Contact Theory

Figure 6: Theoretical Implications of Intergenerational Dementia Programmes

Adapted from Pawson and Tilly (1997) p. 121

In 2004, Vanderven observed that new intergenerational programmes were being initiated without 'an adequate conceptual framework to guide the design and implementation of these efforts' (Vanderven, 2004: 76). A decade later, Kuehne and Melville claimed that, while awareness and use of theory was certainly growing within intergenerational research, nevertheless there remained two differing premises underlying the approach the field should take in future, whether to use existing theories to inform intergenerational practice or whether to develop a 'uniquely intergenerational theory that is specific to intergenerational practice' (Kuehne and Melville, 2014: 332). While the majority of studies integrated into the realist synthesis do cite theory, there is significant variation regarding the degree to which theory is then integrated within programmes.

Kitwood's theory of personhood and person-centred care (Kitwood, 1997) has been especially influential for intergenerational dementia programmes, not least because of its influence within the field of dementia. Personhood, as discussed previously, involves the rights and respects due to all individuals with a focus on social and relational contexts (Kitwood, 1997: 8). In order for intergenerational dementia programmes to effectively harness 'the potential for genuine, reciprocal relationships' between people living with dementia and younger participants they must accord with personhood and person-centred care (Lokon et al., 2012: 341) throughout both context and implementation. O'Connor et al. identified three domains of inquiry in order to promote research on personhood in dementia including exploration into subjective experience, the interactional environment, and the socio-cultural context (O'Connor et al., 2007: 124). The linkages between these domains and the findings presented in the previous chapters suggests that personhood presents a cogent theoretical foundation to structure intergenerational dementia programmes.

In regard to the first domain, O'Connor et al. state that upholding personhood for people living with dementia involves 'understanding the subjective experience of the person with dementia' combined with a 'growing recognition that they are often quite aware of their situation and can contribute important insight about their experiences and needs' (O'Connor et al., 2007: 124 - 125). Ensuring voluntary, informed participation, integrating the preferences of people living with dementia into activity design, providing alternative activities to secure choice and self-determination, and taking account of changing needs through time are all ways that intergenerational dementia programmes can be developed so as to take account of subjective experience and uphold personhood.

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For the second domain, O'Connor et al. relate the interactional environment to both the 'importance of one's interactions with others' as well as other aspects of the immediate environment such as 'the use of physical space and engagement in activities' that further 'provide interactional opportunities which can either foster or erode one's sense of personal competence and uniqueness, and hence personhood' (O'Connor et al., 2007: 127-128). The importance of using accessible venues and providing safe transportation during programmes was reiterated throughout the findings and was especially critical in the Scottish context. Similarly, programme design was strongly associated with the goal of enhancing the quality of interactions between older and younger participants, and thus intergenerational dementia programmes in general can be understood to aspire towards reinforcing personhood within the interactional environment.

For example, ensuring that activities enabled older participants to play a suitable role and make a contribution, and developing activities that facilitated sharing and learning between the different participants were key recommendations for enhancing interactions. Training and support provided to younger participants of school-age and older further was perceived to be important towards enhancing interactions by equipping younger groups with the skills and knowledge to engage with older groups respectfully, confidently, and empathetically. As O'Connor et al. relate, personhood in the interactional environment must necessarily be bidirectional in this way by informing an 'understanding of the experience of dementia, not just for the person with dementia, but also for those in his or her social world' (O'Connor et al., 2007: 129).

In regard to the third domain concerning the socio-cultural context, the linkages between enacted programmes and personhood were less immediate but nevertheless influenced the perceptions and approaches of researchers and practitioners. O'Connor et al. describe how personhood in the socio-cultural context concerns 'the ways in which health policies, institutional cultures and practices, and socio-cultural norms and values shape the experience of dementia' (O'Connor et al., 2007: 131). Intergenerational dementia programmes were seen to be vehicles for reducing stigma towards people living with dementia, increasing dementia knowledge, and normalising dementia among younger generations. Moreover, programmes were seen to be a means to encourage institutional cultures and practices founded in personhood by creating a consensus among stakeholders that intergenerational activities involving people living with dementia were both feasible and beneficial.

In addition to personhood, intergroup contact theory has been commonly utilised within international research investigating intergenerational dementia programmes (Allport, 1954; Pettigrew, 1998). Caspar et al. (2019: 152), for example, provided a demonstrative overview of how intergroup contact theory could be used as a theoretical foundation within intergenerational practice:

'Intergroup contact theory provides an especially useful foundation for the development and testing of intergenerational programs because its application fosters positive intergroup interaction, which is the goal of these programs. In intergenerational programming, age is the key dimension of disparity.' (Caspar et al., 2019: 152)

The findings presented in this study overlap with the 'conditions' propounded by intergroup contact theory, suggesting that this theory, in addition to personhood, offers a strong theoretical basis. For example, ensuring equality (Pettigrew et al., 2011: 273) between groups was apparent in the training provided to younger participants in a number of programmes with the aim of increasing their dementia knowledge and understanding of the condition. This accords with a finding reported by Caspar et al. in their study (Caspar et al., 2019: 154). In Scotland, several interviewees further spoke of the need to 'prepare' different age groups to meet each other by addressing the misconceptions and fears they may hold in regard to their 'age others' that may prevent equality from being fully established. Similarly, ensuring the 'support of authorities, law or custom' (Pettigrew et al., 2011: 273) was apparent in the recommendations for building strong partnerships to deliver programmes, particularly through training staff in intergenerational practice and even in some instances creating dedicated staff roles to specialise in the coordination and delivery of intergenerational work. Cooperation and common goals (Pettigrew et al., 2011: 273) were implicit in the recommendations for activities predicated on sharing and learning combined with matching between participants on the basis of interests and preferences. The final condition, concerning the generation of affective ties and friendships (Pettigrew, 1998: 76), strongly related to the perceived outcomes of reciprocal relationships that were often perceived to emerge from intergenerational dementia programmes.

Developing theoretical complementarity between intergoup contact theory and personhood could be a beneficial line of enquiry for understanding how intergenerational dementia programmes in particular are designed and allow for greater insight into how intergenerational dementia programmes may differ from intergenerational work in general. In intergenerational dementia programmes, it is both age *and* dementia that are 'key dimensions of disparity' between participant groups, requiring special sensitivity to and awareness of the status and rights of people living with dementia. Personhood theory could thus be useful in guiding and structuring the approach taken towards intergroup contacts involving people living with dementia. Jarrott and Bruno (2007: 242), in this vein, suggest that intergroup contact theory applied under the 'umbrella' theory of personhood could provide a useful framework that promotes personhood and wellbeing through intergenerational contact.

Intergenerational dementia programmes often bring together disparate organisations focussed on age-specific client groups and partnerships may require 'a subtle use of several...theoretical perspectives' to guide programming (Clark et al., 2016: 306). For example, intergoup contact theory may not be sufficient to convince all partners if the subsequent intergroup contacts are predicated on reducing ageism among younger participants alone – while this may resonate with organisations providing services for older adults, it may not be sufficient to meet the outcomes of organisations focused on children and young people (Clark et al., 2016: 305). Equally, developmental theories like Personhood may need to 'articulate' personhood goals for all participants and not just participants living with dementia (Clark et al., 2016: 306).

Combining theories may offer the prospect of overcoming service-based age segregation by appealing to different partnering organisations and may be advantageous for structuring future inquiries. However, a combined theoretical foundation faces the dual risk of being either too general or too complex to be of much use. Blending theories can be problematic in other ways. Theories may 'assign profoundly different value to variables' and thus be in 'fundamental conflict' on critical points (Kuehne and Melville, 2014: 334). Ensuring that the relational premises involved in intergroup contact, an interactive theory, are unified with the 'relationship context' of Personhood, an individual development theory situated in social being, could present theoretical challenges.

An additional theoretical implication arising from the findings centres on the interplay between relationships and activities, with relationship and activity theories having both been identified as bases associated with intergenerational practice (Vanderven, 2004: 80). The findings presented in this thesis clearly endorse the view that 'the centrality of relationships is unquestionable' within intergenerational practice (Vanderven, 2004: 80). However, Vanderven further proposed greater theoretical treatment of how relationships were related to activities and vice versa in practice, observing:

> "...there is a dialectical relationship between how people interact, what they do, the tools and objects that mediate these interactions and activities, and the contexts that situate both...Doing the activity affects the relationship. Conversely, there can be no real relationship between two people...until the art activity is introduced and conducted." (Vanderven, 2004: 81)

Canning et al., in this way, perceived the dance activity that structured the programme to be intrinsic to the relationship building process, whereby the decrease in physical distance between participants mutually engaged in ballet exercises was paralleled by a corresponding shift in perceptions. Moreover, one interviewee described activities as 'props' that 'got things going' in terms of relationship building (Participant 006). The findings not only uphold the importance of relationships but further suggest a strong linkage between activities and relationships that could bear further theoretical treatment.

