Hamilton, Lorna ORCID:
https://orcid.org/0000-0003-0526-8252 and Mesa, Sue ORCID:
https://orcid.org/0000-0001-5933-3270 (2016) "There's a lot of
places I'd like to go and things I'd like to do": Personalised social
care, austerity, and adults with learning disabilities in York. A report
on the 'LD Voices, York' project. Project Report. York St John
University. (Unpublished)

RaY

Research at the University of York St John

For more information please contact RaY at ray@yorksj.ac.uk

"There's a lot of places I'd like to go and things I'd like to do"

Personalised social care, austerity, and adults with learning disabilities in York

A report on the 'LD Voices, York' Project
March, 2016

Lorna Hamilton & Sue Mesa
York St John University

Table of Contents

1. EXECUTIVE SUMMARY

1.1 Background:

Social care in the United Kingdom has been transformed in recent years, driven by the implementation of the personalisation agenda alongside significant budget cuts, which have resulted in restricted eligibility for social care services. The personalisation agenda aims to eradicate a 'one size fits all' service, by providing individuals with the opportunity to contribute to the identification of their needs and the opportunity to choose and manage their own care through a personal budget.

Previous studies evaluating the effectiveness of the personalisation model in the UK have reported that individuals who are more able, and who have stronger support networks, benefit most from personalised social care [1]; however, this same group is considered most at risk of becoming ineligible for statutory service provision due to restricted eligibility criteria. Reduction of budgets at a local authority level has also been associated with services only being provided to those individuals classified as having critical or substantial needs [2].

The current study aimed to explore the daily living experiences of a group of adults with mild to moderate learning disabilities (LD), who were either not accessing statutory social care services, or who were considered at risk of becoming ineligible for continued statutory support. The study was undertaken following a request from a voluntary sector forum, whose members were concerned about the impact of changes in the social care system on the lives of people with mild and moderate LD.

1.2 Method:
- Seven focus groups were conducted, including 26 people with LD and 15 support workers, who were recruited via third-sector organisations. Participants were aged between 23 and 60.
- A semi-structured question schedule was implemented, through which people were asked about their experiences in relation to managing their home, involvement in their local community, and access to healthcare, support services, education, employment and leisure activities.
- The focus groups were video-recorded, transcribed and analysed thematically.

1.3 Findings:
Themes identified in the focus group discussions are summarised below.

Independence and control

- People often wanted to live independently, but many found managing the transition into supported or independent living challenging.

- Conflicts between the wishes of people with LD and their family carers can result in individuals becoming less of a priority for supported living allocation.

- People valued employment and wanted paid work, but were concerned about the impact of this on their benefits.

- People had difficulty in managing personal assistants (PAs) and reported having to fit in with PAs' timetables. The role of employer was identified as stressful, with a lack of training and support provided.

- The limited range of employment, social activities and educational opportunities available for people with LD is a barrier to independence.

- Stereotyping of people with LD negatively influences employment and education opportunities.

- Bullying and harassment in the community can impact on social inclusion and independence for people with LD.

Social networks and wellbeing

- Voluntary sector organisations offered opportunities to socialise within the local community, which were highly valued and improved quality of life.

- Social networks have been fragmented following the closure of specialist day services, resulting in social isolation for some people.

- Statutory assessment of need places more emphasis on basic living needs than on social relationships.

- The high turnover of PAs made forming and maintaining relationships difficult.

- A lack of social support limited opportunities for independence.

- Mental health can be adversely affected by the breakdown of social networks.

1. 4 Conclusions

Participants used the language of personalisation when talking about their aspirations for greater independence. However, they also identified a number of barriers to greater independence, e.g. not having adequate training and support in navigating the benefits system, or 'managing' a PA under the personal budget system, the lack of availability of educational, employment, and leisure opportunities and experiences of discrimination and harassment in the community.

There were also examples of people who did not aspire to greater independence and who wanted more support but were not able to get this. The personalisation agenda,

delivered in the context of an imperative to reduce spending, perhaps is not a good fit for these individuals.

Voluntary sector organisations were seen as central to supporting social relationships, yet many of these organisations are also facing funding cuts. Strong social support networks were described as having a clear influence on quality of life and wellbeing. Wellbeing is now the responsibility of local authorities [5, 6] yet statutory assessment was described as not focusing on the development or maintenance of social networks.

