The impact of personalisation on the lives of the most isolated people with learning disabilities

A review of the evidence

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Introduction

Research on the impact of certain aspects of personalisation has revealed some very positive outcomes on the lives of people with learning disabilities (Glendinning et al., 2008; Hatton & Waters, 2013). However, through our work on various projects with people with learning disabilities and their families, the National Development Team for Inclusion (NDTi) have become increasingly aware that not everyone with learning disabilities is experiencing these positive outcomes equally. In particular we are interested in learning about the impact of personalisation on the lives of the most isolated people with learning disabilities.

As a first stage of our work in this area, we conducted a review to find out whether any research has looked at the impact of personalisation for the most isolated people with learning disabilities and if so, what the evidence says. We took an open approach to who we define as the "most isolated" as we did not want to exclude groups we had not previously considered to be isolated, but our particular interest initially was around people without family, people in residential care, and people in out of area placements.

As well as searching for evidence on the impact of taking a general personalised or person-centred approach, we searched for evidence on the impact of specific mechanisms including personal budgets, direct payments and person-centred planning. Systematic searches were conducted using an academic search engine, the Social Care Online database, reference lists and websites and publication databases of relevant organisations. Both peer reviewed articles and grey literature were included. Articles and reports were limited to those based on research which was conducted in the UK.

This paper provides a short summary of the findings of the evidence review. The search and review was time and resource limited so this paper should not be read as a comprehensive review of all evidence on the subject.

Findings

Has any research focused on the impact of personalisation on the lives of the most isolated people with learning disabilities?

Overall the search did not reveal any research which specifically focuses on how a personalised approach, including specific mechanisms such as personal budgets or direct payments, impacts on the lives of particularly isolated people with learning disabilities. Research on personalisation tends to focus on people with learning disabilities as a homogeneous group (for example Hatton & Waters, 2013; Netten et al., 2012) and rarely makes a distinction based on, for example, domestic circumstances, relationships/networks, level of need, residential status or whether individuals have capacity or lack capacity (Harkes et al., 2014). Two recent literature reviews on personalisation and learning disabilities both highlight the limited number of research studies which focus specifically on people with learning disabilities (Harkes et al., 2014; Sims & Gulyurtlu, 2014). Given the limited research which focuses on personalisation and people with learning disabilities in general, it is perhaps not surprising that we did not come across any research which specifically looks at the impact of personalisation on particularly isolated people with learning disabilities.

What does the available evidence *suggest* about the impact of personalisation on the lives of the most isolated people with learning disabilities?

Due to the lack of research with a direct focus on this area, the findings presented below are from studies with a different, or broader focus but include points, factors or findings which are relevant, or have relevant implications. The review found evidence from a number of studies to suggest that there some groups of potentially isolated people with learning disabilities who are missing out on personalisation in one or both of two ways:

(i) They are less likely to have access to a personalised approach or mechanism in the first place.

(ii) If they do have access to a personalised approach or mechanism they are less likely to experience the most positive outcomes from it.

The evidence points to at least three potentially isolated groups of people with learning disabilities who may be missing out – those with complex needs, those in residential care or out of area placements, and those without families.

People with multiple or complex needs, challenging behaviour or profound and multiple learning disabilities

A report to the Commission for Social Care Inspection on the support for people with multiple and complex needs[1] noted the limited use of personalisation among people with multiple and complex needs (Henwood & Hudson, 2009). Various studies suggest that people with multiple or complex needs, people with challenging behaviour, or people with profound and multiple learning disabilities are less likely to have a person-centred plan than people with less complex learning disabilities. A review of the literature on the effectiveness of person-centred planning, refers to four studies which find that those with communication difficulties, challenging behaviour or severe learning disabilities are often excluded from the person-centred planning process (Claes et al., 2010). A study on people with profound and multiple learning disabilities living in Lambeth found that only half of the people identified in the study had a person-centred plan (Lambeth Mencap, 2010). A report on a project which aimed to support the development of a personalisation plan for 26 people with learning disabilities and behaviour described as challenging revealed significant barriers to taking a personalised approach – by the end of the one year project just 14 of the 26 people had partially developed personalisation plans (Lingard et al., 2013). In their literature review, Harkes et al refer to five studies which found that practitioners were reluctant to offer self-directed support to those who they deemed incapable of managing their own support due to the severity of needs (Harkes et al, 2014).