A final theoretical implication relates to the references to Scottish heritage and culture apparent in the interview data from the Scottish context and potential linkages to the concept of generativity, which involves a concern in establishing and guiding the next generation (McAdams et al. 1993; 221; Erikson, 1997: 67) and has been understood within intergenerational dementia programmes as 'involving the passing down and recycling of human understanding, experiences and cultures to children' (Lim et al. 2019: 375) as well as 'conversations and experiences shared between the generations' (George et al., 2011: 391). The references to Scottish heritage and culture support the conceptualisation of intergenerational solidarity as a 'cultural idea' with structural properties that affect the agency of individuals, with participants in intergenerational programmes transforming and/or reproducing these intergenerational structures through their interactions and relationship building (Hinds and Dickson, 2021: 3). Bengtson and Oyama observed that

intergenerational solidarity and interaction necessarily involved the 'renegotiation of the balance between continuity and innovation over time through the succession of one generation by another' (Bengtston and Oyama, 2007: 3). Therefore, intergenerational dementia programmes may allow for the transmission of cultural experience and memory from older participants to younger participants, while crucially providing the opportunity for older participants to engage with social change and innovation by learning about the lives of younger participants. This view was expressed by one interviewee who described how intergenerational programmes could be a means for older people to learn about the lives of younger people and learn about changes in society, contrasting this with the days of their own youth.

These cultural aspects of intergenerational dementia programmes in Scotland could bear further investigation utilising the concept of generativity and a more critical interrogation of Scottish national culture, 'Scottishness', and cultural homogeneity. Within the literature, national culture as a meaningful concept and a legitimate point within the cultural comparisons of nations is problematic and contested (Minkov and Hofstede, 2012: 134). A more in-depth analysis of Scottish cultural transmission among generations within intergenerational contexts would benefit from consideration of how intra-national diversity (Tung, 2008: 44), as well as dimensions of social location such as ethnicity, class, and gender (Anthias, 2012: 130-131) may affect, constitute, and problematise the course of intergenerational cultural transmission in Scotland in implicit and explicit ways.

Strong connections can thus be made to personhood, intergroup contact, and relationship/activity theories, with additional indications of generativity in the Scottish context. Further exploration of these theories offers rich lines of enquiry into the field of intergenerational dementia programmes specifically and it is recommendable that these theories be pursued before attempts to generate a new explicit intergenerational theory are made.

## Conclusion

This discussion chapter opened with a comparative examination of how intergenerational inclusion has been understood and operationalised internationally and nationally in Scotland. While definitions of intergenerational practice were found to be variable ranging from prescriptive to fluid, there was strong agreement that intergenerational inclusion was pertinent to a range of different settings from care homes to communities, that programmed

intergenerational activities offered potential to enhance inclusion between age groups, and that people living with dementia could successfully participate within intergenerational programmes. However, consideration of the types of younger people that may be uniquely placed to benefit from inclusive interactions with people living with dementia emerged as a stronger finding in relation to the Scottish context. The findings showed some continuity regarding the barriers that both older and younger participants could face in terms of their participation in intergenerational programmes, as well as convergence on outcomes that could arise for participants throughout the course of their participation. In terms of activity development, it is important to note that references to Scottish heritage and culture informed activity development in the Scottish context, endorsing the theoretical concept of 'generativity' whereby older generations can impart skills and knowledge to younger generations. The chapter then proposed three distinct context-mechanism-outcome propositions in order to explicate how intergenerational dementia programmes were perceived to work for the main groups involved, including older participants living with dementia, younger participants engaging in programmes, and finally programme organisers and staff. The chapter then moved on to a discussion of the role of policy in relation to intergenerational practice primarily in reference to the Scottish context. A key finding was that interviewees felt that there was no explicit intergenerational policy in Scotland, nevertheless, intergenerational practice could be linked to additional areas of policy such as education and could support several high-level policy aims in Scotland. This discussion of findings regarding the 'working' of intergenerational dementia programmes concluded with some key recommendations for the further development of programmes both internationally and nationally.

Finally, this chapter discussed a number of methodological and theoretical concerns. Firstly, some methodological reflections were presented regarding the application of realist evaluation to intergenerational dementia programmes. Difficulties in generalising across programmes contexts were discussed in terms of complexity, with context complexity precluding the ability to fully identify those contexts that were contributing to successful outcomes. Structure and agency were then discussed as key explanatory factors in relation to intergenerational dementia programmes, however, relying on the analytical categories of context, mechanism, and outcome may limit exploration of structure and agency. Finally this chapter discussed how the findings were strongly related to both personhood and intergroup contact theory. In addition, the findings suggested that relationship, activity, and generativity

theories could be additional lines of theoretical enquiry when researching intergenerational dementia programmes.

# Chapter 9: Conclusion

#### Introduction

This chapter provides a conclusion to the thesis overall. It begins by recounting my reflections on the process of undertaking this PhD, comprising policy-orientated and methodological reflections. These reflections are then followed by some recommendations for further research into the area of intergenerational inclusion for people living with dementia, and some final thoughts on this topic.

## Policy-Orientated Reflections

An original interest I had when beginning this thesis was to understand intergenerational inclusion as a policy issue in Scotland informed by Kingdon's 'Multiple Streams' conceptualisation of the policy process (Kingdon, 2014). This conceptualisation involves a 'problem stream' comprising key indicators or dramatic events that signify that a problem exists; a 'policy stream' involving the gradual accumulation of knowledge and perspectives among specialists in a given policy area and the generation of policy proposals; and finally a 'politics stream' involving factors such as the national mood, political opinions, election results, and changes of administration (Kingdon, 2014: 16-18). In order to explore intergenerational inclusion as a policy issue, one of my first methodological lines of enquiry therefore cohered around attempting to conceive of the scale of the 'problem' through key data indicators such as the prevalence of dementia (Alzheimer Scotland, 2020) and fluctuating dependency ratios (Scottish Government Statistics, 2022) throughout Scotland, data that pointed to the scale of ageing demographic trends nationally and the potential for/lack of intergenerational inclusion apparent across different areas.

However, as I investigated intergenerational issues in the Scottish context in particular, I discovered that intergenerational inclusion was by and large practice led, that is to say, practitioners, organisations, and service providers were implementing intergenerational dementia programmes and achieving beneficial outcomes, but without necessarily following a specific policy directive in doing so. Intergenerational inclusion for people living with dementia existed in practice and was being implemented in different ways in Scotland but was not fully integrated with or recognised by Scottish dementia policy across its problem, policy, or political streams. This realisation necessitated the first major shift in my methodological approach: if intergenerational inclusion for people living with dementia in Scotland was being led by practitioners in the form of intergenerational dementia

programme implementation, then I needed a methodological approach that reflected this state of affairs. This led me towards adopting realist evaluation, an approach that seeks to unpack 'programmes and interventions' that 'spring into life as ideas about how to change the world for the better' (Pawson, 2013: 9). Both the programme and policy findings that emerged particularly over the course of the second phase of this study endorsed this methodological pivot. Interviewees often cited a lack of explicit intergenerational policy in Scotland. While loneliness, ageing demographics, and dementia are recognisable issues that have marshalled an array of policy responses, intergenerational programmes are not always explicitly recognised as a solution towards addressing these issues, at least not within higher policy spheres. Nevertheless, intergenerational practice in Scotland has flourished in a multitude of ways and provided a rich field of study for this thesis as guided by realist evaluation.

#### Methodological Reflections

The methodology for this PhD went through several further developments to, firstly, reflect the reorientation of the research questions towards intergenerational practice and implementation; and, secondly, to accommodate research limitations that were increasingly exacerbated by the pandemic.