This study highlights the need to listen to the voices of people with LD. The findings of this report will be shared with organisations that plan, commission and deliver care to people with LD in York.

2. Easy Read Report

Background:

The government introduced a personalisation agenda in the 2007 paper 'Putting People First'.

The personalisation agenda aims to give people more choice and control over their lives and the services they use.

The council has not got much money. There is concern that because of this some people will not get the right amount of support, and personalisation won't work very well.

We were asked by York Voluntary Sector Forum for Learning Difficulties to find out what life was like for people with learning disabilities living in York.

What we did:

We met with 7 groups of people with learning disabilities and their support workers.

We talked about what it's like living in York. We asked questions about where people live,

their access to education, employment and leisure. We also asked about their contact with health and social care services.

We put all of this information into this report.

What we found out:

Independence and control

Some people described feeling in control of their lives, which was positive.

Many people wanted to be independent and live in their own accommodation. Some people had found the transition out of the family home difficult, and had to wait a long time.

Sometimes families didn't want people to be independent and this meant people could miss out on opportunities to live independently.

There were also some people who wanted more supportive accommodation, but they had not been able to get more support. They felt they would not get this until they were in crisis.
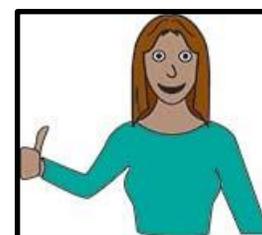
People wanted to get paid work, but they were worried about how this might affect their benefits.

The lack of availability of education, employment, and leisure opportunities made being more independent difficult.

People found it difficult to manage their personal assistants (PAs). Often it was the PA who decided when they came to provide support.

People had not been given any support or training to help them to be employers to their PAs, and this was stressful.

People talked about others having low expectations of their ability, and some people had experienced harassment in the community.

Social networks and wellbeing

Many people did activities with voluntary sector groups, which was a good way to make friends.

There were concerns that some people who lived with families couldn't access these groups.
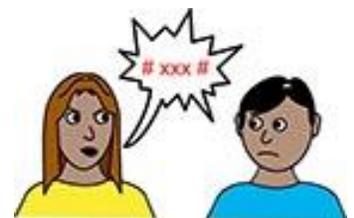
Assessments for care packages are focused on practical daily living tasks and not on social relationships.

Day services for people with learning disabilities had closed. This meant people lost opportunities for socialising, and had lost contact with their friends.

Personal assistants (PAs) often changed, and this makes it hard to keep a relationship with them.
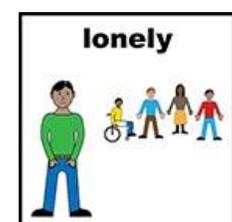
Being socially isolated and lonely is bad for people's mental health.

What we are going to do now:

We are going to feed these findings back to the Voluntary Sector Forum for Learning Difficulties, who asked us to do the project.

We are going to share the findings with other people involved in planning and delivering support and services for people with learning disabilities in York.

3. FULL REPORT

3.1 Background:

Personalisation of support has underpinned reform of adult social care in the UK under successive governments for the last two decades [3, 4] and is embedded in recent health and social care legislation [5, 6]. The personalisation agenda aims to put individuals at the centre of their care; contributing to the identification of their needs, and choosing, purchasing, and managing their own support package in the form of a personal budget or direct payment [7].

Evidence for improved service user outcomes associated with personalised social care is mixed [8, 9] and there are questions about whether it is really cost effective for people with LD due to higher costs associated with the care-planning and assessment process [1].

The personalisation agenda emerged when spending in the UK was historically high, and may be compromised under current government spending cuts [10, 11]. The combination of reduction of budgets [4] and increasing pressure on LD services caused by the increasing numbers of people with LD [12, 13], has resulted in many local authorities tightening their eligibility in order to manage resources [14]. Thus many local authorities only provide services to individuals classified as having 'critical' or 'substantial' support needs [2], despite evidence that 'limiting access by raising eligibility has only modest and short term effects on expenditure' [4, p.6].

Other authors have suggested that future research could usefully examine the effect of changes in welfare and public spending on individuals who use services and their carers [15]. Despite these suggestions, at the present time, the impact on those classified as having mild or moderate needs is under-researched. Those most likely to be assessed as having low or moderate needs are those with mild/moderate LD, who at the same time are the group of people with LD most able to benefit from managing their own budgets [1].

