# Exploring Loneliness and Isolation in Blackburn with Darwen
## October 2017

**Report Author**
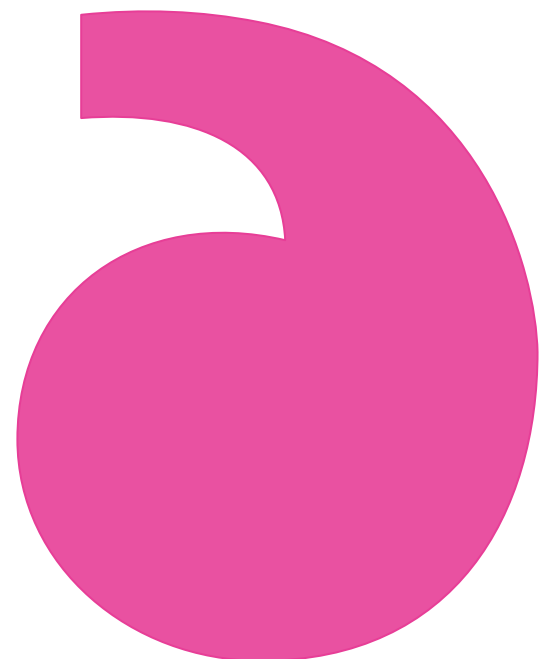**Nancy Kinyanjui, Healthwatch Blackburn with Darwen**

## About Healthwatch Blackburn with Darwen

Healthwatch gives people a powerful voice locally and nationally. At a local level, Healthwatch BwD helps local people get the best out of their local health and social care services. Whether it's improving them today, or helping to shape them for tomorrow, Healthwatch BwD is all about local voices being able to influence the delivery and design of local services.

Healthwatch was created by the Health and Social Care Act, 2012.  We are part of a network of local Healthwatch which helps to ensure that the views and feedback from patients and carers are an integral part of the design and delivery of local service.

Every voice counts when it comes to shaping the future of health and social care, and when it comes to improving it for today. Everything that Healthwatch does will bring the voice and influence of local people to the development and delivery of local services.

Find out more at: **www.healthwatchblackburnwithdarwen.co.uk**

## Disclaimer

This report relates views obtained by Healthwatch Blackburn with Darwen volunteers about loneliness and isolation in the borough. It contains findings from 150 individuals who contributed to the project and is therefore not intended to be representative of the experience and views of all Blackburn and Darwen residents.

## Project Limitations

The views of people of South Asian origin, those receiving home care, residing in care homes, supported housing, hostels and halfway houses, unpaid carers as well as persons aged 16-24 and 64+ are underrepresented.

## Scope Limitations

We found that there was reluctance in supporting the project by some services that serve the most vulnerable and at risk in our community: for example; care homes, housing associations, and organisations that shelter and/ or assist individuals in transition after experiencing difficult circumstance. While we understand and accept that it takes a long time, hard work, and dependability for such providers to build a relationship of trust with their clientele, we disagree that this in itself should become a barrier to giving a voice to those most vulnerable and at risk in our communities. Hence we recommend that such service providers adopt the guidelines proposed by the Campaign to End Loneliness in their "toolkit for Health and Wellbeing Boards" (Jopling, 2015; Rawsterne, 2013). That is:

• Cooperate and strengthen partnerships with statutory organisations such as Healthwatch who are tasked with giving people a voice to help tailor local services for local people

• To be proactive in gathering information and keeping records that can be analysed later for keywords to feed into research that helps inform strategy development, without risking client confidentiality or breaking trust

• To regularly and evidently monitor and evaluate their clienteles' level of satisfaction with the service they provide to ensure needs are met and people are signposted effectively if need be

We also recommend that such services are suitably and continually monitored by independent organisations like Healthwatch to ensure that barriers to service provision are identified and clientele's views are listened to when local public health and care services are planned and commissioned.

## Date of Project

Engagement activity took place October 2016 - March 2017

## Acknowledgements

Healthwatch Blackburn with Darwen (BwD) volunteers give a hearty thank you to borough residents who gave us their time, shared their thoughts, concerns, and experiences on the topic of loneliness and isolation.

We extend a warm thank you to Donna Talbot, Julie Walsh, Naomi Wood, Patricia Cooper, Paul Hardman, Sheila Orrell, Stephen Sharp, Tracey Handley, and Wajid Bashir for their support, dedication and tireless contribution to the project.

The following organisations for supporting the project and giving us the

opportunity and space to engage with their clientele:

- Almond Villas
- ARC Project drop-in (Wesley Hall)
- BB1 for Life
- Bipolar UK (Blackburn Support Group)
- Blackburn with Darwen Adult Services
- Carers Network
- Chrysalis Blackburn Trans Group
- Community CVS
- Community Re-Start
- Creative Support (Social Inclusion Service)
- DARE drop-in Darwen
- Darwen Resource Centre
- Lancashire Care

- Moorings Trust
- Shelter
- SHINE Group
- Sliding doors (Blues Cafe Bar)
- The Foyer
- Weatherspoons (Postal Order) Blackburn
- Your Support Your Choice (Relax and Chat group)

The following Healthwatch Blackburn with Darwen Volunteers for planning and executing the project: Adrian Douglas; Adrian Polding; Alwyn Cooper; Angie Allen; Diane Adams; Karl Riding; Nancy Kinyanjui; Richard; Rita Adams; Ronan Keith; Stephen Gallagher

# Contents

## Executive Summary

Healthwatch Blackburn with Darwen has worked in partnership with volunteers to explore loneliness and isolation in the borough.