Originally, I was interested in policy-led comparative methods as a means of exploring intergenerational issues, scrutinising those cultural and policy factors that may predispose some countries to prioritise intergenerational inclusion more than others. I aspired to investigate those countries that had both implemented intergenerational initiatives *and* had developed broader policy approaches towards intergenerational inclusion for all age groups, with the aim of understanding whether or not Scotland could learn from these countries and adopt similar approaches. For example, Germany has a federal programme aimed at fostering community development and intergenerational interactions entitled the *mehrgenerationenhäuser* programme that is organised almost everywhere across the country and is an initiative of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (Mehrgenerationenhäuser.de: 2022). In terms of policy, I was interested in understanding the reasoning and motivations that made particular policymakers more proactive in addressing the socio-economic issues of the ageing society. Ageing demographics are undeniable and necessitate a coherent, coordinated policy response to manage effectively, however, ageing demographics are rarely top of the policy agenda in the

UK or in Scotland. Kingdon in his analysis of policy agendas claimed that the 'present and future aging of the population indicates a problem that will become more pressing... But advocates have not devised solutions that are affordable' (Kingdon, 2014: 178), with this lack of feasible, affordable policy solutions resulting in a reluctance to address issues that cannot easily be resolved.

However, international comparative research became impracticable for two reasons. Firstly, I was interested in exploring intergenerational inclusion specifically for people living with dementia, however, I found that often in intergenerational commentary and research it was not always clear the degree to which intergenerational practice had been targeted at or had involved people living with dementia. Tackling this ambiguity in a language of which I had limited knowledge, such as German, presented a research barrier which I did not have the time or resources to circumvent. Secondly, the COVID-19 pandemic that took hold from early 2020 while I was in the midst of developing my research effectively rendered research trips to another country such as Germany undoable.

I had also envisaged organising discussion groups directly with people living with dementia in Scotland in order to understand their lived experiences of interacting with younger age groups, and their preferences and experiences in regard to participating in intergenerational programmes. The involvement of people living with dementia towards personalising services and activities can be lacking, including in the development of intergenerational initiatives. Weeks et al., for example, observed that 'consulting with nursing home residents with dementia in the development of intergenerational programing is lacking' (Weeks et al., 2020: 3).

However, the onset of the COVID-19 pandemic resulted in several barriers that made this method difficult to implement. Firstly, the pandemic increased the risks attached to inperson research with people living with dementia and at times prohibited non-household interactions, therefore I would have been unable to protect the dignity and wellbeing of research participants under such conditions. Moreover, services for older people both within care homes and within communities were under great strain throughout this time and managers would not have been able to facilitate recruitment and access for research purposes. While it may have been possible to organise discussion groups using digital technology, the priorities for the rollout of digital technology at this time were more fundamental, such as ensuring people living with dementia could continue to socialise to

some degree and have virtual contact with their family members, friends, and carers. However, speaking directly to people living with dementia in Scotland about their lived experiences and personal perceptions of intergenerational inclusion remains a direction for future research that I am interested in pursuing.

Given the risks and barriers, I took the decision with my supervisors to adapt the research methods of this thesis in order to contend with this unique context presented by the pandemic. In the place of discussion groups with people living with dementia, I successfully organised qualitative interviews with Scottish stakeholders involved in intergenerational dementia programmes and the provision of services for people living with dementia. However, even with this adapted methodology I encountered several issues related to the pandemic. For example, I faced difficulties recruiting care home staff to participate in my study, likely due to ongoing strain and staffing issues related to COVID-19 in the sector at the time. The implementation of the interview method, from recruitment to the organisation of interviews, was often delayed due to annual leave more so under normal conditions as pandemic restrictions eased during 2021 – arguably due to people not having taken as much leave due to travel restrictions and while working from home throughout the pandemic in 2020.

#### **Research Limitations**

The main limitation of the realist synthesis method used in this research is that it differs from a systematic review method that seeks to synthesise empirical evidence generated through Randomised Control Trials (RCTs) and/or conduct a metanalysis. However, realist synthesis review was developed for exploring complex interventions through which it is difficult to achieve experimental closure, and further advocates close cooperation with stakeholders and the incorporation of heterogenous evidence. The realist synthesis approach was thus deemed an appropriate method with which to explore the complexity of intergenerational dementia programmes and achieve a robust evaluation drawing upon a range of evidence given the scarcity of trials that have been conducted within intergenerational dementia programmes.

Semi-structured interview techniques are limited in several ways. They involve timerestricted situations in which researchers and interviewees are not normally known to each other, which can invoke particular balances of power, and which can affect the accounts given by interviewees in implicit and explicit ways. Interview techniques are interpretative

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exercises that can involve problems of understanding and communication on the part of both researchers and interviewees. Researchers and interviewees may be influenced by factors such as their own class, age, gender, social background, and other cultural scripts that may render it difficult for them to accurately determine the meaning and purport of either questions or responses depending on the interpretative role they assume in the interview situation. The interview structure and delivery may inhibit interviewees such that they may omit sharing data that may be relevant. Data that is forthcoming and freely shared may further be prone to errors of recollection and inaccuracy. Nevertheless, semi-structured interviews are a beneficial method with which to explore phenomena in rich detail in relation to the understandings and lived experiences of participants and was an appropriate methodology for the research questions of this thesis.

As the interviews for this research were conducted remotely this may have exacerbated communication issues and fatigue among interviewees, however, remote interviewing was necessary given restrictions imposed by the COVID-19 pandemic. Additional limitations included the fact that qualitative interviews were limited to the Scottish context and Scottish stakeholders, however, this focus did allow for an in-depth analysis of the operationalisation and understanding of intergenerational inclusion on the Scottish level and contributed Scottish-specific insight and knowledge that can contribute to further socio-cultural comparative research.

Moreover, it was beyond the scope of this research to interrogate outcomes arising from intergenerational dementia programmes in comparison to other non-intergenerational activity-based interventions for people living with dementia, or to clearly delineate the degree to which outcomes were generated specifically by the 'intergenerational' nature of programmes, rather than the nature of the activities that were often therapeutically focused on music and art in conjunction to being intergenerational. This remains a limitation in the intergenerational research field in general that it was beyond the scope of this thesis to address and that has been noted as a limitation in additional studies (Low et al, 2007: 482), however, it should be noted that this theme has provided the focus of at least one study in the USA (Lokon et al, 2019).

Given these limitations, the adoption of the two-phase study design encompassing a realist synthesis and qualitative interviewing technique was nevertheless considered a thorough research methodology with which to explore intergenerational dementia programmes,

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particularly given the restrictions imposed by the COVID-19 pandemic that precluded other methods that were under consideration.

#### Recommendations for Future Research

This thesis has shown, firstly, that intergenerational dementia programmes are of interest across a wide array of research disciplines and often involve multidisciplinary research teams. Understanding the conceptualisations, theoretical approaches, and measurement preferences of different research teams and research disciplines in relation to intergenerational practice, and the consequences for how intergenerational practice is thus framed and understood within both academia and policy spheres, merits further investigation, especially given the fluidity and changeability of definitions of intergenerational practice in general.

Further research exploring the lived experience of people living with dementia in regard to intergenerational inclusion, including their perspectives of, preferences, and experiences in regard to intergenerational programmes are critical to better inform the purpose, design, and implementation of future programmes. While it was not within the scope of this research to organise discussion groups with people living with dementia in Scotland, this is a core future research direction I will aim to explore. In particular, future research may seek to consolidate the evidence base regarding the effect of intergenerational inclusion and participation on the loneliness subjectively experienced by people living with dementia. Moreover, this thesis has indicated the ways in which a methodology aligned to critical realism could enhance exploration of lived experience by emphasising ethical judgements and the role of agency within data analysis. As Porter relates, critical realism can be used to evaluate an intervention 'on the basis of whether [beneficiaries and organisers] interpret it as promoting their human needs, or whether they regard it as alienating, along with an analysis of the conditions that ground their interpretations' and thus reinforces 'the need for the inclusion of agency as a distinct analytic category in the evaluation formula' (Porter, 2015: 79).

There remain several gaps within the evidence base that can further inform future research in the field. Galbraith et al. recommended further 'randomized control trials with larger sample sizes' along with consistent use of validated tools to facilitate more direct comparisons across studies (Galbraith et al., 2015: 374). The two main studies adopting a randomised control trial methodology included in the realist synthesis provided some

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indications of inconclusive results (Low et al., 2015; George and Singer, 2011), and thus reinforce this need for larger scale studies that adopt similar validated tools.

