

To cite this article: Stephen J. Macdonald, Lesley Deacon, Jackie Nixon, Abisope Akintola, Anna Gillingham, Jacqueline Kent, Gillian Ellis, Debbie Mathews, Abolaji Ismail, Sylvia Sullivan, Samouka Dore & Liz Highmore (2018): 'The invisible enemy': disability, loneliness and isolation, *Disability & Society*, DOI: 10.1080/09687599.2018.1476224

'The invisible Enemy': Disability, loneliness and isolation

Abstract

The aim of this article is to quantitatively explore the relationship between disability, emotional loneliness and social isolation. The data analysis presents a number of statistically significant findings which illustrate that disabled people (N = 250) were at increased risk of experiencing emotional loneliness and social isolation compared with the nondisabled group (N = 355). This study identifies a number of disabling barriers which result in this overrepresentation of disabled people. The study aims to move away from a pathological explanation of linking loneliness and social isolation to disability, in order to explain this occurrence from a barrier-based approach.

Stephen J. Macdonald, Lesley Deacon, Jackie Nixon, Abisope Akintola, Anna Gillingham, Jacqueline Kent, Gillian Ellis, Debbie Mathews, Abolaji Ismail, Sylvia Sullivan, Samouka Dore & Liz Highmore

Introduction

The aim of this paper is to explore the impact that emotional loneliness and social isolation have on the disability community. This paper applies a quantitative analysis comparing data from individuals who have identified themselves as being lonely or isolated within their communities. The data was collected from a study conducted in the

north-east of England using a mixed method approach to examine the extent to which loneliness and isolation affect people living in the Sunderland district. The data analysis was conducted on a sample of 680 participants living in the city.

When analysing data on loneliness and isolation it became clear that disability was a significant factor in the experience of loneliness and isolation. This study presents data suggesting that disabled people are more likely to experience social isolation and emotional loneliness than the nondisabled population. The findings identify key risk factors such as employment status and relationship status that vary between the disabled and nondisabled groups. However, the findings conclude by referring to significant disabling barriers which appeared within the data, such as inaccessible communities, poorly resourced social care and the psychosocial emotional impact these experiences have on participants. This paper concludes by offering a social model interpretation of the statistical correlations in an attempt to explain why disabled people are overrepresented within this socially isolated population in Sunderland.

Defining the concept of loneliness and isolation

The issue of loneliness was first empirically studied in Sheldon's (1948) classic study in the UK examining older people's experiences of family life. Within this study there was a rejection of the pathological notion of old age which previously dominated the academic literature (Townsend 1959). He attempted to understand old age as a natural part of everyday life and sought to comprehend the everyday experiences of older people living in the community. In his work he reported that 8% of his sample was classified as substantially lonely and a further 13.7% were classified as experiencing periods of loneliness (Sheldon 1948; Victor and Bowling 2012). Townsend (1959) expanded on this

work and suggested that older people were predominantly protected from the experience of loneliness due to family ties and established community networks. For Townsend, the concept of loneliness affected only a minority of people within post-war society. Interestingly, statistics concerning loneliness have stayed relatively stable since these early studies in the UK (Bowling 2005; Victor and Bowling 2012).

However, measuring and defining the concept of loneliness has been somewhat problematic over recent years. Firstly, research projects in the UK and globally have used different methodologies in order to collect data on the concept of loneliness. Secondly, the concept of loneliness is a subjective interpretation of a person's day-to-day interactions. For example, an individual can feel lonely in a room full of people. From this perspective, in previous research the concepts of loneliness and isolation have been somewhat interconnected and even misinterpreted. In research by Victor and Bowling (2012), the term loneliness encapsulates both experiences of isolation and feelings of loneliness. Other studies, such as Dahlberg and McKee (2014), have attempted to separate the concept of loneliness into two distinct categories, referring to the social and emotional. When referring to Weiss's definition (1973), the authors suggest that 'social loneliness refers to the absence of an acceptable social network, that is, a wider circle of friends and acquaintances that can provide a sense of belonging', i.e. isolation, and 'emotional loneliness refers to the absence of an attachment figure in one's life and someone to turn to' (Dahlberg and McKee 2014: 504).

Tanskanen and Anttila (2016) have attempted to clarify this definition further and have separated the concepts of loneliness and isolation into different quantitative categories. They suggest that in previous studies the concepts of social isolation and loneliness have

often been interchangeable concepts. Yet these are distinctly different analytical categories, where the first relates to concrete interactions and the second relates to subjective interpretations of emotional reactions to a person's environment. Tanskanen and Anttila (2016: 2042) suggest that 'social isolation is concerned more with environmental impoverishment or restrictions than with the individual's ability to create and maintain social relationships'. From this perspective social isolation is underpinned by environmental factors which relate to the breaking down of social networks. From their perspective, 'loneliness, is a subjective feeling of being without the type of relationship one desires ... a deficit between the actual and desired quality and quantity of social engagement' (Tanskanen and Anttila 2016: 2042). Therefore, loneliness can occur due to social isolation because of a lack of contact with family members or friends, but it can also occur even when people do have significant contact with other social groups but due to a 'lack of desired quality of social engagement'. Individuals can also be socially isolated but not experience feelings of loneliness. From their perspective, it is important to separate these two concepts, although they recognise that they are often interlinked. Within this research, the concept of 'loneliness' refers to Dahlberg and McKee's (2014) notion of 'emotional loneliness' as a subjective interpretation relating to the perceived quality of a person's relationships with others, as well as Tanskanen and Anttila's (2016) notion of 'social isolation' which refers to a breakdown in concrete social networks.

'Risk' factors into loneliness and social isolation

Contemporary studies into loneliness and isolation have predominantly focused on older people over the age of 50 (Bowling 2005; Victor and Bowling 2012; Victor *et al.* 2012; Dahlberg and McKee 2013; AgeUK 2014). In research by Dahlberg and McKee (2013),

examining the experiences of people over the age of 65 (N = 1255), they discovered that loneliness had a significant impact on a person's quality of life. In their study, they reported that 7.7% of participants experienced social loneliness (i.e. social isolation) and another 38.3% reported feelings of emotional loneliness. They found that social loneliness had a significant impact on the health and well-being of their research participants. They also proposed that there were key risk factors which resulted in social isolation, such as becoming a widow, low self-esteem, and poor engagement with social activities outside the home. However, Dahlberg and McKee reported one of the defining factors which lead to social and emotional loneliness was poverty within old age. They explained restrictions on social activities and the breakdown in social networks due to poor economic resources resulting in social isolation (Dahlberg and McKee 2013).

