Independent Advisory Council to the NDIS

Attachment C

Risks related to abuse for self-managing participants

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Introduction

Building on the experience in the UK and US, the NDIS is founded on the premise that increased choice and control is beneficial for its potential to empower participants with self-management as the pinnacle of NDIS choice and control. Others have expressed concern that increased choice and control may increase the risk of abuse of some participants.

This advice examines the risks of abuse associated with self-management drawing on UK research in relation to Personal Budgets[1] (PB) and Direct Payments[2] (DP). The advice examines risks of financial, physical, emotional and sexual abuse for self-managing participants perpetrated by care workers, primary carers and other family members and concludes with mitigation strategies used to reduce the prevalence and impact of the abuse.

Terminology

In England, all social care recipients are allocated Personal Budgets (PBs) based on an assessment of need. PBs can be managed by local council staff as a Managed Personal Budget (MPB) or offered either in full or in part as a Direct Payment (DP). DPs were declared the 'preferred option (UK Dept. of Health, 2010)[3].

Translated to NDIS language, PB is the budget of reasonable and necessary support, MPB represents the plan management option of Agency managed and DP represents the plan management option of self-management.

Personalisation versus safeguarding debate

Many commentators argue "enhanced choice arising from the use of PBs may inherently promote safeguarding (or freedom from abuse or neglect) because care users choose who provides their support and how it is provided. This potentially creates the correct framework for preventing abuse by strengthening citizenship and communities"[4].

Early UK studies revealed concerns that PBs would increase risk. Some perceived risks stemmed from misconceptions about PBs, including the belief that all social care would be provided as cash payments (Glendinning et al, 2008)[5]. The development of infrastructure to

[1] Personal Budgets
[2] Direct Payments
[3] Department of Health (2010) *A vision for adult social care: Capable communities and active citizens*, Department of Health London
[4] Ismail, M et al, 2016, p293
[5] (Glendenning et al, 2008) (Ismail, p310)

support PBs including support from care managers through MPB and the evolution of third sector organisations such as Centres for Independent Living allayed some of these fears.

However, scepticism has also been expressed about the potential of PBs to meet social care outcomes, particularly when extended from people with disability to other groups eligible for social care such as older people. Particular concerns have been voiced about potential risks for vulnerable individuals and those who may lack decision-making capacity and for whom 'suitable persons' (nominees) hold the money. Concerns about risks of financial exploitation and abuse in particular were expressed in several studies (Henwood and Hudson, 2007 and Manthorpe and Samsi, 2013) especially in the context of marketization of care, outsourcing of services and reduced funding from central government. The ability of people receiving DPs to purchase their care from family, friends and others who are not regulated and for whom criminal record disclosure is not mandatory, heightened the perceived risk.

The evidence

A recent study by Ismail et al[6] provides empirical evidence about the uptake of PBs and safeguarding referrals in England, based on in-depth analysis of national data at aggregate, local council level, covering 152 Councils. This is complimented by analysis of 2,209 individual referral records obtained from three purposively selected study sites with the aim of exploring whether available data could provide evidence of association between the uptake of PBs and safeguarding referrals.

In summary, analysis of the national data sets found no significant relationships between PB uptake and the level and type of alleged abuse. The analysis suggested slightly higher levels of referral and repeated referrals in significantly rural areas. However, analysis of individual-level safeguarding referral data, from the three selected sites did find some significant associations particularly with financial abuse and found the main perpetrators of the alleged abuse to be home-care employees.

Financial abuse

The analysis of national data sets demonstrates that being on a DP did not make a participant more likely to experience financial abuse[7]. The evidence demonstrated no clear differences associated with local area deprivation levels for both income and employment but slight but not significant differences in financial abuse in relation to the level of rurality.

Further analysis was conducted on the probability of experiencing financial abuse by examining the relationship between individual factors and receiving a PB through either a DP

[6] Ismail, M., Hussein, S., Stevens, M., Woolham, J., Manthorpe, J., Aspinal, F., Baxter, K. & Samsi, K., *Do personal budgets increase the risk of abuse? Evidence from English national data,* Journal Soc.Pol. (2017) 46, 2, 291-311 Cambridge University Press 2016
[7] Ismail, M. et al p300

or a MPB. The only association observed to be significant was among people in receipt of a MPB and those with reported physical disability.