Galbraith et al. further argued that 'little to no attention (has been) placed on how gender, race, ethnicity, or socioeconomic status may influence children's perceptions of [people living with dementia], [people living with dementia's] tolerance and enjoyment of the presence of children, and how these characteristics might promote or impede intergenerational relationship-building' (Galbraith et al., 2015: 375). While several studies have been informed by personhood and intergroup theories, further studies may benefit from incorporating the citizenship lens of dementia developed by Bartlett and O'Connor in order to emphasise factors such as gender and socioeconomic status within determining people's experience of dementia along with their experiences of intergenerational inclusion (Bartlett and O'Connor, 2010: 5-6).

Gerritzen et al. identified a need for a more nuanced approach capable of identifying whether specific participant group characteristics affected the outcomes of intergenerational dementia programmes, such as whether the age of younger participants or the different levels of cognitive impairment among older participants contributed to programme 'success' (Gerritzen et al., 2020: 242). This research gap is supported by the findings of this thesis which demonstrated high diversity in older and younger participant groups included in programmes both internationally and in Scotland, along with substantial context and implementation complexity. These contextual elements of diversity and complexity were undoubtedly critical to scrutinising the 'working' of intergenerational programmes, however, they rendered it difficult to meaningfully assess which contexts would lead to optimal outcomes. In particular, a key finding from the Scottish context was the inclusion of younger participants who may be uniquely positioned to benefit from intergenerational programmes such as younger people who may lack confidence or who may find academia challenging, and this could be a future research direction related to intergenerational practice in Scotland. Additional factors regarding the make-up of participants involved in programmes could also be incorporated into future studies. For example, Lu et al. recommended that information regarding the medication and medical care given to older participants living with dementia be incorporated into intergenerational research conducted in care environments in particular to better understand how medication factors may affect intergenerational participation among older participants (Lu et al., 2021: 10).

Gerritzen at al., moreover, recommended that future research 'explore the possible influence of the social-cultural setting by comparing programs that were conducted in different countries' (Gerritzen et al., 2020: 242). While this thesis has generated sociocultural insight into the perspectives of Scottish stakeholders regarding intergenerational inclusion in Scotland, arguably there remains a need for additional studies that adopt a comparative socio-cultural research design. This direction for future research could utilise generativity as a theoretical foundation towards understanding how different generations perceive, interact, and provide for each other within different cultural settings. Documentary analysis of the different policy approaches towards intergenerational inclusion and ageing demographics adopted in different countries remains a potential research direction in addition.

Moreover, studies could explore differences in professional perspectives among programme organisers in different countries, or experiential differences arising through programme participation for participant groups drawn from different countries. Along with comparisons across different countries, different settings may also be compared to understand differences in programme implementation and outcomes between, for example, care homes and community-based services. Variations in staff perspectives of and attitudes towards intergenerational practice across different settings, in particular, could be a beneficial line of enquiry.

Research into intergenerational and other forms of social inclusion for people living with dementia using digital technology has formed the basis of more recent research (Zamir et al., 2021; Heins et al., 2021) and interest in this area will likely continue in the post-pandemic context that has emphasised both the possibilities and necessities of inclusion through digital means for all groups. The UK-based study conducted by Zamir et al. indicated that digital intergenerational activities appear to be both feasible and beneficial for those who participate (Zamir et al., 2021), however, further research would be beneficial in consolidating the evidence base of this activity sub-type. Moreover, studies comparing differences in outcomes arising from in-person and digital intergenerational interactions for both older and younger participant groups could also form the basis of additional research in this area.

### Conclusion

Intergenerational inclusion, while by no means a novel concern for social science, nevertheless represents a rich field of study and one that is gaining increasing interest from researchers, practitioners, and policymakers alike. Moreover, given the global projections of dementia in our societies for the foreseeable future, efforts to continually expand and enhance intergenerational inclusion for people living with dementia remains an important aim. Whether through raising levels of awareness about dementia across all age groups or through creating meaningful interactive opportunities for different age groups to come together to share and learn from each other, intergenerational dementia programmes, when implemented with sufficient care and planning, appear to be capable of generating considerable, multi-faceted outcomes for the groups involved. In this thesis I have marshalled a realist evaluation approach in order to better understand the contextual and explanatory factors that account for different outcomes arising from intergenerational dementia programmes both internationally and nationally.

By combining a realist synthesis review with stakeholder interviews throughout two in-depth study phases, I have been able to interrogate existing findings as well as offer some additional new findings in regard to the understanding and operationalisation of intergenerational inclusion across different levels of analysis. The main contributions of this research include:

- the provision of a definition of intergenerational dementia programmes as well as generating some critical reflections on the current use of definitions of intergenerational practice
- the synthesis of findings both internationally and in Scotland in accordance to the context-mechanism-outcome configuration
- the thematic analysis of insights into intergenerational dementia programmes in Scotland as generated by Scottish stakeholders with relevant experience and expertise
- recommendations to guide the understanding and operationalisation of intergenerational inclusion for people living with dementia both internationally and in Scotland
- a reflection on how the findings of this research can be linked to intergenerational theory.

The realist evaluation approach has been valuable towards understanding *why* intergenerational dementia programmes 'may or may not work, in what contexts, how and

in what circumstances' (Rycroft-Malone et al., 2012: 2) and has distilled a number of recommendations for practitioners aiming to implement such programmes. That said, in order to meaningfully realise the potential benefits that intergenerational dementia programmes can offer appears to require substantial resources – not necessarily monetary resources, but certainly resources of time, planning, preparation and activity development, along with a willingness among organisers to engage with the personhood and preferences of individual participants. Given contexts governed by complexity, scarcity, competition, and uncertainty, the degree to which intergenerational programmes are commonly achievable in these more holistic, optimal forms is debatable. Intergenerational inclusion, particularly in Scotland, may continue to be intermittent and flourish only in 'pockets' despite the potential benefits on offer.

Intergenerational inclusion sits at an interesting theoretical and empirical junction that attempts to bridge the individual's experience of, contribution to, and role within age-diverse interactive environments. Personhood, by exploring the individual's positioning within social relationships, thus offers ample scope for theorisation. The interplay of activities and relationships that is so central to intergenerational dementia programmes further resonates with theories of intergoup contact and cooperation. While realist evaluation has offered indepth insight into the implementation contexts and process explanations of how intergenerational dementia programmes further focus on agency and structure through a critical realist lens as a particularly compelling direction for future research.

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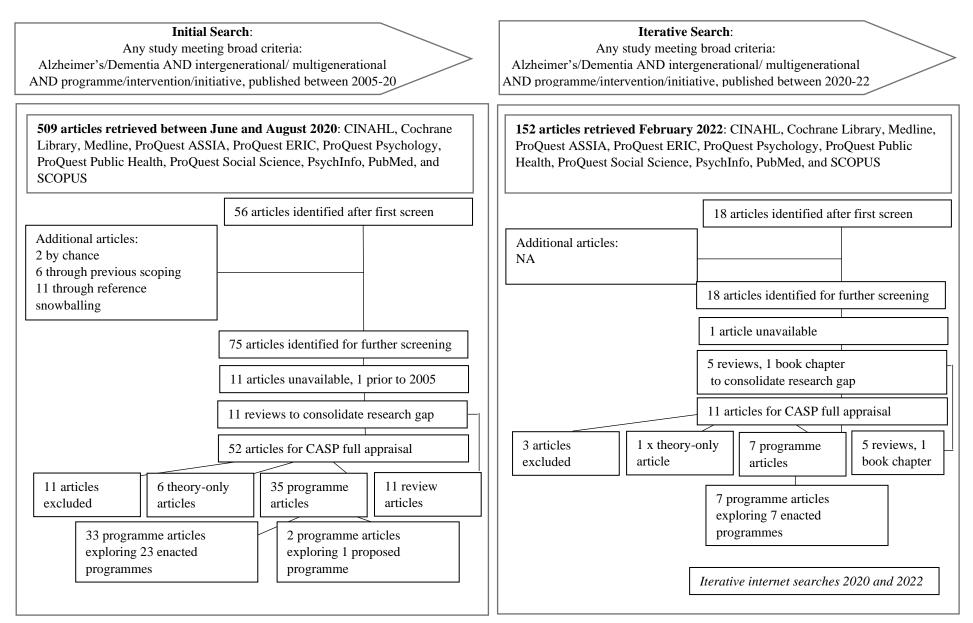
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## Appendix 1: Flow Diagram illustrating search process and article disposition (adapted from Wong et al, 2013a: 1016)