Another large-scale study which focused on participants over the age of 65 years was conducted by Victor and Bowling (2012). This was a longitudinal study which conducted a follow-up analysis of 999 individuals from a survey originally conducted in 1999–2000 (Bowling 2005). The aim was to discover whether loneliness has increased/decreased in the United Kingdom. This was a national survey which collected follow-up data from 287 participants eight years after the initial survey (416 participants had died since the previous study). The authors discovered that the experience of loneliness stayed relatively the same over an eight-year period, at 9%. However, people who reported occasional loneliness (i.e. emotional loneliness) increased from 32% to 42% over this period. Additionally, the number of participants who described never experiencing loneliness had decreased from 61% to 50% in the follow-up study. Further, they found that the mortality rate was 12% higher for participants that experienced high levels of

loneliness (i.e. social isolation) compared with participants who had never experienced loneliness.

Building on this study, Victor *et al.* (2012) acknowledged a lack of ethnic minority groups within their previous longitudinal research. In their previous studies (Bowling 2005; Victor and Bowling 2012), the team noted that there were only three participants from an ethnic minority background out of 999 participants. This study therefore targeted British minority groups, including participants from Indian, Pakistani, Bangladeshi, African Caribbean and Chinese backgrounds. The authors discovered that loneliness for participants from ethnic minority backgrounds over the age of 65 was significantly higher compared with the general population. They reported that experiences of loneliness and isolation ranged from 24% to 50% of participants from China, Africa, the Caribbean, Pakistan and Bangladesh. Yet people from an Indian background were comparable to white British rates of loneliness and isolation, at 8–10%. The significance of these findings is that they indicate that rates of loneliness and isolation are not universal and affect minority populations in different ways within the UK (Victor *et al.* 2012).

Although UK studies have predominantly focused on older people, a number of international studies have included a wide range of ages when investigating loneliness. An example of this can be viewed in a large-scale study (N = 8650) in Finland by Tanskanen and Anttila (2016). This was a longitudinal study that included a wider demographic of age ranges (16 years +) over a 17-year period from 1995 to 2011. For the authors social isolation significantly impacted on a person's mental and physical health. They reported a direct correlation between social isolation and its effect on mortality rates. However, although there was a significant relationship between social isolation and

high mortality rates this was not the case with regard to (emotional) loneliness. These findings suggest that the subjective experience of loneliness did not have the same impact compared with the experience of social isolation with reference to mortality rates. Tanskanen and Anttila (2016) concluded by suggesting that it is impossible to determine if poor health was because of social isolation or if poor health resulted in social isolation.

In a similar study examining how loneliness affects individuals throughout their life course, Luhmann and Hawkley (2016) discovered that loneliness impacted on people's experiences at key points in a person's biography. This study was conducted in Germany (N = 16132) and discovered that loneliness tends to peak in younger adults below the age of 30. They reported that loneliness gradually drops during midlife (30–65 years) and begins to rise in early old age (65 years) and again peaks for the 80 years group. Interestingly, what they discovered was that for the younger group living alone was not necessarily a key risk factor, but rather their engagement with wider social networks. This was not the case for older participants, as living alone was a key factor resulting in loneliness for the older age groups. The authors suggest that income was a key risk factor for people in the middle-aged category compared with other age groups (Luhmann and Hawkley 2016). However, experiences of poverty combined with socio-economic status were reported as universal risk factors which affected all groups experiencing loneliness. They concluded by suggesting that work status is central in creating and maintaining social networks in order to combat loneliness during people's life course. In their study, unemployment was an important risk factor leading to pathways into social isolation and loneliness.

It should be emphasised that only a small number of studies have focused on loneliness in adolescence (Heinrich and Gullmore 2006; Marlies *et al.* 2015; Zhang *et al.* 2015). Zhang *et al.* (2015) conducted research into three cities across mainland China, exploring the relationship between adolescence, gender and loneliness in high school. Their sample (N = 1674) included participants up to the age of 17 years old, and their results highlighted that a lack of same-sex relationships was the strongest predictor associated with risk factors into loneliness. Zhang *et al.* (2015) discovered that younger people's experience of loneliness and isolation relies more on same-sex friendships to prevent loneliness than any other relationship during adolescence. Similar research conducted by Heinrich and Gullmore (2006) in Australia explored the effect that loneliness had on adolescence, but also linked loneliness to mental and physical health problems. They illustrated that the experience of loneliness in adolescence occurred generally because of peer rejection, which was similar to a finding by Zhang *et al.* (2015). However, Heinrich and Gullmore (2006) discovered that this rejection had a significant impact on a child's life, leading to issues of alcoholism, low self-esteem, anxiety/depression and even acts of suicide. It should be noted that all of these studies refer to the concept of disability, yet this is usually conceptualised as a secondary factor, linked to the ageing process (with reference to physical impairment), or as a result of experiences of loneliness (with reference to mental health). Although research into loneliness has successfully illustrated the prevalence of impairment and long-term illness, these studies have not attempted to conceptualise this from a barrier-based approach.

Disability, loneliness and isolation

Although previous UK studies into loneliness/isolation have predominantly focused on older people, studies linking disability with loneliness have been essentially

conceptualised as a public health issue (Valtora *et al.* 2016). This biomedical interpretation of disability, referred to as the biopsychosocial approach (see Shakespeare *et al.* 2016), has dominated contemporary studies concerning loneliness and disability. This conceptualises the relationship between disability and social isolation from an individualised perspective, which subsequently pathologises disability in order to explain the experience of loneliness. This relationship is explained by either: the experience of loneliness causing health issues which can progress into a long term disability; or the experience of disability disrupting social participation and exacerbating the occurrence of loneliness and isolation. An example of this can be seen in a study by Paul *et al.* (2006) investigating the impact of disability on experiences of loneliness and mental distress in old age (N = 999). Developing a biopsychosocial approach they suggested that 'illness and disability may limit social interaction and foster the feeling of loneliness, which seems particularly likely during old age' (Paul *et al.* 2006: 224). From their perspective, physical impairment, mental distress and loneliness are all interlinked, hence loneliness occurs because of changes in a person's pathology due to the aging process.