3.1.1 The current study

Members of academic staff at York St John University were requested by the York Voluntary Sector Forum for Learning Difficulties to research the impact of cuts to services on people with mild/moderate LD who may no longer eligible for services, or who are at risk of 'falling between the cracks' of service eligibility. This study aims to explore experiences of daily life within this group of people in the context of the introduction of personalisation and social care budget cuts.

3.2 Methods

Ethical approval for the study was obtained from the York St John University Ethics Committee. A total of 26 adults with mild to moderate LD (19 male and 7 female) and 13 support workers (6 male and 7 female) were recruited to the study via voluntary sector organisations. They were aged between 23 and 60 years and all York residents, living either in family homes or in assisted living accommodation.

We conducted seven focus groups. At the outset of each group discussion, an accessible information sheet (formatted in easy-read with visual aids) was given to each participant and read aloud by a member of the research team. Care was taken to ensure that everybody understood the aims of the research, and their rights of withdrawal, confidentiality and anonymity, before participants were requested to sign consent forms.

We asked participants to describe their daily living experiences (or those of people for whom they provided support) in terms of care and support needs assessments, housing, transport, finances, employment, education, health and socialising. Two members of the research team acted as facilitators at each focus group; facilitators took care to allow each member of the group to contribute to the discussion. The presence of support workers who were familiar with the service users was helpful, as on occasion they were able to interpret contributions where speech was unclear.

Focus group discussions lasted for an average of 70 minutes (range 53-106) and were video-recorded. Each group discussion was subsequently transcribed in full verbatim; participants' names were changed to preserve anonymity. The data were analysed from a critical realist perspective, using thematic analysis [16].

3.3 Findings

3.3.1 Independence and Control

A desire for independence

> "I was so desperate to move to get my own independence."
>
> *Mary, participant*

Many within the focus groups expressed a desire for independence. Independent living outside of the family home was considered an important factor, although for some the management of the transition out of the family home was difficult.

The ability to do paid work was seen as crucial to being independent. Participants talked about work as a way to gain financial stability and also an opportunity for social contact. There was a common concern among participants that taking a paid

job would jeopardise benefits payments, leaving them financially worse off. Participants tended to be unsure about where to find information and seek support with navigating the transition to employment. Those who were already in employment (unpaid or nominally paid in all cases) tended to express satisfaction in their work.

However, some participants noted independence to be the goal of services, as opposed to their own, and were seeking more support.

"I've been begging the social services to help me and they've done an assessment on me recently... I've been saying I want to go into a residential care home because I feel like I can't cope any more and they just ignoring- ignoring this and they've said as well I can't go into a care home but I can't have a support worker either."

Michael, participant

Michael expressed the view that he would not get any support until he had reached crisis, something that has been highlighted in the literature as a likely costly outcome of failure to provide early intervention to those with mild and moderate needs [3, 4].

Prioritisation of needs

Many participants described having choice and control in how they spent their time, which was often described with satisfaction.

Participants also identified that their goals could be at odds with what families and carers wanted for them. For instance, it was highlighted that when family members were not fully behind a move into supported living accommodation, people became less of a priority on a long waiting list.

"Yeah, I go to work ... I do things on my own and I do get buses, I get bus on time ... But I generally decide what I do independently on my own and things."

Terry, participant

Similarly, participants discussed instances when they felt that their needs had been secondary to the timetables of their personal assistants. Taking on the role of 'employer' under the personal budgets system was experienced as difficult by some individuals, and relationships with personal assistants could be problematic. Participants felt that they did not receive adequate support or training in this role.

"And it's also difficult when you have got personal assistants sometimes, I know it has happened to me, you feel as though you're fitting in with their lives."

Jim, participant

"It's difficult y'know because I am the employer and I am trying to be a bit more assertive…"

Graham, participant

Barriers to independence

Participants identified a number of external factors that impacted on their ability to be more independent. Individuals expressed the view that a sense of choice, advocated within the personalisation agenda, was lost as a result of the limited range of employment, educational opportunities and social activities available to adults with LD.

"The thing about education is that there's no assumption that people with learning disabilities are still learning. … Maybe enough people in education don't really know very much about people with learning disabilities. … Jim might not learn in the same way as some people you know, but get to know Jim. How does he learn?"