In perhaps the most relevant piece of research we came across, an English study aimed to measure the impact of a person-centred plan on the life experiences of people with learning disabilities and to identify factors which facilitate or impede the introduction and effectiveness of person-centred plans (Robertson et al., 2005; Robertson et al., 2007a; Robertson et al., 2007b). A range of information was collected about 93 adults with

[1] Note that by complex needs they refer to different aspects of complexity including where the prime needs related variously to learning disability, mental health, physical and sensory disabilities and older age.

learning disabilities in England over a period of two years, before and after having a person-centred plan. The study found that there were some powerful inequalities in the extent to which people are likely to receive a person-centred plan. They found that people with learning disabilities who *also* had mental health problems, emotional problems, behavioural problems, autism or health problems were less likely to get a person-centred plan. The study also found that where people did get a person-centred plan, there were inequalities in the level of benefit that could be expected. People who also had mental health, emotional or behavioural problems were less likely to benefit in the areas of the size of social networks, contact with friends and family, choice, hours of scheduled activity, and number of community activities. While the data collected for this research is now over 10 years old, the sources referred to above suggest that the findings may still be relevant.

People in residential care homes, hospitals or out of area placements

A number of studies suggest that people with learning disabilities who live in residential care homes, hospitals or out of area placements are less likely to receive a person-centred approach to their care than people living in other types of accommodation. A study which compared people with severe intellectual disabilities and challenging behaviour in Wales living in community houses, with those living in traditional hospitals or hostels, found that community houses were more likely to be following person-centred and individual planning approaches than traditional hospitals or hostels (Lowe et al, 1998). A study comparing people resettled into residential placements and those in supported living found that those in a residential placement were less likely to have had a person-centred plan taken into account in the care planning (Williams & Suzanne Battleday, 2007). A very small study which looked at the quality of services for people with challenging behaviour placed out of borough found that only 20 per cent of the people in residential placements were receiving person-centred planning (Becker, 2006). Some research on “forgotten” people with learning disabilities living in residential services for older people found that few were receiving a person-centred approach to care (Thompson & Wright, 2001; Thompson et al., 2004). Another study emphasises the difficulties in attempts to introduce person-centred planning into a long-stay hospital (Cook & Abraham, 2007), and a review of the evidence of person-centred planning highlights the difficulties in making person-centred planning work in large traditional service systems (Claes et al, 2010). Data on the use of resources in adult learning disability services shows that local authorities which spend more on residential and nursing care have less people on direct payments – this indicates that at a local authority level there may be a relationship between a high number of people in residential care and a low level of personalisation (Dehaney, 2010).

It should be noted however, that this evidence is not conclusive – one study comparing people with profound and multiple learning disabilities living in a family home and those in

residential accommodation found that those in residential accommodation were more likely to have a person-centred plan (Lambeth Mencap, 2010).

Those without families or close friends

A third set of studies comes from research which seeks to identify what factors lead to positive outcomes of personalised approaches. There is strong evidence within this literature which highlights the need for family support to enable access to, or to get the best outcomes out of, various elements of personalisation – including personal budgets (Neville, 2010; Sheikh et al., 2012), direct payments (Williams et al., 2003), person-centred plans (Robertson et al, 2007a) and self-directed support (Harkes et al., 2014; Mansell, 2010).

A three year study into the impact of self-managed personal budgets found that family resources can enable better outcomes in at least three ways – through use of social networks, financial resources and skills and knowledge of the family (Neville, 2010, Sheikh et al, 2012). The study found that those with more extensive social networks were in a better position to both take up, and get the best outcomes out of personal budgets, a finding also supported by Rabiee et al (2009). The study also found that financial resources of the family are used to enable better outcomes of personalisation by filling gaps or supplementing personal budgets. Similarly, the additional financial resources of the family were found to be key to securing a positive outcome in a set of case studies which looked at the impact of an emphasis on 'choice and control' (Simpson & Price, 2010). Thirdly, the study found that skills of family members (for example confidence, assertiveness, negotiation skills, being articulate, and money management) can enable better outcomes from personal budgets. A study of the role of parents in direct payment provision found that parents often had to find out information about direct payments for themselves and had to fight for access to services (Williams et al., 2003).

The implications of this evidence are that those with no or limited support of family or friends are at a distinct disadvantage. Hall (2011) argues that while the emphasis on choice in personalisation provides new opportunities for some, it poses significant challenges for those without resources or limited networks.

It is also worth noting however, that two studies on person-centred planning find that it is the role of staff, rather than family that is key to enabling person-centred plans (McConkey & Collins, 2010; Robertson et al., 2007b). It may be that supportive and skilled staff can compensate for a lack of support from family or friends, though further research would be needed to explore this.