A similar study (N = 664) conducted in the USA reported a significant relationship between loneliness and physical impairment (Rokach *et al.* 2006). Similarly, this study adopted a biopsychosocial perspective and examined how physical impairment restricted social participation. They discovered that participants with a physical impairment scored significantly higher with reference to 'emotional distress, social inadequacy, and self-alienation' (Rokach *et al.* 2006: 691). As Rokach *et al.* (2006) state:

'emotions as shock, denial, depressive reaction, reaction against dependency and dealing with the devastating loss of one's ability to independently navigate through life's trials and tribulations, seems to support the perception that the loneliness that accompanies such a dramatic experience such as chronic physical disability is not perceived in positive terms' (Rokach *et al.* 2006: 694).

Rokach *et al.* (2006) concluded that disabled people's negative self-perception of their physical characteristics naturally led to individuals engaging in 'self-alienation'. From this perspective, physical impairment has a significant impact on the emotional and psychological abilities of an individual, which renders them at risk of emotional loneliness and social isolation.

From within disability studies, the concepts of loneliness and social isolation have been somewhat under-investigated, but for studies that have discussed the concept of loneliness, the phenomenon has been explained due to structural inequalities. In the classic work by Mike Oliver (1996) he illustrates the relationship between personal problems and structural exclusion. From Oliver's perspective, communication problems, limited community interactions, unemployment and community isolation are not due to pathological factors but because of structural alienation. With reference to studies exploring links between disability and isolation, these have predominantly focused on people with intellectual impairments, although alternative studies have also focused on isolation and deafness (see Taylor 1999). With reference to people with learning impairments, Chappell (1994) investigated how the quality of social relationships impacted on the quality of life for disabled people. She discovered that relationships between disabled people were often discouraged and stigmatised in professional

practice. She further suggests that due to the normalisation movement people with learning impairments were encouraged to develop relationships with their nondisabled peers rather than with other disabled individuals.

Although many people with learning impairments attended day centres, Chappell (1994) suggests that the relationships that were formed in these institutional environments were not encouraged outside in the community. She proposes that due to the stigmatisation of disability, disabled people that associated with other disabled people are heralded as examples of failures of community integration. However, she also illustrates the importance of these relationships both politically and emotionally. She submits that many of her participants found it extremely difficult to create relationships with their nondisabled peers within their communities, which resulted in loneliness and social isolation. This was not because of an impairment effect which disrupted interaction, but due to her participants' lack of access to income and very little control over their personal lives in order to develop their own social networks. Chappell (1994) further suggests that loneliness and isolation result from the structural exclusion of people with learning impairments, rather than their inability to develop relationships of mutual affection.

Although Chappell illustrates how structural factors can directly impact on experiences of social isolation, other studies discovered that disabled people are generally at increased risk of loneliness even when living in shared accommodation. Forrester-Jones *et al.* (2002) examined the experience of people with learning impairments and mental health issues living in the community (N = 298). Participants in their study had lived through the deinstitutionalisation of care, where service users were initially housed

within a hospital environment and were subsequently rehoused in the community. Yet they revealed that for many service users deinstitutionalisation entailed living in a residential care setting. They reported that loneliness was a key problem experienced by service users and that deinstitutionalisation has had both a positive and negative impact on service users' lives. Furthermore, many service users discussed experiences of bullying or living with people who they found difficult. A significant number of participants reported that they struggled to develop any personal relationships within these care settings. This study illustrated that many participants had very little choice over their living arrangements within this shared accommodation. Because of this, although service users were housed with other people with similar impairments, many reported experiencing loneliness in their day-to-day lives.

In a more recent article by Merry Cross (2013) she notes that changes in social policy have directly resulted in social isolation. She highlights the impact that the removal of Disability Living Allowance (DLA) has had on people with a range of impairments within the UK and notes that DLA was introduced to offset the extra cost of living with a disability. She suggests that the replacement of DLA with Personal Independent Payments has significantly disadvantaged and alienated disabled people within England. For her, the removal of DLA, and in light of current austerity measures, has disproportionately affected disabled people. She also reports that the change from DLA to PIP will save the government around £2.2 billion, but this saving has forced many disabled people into poverty and social isolation; and further, that the removal of support networks has increased the likelihood of people becoming long-term unemployed and dependent on others. From her perspective this policy change is a direct attack on disabled people's welfare resulting in an increased experience of social isolation.

As stated, the intention of this article is to apply a barrier-based approach within the research. Therefore, the aim of this quantitative article is not just to determine if disabled people experience higher levels of loneliness and isolation compared with the nondisabled population, but also to interpret these experiences from a structural perspective. This paper aims to: (a) discover if disabled people are more likely to experience social isolation and loneliness than nondisabled people; (b) understand how this affects individuals with different impairment types; and (c) interpret key risk factors which lead people into pathways of social isolation and emotional loneliness from a disabling barrier-based perspective.

Methodology

This article presents findings from a study examining the impact of loneliness and isolation on communities within the City of Sunderland. The project employed a mixed method approach (Hesse-Biber and Johnson 2015) incorporating quantitative data collection (De Vaus 2014) in conjunction with a biographical research methodology (Wengraf 2001). This article focuses exclusively on the quantitative findings which indicated that disabled people experienced elevated levels of loneliness and isolation compared with other social variables such as age, sex, ethnicity and sexuality (De Vaus 2014). This study was funded by Sunderland City Council in order to try to comprehend pathways into loneliness/isolation, and was conducted to improve and to develop effective services within the district. Although this study was predominantly quantitative, it was decided that the team would develop a methodology that would not only incorporate the voices of service users within the qualitative stage, but also include their voices within the quantitative design stage.