The engagement took place over a 6-month period between October 2016- March 2017.

The report details the findings which found:

- A need for third sector organisations to work more cooperatively to tailor services for all age groups.

- A negative impact of welfare cuts upon people who rely on benefits and upon how care and support is given in the community.

- A need for health and wellbeing strategies to be implemented to consider the needs of individuals.

- Training and mediation support is needed in community groups for those individuals who have faced stigma due to ill health.

- A lack of links between the local health care service and third sector services.

- A lack of awareness of the services for residents such as access to psychological therapies (IAPT), third sector organisations or community support/ activity groups.

## Introduction

Healthwatch BwD empowered its volunteers with the opportunity to lead on a project of choice. Volunteers voted to explore the views of people who have been identified as vulnerable to or currently experiencing loneliness and/ or isolation. The project name emerged from our questionnaire heading 'Exploring Loneliness and Isolation (ELI).'

## Why Loneliness and Isolation?

Loneliness and isolation were identified as recurring issues in previous Healthwatch BwD community engagement projects and we recognised that these feelings can occur in wide-ranging settings and all life stages. For this reason, we chose to carry out an all-inclusive exploration of the subject so no specific group was targeted.

## Project Aim

To speak to BwD residents about why some individuals experience loneliness and/ or isolation; explore community awareness of services or activity groups in the borough that people use/ can use to limit the effects of loneliness and isolation; discover good practice in existing provision; identify gaps in provision and find out how barriers can be overcome.

## What we mean by loneliness and isolation

BwD residents told us being alone does not equate loneliness as one can feel lonely in a crowd and preferring one's own company does not necessarily mean one prefers isolation. In view of that, we define loneliness as a personal experience linked to negative feelings about the quality of existing relationships combined with a desire for enduring and better ones. On the contrary, isolation refers to feeling cut off with regard to the quantity of meaningful social relationships and connections – short or long term (Grant, 2016; Jopling, 2015; Rawsterne, 2013).

By inference, people decided that loneliness is a personal mental attitude that is more likely to cause intense feelings of isolation that lead to distress whereas isolation is an objective outlook that can be rectified more easily through increased activity or by increasing one's social circle.

## Previous Research

A statistical overview of results from studies looking at the link between mortality and loneliness, social isolation, living alone, ageing, and welfare in technologically advanced countries such as the UK finds that a lack of social connections is damaging to health, puts people at greater risk for premature mortality and raises major issues about the impacts of loneliness in relation to differences in regional and global experiences (Holt-Lunstad, Smith, Baker, Harris, and Stephenson, 2015; Jones, Smith, Gibson, Milward, Cooper, Jones, & Evans, 2016; Snell, 2015). Holt-Lunstad et al. found that of the 70 independent studies they reviewed, most involved older adults (50+) and, only 9% involved people younger than 50 at initial data collection. They recommended that future research should include a broad range of age to better understand prevalence and tailor services (Holt-Lunstad et al., 2015).

On the other hand, ACEVO commissioned a nationwide specialist research carried out by "Get Connected" (a young people's charity) who analysed their records for calls recorded with the keywords 'lonely' or 'isolated'. From a sample of 694, 11% of lonely and isolated

young people were from North West England, which was the second largest number as compared to London. This research found that the biggest group of lonely young people was in the 18-24 age range, ethnic minorities were 50% more likely to be lonely than would be expected, and nearly three quarters of lonely people were women (relative population ratio: 50%). The authors concluded that loneliness among young people "is as much of a problem as loneliness among the elderly, if not more" (ACEVO, 2015).

These findings show that change in modern society (Griffin, 2010; Snell 2015) has caused more people to live far away from family and friends which increases reliance on social technology for interaction rather than face to face. This can cause relationships to feel more artificial or less rewarding and make people feel less connected and therefore lonely and or isolated.

## Risk factors

While loneliness is not the single cause, it is a contributing factor to increasing costs for health and care services in relation to treating mental health conditions like anxiety and depression (Snell 2015) preventing crime and radicalisation linked to poor social cohesion and unemployment linked to poor social connections (ACEVO, 2015; Henderson, 2013; Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015; Jopling, 2015; Rawstern, 2013). Researchers have found that:

• Isolation in adolescence has long term impacts associated with addictive behaviours right through adulthood which increases the risk of young people not being in education, employment or training (NEET) (Neale, Piggott, Hansom, Fagence, 2016)
• Widening national socioeconomic and area-based inequalities can cause people

to feel lonely, socially-excluded, powerless, deprived, and distrustful (Griffin, 2010; Snell, 2015)
• The effect of loneliness and isolation is more damaging than obesity and can be as harmful to health as smoking 15 cigarettes a day (Jopling, 2015)
• Lonely people are at greater risk of experiencing disability or cognitive decline and have a 64 per cent increased chance of developing clinical dementia (Jopling, 2015)

## Statistics

## England

A 2010 UK survey of 2,256 adults carried out by Opinium Research LLP for the Mental Health Foundation suggests that loneliness affects many of us at some stage (Griffin, 2010). The poll found that only 22% of those surveyed never feel lonely, 11% feel lonely often and 10% do not have company when needed. 24% said they worry about feeling lonely and this was more common in the 18-34 age range (36%, compared to 17% of those over 55). Also, 42% felt depressed because they felt alone and this was higher among women (47%, compared to 36% men) and among the 18-34 age group (53%, compared to 32% of those over 55). 37% said they had a close friend or family member they thought was very lonely; again higher among women (41%, compared to 33% men) and those aged 18-34 (45%, compared to 31% of those over 55) (Griffin, 2010).