Laura, support worker

"We have a joke about people with learning difficulties are always taught to make buns."

Laura, support worker

"I feel as though there's a lot of resistance, because of disabilities, there's a lot of resistance from employers."

Steve, participant

Participants highlighted negative stereotypes about people with LD as being a contributing factor to a lack of paid employment opportunities, despite people being capable of working. Support staff also identified that low expectations meant people often did not progress within workplaces, remaining as unpaid staff rather than moving to paid positions. Participants and support workers described commonplace experiences of discrimination, harassment, and hate crime that impact on the ability of people with LD to be independent.

3.3.2 Social networks and wellbeing

Interdependent social networks

Participants frequently discussed their social networks of friends, family members and support workers. The quality of these networks was central to participants' perceived wellbeing. Opportunities to socialise within the local community were seen as important in relation to quality of life.

> "You want to go out, socialise, do everything that everybody else does."
>
> *Sarah, participant*

Third-sector organisations were identified as playing a key role, both in providing a context in which individuals can make and maintain relationships with peers, and in providing support to access activities in the local community. However, it was highlighted that people often rely on support from their wider social network to be able to access these third-sector organisations.

> *Mark (support worker):* Yeah, we're trying to get your mum to sort of erm-
>
> *Rachel (participant):* Let me have my wings.
>
> *Mark:* Yeah! Exactly, just let you go really.

Fragmentation of social networks

Concerns were expressed in several focus groups about people with LD who were not accessing voluntary sector organisations for support, socialising and participation in activities. The closure of specialist day services was identified as negative in terms of being able to maintain social networks. Particular concern was voiced about individuals who lived alone, without a network of family members to help access information about voluntary sector groups.

> "And then these places closed and people weren't given contact details for people they'd lived with for years and years. So their friends just kind of disappeared off the edge of a cliff it felt like, I think."
>
> *Emma, support worker*

"You've got a support network there but erm people that don't have families then they're the ones, the guys that erm probably struggle more because like they don't have that. They rely on care managers to make decisions for them."

Mark, support worker

"They have to see progression and progression to the council is often the practical things, are they keeping up with their housing? You know sometimes you have to work maybe a year with someone to get that relationship, to maybe then be able to go into their house and help them with that kind of thing, but you've got to go in with someone's interests and build a relationship that way to build their confidence around going out and doing social things. It's kind of deemed as not important"

Amanda, support worker

Despite social networks being identified by participants and support workers as crucial to quality of life, they also felt that statutory assessments focused on and prioritised basic living needs over the need to make and maintain social relationships.

Another factor identified as contributing to the fragmentation of social networks was the high turnover of staff in personal assistant roles. This made it difficult for some participants to form meaningful social relationships with the people supporting them.

"It's OK if I know which one I have. Sometimes I click with someone, know which number to phone, then about a week after he say, 'Oh I'm leaving, it'll be our last day the next day.' Oh, have to get a new one to come, then new one comes in, have her for a couple of weeks or something, then they say, 'Oh, I've got bad news, I'm leaving. You have to have another one'."

Robert, participant

Isolation and Exclusion

> "There's a lot of places that I would like to go and things that I would like to do, and I don't have anyone that I can go with and I would never go by myself."
>
> *Susan, participant*

Positive experiences associated with accessible support were outlined, with a particular individual indicating that before he joined a community social group, he had used to spend a lot of time alone in his home. Through engaging with others in the community, such individuals were able to meet people and continue to develop skills.

Experiences of isolation and loneliness were recounted by some, with a lack of daily routine in their lives seen to contribute to agitation and anxiety. A lack of social support was associated with limited independence.

3.4 Conclusions and Next Steps

The participants in this study described the wide range of daily living experiences of people with mild and moderate LD in York. Many people with LD used the language of personalisation when talking about their aspirations for greater independence (e.g. through transition to independent living or paid employment) or about the autonomy they felt they already had in their daily lives.

Previous research has identified those who are more able as having better outcomes of personalisation [1]. However the experiences described by focus group participants suggest that the language of personalisation does not always translate into their everyday life. Participants identified significant barriers standing in the way of them being more independent. For example, some people identified a lack of training and support in navigating the benefits system, or 'managing' a PA under the personal budget system. The limited range of educational, employment, and leisure opportunities available to people with LD was reported as constraining choice and control. People also described experiences of discrimination and harassment in the community.