In order to achieve this we developed a Community Research Group within the local area. Establishing a Community Research Group was accomplished in partnership with a senior public health professional from Sunderland City Council. Hence, the local authority advertised for volunteers from within the community and from within health and social care practice to join the university team. All volunteers had to agree to commit their time to engage with research training and become active researchers for the project, and all volunteers would receive 10 university credits for completing the research training. Initially we had 20 volunteers, but this decreased to 10 once individuals understood the level of commitment required. From the 10 volunteers, four were practitioners working in health promotion or social care, and six were lay volunteers from a range of socio-economic backgrounds and ethnic-minority groups, and from the disabled community. Within the team, four individuals identified themselves as being disabled, including the Principal Investigator. The team consisted of individuals with physical, sensory and specific learning impairments, as well as one person who identified as having a significant mental health issue. All volunteers were trained in research methods designed to equip volunteers with the relevant ethical/theoretical, qualitative and quantitative skills (Wengraf 2001; De Vaus 2014; Hesse-Biber and Johnson 2015) in order to conduct a relatively large-scale study within the city. Therefore, the Community Research Team successfully utilised a range of expertise from a range of backgrounds including service users, practitioners (voluntary and statutory sectors) and academics¹.

¹ In order to develop an inclusive research team all community volunteers are to be named on all future publications.

The research project was conducted over a one-year period from September 2016 to September 2017. In total, 680 participants took part in the research. Anyone living in the city was invited to take part in the study whether they identified as experiencing loneliness and/or isolation or not. In total, 240 participants self-identified as either experiencing loneliness, isolation or both, which was 35.3% of the sampled population. This allowed us to make comparisons between the participants who identified as lonely/isolated and the participants who did not (N = 440). Furthermore, with reference to disability, 36.7%² of participants (N = 250) identified as having an impairment. The aim of this study was to examine statistical trends between these two groups, and further explore these trends with qualitative interviews.

Before the research was conducted a systematic search strategy was devised to direct a review of current literature to comprehend 'loneliness' and 'isolation'. This included both qualitative and quantitative literature starting from the UK and then moving to international research; as UK research was primary focused on age-related loneliness and isolation whereas international research studies took a broader focus including participants from multiple age groups. Relevant articles were then thematically analysed where methodology and findings were compared. Once the analysis of the data was completed and disability emerged as our dominant theme, a further literature review was conducted within Disability Studies looking at any article which referred to loneliness and isolation as a secondary factor.

² It should be noted that the 36.7% result is calculated on the total sample size of 680 participants. This includes missing data of 75 participants who did not state if they had an impairment or not. The later population sample of disability that refers to 41.3% (see table 1) excludes any missing data and is calculated on a population sample of 605 participants. It is this population sample that has been used in the data analysis.

The team used SPSS in order to analyse the results in the means of descriptive statistics. Only statistically significant data ($p \leq 0.05$) was used in the research findings. Data was analysed by engaging in univariate, bivariate and multivariate analysis (De Vaus 2014). The data was predominantly coded at nominal and ordinal level. Due to this, the team analysed the data using frequency tables at univariate level, and cross-tabulations at bivariate and multivariate level, in order to produce statistically relevant information (De Vaus 2014). At the bivariate and multivariate level, frequency distributions were analysed using a chi-square statistic (χ^2). Data was considered significant if it fell below the 0.05 statistically significant threshold (De Vaus 2014). Within this paper disability was used as the independent variable in order to discover if disability impacted on the experiences of emotional loneliness and social isolation. The authors applied a critical realist interpretive approach within the data analysis (Shakespeare 2015), and the team also used the standard social model definition of 'disability' referring to structural barriers, and 'impairment' as a biological/neurological variation, to conceptualise disability (Oliver 2009). This is the first paper which will present the quantitative data results and will be shortly followed by an article describing the qualitative findings.

Social demographics

At the multivariate stage of analysis the team discovered that there were no significant (complex and statistically inter-relating) relationships between disability, age, gender, sexuality and ethnicity with reference to loneliness and isolation ($p > 0.05$). The project attempted to collect data on a wide range of social demographics to examine social loneliness and emotional isolation within the area. As we can see from Table 1, our sample consisted of a relatively equal age range. The younger category represented participants aged between 17 to 44 years, which consisted of 28.7% of the sample. The

older category of 60 years plus consisted of 33.8% of the sample. The largest category, at 37.5%, consisted of the middle-aged group who were aged between 45 and 59 years. Unfortunately, the study did have a gender bias, as the majority of participants who completed the study were female at 69.4% compared with male at 30.6%. With reference to sexuality, the vast majority of the group at 92.7% identified as straight compared with LGBT at 7.4%. This is consistent with the reported demographics of Sunderland, where 6% of the population come from a sexual minority background (ONS 2010). Furthermore, the vast majority of participants (97.8%) identified as from a white ethnic group, with only 2.2% reporting they were from an ethnic minority background. Again this is consistent with the ethnic demographics of Sunderland, which has a relatively small ethnic minority population at 4.4% (ONS 2009). However, this study recorded a relatively high population of disabled people at 41.3% compared with the nondisabled population of 57.7%. Data on Sunderland demographics report 20.6% of the population either have a physical or learning impairment (ONS 2012). Therefore this may give some indication, in our survey, that the disabled population is over represented compared to the disabled population in the City of Sunderland. With reference to loneliness and isolation, in total 35.3% reported experiencing emotional loneliness and social isolation within the sample. Again this is relatively consistent with previous contemporary studies investigating both loneliness and social isolation, which ranged from 33% to 46% (Bowling 2005; 2009; Dahlberg and McKee 2013; Luhmann and Hawkey 2016; Tanskanen and Anttila 2016; Victor and Bowling 2012).