Similarly, a 2014 BBC Radio 5 live and ComRes survey of 2000 people found that 28% of British adults (almost three in ten) feel lonely at least some of the time, 33% (and 27% of 18-24 year olds) feel left behind by new ways of communicating, and 85% prefer speaking to friends and family face to face. The survey also found that 18-24 year olds are nearly as

likely (30%) to feel lonely as those over 65 (31%) (BBC 2014 cited in Grant 2016).

## Lancashire

We could not find precise polls, current or old, for how many people are identified as vulnerable to or experiencing loneliness and or isolation across all age groups in Lancashire. A Lancashire Public Health Report has suggested that reaching people who could most benefit from actions taken to measure and address loneliness and isolation "is often a huge challenge". As a result, existing activities may not be fully accessible or suited to those who need them most (Jones et al., 2016). A Lancashire County Council's Adult Social Care Survey (cited in Jones et al., 2016) found that "roughly half of both adult social care users and their carers consider themselves as socially isolated". The report by Jones et al. (2016) estimates that at least 35,000 people are chronically socially isolated across Lancashire, especially older adults aged 70+. The authors recognise that general ill-health, reduced confidence, low self-esteem, depression, anxiety, a short attention span, increased forgetfulness and risk of substance or alcohol misuse could indicate that a person feels isolated and is therefore at risk of experiencing loneliness.

Although up-to-date research mostly looks at those aged 50+ and identifies that both isolation and loneliness impair quality of life and well-being (e.g. Jones et al., 2016; Jopling, 2015); those below the age of 50 are heavily underrepresented in polls yet there is significant evidence showing that younger people are as likely to experience loneliness and feel isolated as older people (ACEVO 2015; Griffin, 2010; Murphy, 2010; Neale, Piggott, Hansom, Fagence, 2016). We therefore recommend that a detailed survey is carried out across all age groups and key

risk factors to provide high quality evidence that shows both the rate of loneliness and isolation and the outcome of different actions taken to reduce impact.

As suggested by Jones et al. (2016) we agree that everybody has a role to play in helping plan interventions that shape and improve services to tackle loneliness and social isolation. This can be done through participation in the NHS Five Year Forward View and associated local Sustainability Transformation Programs and also by linking in with New Models of Care, Vanguard sites and Healthy New Towns (Jones et al., 2016).

## Blackburn with Darwen

Available loneliness and isolation polls for BwD are also mostly centred on those aged 50+ (BwD Joint Health & Wellbeing Strategy 2012-2015; Rawsterne, 2013). However, the 2011 census indicates that BwD has a population of 147,000 of whom 91,700 are aged 16-64 (Office of National Statistics, 2017; White, 2013). As of 2011, 29% of BwD residents were aged 0-19 compared with 24% nationally (White, 2013). Of the working-age population, 18% had no qualifications at all, compared with 11% nationally and it was predicted that the proportion of people aged 65+ would increase with the number of very elderly residents (85+) almost doubling. Population in BwD's 23 wards also varies greatly with regards to ethnic origin but overall; 69.2% identify as White, 13.4% as Indian, 12.1% as Pakistani, and 5.2% as Mixed, Other Asian, Bangladeshi, Other, Black or Chinese (Blackburn with Darwen Borough Council, 2013).

Current statistics show that residents in some of Blackburn with Darwen's most deprived wards experience many of the risk factors linked to loneliness and isolation (Blackburn with Darwen Borough Council, 2013; BwD Health & Wellbeing

Board, 2015; Rawsterne, 2013). These important structural shifts in age, regional differences and experiences linked to ethnic background and or socioeconomic status are predicted to create significant additional demand for health and social care services over the coming 20 years (Grant, 2016; Griffin, 2010; Henderson, 2013; Rawsterne, 2013; Snell, 2015; White, 2013). Given these findings, we suggest there is a need to carry out a large scale exploration of loneliness and isolation across all BwD wards, age groups, socioeconomic and ethnic backgrounds to identify those most at risk and inform plans.

## Implications for Blackburn with Darwen (BwD)

According to the BwD Joint Health and Wellbeing Strategy 2012-2015 and 2015-2018, many key risk factors for isolation and loneliness are more common in the borough as compared to the national average. That is living alone, no access to a car, public transport or telephone, living in rented accommodation and on benefits as main income, poverty, etc. We believe that involving BwD residents in this exploration of loneliness and isolation is one way of helping identify good practice and gaps in provision to improve quality of care and community wellbeing.

## Research methods

Information was collected using a self-designed 12 item open ended questionnaire, structured steering (task) groups and semi-structured discussion groups. The steering group was initially intended to involve partners and the general public but it became clear that BwD residents wanted to participate through a social support type of group. For this reason, we decided to hold formal monthly meetings that were only open to partner organisations and

Healthwatch BwD volunteers but also hold more informal biweekly discussion meetings to make sure residents' views were reflected in the planning process. The feedback from our task group and public discussion meetings mirror questionnaire responses so we have placed emergent themes throughout these texts to show the issues that were repeatedly mentioned. Both quantitative and qualitative methods were used to analyse data.

## Overall Partner input

• To help us identify, access, distribute and/ or complete the questionnaire with residents who contact and use their service
• To help us involve their clients who are vulnerable but hard for us to reach
• To help publicise the project to community groups they are in regular contact with

## Task Group meetings

Monthly Project Steering Group meetings were initially held to plan the project and design our publicity materials. Partner organisations were directly involved in sharing their knowledge and experience of engaging with people who may be lonely and/ or isolated but hard for us to reach. Progress was reviewed and approaches adjusted if, where, and when necessary all through the project. Views were agreed with those present and recorded as "meeting minutes" which were later analysed for common themes.