Authors	Year Published	Country	Programme Overview	Dementia- only	Dementia- stage	Older participants	Younger participants	Appraisal
Gigliotti et al	2005	USA	Intergenerational summer school implemented at a co-located adult day service (ADS) and child development lab school (CDLS) involving miscellaneous programmed activities	No, majority with dementia	Not given	N = 14, Age range not given	N = 10, Age range = $2 - 10$ years	Mixed methods comprising interviews, evaluations, and surveys to achieve a multi- layered analysis
Jarrott & Bruno <sup>i</sup>	2007	USA	Shared site intergenerational programme (SSIP) serving older adults and preschool aged children, involving miscellaneous programmed activities	Yes	Mild, moderate, and severe cognitive impairment	N = 39, Mean age = 80 years	Number not given, Age range = 0-6 years	Case study comprising surveys, interviews, and observations
Lee, Camp & Malone	2007	USA	Montessori-based intergenerational programme bringing together nursing home residents from a skilled nursing facility with preschool children from the facility's on-site childcare centre	Yes	Minimal to severe cognitive impairment	N = 14, 85 – 94 years	N = 15, Age range = 2.5 – 5 years	Positive and negative engagement evaluated through the Myers Research Institute Engagement Scale (MRI-ES)
Femia et al	2008	USA	ONEgeneration co-located daycare comprising a day care and preschool for children and an adult day service programme for older adults with cognitive disabilities	No	Cognitive disabilities	Not given	N = 34 (13 single- generation programme and 21 inter- generational programme), Mean age = 6 years	Quasi-experimental, single time-point study comparing (a) children who attended a preschool offering intergenerational programming to (b) children who attended a traditional single- generation preschool, multiple measures deployed to explore potential long-term effects

# Appendix 2: Document Characteristics

Authors	Year Published	Country	Programme Overview	Dementia- only	Dementia- stage	Older participants	Younger participants	Appraisal
Chung	2009	China	Reminiscence sessions bringing together people with dementia and young volunteers either in the community daycare centres or homes of the older participants	Yes	Early-stage dementia	N = 49, Mean age = 79 years	N = 117, Age range = 16 - 25 years	Pre- and post- one group design comprising Chinese version of the Mini Mental State Examination (MMSE), Quality of Life Alzheimer's Disease (QoL-AD), and Geriatric Depression Scale (GDS)
George <sup>ii</sup>	2011	USA	Older participants from a local assisted living facility volunteered in two classes at The Intergenerational School within a community setting and engaged in miscellaneous/reminiscence activities; generic ageing seminars were delivered to the control group	Yes	Mild to moderate dementia	N = 15 (8 intervention group and 7 control group), Age range = 50> years	N = 32, Age range = 5 – 14 years	Randomised control trial with control and intervention groups, quantitative measures including Mini Mental State Examination (MMSE), Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI), and sense of usefulness/purpose single-item questionnaires; and qualitative participant observation ethnography
George & Singer	2011	USA	As above	As above	As above	As above	As above	Randomised control trial with control and intervention groups, quantitative measures including Mini Mental State Examination (MMSE), Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI), and sense of usefulness/purpose single-item questionnaires

Authors	Year Published	Country	Programme Overview	Dementia- only	Dementia- stage	Older participants	Younger participants	Appraisal
George, Whitehouse & Whitehouse	2011	USA	As above	As above	As above	As above	As above	Randomised control trial with control and intervention groups, quantitative measures including Mini Mental State Examination (MMSE), Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI), and sense of usefulness/ purpose single-item questionnaires; and qualitative participant observation ethnography, presented in a broader thematic and theoretical study
Lokon, Kinney & Kunkel <sup>iii</sup>	2012	USA	Opening Minds Through Art (OMA) programme bringing together younger volunteers with older people with dementia to focus on person-centred art-based activities generally within continuing care retirement communities	Yes	Moderate to late stage dementia	Not given	N = 59, Age not given	300 hundred journals written by 59 students between 2009-10 were analysed using Grounded Theory and the constant comparison method
Yamashita, Kinney & Lokon	2013	USA	As above	Yes	Not given	Not given	N = 574, Age range = 15 - 29 years	Pre- and post-test attitudinal survey – Student Assisted Independent Living (SAIL) questionnaire and qualitative open- ended comments from journals
Biggs & Knox	2014	USA	Co-location via a girl scout troop that has been volunteering and visiting with residents at an assisted living facility	No, majority in focus group having dementia	Dementia	N = 5, Age = 75> years	N = 13, Age range = 5 - 10 years	Qualitative study with two components including focus groups with girl scouts, parents, residents, and staff; and analysis of girl scout competition essays

Authors	Year Published	Country	Programme Overview	Dementia- only	Dementia- stage	Older participants	Younger participants	Appraisal
Harris & Caporella <sup>iv</sup>	2014	USA	An intergenerational choir based in a university community setting bringing together people with dementia and their family members with students	Yes	Early-stage dementia, mild cognitive impairment	N = 6, Age range = 61 - 85 years	N = 13, Age range = 18 - 22 years	Phenomenological inductive approach comprising pre-, during, and post-test word association and open- ended feedback to understand student attitudes and a focus group with people with dementia and their families using a topic guide
Isaki & Harmon	2014	USA	An intergenerational reading programme undertaken at an assisted living facility bringing together school children with reading needs and older adults with cognitive- communication deficits for reading and craft activities	Yes	Mild dementia, mild neuro- cognitive disorder	N = 6, Age range = 72 - 88 years	N = 12, Age range = 8 – 11 years	Mixed methods comprising the Blessed Dementia Scale (DBS), Mini Mental State Examination (MMSE), and a 10-item adult mood and communication questionnaire for older participants; and a pre- and post-test measure adapted from the Children's Views on Aging questionnaire. Additional feedback from staff, teachers, and family members
Skropeta, Colvin & Sladen	2014	Australia	Intergenerational playgroup programme in an aged care facility involving older people, child carers, and children utilising diversional therapy and leisure lifestyle approaches	No	None, mild, moderate, and severe	N = 48, Age range = 68 - 101 years	N = 50, Age range $=$ 0 - 4 years	Mixed method study based on a pre- and post- test design using the SF36 and Geriatric Depression Scale along with qualitative interviewing of child caregivers and older participants

Authors	Year Published	Country	Programme Overview	Dementia- only	Dementia- stage	Older participants	Younger participants	Appraisal
Alant, Geyer & Verde	2015	South Africa	Intergenerational training programme, the Memory Bridge Initiative (MBI), that involves buddy partnerships between local school learners and residents in a care home	Yes	Irreversible form of dementia	Not given	N = 7 (learners only), Age not given	Qualitative case study design comprising focus groups with teachers and learners, as well as analysis of word associations and descriptions
Low et al	2015	Australia	Grandfriends intergenerational programme for people living in nursing homes and children attending a co-located preschool, involving miscellaneous activities	Yes	Cognitive Impairment	N = 40, Mean age = 91 years	N = 21, Age = 4 years	Randomised control trial design for older participants using the Menorah Park Engagement Scale along with the Cohen- Mansfield Agitation Inventory (CMAI), the Brief Sense of Community Scale (BSCS), and the Long Term Care Quality of Life scale (LTC-QoL); pre- and post-test design for young participants using the Children's Attitudes to the Elderly Interview (CATI)
Weeks et al <sup>v</sup>	2016	Canada	Examination of the proposed development of an intergenerational shared site involving a nursing home and childcare centre, collation of staff views	-	-	-	N = 42 (Nursing home staff only)	Staff survey comprising seven open- and close- ended questions and involving descriptive statistics and chi-square analysis for quantitative results and thematic analysis for qualitative results

Authors	Year Published	Country	Programme Overview	Dementia- only	Dementia- stage	Older participants	Younger participants	Appraisal
Baker at al	2017	Australia	Avondale Intergenerational Design Challenge (AVID) bringing together technology students with aged-care residents to undertake a personalised design project	No	Range of cognitive impairment	N = 24, Age range = 65 – 99 years	N = 59, Age range = 13 - 15 years	Repeated-measures within-subject study using the Homecare Measure of Engagement Staff Report, resident affect self-report, and the Psychogeriatric Assessment Scales – Cognitive Impairment Scale (PAS-CIS) for older participants, and the Rosenberg Self- Esteem Scale, Toronto Empathy Questionnaire, and Children's Perception of Aging and Elderly measure for younger participants
Collins, Kenney & Hesk	2017	UK	Intergenerational community Christmas event held at the University of Salford bringing together older guests with university staff and student volunteers	No	Not given	N = 15, Age range = 62 - 86 years	N = 28, Age range = 23 - 58 years	Qualitative multi- method evaluation approach involving semi-structured interviews with guests and a group interview with staff and student volunteers
Guerrero, Jimenez & Tan	2017	USA	Intergenerational respite care and workforce development programme, TimeOut@UCLA, that recruits student volunteers to bring companionship to older participants in a community setting	Yes	Early-stage AD or other form of dementia	N = 89, Age not given	N = 86, Age not given	End-of-quarter student volunteer survey, article lacks detail regarding content and analysis of survey hence rigour is low