Social demographics		%	N
Sex	Male	30.6%	205
	Female	69.4%	466
	Total	100.0%	671
Age	17–29	10.1%	66
	30–44	18.6%	121
	45–59	37.5%	244
	60–74	26.4%	172
	75+	7.4%	48
	Total	100.0%	651
Sexuality	Straight/heterosexual	92.7%	613
	LGBT	7.3%	48
	Total	100.0%	661
Ethnic groups	White	97.8%	655
	Mixed	0.2%	1
	Asian	1.0%	7
	Black	1.0%	7
	Total	100.0%	670
Disability	Yes	41.3%	250
	No	58.7%	355
	Total	100%	605
Lonely or isolated	No	64.7%	440
	Yes	35.3%	240
	Total	100%	680

Table 1: Social demographics

Findings: Disability, impairment and emotional loneliness

In order to assess if a correlation exists between disability and loneliness, the study compared participants with and without a range of impairments who had experienced emotional loneliness and social isolation. With reference to emotional loneliness, the data revealed that disabled people were significantly ($p = 0.00$) more likely to experience feelings of loneliness compared to their nondisabled peers. As we can see from Table 2, 51.6% of disabled people reported feelings of loneliness. This is compared to only 15.5% of the nondisabled population, indicating a 36.1% variation between the two groups. When comparing this with previous research, this indicates a far higher proportion of the disabled population experiencing loneliness compared to the findings of other studies (Bowling 2005; Rokach *et al.* 2006; Paul *et al.* 2006; Tanskanen and Anttila 2016; Victor and Bowling 2012). The disability category was subsequently organised into impairment

types which included physical, sensory, learning and specific learning impairments, as well as mental health and dementia.

This analysis examined if there was any variation between disability and impairment types within the data findings. When observing if there were any significant differences between impairment types ($p = 0.00$), people with physical and sensory impairments were comparable in their experience of emotional loneliness at 50.8% and 48.6% (see Table 2). Individuals with mental health issues reported a slightly higher experience of emotional loneliness compared with the previous two impairment types, at 63.1%. The groups that reported the highest level of feelings of emotional loneliness were individuals with some form of learning impairment. When examining this data, 73.1% of participants with an intellectual impairment reported feelings of loneliness. This is comparable with participants with a specific learning impairment at 73.7%. It should be noted that no significant relationship was discovered between emotional loneliness and dementia in the data analysis ($p = 0.25$). This data indicates that although disabled people report far higher feelings of emotional loneliness compared with the rest of the population, it is participants with a learning impairment who are most at risk of emotional loneliness.

Disability or mental health condition			Yes	No	Sig.
Are you lonely?	Yes	N = %	129 51.6%	55 15.5%	p ≤ 0.00
	No	N = %	121 48.4%	300 84.5%	
Physical impairment			Yes	No	Sig.
Are you lonely?	Yes	N = %	60 50.8%	138 24.6%	p ≤ 0.00
	No	N = %	58 49.2%	424 75.4%	
Sensory impairment			Yes	No	Sig.
Are you lonely?	Yes	N = %	17 48.6%	181 28.1%	p ≤ 0.00
	No	N = %	18 51.4%	464 71.9%	
Learning disability			Yes	No	Sig.
Are you lonely?	Yes	N = %	19 73.1%	179 27.4%	p ≤ 0.00
	No	N = %	7 26.9%	475 72.6%	
Specific learning difficulty (i.e. dyslexia, ADHD, AS, dyspraxia, etc.)			Yes	No	Sig.
Are you lonely?	Yes	N = %	14 73.7%	184 27.8%	p ≤ 0.00
	No	N = %	5 26.3%	477 72.2%	
Mental health issues/illness			Yes	No	Sig.
Are you lonely?	Yes	N = %	94 63.1%	104 19.6%	p ≤ 0.00
	No	N = %	55 36.9%	427 80.4%	

Table 2: Disability and emotional loneliness

Disability, impairment and social isolation

When analysing the experiences of social isolation, the data revealed that there were significant variations ($p = 0.00$) between the disabled and nondisabled groups, as well as significant variations between impairment types ($p \leq 0.01$). As indicated in Table 3, 26.4% of disabled people reported that they experienced social isolation, which is compared with only 8.5% of the nondisabled group. Again, this reveals a 17.9% variation between the disabled and nondisabled groups. Similar to emotional loneliness, the data reveals that disabled people are at increased likelihood of experiencing social isolation compared with the nondisabled group. Previous studies suggest social loneliness affects about 7–10% of the population (Bowling 2005; 2009; Victor and Bowling 2012; Dahlberg and McKee 2013; Luhmann and Hawkey 2016; Tanskanen and Anttila 2016). This

indicates that the disabled population experience an increased effect of social isolation compared with the findings of other studies examining this phenomenon.

When comparing the variations between impairment types and social isolation, participants with either a physical impairment, at 25.4%, or a mental health issue, at 25.5%, were least likely to experience isolation within the disability group. It should be noted that there was no significant relationship between social isolation and sensory impairments within the data analysis ($p = 0.68$). The next elevated group were participants with dementia, at 50% of the population, although it should be noted that there were only six participants who had this impairment within the study. In concurrence with feelings of emotional loneliness, it was participants with some form of learning impairment who were at an increased likelihood of experiencing social isolation. As can be observed in the data analysis, 53.8% of participants with an intellectual impairment, and a further 63.2% with a specific learning impairment, reported experiencing social isolation. This data reveals that not only is there a significant difference between the disabled and nondisabled populations with regard to social isolation, but there is also a variation between impairment types in this study.

Disability or mental health condition			Yes	No	Sig.
Do you consider yourself isolated?	Yes	N = %	66 26.4%	30 8.5%	p ≤ 0.00
	No	N = %	184 73.6%	325 91.5%	
Physical impairment			Yes	No	Sig.
Do you consider yourself isolated?	Yes	N = %	30 25.4%	72 12.8%	p ≤ 0.00
	No	N = %	88 74.6%	490 87.2%	
Learning disability			Yes	No	Sig.
Do you consider yourself isolated?	Yes	N = %	14 53.8%	88 13.5%	p ≤ 0.00
	No	N = %	12 46.2%	566 86.5%	
Specific learning difficulty (i.e. dyslexia, ADHD, AS, dyspraxia, etc.)			Yes	No	Sig.
Do you consider yourself isolated?	Yes	N = %	12 63.2%	90 13.6%	p ≤ 0.00
	No	N = %	7 36.8%	571 86.4%	
Mental health issues/illness			Yes	No	Sig.
Do you consider yourself isolated?	Yes	N = %	38 25.5%	64 12.1%	p ≤ 0.00
	No	N = %	111 74.5%	467 87.9%	
Dementia and Alzheimer's			Yes	No	Sig.
Do you consider yourself isolated?	Isolated	N = %	3 50.0%	99 14.7%	p ≤ 0.01
	No	N = %	3 50.0%	575 85.3%	