## Feedback

Partner organisations told us that:
• Healthwatch should consider holding discussions and completing questionnaires on this topic with individuals in care homes and supported accommodation

• Services should listen to service users when reviewing themselves and the support they provide
• A dilemma exists for public service providers in relation to giving too much care to people who may not need it and too little to others who clearly need it but are unable to navigate the application process and ask for a care and support needs assessment or communicate their need adequately
• People who are likely to experience loneliness and isolation need choice and encouragement to join existing support groups but this is difficult because data protection laws make it hard to share information that can help identify and target those most at risk for advertising by suitable third sector organisations

## Partner Observations

• Intelligence gathered through Healthwatch community engagement projects is vital and beneficial to both service users and providers; Healthwatch BwD should do more to highlight this benefit to partners as it might lead to greater cooperation
• Organisations who enlist volunteers should do more to publicly acknowledge volunteer contribution (especially in terms of monetary value, volunteer hours, and volunteer case studies in reports and or web-pages) as this may help encourage people with needed experience to volunteer and fill existing gaps in staff shortages

**Informal Chats**
These meetings were used as a means of involving the general public and allowing partner organisations to hear and respond to concerns raised by BwD borough residents. Discussions on subjects related to loneliness and isolation were held in three public venues; that is, Blackburn Weatherspoons (Postal Order), Coffee Exchange Flemming Square Blackburn, and BB1 for Life Café Blackburn. Topics discussed included respect, personal

safety, mental resilience, communication technology, social support/ activity groups, and transport/ travel costs. Key issues and concerns from these discussions were evidenced by meeting minutes and later analysed for the following.

Those who attended discussion sessions told us that they feel:
• All organisations providing support to the public should clearly identify and communicate the area and extent of their responsibility to minimise confusion about who does what and make it easier for the public to get to information
• People living with visible disabilities find it both disrespectful and isolating when they are discussed by service providers with their carer instead of being addressed themselves; the role of support staff should be clearly understood
• How other people see and treat us is important so negative behaviour towards vulnerable members of our community can create fear of being taken advantage of or "told off" and cause a person to lose the interest and or confidence to go out on their own
• Welfare cut backs are affecting the way support workers can care for the most vulnerable and at risk in our community
• Long term carers often find it difficult to adjust to life without caring due to the extra time and previous lack of socialisation; so, there is need for support during this transition period
• Social groups are hard to find due to a lack of correct signposting; a single point of access like Your Support Your Choice (*now called Care Network Hub) or a trustworthy website that holds up-to-date information about local support and activity groups would help (e.g. run by borough councils)
• The time some social activity groups like gateway clubs meet is not ideal in terms of access to transport and personal

safety; council run transport services used to help but they no longer exist
• Themed support groups can be very beneficial for those living with certain mental or physical health conditions but they can also be off-putting for those who have experienced stigma due to ill-health and do not want to be identified by their health status; people told us they are much more than the state of being in poor physical or mental condition
• Public support and community interest organisations need to work together and share information with their clienteles about helpful activities such as the Community CVS football club Men Dive In FC (Mental Health and Well-being, Diversity and Inclusivity) and Creative Support Social Inclusion Services
• Most people know about regularly run social groups that support those aged 50 and over but there are no known groups in BwD for non-South Asian subgroups, those aged 25-50, and adults living with autism
• People diagnosed with certain medical and psychiatric conditions that disturb sleep said they would benefit greatly from a 24 hours a day, 7 days a week service that provides a safe environment and a variety of activities; the only known 24/7 service is the gym in Blackburn
• Being out and about can be expensive for those on benefits as main income
• In-out-groups or "cliques" often form within social support groups which can create tension and cause some people to stop attending; everybody needs to feel valued and included
• Volunteer run support and activity groups often start up and fail because there is a lack of experience with resolving disputes successfully when they occur
• Good friendships are often lost when groups stop running and it can be difficult for some to "bounce back", move on, and find other groups

• Volunteers often feel unable to contribute fully because their abilities are "not made use of" effectively in their volunteering role which can cause feelings of isolation and disillusionment
• Volunteers skills should be recognised to reduce 'unskilled' stigma attached to volunteers

## Recommendations

• There is need for a mediation service that is available to volunteer run social support/ activity groups since they are often the main or only source of help for people at risk of experiencing loneliness or becoming isolated in Blackburn with Darwen
• Those who have faced stigma due to ill-health may be anxious about making new friends, may be distrustful of others and feel low about their own social skills. There is need for support that can help people feel empowered and grow in confidence (e.g. talking therapy)
• There is need to provide a safe and organised way for people living with disorders that disturb sleep. People told us that the lack of safe places and activities to participate in afterhours maintains other harmful coping strategies such as gambling and drinking excessively
• There is need for less labelled activity groups to cater for people who would like to connect with others who do not necessarily have a similar physical or mental health condition. Services like Creative Support Social Inclusion and activities such as Men Dive In FC are popular with residents because they inspire a sense of unity and enable people living with diverse physical and mental health conditions to come together