Authors	Year Published	Country	Programme Overview	Dementia- only	Dementia- stage	Older participants	Younger participants	Appraisal
Lokon, Li & Parajuli	2017	USA	Opening Minds Through Art (OMA) programme bringing together younger volunteers with older people with dementia to focus on person-centred art-based activities generally within continuing care retirement communities	Yes	Moderate to late stages of dementia	Not given, Age range = majority in their 80s	N = 156, Age range = 18 - 45 years	Pre- and post-test design using the Dementia Attitude Scale (DAS) to measure changes in student attitudes
Lokon, Li & Kunkel	2018	USA	As above	Yes	Moderate dementia	Not given	N = 715 (control and intervention)	Pre- and post-test design using the Allophilia Scale to compare student volunteers in the intergenerational programme to students in a control, non- participating group
Chow et al	2018	Canada	Partnership between a high school and a dementia residence called the Dementia Awareness Programme undertaken in a care home and using miscellaneous activities	Yes	Not given	Not given	N = 4, Age range = 15 - 17 years	Case study of the pilot programme involving a pre- and post-test design with two questionnaires designed to evaluate changes in students' attitudes, including the Palmore Facts on Aging Quiz and a questionnaire designed for the project
Canning & Blakeborough <sup>vi</sup>	2019	Canada	Imagine Dance intergenerational dance initiative blending dance music therapy and intergenerational programming in long-term care residential homes, involving people with dementia and school-aged children	Yes	Not given	Not given	Not given	Case study discussion article involving interview and filmic data collection

Authors	Year Published	Country	Programme Overview	Dementia- only	Dementia- stage	Older participants	Younger participants	Appraisal
Caspar et al	2019	Canada	LINKages intergenerational programme involving pairings between residential care homes and local schools, youth and older participant partners engaged in miscellaneous activities in the care home setting	No	Cognitive or physical impairment, or both	N = 52, Age not given	N = 87, Age not given	Exploratory case study involving the Observational Measurement of Engagement (OME) and the Observed Emotional Rating (OER) for older participants; and pre- and post-test surveys for young participants including the Youth Experiences Survey (YES 2.0) and the Aging Semantic Differential- refined (ASD-refined)
Di Bona, Kennedy & Mountain	2019	UK	Adopt a Care Home intergenerational programme involving dementia teaching and visits to a local care home for school-aged children to engage in life story and reminiscence activities with people with dementia	Yes	Mild, moderate, and severe dementia	N = 10, Age range $=$ 70 - 90 years	N = 41 (16 visiting care home), Age range = 9 – 10 years	Mixed method case study design involving non-participant observations, semi- structured interviews with staff, and a focus group with the children along with the Dementia Awareness Questionnaire pre- and post-curriculum
Hannan et al <sup>vii</sup>	2019	Canada	Zeitgeist Publication intergenerational programme bringing together communication design students with residents in a long-term care facility to co-design and co-author mini publications about the residents' life stories	Not given	Not given	Not given	Not given	Evaluative and descriptive case study describing the approach, impact, and learning of the programme, lack of detail regarding participants and data analysis hence rigour is low

Authors	Year Published	Country	Programme Overview	Dementia- only	Dementia- stage	Older participants	Younger participants	Appraisal
Raber et al	2019	Canada	As above	No	Mild to moderate dementia	N = 15, Age not given	N = 18, Age not given	Narrative identity and storytelling approach structuring a case study of the programme, lack of detail describing study design and data analysis hence rigour is low
Harris & Caporella	2019	USA	An intergenerational choir based in a university community setting bringing together people with dementia and their family members with students	Yes	Early-stage dementia, mild cognitive impairment	N = 22, Mean age = 72 years	N = 62, Age range = 18 – 29 years	Phenomenological inductive approach comprising pre-, during, and post-test word association and open- ended feedback to understand student attitudes and a focus group with people with dementia and their families using a topic guide
Janke et al	2019	USA	Intergenerational programming through a shared site daycare programme comprising a long-term care facility and co-located child daycare using miscellaneous activities	Yes	Mild, moderate and severe dementia	N = 15, Age range = 62 - 96 years	Number not given, Age range = 0 – 6 years	Study design comprising participation and engagement of older participants using the Menorah Park Engagement Scale (MPES) and the Quality of Life in Dementia Scale (QUALID), as well as Brief Interview for Mental Status (BIMS) and Patient Health Questionnaire (PHQ-9)

Authors	Year Published	Country	Programme Overview	Dementia- only	Dementia- stage	Older participants	Younger participants	Appraisal
Landi & Smith	2019	Nether -lands	Humanitas© innovative co-living care home model incorporating affordable student accommodation	Yes	Early-stage dementia	N = 4, Age range = 65> years	N = 4, Age range = 65> years	Qualitative Post- Occupation Evaluation framework involving a living-lab and co- creative research approach and interviews/semi- structured questionnaires for older residents, young residents, and staff
Lim et al	2019	Singapore	Co-located adult daycare and childcare centres in a community hub partnered for an intergenerational programme bringing together older participants with young children to engage in miscellaneous activities and cultural celebration	No	Mild to moderate dementia	N = 27, Age range = 70 - 95 years	N = 50, Age range = 4 – 5 years	Mixed method study design involving the Bradford Wellbeing Profiling Observational Tool and feedback forms for older participants, as well as additional comments from family members and staff
Lokon, Sauer & Li	2019	USA	Opening Minds Through Art (OMA) programme bringing together younger volunteers with older people with dementia to focus on person-centred art-based activities generally within continuing care retirement communities	Yes	Moderate to severe dementia	N = 67, Age not given	Not given	Case study design based on a comparison of activity types evaluated using the Scripps Modified Greater Cincinnati Chapter Wellbeing Observational Tool (SM-GCCWOT)
Canning, Gaetz & Blakeborough	2020	Canada	Imagine Dance intergenerational dance initiative blending dance music therapy and intergenerational programming in long-term care residential homes, involving people with dementia and school-aged children	Yes	Mild, moderate, and advanced dementia	N = 15, Age range = 65> years	N = 7, Age range = 7 - 9 years	Mixed method qualitative study design comprising participant observation, field notes and pre-, during, and post-interviews with younger participants

Authors	Year Published	Country	Programme Overview	Dementia- only	Dementia- stage	Older participants	Younger participants	Appraisal
Weeks et al	2020	Canada	Examination of the proposed development of an intergenerational shared site involving a nursing home and childcare centre	Yes	Mild to moderate dementia	N = 12, Age not given	-	Strengths-based Community Capacity Framework approach involving face-to-face interviews (research conversations) with nursing home residents
Smith et al	2020	Australia	Dementia education programme implemented in a primary school with embedded intergenerational interactions at a social day programme for older adults	Yes	Cognitive impairment commonly dementia	Not given	N = 37 excursion group & N = 22 no- excursion group Age = 9 years	Non-randomized, mixed methods, quasi- experimental evaluation approach based on the RE-AIM framework combining the Kids Insight into Dementia survey (KIDS) and semi- structured qualitative interviews with older adults, carers & parents
Reel et al	2021	USA	Bringing Art to Life (BATL) programme involving activities led by a certified arts therapist within an adult day service incorporating service learning undertaken by college students	No	Mild to moderate Alzheimer's disease, other dementias, or other cognitive impairment i.e. traumatic brain injury	N = 47 Age range = 25 - 94, mean age = 74	Not given	Field notes based on the methodology of recording ethnographic observations for 100 one-hour art therapy sessions with a modified Engage research instrument to measure meaningful engagement retrospectively from the field notes