Access to advocacy for the most isolated people with learning disabilities

For the groups of people identified above who may be missing out on the positive outcomes of personalisation, advocacy is one crucial mechanism which should enable people to have a voice and ensure equality of access. A review of services for adults with profound intellectual and multiple disabilities recommends access to advocacy as a way of ensuring that people who do not have family benefit from self-directed support (Mansell, 2010). However, while the concept of advocacy is promoted under personalisation (Chapman et al., 2012), research has highlighted that those with high or complex needs are less likely to have access to advocacy (Lawton, 2009; Chapman et al., 2012). This suggests that as well as being less likely to have access to personalised approaches, the same groups may *also* be less likely to have access to the mechanism which could address this inequality.

Positive examples of the impact of personalisation for isolated people with learning disability

Despite the evidence above which suggests that certain groups of people may be missing out on the benefits of personalisation, it should be highlighted that the search also revealed some examples of personalisation providing positive outcomes for some of the most isolated people with learning disabilities. For example Scown and Sanderson (2011) report on the positive changes experienced in a residential care home as a result of a change from block contract funding to individual service funds. Henwood and Hudson's (2009) report on support for people with multiple and complex needs found examples of ambitious, inspired, creative, highly individualised solutions – although they did note that these were despite, rather than because of, the systems they were operating in. Mansell (2010) found that where families of people with profound and multiple learning disabilities were supported they were getting what they needed and wanted through personalised approaches. These findings, though limited, do highlight that personalisation can produce positive outcomes for some of the most isolated people with learning disabilities.

Conclusion

This review has revealed a clear gap in the evidence around how personalisation has impacted on the lives of the most isolated people with learning disabilities. As no research was found which looked at this specific question, and the evidence presented above has been drawn from a wider body of research, the conclusions drawn from these studies should be considered as tentative. However they appear to *suggest* that:

- Some of the most isolated people with learning disabilities are missing out on personalised approaches to care altogether.
- Some of the most isolated people with learning disabilities do not have access to the support or resources to get the most positive outcomes from particular elements of personalisation.
- Some of the most isolated people are also less likely to have access to advocacy - the mechanism which should be in place to address this inequality.

In summary, it appears that some of the most isolated people with learning disabilities are less likely to have access to various aspects of personalisation (e.g. personalised care and support plans, personal budgets etc), less likely to benefit when they do, and less likely to have access to the advocacy needed to address this. As personalisation is a core element of current and future health and social care policy and provision, this raises serious concerns.

NDTi are planning to do some further work to address this gap in knowledge and we welcome any views, comments or examples of research or practice in this area which could inform this work. If you would like to get in touch, please contact Naomi Harflett, Research Manager at Naomi.Harflett@ndti.org.uk or 01225 789135.

References

Becker, P. (2006). Assessing the quality of service provision for people with challenging needs placed out of borough. *Tizard Learning Disability Review*, 11(4), 12–18.

Chapman, M., Bannister, S., Davies, J., Fleming, S., Graham, C., Mcmaster, A., Seddon, A., Wheldon, A., Whittell, B. (2012). Speaking up about advocacy: findings from a partnership research project. *British Journal of Learning Disabilities*, 40(1), 71–80.

Claes, C., Van Hove, G., Vandevelde, S., van Loon, J., & Schalock, R. L. (2010). Person-centered planning: analysis of research and effectiveness. *Intellectual and Developmental Disabilities*, 48(6), 432–53.

Cook, T., & Abraham, L. (2007). An Evaluation of the Introduction of Facilitated Person-Centred Planning with People with Learning Disabilities Leaving a Hospital Setting: Sharing the Knowledge. *Learning Disability Review*, 12(4), 11–19.

Dehaney, C. (2010). Use of resources in adult learning disability services. *Tizard Learning Disability Review*, 15(3), 53–56.

Glendinning, C., Fernández, J., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M., Wilberforce, Wilberforce, M. (2008). *Individual Budgets Pilot Programme: Final Report*. York: Social Policy Research Unit.

Hall, E. (2011). Shopping for support: personalisation and the new spaces and relations of commodified care for people with learning disabilities. *Social & Cultural Geography*, 12(6), 589–603.

Harkes, M. A., Brown, M., & Horsburgh, D. (2014). Self Directed Support and people with learning disabilities: a review of the published research evidence. *British Journal of Learning Disabilities*, 42(2), 87–101.

Hatton, C., & Waters, J. (2013). *The second POET survey of personal budget holders and carers 2013*. London: Think Local Act Personal.