## Leapfrog Storyboard tool

These tools were intended to bring peoples experiences and ideas to life (visually) and use their own

interpretations to talk about the things they did or could have done to stop feeling lonely or isolated. We provided each person with two storyboard contract sheets and asked them to independently draw, use emoji icons or write to explain their activities over the last week (a before scenario) on one sheet and use the other to show what they would have liked to do differently or create a fantasy week (an after scenario). Adhesive Leapfrog emoji icons were provided as aids to help show how people felt about the things they did and communicate ideas about what went well and what could have been better.
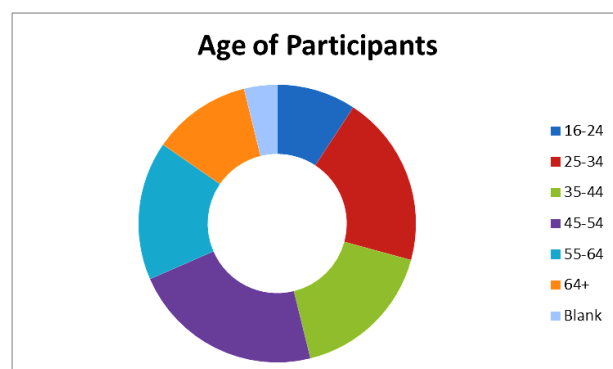
## Questionnaire

We devised our own questionnaire to explore issues such as overall lack of social contact or communication, participation in social activities, and living alone versus living with others. We used opportunity sampling methods in public venues and attended various social support/ activity groups in Blackburn and Darwen to complete questionnaires and speak to residents about their views and or experience of loneliness and isolation.
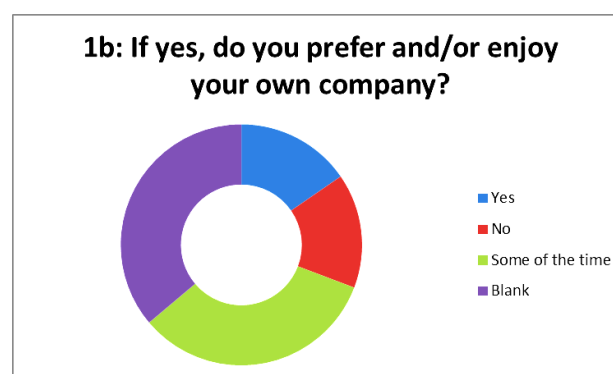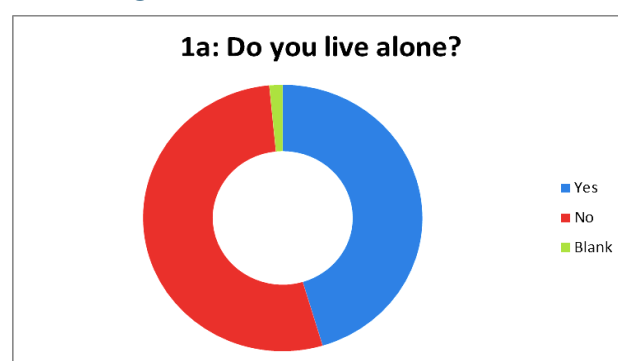
## Who we spoke to

We spoke to 250 individuals over the course of the project and completed 130 questionnaires.

44% identified as Female; 52% as Male; and 4% as Trans-female or other.

The views of residents aged 16-24 (9%) and 64+ (12%) are underrepresented in the following data.



Age of Participants

16-24, 25-34, 35-44, 45-54, 55-64, 64+, Blank

## Findings



1a: Do you live alone?

Yes, No, Blank



1b: If yes, do you prefer and/or enjoy your own company?

Yes, No, Some of the time, Blank

59 (45%) people told us they live alone and 69 (53%) live with someone else. 70 people responded to the question "do you live with or care for anyone with a Physical/ Mental Health need or substance misuse issue". Of this, 53 (41%) individuals answered "no" while 17 (13%) said "yes".

When asked if they prefer/ enjoy their own company; 43% said "some of the

time". Of this, nearly half (49%) felt that being alone had a negative effect. Poor mental health, loneliness, and limited social connection were reasons mostly said to cause the negative effect. 15% said they do not prefer/ enjoy their own company.

Some of the comments received included:
- No – "when I am alone I don't feel good, seems like there is no earth in front of me, could not walk. No hope" (35-44 Male)
- No – "I get lonely and depressed" (45-54 Male)
- Some of the time – "my grown up boy is always going to his friend and I spend most of the day alone in my bedroom" (55-64 Female)
- Some of the time – "I have 3 children but they cannot understand the things I would like to talk about - too young" (35-44 - Female)
- Some of the time – "this is what my life is so I have adapted to the situation. I don't enjoy being by myself but accept it" (35-44 Female)



2. How do you feel that being alone affects your health and wellbeing?

- Positively
- No effect
- Negatively
- Blank
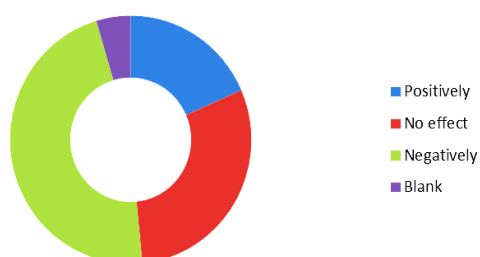
61 people (47%) told us being alone has a negative impact on their health and wellbeing. "People need other people" (35-44 Female)

**Common Themes:** Mental and or physical ill-health, negative thoughts,

unhappiness, and sleeplessness were often mentioned by those who said being alone affects them negatively.