Authors	Year Published	Country	Programme Overview	Dementia- only	Dementia- stage	Older participants	Younger participants	Appraisal
Zamir et al	2021	UK	Use of Skype for online, remote conversations connecting care home residents with local high school students	No	Advanced/ moderate dementia and signs of cognitive decline	N = 20 Age range = 85 – 90 years	N = 6 Age range = 16 – 17 years	Mixed methods including both quantitative feedback forms, and qualitative ethnographic methods. Ethnographic methods allowed for observations such as noting older people's reactions to seeing faces on video- call technology, and obtaining feedback from participants
Lyndon & Moss	2021	UK	Nursery school visits to a local care home supported by early year practitioners	Yes	With dementia	N = 8 Age range = 65 - 95+ years	N = 6 Age range = $3 - 4$ years	Narrative dialogic approach exploring meaning making including qualitative naturalistic observations of the intergenerational sessions at the care home and semi- structured interviews with the three nursery school practitioners
Brandão et al	2021	Brazil	Playful Living intergenerational programme designed to engage socially diverse groups of older adults with undergraduate students from the areas of arts and health using WhatsApp calls and Zoom group sessions	No	Clinical diagnosis of dementia	N = 24 Age range = 60 - 90 years, mean age 71.8 years	N = 22 Age not given	Functional Assessment of Communication Skills for Adults (ASHA- FACS), Geriatric Depression Scale and the Geriatric Anxiety Inventory for screening combined with participatory observation, thematic analysis & open-ended evaluation questions put to participants

Authors	Year Published	Country	Programme Overview	Dementia- only	Dementia- stage	Older participants	Younger participants	Appraisal
Jenkins, Farrer & Aujla	2021	UK	Hear and Now, an intergenerational arts and health project in which participant groups collaborated to devise a music and dance piece rehearsed and performed at the university theatre	No	People living with a diagnosis of dementia or cognitive impairment	N = 9 Age range = approx. 82 – 86 years	N = 9 Age range = approx. 11 – 13 years	Focus groups and observations analysed in relation to Seligman's multidimensional PERMA model to measure wellbeing
Hernandez, Murray & Stanley	2022	Australia	An intergenerational playgroup (IGP) located in an Australian residential aged-care facility (RACF) in affiliation with Playgroup Australia	No	Older adults with and without cognitive impairment	Not given	Number not given Age = <5 years	Ethnographic observations and interviews conducted with consenting clients, staff, and caregivers

<sup>&</sup>lt;sup>i</sup>Jarrott and Bruno (2007) present a case study investigating intergenerational programming at ONEgeneration daycare in Southern California, USA. In a separate study, Femia et al (2008) undertook data collection at the same ONEgeneration day care facility.

<sup>&</sup>lt;sup>ii</sup>George (2011) presents quantitative and qualitative findings from an RCT enacted at The Intergenerational School in Cleveland, Ohio in 2011. George & Singer (2011) focuses on the quantitative findings from this RCT; and George, Whitehouse & Whitehouse (2011) presents the mixed method RCT findings within a broader study.

<sup>&</sup>lt;sup>iii</sup>Lokon, Kinney & Kunkel (2012), Yamashita, Kinney & Lokon (2013), Lokon, Li & Parajuli (2017), Lokon, Li & Kunkel (2018), and Lokon, Sauer & Li (2019) present research data gathered through the 'Opening Minds Through Art (OMA)' initiative. Different methods and data are presented in each study.

<sup>&</sup>lt;sup>iv</sup>Harris & Caporella (2014) present findings from an intergenerational dementia programme focusing on a university choir. The repeat study, Harris & Caporella (2019), presents aggregated data from four iterations of the university choir programme.

<sup>&</sup>lt;sup>v</sup>Weeks et al (2016) and Weeks et al (2020) investigate a proposed intergenerational co-located care programme from the perspective of staff and nursing home residents respectively. <sup>vi</sup>Canning & Blakeborough (2019) presents a broad conceptual case study examining an intergenerational ballet programme. Canning, Gaetz & Blakeborough (2020) explores the same programme through qualitative research data.

v<sup>ii</sup>Hannan et al (2019) and Raber et al (2019) explore the same intergenerational design project involving people with dementia entitled the Emily Carr University Zeitgeist Publication programme.

## Appendix 3: Realist Synthesis Data Extraction Sheet

Evidence Source Details	
Article Number	
Database Search	
Review Date	
Title	
Year	
Authors	
Journal (Vol, issue, pages)	
Discipline	
Quick Characteristics	
Data Collection Method	
Outcomes for older/younger/	
both participant groups	
Project Year	
Country and Region	
Setting Simplified (label)	
Setting Detailed	
Activity	
Duration	
Frequency Simplified (label)	
Frequency Detailed	
Dementia-only programme	
Older participants age	
Dementia stage	
Young participants age	
Young participants affiliation	
Outcome Simplified (label)	
Context	
Theory constructs underlying	
primary data collection	
Context of intervention	
Mechanisms	1
Overview of intergenerational	
programme/service/intervention	
Programme/Policy-orientated	
mechanisms	
Policy/programme barriers	
Outcomes	
Results/effectiveness/findings	
Policy recommendations/	
conclusions	
Other comments/points	

## Appendix 4: Interview Topic Guide

#### **INTERVIEW TOPIC GUIDE**

The purpose of this interview is to explore intergenerational inclusion and intergenerational programmes for people with dementia in Scotland. Questions are guided by a realist interview approach focusing on components such as intervention, context, actor, mechanism, and outcome. Interviews are also focused on understanding the linkages that can be made between Scotland's dementia strategies to date, intergenerational inclusion for people with dementia, and intergenerational dementia programmes. Questions may be adapted according to the job role and expertise of each participant.

enper tie	
Introdu	ction
1 (a)	Can you tell me about your current job role and how you are involved in Scotland's
	dementia policy network/provision of services for people with dementia in Scotland?
Interve	ntion (Intergenerational Dementia Programmes)
2 (a)	Are you aware of intergenerational dementia programmes in Scotland?
	-Examples?
	-Settings?
	-Activities?
	-Partnerships?
2 (b)	How would you define intergenerational dementia programmes?
	-How would you define intergenerational inclusion for people with dementia?
Context	, Actor
3 (a)	What are your perceptions of intergenerational inclusion for people living with dementia in Scotland today?
3 (b)	Is there a need for intergenerational dementia programmes in Scotland?
	Drivers – demographics, dementia prevalence, workforce development etc
	Would such programmes link in with increased inclusion?
3 (c)	Is the context in Scotland appropriate for such programmes?
	-Specific areas, rural, urban
	-Specific settings, care homes, communities, day care
3 (d)	What groups do you see being involved in intergenerational dementia programmes?
	-Specific groups and organisations, dementia stage, age of children, children with identified needs
Program	nmes, Programme Theory
4 (a)	How do you understand intergenerational dementia programmes to work?
4 (b)	What enables programmes to be effective?
4 (c)	What makes programmes ineffective?
Outcom	les
5 (a)	What outcomes do you see arising from programmes?
	What benefits, if any, do you see arising from programmes?
5 (b)	What difficulties/drawbacks, if any, do you see arising from programmes?
	Any adverse outcomes
Barriers	

6 (a)	What are the barriers to intergenerational dementia programmes?
	What are the barriers to intergenerational inclusion?
	What are the facilitators?
Policy	
7 (a)	Does Scottish dementia policy to date address intergenerational inclusion for people living with dementia?
7 (b)	Could Scottish dementia policy do more to facilitate intergenerational inclusion and intergenerational dementia programmes?
Pandem	ic
8 (a)	Has the COVID-19 pandemic affected intergenerational inclusion for people living with dementia? If so, in what ways?
Thank y	ou & final comments
9 (a)	Would you like to add anything else?
9 (b)	Is there anyone else you could recommend I speak to?

## Appendix 5: Participant Information Sheet

**Title:** Intergenerational inclusion and intergenerational dementia programmes: implications for Scottish dementia policy

#### Invitation

My name is Heather Emond and I am a PhD candidate at Queen Margaret University's Business School. I am a social scientist with a background in local government, monitoring and evaluation, and data protection.

I would like to invite you to participate in a short interview exploring intergenerational inclusion and intergenerational dementia programmes in Scotland, with particular reference to Scottish dementia policymaking. Interviews will last approximately 45 minutes and will take place through internet video conferencing to ensure the safety of all involved. Questions will focus on the context, barriers, and facilitators of intergenerational dementia programmes and your perceptions of intergenerational inclusion for people with dementia in Scotland today, particularly in view of the pandemic. If you participate in an interview, you are encouraged to discuss what you think is most relevant or important to the topic being investigated. The aim is to capture your professional perspectives and experiences.