Henwood, M., & Hudson, B. (2009). *Keeping it personal: Supporting people with multiple and complex needs: A report to the Commission for Social Care Inspection*. London: Commission for Social Care Inspection.

Lambeth Mencap. (2010). *Lambeth PMLD project: Understanding the lives and needs of people with profound and multiple learning disabilities in Lambeth*. London: Lambeth Mencap.

Lawton, A. (2009). *Personalisation and learning disabilities : A review of evidence on advocacy and its practice for people with learning disabilities and high support needs*.

London: SCIE.

Lingard, J. M., Cooper, V., & Connell, M. (2013). The personalisation challenge: personalisation for people with learning disabilities and behaviour described as challenging. *Tizard Learning Disability Review*, 19(1), 3–10.

Lowe, K., Felce, D., Perry, J., Baxter, H., & Jones, E. (1998). The characteristics and residential situations of people with severe intellectual disability and the most severe challenging behaviour in Wales. *Journal of Intellectual Disability Research*, 42, 375–89.

Mansell, J. (2010). *Raising our sights: services for adults with profound intellectual and multiple disabilities*. Kent: Tizard Centre

McConkey, R., & Collins, S. (2010). Using personal goal setting to promote the social inclusion of people with intellectual disability living in supported accommodation. *Journal of Intellectual Disability Research*, 54(2), 135–43.

Netten, a., Jones, K., Knapp, M., Fernandez, J. L., Challis, D., Glendinning, C., Jacobs, S., Manthorpe, J., Moran, N., Stevens, M., Wilberforce, M. (2012). Personalisation through Individual Budgets: Does It Work and for Whom? *British Journal of Social Work*, 42(8), 1556–1573.

Neville, S. (2010). *Delivering personal budgets for adult social care: Reflections from Essex*. Essex: Office for Public Management.

Rabiee, P., Moran, N., & Glendinning, C. (2009). Individual Budgets: Lessons from Early Users' Experiences. *British Journal of Social Work*, 39(5), 918–935.

Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krinjen-Kemp, E., Towers, C., Romeo, R., Knapp, M., Sanderson, H., Routledge, M., Oakes, P., Joyce, T. (2007). Person-centred planning: factors associated with successful outcomes for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 51(Pt 3), 232–43.

Robertson, J., Emerson, E., Hatton, C., Elliott, J., Mcintosh, B., Swift, P., Krijnen-kemp, E., Towers, C., Romeo, R., Knapp, M., Routledge, M., Oakes, P. (2005). *The Impact of Person Centred Planning.* Lancaster: Institute for Health Research.

Robertson, J., Hatton, C., Emerson, E., Elliott, J., McIntosh, B., Swift, P., Krinjen-Kemp, E., Towers, C., Romeo, R., Knapp, M., Sanderson, H., Routledge, M., Oakes, P., Joyce, T. (2007). Reported Barriers to the Implementation of Person-Centred Planning for People with Intellectual Disabilities in the UK. *Journal of Applied Research in Intellectual Disabilities*, 20(4), 297–307.

Scown, S., & Sanderson, H. (2011). *Making it personal for everyone: From block contracts*

towards individual service funds. Stockport: Dimensions.

Sheikh, S., Vanson, T., Comber, N., & Watts, R. (2012). *Longitudinal study of Personal Budgets for Adult Social Care in Essex Final report.* London: Office for Public Management.

Simpson, G., & Price, V. (2010). From inclusion to exclusion: some unintended consequences of Valuing People. *British Journal of Learning Disabilities*, 38(3), 180–186.

Sims, D., & Gulyurtlu, S. S. C. (2014). A scoping review of personalisation in the UK: approaches to social work and people with learning disabilities. *Health & Social Care in the Community*, 22(1), 13–21.

Thompson, D., Ryrie, I., & Wright, S. (2004). People with Intellectual Disabilities Living in Generic Residential Services for Older People in the UK. *Journal of Applied Research in Intellectual Disabilities*, 17(2), 101–108.

Thompson, D., & Wright, S. (2001). *Misplaced and forgotten: People with Learning Disabilities in residential services for older people* (pp. 1–21). London: The Foundation for People with Learning Disabilities.

Williams, V., Simons, K., Gramlich, S., Mcbride, G., Snelham, N., & Myers, B. (2003). Paying the Piper and Calling the Tune ? The Relationship Between Parents and Direct Payments for People with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 16, 219–228.

Williams, V., & Suzanne Battleday. (2007). *Where do you want to go next? Critical factors in care planning for people with learning disabilities, and their financial implications*. Bristol: Norah Fry Research Centre.