Comments included:
- I start to think about the past when I had all my children around and I feel very sad (55-64 Female)
- I could not sleep at all even I have taken tablets but no use (35-44 Male)
- Feel lost in your own negative thoughts that quickly spiral out of control (25-34 Female)
- It's easy to not bother about my health being alone as feel nobody cares (45-54 Male)
- Being alone when you don't want to be alone seems to be detrimental to my mental health as I seem to dwell on negative memories (45-54 Female)
- I feel scared when I am on my own (16-24 Male).
- Every day I go bad more, bad and bad and bad…. more bad (16-24 Male)

39 (30%) individuals felt being alone had no effect. However, most in this group said they usually access activities in the community (alone/ with support) or live in supported accommodation where they can socialise with other residents. This result clearly shows that social connections play an important part in reducing loneliness and isolation.

18% of people told us that they experience being alone in a positive way and said it gives them time to think, plan and relax while others mentioned that having good friends, a pet, and access to communication technology is often helpful. For example:
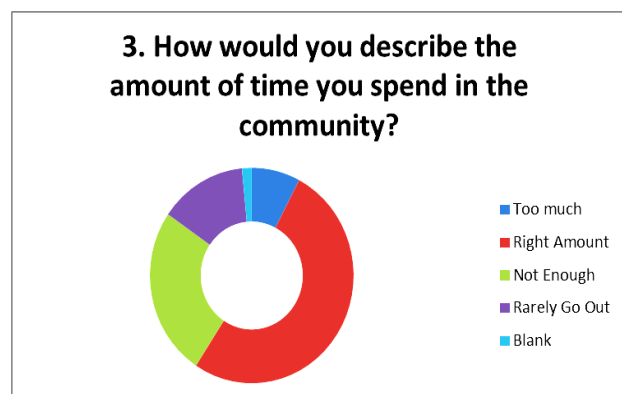
- I sometimes enjoy being alone to think and just relax (45-54 Female)

- I feel like I'm alone every time but I got really good mates to talk to (16-24 Male)

**Good Practice Examples:** ARC Project, Creative Support Social Inclusion Services, SHINE Group, Sliding Doors, Moorings Trust and Almond Villas.

### 3. How would you describe the amount of time you spend in the community?



- Too much
- Right Amount
- Not Enough
- Rarely Go Out
- Blank

67 (52%) individuals said they spent the right amount of time outdoors. Of this, 58% told us they need support from staff and or carers to go out or access social activities. Places people regularly visit and activities they engage in include; Creative Support Social Inclusion Service, SHINE, Sliding Doors, ARC/ DARE drop-ins, Darwen Resource Centre, Relax and Chat group, volunteering, gym and walking.

33 (25%) individuals felt they did not spend as much time in the community as they would like to while 18 (14%) said they rarely go out. People who do not go out enough and those who rarely go out commonly mentioned barriers such as mental ill-health, limited support, social anxiety, poor language skills and unfamiliarity with local areas. Some of the comments made include:

- Not enough – "I am anxious and lack confidence in my immediate community but I am working on this" (35-44 Female)

- Not enough – "Night times are the worst time. It is really bad if you can't sleep. I have bi-polar" (45-54 Female).
- Not enough – "I need 1-2-1 support out in community but haven't always got enough staff" (25-34 Female)
- Rarely go out – "Don't know most/many people and I have no idea where to go or what to do" (25-34 Female)
- Rarely go out – "Scared of the area" (16-24 Male)
- Rarely go out – "After my illness I have isolated myself" (55-64 Female)
- Rarely go out – "It's hard to go out feel like getting stared at and panic" (25-34 Male)
- Rarely go out – "I don't really go out because I am afraid to (climbing the hill)" (25-34 Female)

Of 10 individuals who felt they spent too much time in the community, 50% told us that this is not necessarily good for their well-being and they would like to do less. For example:

- I do too much, I could do with chilling out a bit more (16-24 Male)
- not good for me because it is rife with drugs (25-34 Male)
- I have too many things/activities. I think I should try and relax more (25-34 Male)

When asked "what can be done to support you in going out more, interacting socially and/or meeting new people?" a significant number of people mentioned having someone to motivate them, more information on local support and activity groups, safe and accessible evening groups, organised trips, and having kind and helpful PAs, support workers, carers, friends, and family.

Comments included:

- Nowhere offers night time support or evenings e.g. to have coffee etc. (45-54 Female)
- As before, would like more social groups. They are difficult to find (45-54 Male)
- As I get nervous meeting new people knowing somebody I know is there helps me not going alone (45-54 Male)
- Have a support worker take me to different places (25-34 Female)
- Information about different social clubs/hobby clubs in Darwen. Possibly fibromyalgia support group (45-54 Female)
- More groups for parents (25-34 Female)
- Somebody to help me interact with new people. I get dead nervous. Getting into groups and socialising (16-24 Male)

**5. I feel afraid when out in the community on my own**



- All of the time
- Most of the time
- Some of the time
- Rarely
- Never
- Blank
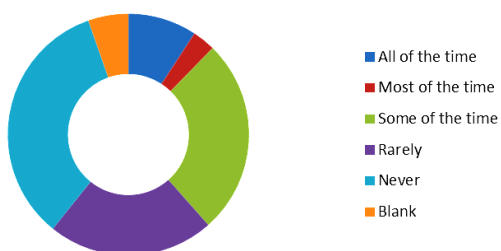
44 (34%) individuals said they never feel afraid when out in the community and 29 (22%) rarely felt afraid. Over half (52%) of those who gave these responses are supported by staff, a family member or friend to go out and get involved in activity groups.