If you decide to participate, you will be asked to:

- ✓ help me arrange an interview with you at a date and time that suits you best
- ✓ complete and return a consent form, ensuring you have read and understood this information sheet
- ✓ attend an online interview using either Zoom or Microsoft Office Teams, making sure you have a good, comfortable location with internet connectivity and where you can speak confidentially
- $\checkmark$  be aware that your interview will be recorded for transcription purposes
- ✓ review how your information and quotations are being used in analysis a few months after your interview, letting me know if you have any concerns.

Further information about the research and what is involved in an interview is provided overleaf.

I am sending you this invitation as I believe your professional role and experiences will make an insightful contribution to my doctoral research project. I will endeavour to ensure that your participation is as productive, convenient, and enjoyable as possible.

If you are interested in taking part in an interview or if you would like more information, please contact me by email hemond@qmu.ac.uk or by mobile telephone 07821 325 881. I will be happy to answer any questions you have about the research and your potential involvement.

#### Purpose and aim of the study

Interest in intergenerational dementia programmes and intergenerational inclusion for people with dementia is being promoted by a number of drivers in Scotland, including ageing populations and dementia prevalence. Intergenerational dementia programmes designed to bring people with dementia together with younger age groups are being used across a variety of contexts, both in and beyond Scotland. Programmes are perceived to be associated with a number of health benefits for people with dementia, as well as achieving reciprocal benefits for younger participants. Intergenerational dementia programmes are further seen to be a way to enhance social inclusion for people with dementia, while simultaneously promoting positive attitudes among children and young people about ageing and dementia.

The main aim of this study is to gather professional perspectives on the development of intergenerational policy and intergenerational programmes aimed at benefiting people with dementia in Scotland. Undoubtedly, intergenerational inclusion for people with dementia is being impacted by the COVID-19 pandemic. A secondary aim of this study is to gather professional perspectives about the current public health situation and how this has, and will continue, to impact the prospects for intergenerational inclusion for people with dementia in local communities.

#### Why have I been chosen to take part?

I am inviting you to take part in this study due to your involvement in Scotland's dementia policy network and/ or your involvement in the provision of services to people with dementia in Scotland. Your professional role and experiences are relevant to the topic being investigated and will allow you to make insightful contributions to the research.

#### Do I have to take part?

Taking part is entirely voluntary. You can refuse to take part now or at any time throughout the study, with no penalty or loss arising from your refusal or withdrawal.

#### What do I have to do?

You will participate in a short interview lasting approximately 45 minutes. The interview will be arranged for a date and time that suits you best. For your safety and convenience, the interview will be held through online video conferencing using either the Microsoft Office Teams or Zoom application depending on your preference. As the interview is being held remotely and online, you will be guided to choose a comfortable, quiet location with good connectivity and where you feel you can speak freely without being interrupted or overheard. Interviews will be recorded for transcribing purposes and this may include audio, Dictaphone, and video recording. If you prefer not to be video recorded, you can indicate this on the consent form, and we will ensure that your video is switched off prior to commencing. All recordings and transcripts will be stored securely through Queen Margaret University.

During the interview, you will be asked a number of questions about intergenerational inclusion, intergenerational dementia programmes, and Scotland's dementia policy. Questions will focus on the context, barriers, and facilitators of intergenerational dementia programmes and your perceptions of intergenerational inclusion for people with dementia in Scotland today, particularly in view of the pandemic. You do not need to answer all of the questions. The questions are prompts that will allow you to share what you think is important to the topic being discussed.

The information that you share will form data for the doctoral research project. Your quotations may be used in the PhD thesis as well as future research, such as publications and articles. You will be given the opportunity to see how your quotes are being used in the context of the research. You will be given sufficient time to comment, clarify, or state if you are unhappy with how your information is being presented and this will be taken into account.

#### Are there any disadvantages or risks to taking part?

The research should not involve any disadvantages or risks. Interviews will be held through internet video conferencing for the safety of all involved. You will be guided to choose a suitable location for your interview and the process will be relaxed, so you will be encouraged to have refreshments and go at your own pace. As with any internet conferencing, there may be connectivity issues, but these will be handled on the day. If connectivity proves particularly difficult, your interview may need to be rescheduled however this is unlikely. Your interview data once collected will be stored securely at all times with access limited to the research team.

You will be asked to give your time to the study, both for the interview and then reviewing how your information is being used in the analysis a few months later. You will not be asked to give more time to the study than is necessary unless you wish to do so voluntarily.

#### Are there any benefits to taking part?

While there will be no direct benefit to your taking part, your participation will contribute towards specific, legitimate research aims and an important research topic that is relevant to your professional role and experiences. Your interview will be an opportunity for you to share your professional perspectives in a safe, comfortable environment and be part of an original doctoral research project focused on dementia policy in Scotland. The current public health situation has heightened awareness of issues of ageism and the importance of intergenerational inclusion and solidarity, and so the topic is current.

#### Will my taking part be confidential?

Your data will be kept confidential and stored securely at all times on either the university server or through back-ups in the university cloud storage. Only the research team will have access to the interview data, including myself and my supervisors. Data will be anonymised and any personally identifying elements removed. For example, in transcripts used for thematic analysis, your name and job title will be replaced with codes for extra security. Recordings will be deleted entirely by the end of the study. Anonymised transcripts may be retained for longer in connection with the PhD. This may include a record of your name and job title, stored separately from the transcript, that would be used for future research purposes subject to the same conditions of confidentiality.

Your name will not be included in the PhD thesis or any related publication or article, either now or in future. Careful consideration will be given to how your job title, role, and the information that you share are presented in the analysis to ensure that you are not identifiable. You may be asked to review how your job title and role is being presented to ensure you are satisfied, and any concerns can be discussed and resolved.

#### What will happen to the results?

Information that you share during your interview will form the data of a doctoral research project and will be used for the PhD thesis and related publications and articles, including future research.

#### **Organising and Funding**

I am only affiliated with Queen Margaret University for the purposes of this research and I am in receipt of a doctoral bursary for this study.

#### Ethics

This interview study has received approval from the Queen Margaret University Ethics Committee.

#### **Researcher Responsibility**

If issues emerge during the interview to suggest that there is a risk to an adult or child that is not being addressed, the researcher will need to discuss this with the supervision team whilst maintaining the confidentiality of those involved and may need to contact the relevant authorities. You will be kept informed of any action.

#### **Contact details**

Please get in touch with me if you have any questions or would like to discuss this research further. My contact details are:

Heather Emond, PhD Candidate, QMU University hemond@qmu.ac.uk 07821 325 881

#### What if I have further questions, or if something goes wrong?

If you have any concerns about this research or your participation in an interview, please contact my supervisor in the first instance:

Dr Fiona Kelly, Lecturer, QMU University Fkelly1@qmu.ac.uk

# Thank you for reading this participant information sheet and for considering taking part in this study. Please retain this information sheet for future reference.

## Appendix 6: Participant Consent Form

**Title:** Intergenerational inclusion and intergenerational dementia programmes: implications for Scottish dementia policy

#### Consent to take part in research:

*Please type your initials next to the statements you agree to:* 

I have read and understood the participant information sheet	
I have had an opportunity to ask questions and, where I had questions, these were answered for me clearly	
I understand that I am under no obligation to participate in this study	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason	
I understand that I can choose not to answer a question during the interview without consequence	
I agree to the interview being recorded and understand that this may involve audio and Dictaphone recordings that will later be transcribed	
I agree to the interview being video recorded	
I understand that all personal information will remain confidential and be stored securely	
I understand that extracts and quotations from the information I share may be used in the PhD thesis as well as related publications and articles, including future research, and that all efforts will be made to ensure I cannot be identified	
I agree that interview data gathered in this study may be stored securely and anonymously, and may be used for future research subject to the same conditions of confidentiality	
I agree to take part in this study	

Signature of Participant	*Electronic signatures are permissible
Name of Participant	
Date	

Signature of Researcher	*Electronic signatures are permissible
Name of Researcher	
Date	

#### **Research Team and Contact Details**

Heather Emond	QMU PhD Candidate	hemond@qmu.ac.uk
Fiona Kelly	QMU Lecturer and supervisor	Fkelly1@qmu.ac.uk