The focus group discussions also contained examples of people who did not aspire to greater independence, but rather felt that they needed higher levels of statutory support and/or greater connectedness to communities in order to prevent future crises. The personalisation agenda, in the broader context of local authorities being required to reduce spending, is perhaps therefore not a good fit for these individuals, and not always able to deliver choice and control or preventative early intervention.

A further consequence of the personalisation agenda operating in a time of financial austerity has been a reduction in specialist services: this for some has led to social

networks being fragmented. Previous research reported those who have stronger support networks fare better under personalised social care. Participants in this study were well engaged in voluntary sector organisations and expressed concern for people who did not have networks of family, friends and support staff to assist in accessing these. These organisations were seen as being central to supporting their socialisation, yet many of these organisations are also facing funding cuts. Strong social support networks were described as having a clear influence on quality of life and wellbeing and local authorities now have responsibility for the wellbeing of their local residents [5, 6]. However, participants felt statutory assessments did not foreground the importance of social relationships.

The findings of this study highlight the need to listen to the voices of people with LD in evaluating current services; and to encourage co-production in future service development and planning.   This report will therefore be disseminated to relevant stakeholders in the York area, including:

- York Voluntary Sector Forum for Learning Disabilities
- Voluntary sector organisations providing support and activities for people with LD
- Local authority social care services
- Local colleges

4. ACKNOWLEDGEMENTS

5. REFERENCES

[1] Glendinning, C. (2008). Increasing choice and control for older and disabled people: A critical review of new developments in England. *Social Policy Administration, 42*(5), 451-469.

[2] Sully, A. & Bowen, R. (2012). Social care in crisis – the need for reform: The Learning Disability Coalition Annual Survey, 2012. Retrieved from: http://www.scie.org.uk/publications/reports/report55/

[3] DH (Department of Health) (2007). *Putting People First: A shared vision and commitment to the transformation of adult social care.* London: DH.

[4] DH (Department of Health) (2010). Prioritising need in the context of "Putting People First": A whole system approach to eligibility for social care – Guidance on eligibility criteria for adult social care, England, 2010. London: DH.

[5] Health and Social Care Act (2012). Retrieved from: http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted

[6] The Care Act (2014). Retrieved from: http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

[7] Slasberg, C. & Beresford, P. (2014). Government guidance for the Care Act: Undermining ambitions for change? *Disability & Society, 29*(10), 1677-1682.

[8] Slasberg, C., Beresford, P., & Schofield, P. (2012). How self-directed support is failing to deliver personal budgets and personalisation. *Research, Policy & Planning, 29*(3), 161-177.

[9] Jones, K., Forder, J., Caiels, J., Welch, E., Glendinning, C., & Windle, K. (2013). Personalization in the health care system: Do personal health budgets have an impact on outcomes and cost? *Health Services Research & Policy, 18*(2), 59-67.

[10] Hudson, B., & Henwood, M. (2008). *Analysis of evidence submitted to the CSCI Review of Eligibility Criteria.* London: Commission for Social Care Inspection.

[11] Needham, C. (2014). Personalization: From day centres to community hubs? *Critical Social Policy, 34*(1), 90-108.

[12] Emerson, E., & Hatton, C. (2004). *Estimating the Current Need/Demand for Support for People with Learning Disabilities in England.* Lancaster: Institute for Health Research.

[13] Emerson, E., & Hatton, C. (2008). *People with Learning Disabilities in England.* Lancaster: Centre for Disability Research.

[14] McInnis, E.E., Hills, A., & Chapman, M.J. (2011). Eligibility for statutory disability services in the north-west of England. Right or luxury? Findings from a pilot study. *British Journal of Learning Disabilities, 40*(3), 177-186.

[15] Slay, J. (2012). *Budgets and beyond: Executive Summary.* New Economics Foundation. Retrieved from: http://b.3cdn.net/nefoundation/dbde656b79d717b71e_ium6bnnew.pdf

[16] Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

 For more information, contact:

Dr Lorna Hamilton | Sue Mesa
York St John University
Lord Mayors Walk
York, YO31 7EX

E: l.hamilton1@yorksj.ac.uk | s.mesa@yorksj.ac.uk