34 (26%) individuals said they feel afraid some of the time mainly because of low confidence and anxiety.

Comments included:

- As I get older I am feeling more nervous. Community is faster/hard to keep up (45-54 Female)
- I am new in the area (2mths) and feel afraid because I don't know the area (35-44 Female)
- Being agoraphobic means that sometimes I get very anxious and my nerves play up (45-54 Male)
- There's always police on our estate? Drug dealers and dogs not on leashes (55-64 Female)

12 people said they felt afraid all of the time and 4 said they were afraid most of the time. The reasons shared by these individuals included fear and insecurity. For example:

- Due to being attacked when younger I don't feel safe day/night on my own (45-54 Female)
- Feel paranoid sometimes have panic attacks (25-34 Male)
- I'm worried that someone might chase after me (45-54 Female)
- The Hill's is not making me safe because I already had accidents on several occasions with my double buggy (25-34 Female)

**6. I feel I need support to be out in the community.**



- All of the time
- Most of the time
- Some of the time
- Rarely
- Never
- Blank
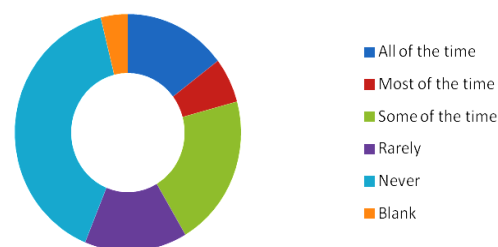
52 (40%) individuals said they never need support and 19 (15%) rarely need support to go out. Of those who gave these responses 48% said they are supported by

staff, a family member or friend to go out and get involved in activity groups. 27 (21%) people said they need support some of the time, 19 (15%) all of the time, and 8 (6%) most of the time.

Comments included:
- I never go out alone. I am always supported either by staff or family (35-44 Female)
- Sometimes I get a little bit paranoid (25-34 Male)
- I have support when going out (25-34 Male)



**7. I feel other people (e.g. neighbours, general public) are tolerant towards me.**

- All of the time
- Most of the time
- Some of the time
- Rarely
- Never
- Blank
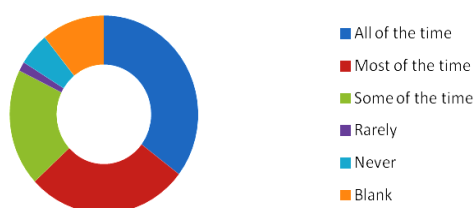
46 (35%) individuals said they feel other people are tolerant towards them all of the time; 36 (28%) most of the time; and 25 (19%) some of the time. Having good neighbours and understanding support staff, family members, and friends were common reasons.

9 people felt other people are never or are rarely tolerant towards them.

Comments included:

- I am careful who I speak to (45-54 Male)
- My neighbours greet me when I get out! (55-64 Female)
- Do not feel accepted by people (16-24 Male)



**8. I feel safe walking on my own in the street.**

- All of the time
- Most of the time
- Some of the time
- Rarely
- Never
- Blank

38 (29%) individuals felt safe walking on their own all of the time and 37 (28%) felt safe most of the time. Comments included:

- I take responsibility where and when I go out although I feel more vulnerable in a car (45-54 Female)
- I feel safe in my own street as its familiar and so are the people who live there (25-34 Female)
- I know how to look after myself I'm 6'2" and people don't bother me (16-24 Male)
- I do go out on my own, try not to think about what may happen to me, try not to think what people think of me (45-54 Male)
- I feel safe, I am used to it all the years but you got to be aware (55-64 Male)

29 (22%) individuals said they feel safe walking in the street on their own some of the time and 13 (10%) rarely or never. Comments included:

- I have the company of a guide dog and have confidence in her (45-54 Female)
- When it's dark I'm afraid of being attacked and also when the streets are slippery (snow) (55-64 Female)
- I have very bad experiences in the past from younger generation and from some officials and these incidents echo in my mind when I am on my own (45-54 Male)

- Not very happy walking in strange areas in the dark (45-54 Male)
- I avoid going out in the dark/dodgy areas so when I'm out its daytime (25-34 Male)
- Because of mobility would not feel safe (64+ Male)



**9. Do you believe using social media (e.g. facebook, twitter) to communicate can make you feel part of a community?**

Legend: Yes, No, Sometimes, Undecided, Blank

39 (30%) individuals said they believe that using social media can make them fell part of a community and 61 (47%) believed it can not. 17 (13%) thought it can sometimes. 13 people were undecided. Comments included:

- **Yes** – although not a permenant solution (35-44 Female)
- **Yes** - best way to get in touch with other people (25-34 Female)
- **No** - I feel it can be quite dangerous when people put too much detail on (45-54 Male)
- **No** - I do not use social media in part due to my dyslexia (45-54 Male)
- **No** - I don't want people finding my details, I need to meet people face to face to communicate before I trust them (25-34 Male)
- **No** - it is not the same as face to face meeting people is better (45-54 Male)
- **No** - If it does I believe it's a 'false' sense of community (25-34 Female)

- **No** - I am wary of social websites (64+ Female)
- **Sometimes** - it can but can also make a person feel more secluded (16-24 Male)
- **Sometimes** - because it leads to knowing the hapenings in the community and can participate (25-34 Female)
- **Sometimes** - I prefer the company of 'real' people (45-54 Female)



**10: How would you describe the amount of time you spend on social media?**

Legend: Too much, The right amount, Not enough, Don't use social media, Blank
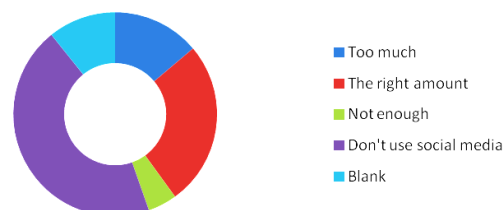
58 (45%) individuals said they do not use social media. Reasons frequently given included mistrust, lack of interest, prefer face-to-face communication. 34 (26%) felt they spend the right amount of time on social media (range 2-5hrs a day). 18 (14%) thought they spent too much time on social media to keep contact with friends and family, for work, to watch films or to stop feeling lonely. 5% did not spend enough time on social media.