Table 3: Disability and social isolation

Key risk factors into loneliness and isolation

Within previous research, the importance of maintaining social networks within communities and the subjective experience of the quality of a person's relationships with others, e.g. family, friends and work colleagues, are regarded as crucial in preventing loneliness and isolation (see Victor and Bowling 2012; Dahlberg and McKee 2013; Tanskanen and Anttila 2016). Thus, in order to understand pathways into loneliness and isolation this study examined differences in participants' living arrangements and issues of employment and unemployment for disabled people (Luhmann and Hawkey 2016). These factors were examined alongside how regularly participants had contact with family and friends, how much time participants spent alone, and if they would like to engage in more activities within their communities (Victor and Bowling 2012). When

examining these risk factors, unemployment status and cohabiting issues became significant factors in the data analysis ($p = 0.00$). As we can see in Table 4 there is a considerable difference in employment and unemployment levels between the two groups.

When analysing employment status, 32.2% of disabled participants were in either full-time or part-time employment. When comparing this with the nondisabled group, 59.6% were in either full-time or part-time employment. This represents a 27.4% difference in employment status between the two groups. This cannot be explained due to age or that the disabled group were more likely to be retired – as we can see from Table 4, retirement was consistent between both groups, and the disabled group were slightly less likely to be retired, at 27.3% compared with the nondisabled group at 31.1%. The biggest difference between groups relates to unemployment levels, as 38.8% of the disabled group reported being unemployed compared with only 6.2% of the nondisabled group. This data reveals a considerable difference in unemployment levels of 27.6% between the disabled and nondisabled groups. These findings may reveal that high unemployment levels could have an extensive impact on disabled participants' professional networks and access to new friendships.

When examining living arrangements, again a number of significant relationships became apparent in the data ($p = 0.00$). As can be observed in Table 4, the disabled group were less likely to be either married or cohabiting with a partner, at 41.7% compared with nondisabled participants at 65.2%. Similarly, the disabled group were more likely to experience divorce or separation from their partners. As we can see from Table 4, 16.6% of the disabled group had experienced divorce/separation compared with 11.8% of

nondisabled participants. Interestingly, the largest difference appeared in relation to participants who were single and had never been married or in a cohabiting relationship with a partner – 27.5% of the disabled group compared to only 12.6% of the nondisabled group. When contrasting this with how much time participants spent on their own, the study discovered a significant difference between the disabled and nondisabled groups ($p = 0.00$). The data revealed that disabled participants were far more likely, at 60.5%, to spend time alone compared with the nondisabled group, at 28%. This reveals a 32.5% difference between the disabled and nondisabled groups with reference to a lack of personal contact with others.

To explore this further, the research examined if disabled participants were less likely to have regular contact with family members or friends compared with the nondisabled group. As we can see in Table 4, disabled participants were less likely to have daily contact with family and friends, at 44.3% compared with 63.2% of the nondisabled group. With reference to having weekly contact with family and friends both the disabled and nondisabled groups reported relatively equal contact, at 34.9% and 31.6% respectively. However, it was the disabled group that were most likely to have diminished contact with family and friends, as 14.9% had monthly contact, 1.3% had yearly contact and 4.7% reported no contact at all. This is compared with the nondisabled group where 4.7% had monthly contact and 0.6% reported never having contact with family and friends. Not a single participant in the nondisabled group reported having yearly contact with family and friends. To summarise, 20.9% of disabled participants reported the maximum of monthly contact with family/friends compared with 5.3% of the nondisabled group. This indicates a difference of 15.6% between the disabled and nondisabled groups, and may

reveal evidence of poor social networks and weak personal relationships for disabled participants.

Finally, the research explored if participants desired the ability to access extra activities away from their homes. Again a significant relationship appeared between the disabled and nondisabled groups ($p = 0.00$). The data analysis revealed that disabled participants were more likely to want access to increased social activities, at 70.8% compared to their nondisabled peers at 46.1%. Thus, not only did disabled people have less regular contact with family and friends and were more likely to spend most of their spare time alone, they also wanted more opportunities to access activities outside their homes. This data seems to suggest that the majority of disabled participants were not opting for social isolation but that this was due to a lack of social networks and access to activities within their communities.

Disability or mental health condition			Yes	No	Sig.
Employment status	Employed, full-time	N = 45 % = 18.1%	45	152	p ≤ 0.00
	Employed, part-time	N = 35 % = 14.1%	35	59	
	Self-employed	N = 3 % = 1.2%	3	6	
	Unemployed	N = 84 % = 33.8%	84	22	
	Retired	N = 68 % = 27.3%	68	110	
	Student	N = 14 % = 5.6%	14	5	
Disability or mental health condition			Yes	No	Sig.
Relationships	Married/Cohabiting	N = 103 % = 41.7%	103	227	p ≤ 0.00
	Divorced/Separated	N = 41 % = 16.6%	41	41	
	Single, never married	N = 68 % = 27.5%	68	44	
	Widowed	N = 35 % = 14.2%	35	36	
Disability or mental health condition			Yes	No	Sig.
Do you spend most of your spare time alone?	Yes	N = 144 % = 60.5%	144	96	p ≤ 0.00
	No	N = 94 % = 39.5%	94	247	
Disability or mental health condition			Yes	No	Sig.
How regularly do you have contact with family and/or friends?	Daily	N = 104 % = 44.3%	104	216	p ≤ 0.00
	Weekly	N = 82 % = 34.9%	82	108	
	Monthly	N = 35 % = 14.9%	35	16	
	Yearly	N = 3 % = 1.3%	3	0	
	Never	N = 11 % = 4.7%	11	2	
Disability or mental health condition			Yes	No	Sig.
Would you like to do more activities away from the home?	Yes	N = 165 % = 70.8%	165	154	p ≤ 0.00
	No	N = 68 % = 29.2%	68	180	

Table 4: Risk factors into loneliness and isolation

Disabling barriers and pathways into emotional loneliness and social isolation

As discussed within the literature, links between disability and loneliness have been explained from a biomedical perspective, where a person's pathology restricts social participation, resulting in experiences of emotional loneliness and social isolation (Rokach *et al.* 2006; Paul *et al.* 2006). As this study applies a structural approach to disability, the data examined key disabling barriers which impact on disabled people's daily lives (Chappell 1994; Taylor 1999; Oliver 2009; Forrester-Jones *et al.* 2002). Within

the data findings, 87.2% of the disabled group suggested that disability had a significant impact on their daily lives ($p = 0.00$); when examining this disabled group, 64.2% of these participants had experienced loneliness and isolation (see Table 5). When examining the impact that environmental factors have on restricting social participation, 53.2% of disabled participants reported difficulties leaving their homes; correspondingly 74.4% of this group experienced loneliness and isolation. When reporting on problems due to communication barriers, only 32.8% of disabled people reported experiencing communication difficulties. Yet 75.6% of this group consisted of disabled participants who had experienced social isolation and loneliness. With reference to problems interacting with others, again only 36% of the group reported difficulties in this particular area. Yet 76.7% were from the socially isolated and emotionally lonely disabled group.

With reference to problems gaining employment only 20.8% reported difficulties in this area due to disabling factors. Yet 86.5% of disabled participants who had experienced loneliness and isolation reported barriers to employment. With reference to accessing leisure activities, 45.2% of the disabled group reported difficulties in this area. Out of this group 70.8% of disabled people had experienced loneliness and isolation. Unsurprisingly, 56.8% of disabled participants reported problems with their confidence and self-esteem. Again it was disabled participants at 71.1% that experienced loneliness and isolation who reported the greatest problems with low self-esteem and confidence. As the data reveals, the majority of disabled people reported experiences of barriers to a certain degree. Yet it was the disabled group that had experienced loneliness and isolation who seem most affected by barriers in this study. These findings seem to suggest that although there are key risk factors which lead to pathways into loneliness and isolation, for disabled people

these are amplified by the experiences of environmental and structural barriers which restrict social participation resulting in emotional loneliness and social isolation.

Do you consider yourself lonely or isolated?			No	Yes	Total disabled population	Sig.
Impact on your daily activities	Yes	N = %	78 35.8%	140 64.2%	218 87.2%	p ≤ 0.00
	No	N = %	22 68.8%	10 31.3%	32 12.8%	
Do you consider yourself lonely or isolated?						
Getting out and about	Yes	N = %	34 25.6%	99 74.4%	133 53.2%	p ≤ 0.00
	No	N = %	66 56.4%	51 43.6%	117 46.8%	
Do you consider yourself lonely or isolated?						
Communication with others	Yes	N = %	20 24.4%	62 75.6%	82 32.8%	p ≤ 0.00
	No	N = %	80 47.6%	88 52.4%	168 67.2%	
Do you consider yourself lonely or isolated?						
Interacting with others	Yes	N = %	21 23.3%	69 76.7%	90 36.0%	p ≤ 0.00
	No	N = %	79 49.4%	81 50.6%	160 64.0%	
Do you consider yourself lonely or isolated?						
Confidence/Self-esteem	Yes	N = %	41 28.9%	101 71.1%	142 56.8%	p ≤ 0.00
	No	N = %	59 54.6%	49 45.4%	108 43.2%	
Do you consider yourself lonely or isolated?						
Gaining employment	Yes	N = %	7 13.5%	45 86.5%	52 20.8%	p ≤ 0.00
	No	N = %	93 47.0%	105 53.0%	198 79.2%	
Do you consider yourself lonely or isolated?						
Engaging with leisure activities	Yes	N = %	33 29.2%	80 70.8%	113 45.2%	p ≤ 0.00
	No	N = %	67 48.9%	70 51.1%	137 54.8%	

Table 5: Disabling barriers, loneliness and isolation

Discussion and Conclusion

This article has explored the relationship between disability, impairment, social isolation and emotional loneliness. Previous research has suggested that 7–10% of the UK

population have experienced social isolation, and an additional 32–42% have reported regular feelings of loneliness (Victor and Bowling 2012; Dahlberg and McKee 2013). Comparable to Victor and Bowling's (2012) research, 9% of nondisabled participants in this study described experiencing social isolation. An additional 15.5% of nondisabled participants reported experiencing emotional loneliness, similar to Heikkinen and Kauppinen's (2011) research. The experience of social isolation and emotional loneliness increased significantly when analysing data on disability. This data revealed that 26.4% of the disabled population described being subjected to social isolation, and a staggering 52% experienced feelings of emotional loneliness. When the team examined social isolation with reference to impairment types, it was participants with a learning impairment that were most likely to experience social isolation, at 54–63%. Once more, when comparing impairment with the experiences of emotional loneliness, it was participants with a learning impairment who reported the highest feelings of loneliness, at 73–4%. This data illustrates that the disabled population, and in particular those with learning impairments, are at considerable risk of experiencing social isolation and feelings of emotional loneliness when contrasted with the nondisabled population.

In previous research a number of risk factors have been identified that can result in a person experiencing loneliness and isolation (Bowling 2005; Paul *et al.* 2006; Victor and Bowling 2012; Tanskanen and Anttila 2016). When examining these risk factors it was the disabled group that were most affected in this study. Hence, disabled participants acknowledged that they spend most of their time alone, at 61% compared with 28% of the nondisabled group. The data also revealed that 28% of disabled people were single and had never cohabited with a partner, compared with only 13% of the nondisabled group. Twenty one per cent of the disabled group reported having very limited contact

with family and friends, compared with only 5% of the nondisabled group. Furthermore, 34% of disabled people were unemployed, compared with only 6% of nondisabled participants. However, when exploring whether the disabled group wanted more contact with their communities, 71% agreed that they would like more contact, compared to 46% of the nondisabled group. These figures indicate that for disabled people, although they desire increased contact outside their homes, in reality they spend more time on their own and have fewer visitors than their nondisabled peers.