**11. Do you feel a sense of community spirit?**

Legend: Yes (a), Yes (b), No, Sometimes, Blank

56 (43%) individuals said they feel a sense of Community with comments such as "people always say hello to me and chat" (55-64 Male); however, 29% of these individuals only felt a sense of community spirit when they attended particular groups. For example:

- I like going to Creative Support and spending time with friends (25-34 Male)
- At Wesley Hall they listen and help you out, I feel I belong (35-44 Female)
- Through football and facebook with friends and family (16-24 Male)
- Yes in Salvation Army (35-44 Female)
- It's good to go to groups and meet new members, I am part of a couple (25-34 Male)
- Between mental health, homeless, people with addictions. Apart from that you feel alien (45-54 Female)
- Happy to belong to certain organisations, Towns Womens Guild, Guide Friendship Club, O.P.F (64+ Female)

23 (18%) told us they did not feel a sense of community for the following reasons:

- no human connection (16-24 Male)
- sometimes feel excluded as an incomer to the area (64+ Female)
- I find society to be selfish and individualistic. It's like people don't care about those who have disability (35-44 Male)
- I don't feel like I am accepted (16-24 Male)
- too many families moving in and out and a lot of people don't

respect where they live (55-64 Female)

45 (35%) felt a sense of community spirit sometimes with most speaking of organised group activities, good neighbours, and voluntary work. For example:

- If I was on my own I'd be happy to spend time litter picking in a group, however I just litter pick in my immediate area (64+ Female)
- occassionally eg creative support catching up with neighbours (25-34 Female)
- I do quite a lot of voluntary work which gives me a stake in my local community (35-44 Male)
- I feel there could be more community spirit around and more advertised to let people know what is going on in the community (45-54 Male)

## Signposting

Over the course of the project, 10 people were given information about local support/ activity groups, one person was signposted to the ARC project for help with accommodation and another to Your Support Your Choice for advice.

## Conclusion

The views and experiences of the 250 individuals we spoke to reveals that loneliness and isolation in Blackburn with Darwen (BwD) is a problem that needs further investigating. Like most of the other research mentioned above, we found that people across all ages, genders, and cultural backgrounds prefer face to face interaction regardless of their ability to access social media.  BwD residents said that voluntary work and membership in proactive support and activity groups helps them build social contact and reduce the risk of engaging in harmful behaviours to stop feeling lonely and isolated. For example, people living with medical and psychiatric conditions that disturb sleep said a lack of safe places and activities to participate in afterhours maintains harmful coping strategies such as gambling and substance abuse.  These individuals would benefit greatly from an after-hours service that provides a variety of activities in a safe environment. Also, people adjusting to life after being carers for a long time said they would benefit from a service that offers attainable everyday support during this transition period.

It is important to people living with visible disabilities that both public and third sector health and care service providers clearly understand the role of support staff as most said they feel invisible, upset, and isolated when they are discussed with their carer instead of being addressed directly.

Organisations providing support to the public should clearly identify the area and extent of their responsibility to minimise confusion and make it easier for the public to get to the information they need.

People who regularly attend volunteer run support groups felt that good friendships are lost when groups stop running and this can make it difficult for some to repeatedly "bounce back", move on, and find other groups. Having trained conflict management workers to intervene, guide and help resolve disputes when they occur within groups can help ensure continuity and stop people feeling let down which would indirectly promote resilience.

We found that having caring staff, friends or family members are important in motivating and encouraging people to go out more and get involved in organised group activities whereas feeling accepted by others helps people build resilience because they feel happier in their environment. However, welfare cuts are having a negative effect on people who rely on benefits as main income and affecting the way support and care for the most at risk in our community is given. Launching a local information sharing campaign could ensure that those identified as experiencing loneliness or at risk of becoming isolated are supported and signposted appropriately before their support needs increase.

## Summary of Key Recommendations

- There is need for conducting a large scale study on loneliness and isolation across all demographic factors in BwD to better evaluate prevalence, differences in area or ward experiences, and real world impact of welfare cuts for those who need support to socialise

- Third sector organisations to work more cooperatively to research,

uncover, and communicate the experiences of lonely and isolated minors, the 18-40 age group, at risk and marginalised groups to better understand how to tailor services for all age groups

- The local authority to adopt a long term commissioning policy for preventative services to make sure that loneliness among all age groups is considered in their Needs Assessment as well as Health and Wellbeing strategies

- Training and mediation support to be available for independently run community support groups to ensure continuity

- Ensuring loneliness prevention and alleviation are incorporated into the integrated care agenda

- Encouraging GPs, NHS professionals, and community healthcare workers to build links with relevant third sector services aimed at preventing or alleviating loneliness for every age group

- Launching a local information campaign to ensure those identified as experiencing loneliness are signposted to services such as the local Improving Access to Psychological Therapies (IAPT), relevant local third sector organisations or community support/ activity groups

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