Rather than explaining these risk factors from a pathological perspective, the authors have attempted to conceptualise these pathways into loneliness and isolation, not due to the physiological nature of impairment, but because of structural barriers which impact on social participation (Chappell 1994; Taylor 1999; Oliver 2009). Thus, this study illustrates that 64% of disabled participants who experienced loneliness and isolation described disabling barriers affecting their daily actions. A further 74% of disabled people who experienced loneliness and isolation experienced environmental barriers within their communities. Furthermore, 70% of disabled participants who experienced loneliness and isolation reported that disabling barriers impacted on them accessing leisure activities outside the home. Although the majority of the disabled group reported not experiencing communication barriers, for participants that did 76–7% had experienced loneliness and isolation. Finally, unsurprisingly, 57% of the disabled population reported having self-esteem and confidence issues, with 71% of this group experiencing loneliness and isolation.

Based on these findings, the authors suggest that rather than conceptualising loneliness and isolation as inevitable results of having an impairment, it is more beneficial to

examine the structural barriers which lead disabled people into being overrepresented in this population. By exploring the disabling factors that lead to emotional loneliness and social isolation we may help to emancipate many disabled people who are prisoners in their own homes due to inadequate housing (Chappell 1994), poor social services (Forrester-Jones *et al.* 2002), rising unemployment (Oliver 2009) or discriminatory welfare policies (Cross 2013). Therefore, this study implies that a greater focus on disabling barriers is needed in order to conceptualise pathways into loneliness and isolation (Chappell 1994; Cross 2013).

Reference Page

Bowling, A. (2005). *Ageing well: quality of life in old age*. Maidenhead, UK: Open University Press.

Chappell, A. L. (1994) A Question of Friendship: Community Care and the Relationships of People with Learning Difficulties. 9 (4). pp. 319-34.

Cross, M. (2013) Demonised, impoverished and now forced into isolation: the fate of disabled people under austerity. *Disability & Society*, 28 (5). pp. 719-723

Dahlberg, L. & McKee, K. J. (2014) Correlates of social and emotional loneliness in older people: evidence from an English community study *Aging & Mental Health*. 18 (4), pp. 504-514.

De Vaus, D. A. (2014) *Surveys in social research (6th Ed)*, London: Routledge.

Forrester-Jones, R. Carpenter, J. Cambridge, P. Tate, A. Hallam, A. Knapp, M. & Beecham, J. (2002) The Quality of Life of People 12 Years after Resettlement from Long Stay Hospitals: Users' views on their living environment, daily activities and future aspirations. *Disability & Society*. 17 (7), pp. 741-758.

Garthwaite, K. Smith, K. E., Bambra, C. and Pearce, J. (2016) Desperately seeking reductions in health inequalities: perspectives of UK researchers on past, present and future directions in health inequalities research. *Sociology of Health & Illness*. 38 (3), pp. 459–478.

Heinrich, L. M., & Gullone, E. (2006) The clinical significance of loneliness: A literature review. *26* (6), pp. 695-718

Hesse-Biber, S. N., & Johnson, R. B., (2015) *The Oxford Handbook of Multimethod and Mixed Methods Research Inquiry*. Oxford University Press: Oxford.

Luhmann M., & Hawkley L. C. (2016) Age differences in loneliness from late adolescence to oldest old age. *Developmental Psychology* 52(6): 943-59

Maes, M., Klimstra, T., Van den Noortgate, W., & Goossens, L. (2015) Factor Structure and Measurement Invariance of a Multidimensional Loneliness Scale: Comparisons Across Gender and Age. *Journal of Child and Family Studies* 24:pp. 1829–1837

Oliver, M. (1996). *Understanding Disability from Theory to Practice*. Basingstoke: Palgrave

Paul, C., Ayis, S. & Ebrahim, S. (2006) Psychological distress, loneliness and disability in old age. *Psychology, Health & Medicine*. 11 (2) pp. 221-232

Rokach, A. Lechcier-Kimel, R., & Safarov, A. (2006). Loneliness of people with physical disabilities. *Social Behavior and Personality: An international journal*, 34, pp. 681-700.

Shakespeare, T (2015) *Disability Research Today*. Routledge: London.

Shakespeare, T, Watson, N and Abu Alghaib, O (2016) Blaming the victim, all over again: Waddell and Aylward's biopsychosocial (BPS) model of disability. *Critical Social Policy*, 36 (4): 1–20.

Sheldon, J. H. (1948). *The social medicine of old age*. London: Oxford University Press.

Tanskanen, J., and Anttila, T. (2016) A Prospective Study of Social Isolation, Loneliness, and Mortality in Finland. *American Journal of Public Health*. 106 (11), pp. 2042-2048

Taylor, G. (1999) Empowerment, Identity and Participatory Research: Using social action research to challenge isolation for deaf and hard of hearing people from minority ethnic communities. *Disability & Society*, 14 (3). pp. 369-384

Townsend, P. (1959). Social surveys of old age in Great Britain, 1945–58. *Bulletin of the World Health Organization*, 21, 583–591.

Valtorta, N. K., Kanaan, M., Gilbody, S. Hanratty, B.(2016) P39 Changes in loneliness and social isolation over time in adults aged over 50: the English Longitudinal Study of Ageing. *Journal of Epidemiology Community Health* 70;pp. 70.

Victor, C. R. & Bowling, A. (2012) A Longitudinal Analysis of Loneliness Among Older People in Great Britain. *The Journal of Psychology*: 146(3), pp. 313–331

Victor, C. R. & Burholt, V & Martin, W. (2012) Loneliness and Ethnic Minority Elders in Great Britain: An Exploratory Study. *Journal of Cross-Cultural Gerontology*: 27, pp. 65–78

Wengraf, T. (2001) Qualitative Research Interviewing, Biographic Narrative and Semi Structured Methods, Sage Publications: London

Zhang, B.,Gao, Q., Fokkema, M., Alterman, V., Liu, Q. (2015) Adolescent interpersonal relationships, social support and loneliness in high schools: Mediation effect and gender differences. *Social Science Research*. 53, 104–117