Other forms of abuse

The analysis of national data sets demonstrated no relationship between the level of uptake of DPs and the level of physical abuse[8], the level of emotional abuse[9] and the level of sexual abuse[10].

Physical abuse

National aggregate data and analysis of individual records did not indicate any clear relationship between the level of uptake of DPs and the level of referral of physical abuse. There were however differences between those with DP and those with MPB with people with MPB showing a significantly lower prevalence of allegations of physical abuse compared to people with DP and those not receiving any form of PB.

Emotional abuse

Analysis of national data indicated referrals involving allegations of emotional abuse were almost identical among local councils with different levels of DPs and MPB uptake.

Analysis of individual records from the three sites however indicated some level of difference in allegations of emotional abuse with those in receipt of DP having a higher prevalence of allegations of emotional abuse compared with those with MPB compared to those who did not receive any form of PB.[11]

Sexual abuse

The analysis of national data sets demonstrated no relationship between the level of uptake of DPs and the level of sexual abuse. Analysis of individual records however revealed a lower level of sexual abuse among those in receipt of a DP compared to MPB and those receiving traditional services.

The analysis suggests however a tentative relationship between allegations of sexual abuse and local deprivation level.[12] The findings point to a higher prevalence of referrals with allegations of sexual abuse within more affluent areas. While these

[8] Ismail, M et al, 2016, p301
[9] Ismail, M et al, 2016, p302-3
[10] Ismail, M et al, 2016, p303
[11] Ismail, M et al, 2016, p303
[12] Ismail, M et al, 2016, p303

differences may not be significant, they may be related to other factors in these areas such as higher levels of awareness, greater monitoring and active reporting.

There was some difference in relation to the level of rurality with median referrals of alleged sexual abuse being higher, but not significantly so, in rural areas.

Relationship to abuser

The analysis of national data sets demonstrated no relationship between the level of uptake of DPs and abuse by care workers[13], primary carers[14] and by other family members[15].

Care workers

Analysis of national aggregate data indicated a similar level of allegations of abuse by home care workers. **Very few councils however reported any referrals where alleged abusers were workers employed by PB holders** (i.e. self-directed support paid workers). There were slight differences however in the prevalence of allegations related to home care staff according to income and employment deprivation scale at the local authority.

Examination of individual records from three local councils found that for people on PB, the abuser was more likely to be a home care worker than family, other staff or volunteers. Regression analysis indicated a significantly positive association between receiving MPB and the likelihood of the alleged abuser being a home care worker.

Main carer as alleged abuser

Analysis of aggregate data indicates no association at the local council level of uptake of PBs, level of local deprivation or rurality and the alleged abuser being the main carer.

Other family member as alleged abuser

Analysis of national aggregate data indicated that alleged abuse by other family members was lower for recipients of any form of PB compared to recipients of traditional services.

Risk mitigation strategies

At the systems level

The need to focus effort at personal safeguarding to mitigate risk of abuse was recognised early in the development of PBs. Many suggestions came from participants and as a result

[13] Ismail, M et al, 2016, p304
[14] Ismail, M et al, 2016, p305
[15] Ismail, M et al, 2016, p305

changes were made to Adult Protection policies and Protection of Vulnerable Adults (POVA) List, risk enablement panels[16] were introduced and publicity and information was disseminated to PB users and training provided.

Other strategies to mitigate risk of abuse include multi-agency training and public awareness training were provided to ensure people were aware of what counted as abuse, identifying any risk factors for abuse and how these could be recognised in an individual support plan and preparing a guide for social workers about co-working issues, protection and risk management[17].

In responding to concerns that persons using personal budgets may not undertake criminal record checks, some authorities actively provided information about access to criminal record checks and the POVA list to ensure PB holders were fully informed. Some authorities enabled persons on individual budgets to access criminal record checks free of charge.

Increased monitoring was also put in place where vulnerability was a cause of concern. Monitoring involved visits and telephone calls to check how the person was and whether arrangements were working. This was considered essential in the first few weeks in order to be able to make changes quickly if necessary. The frequency and duration of visits varied in relation to the perceived level of vulnerability.

At the personal level

Other strategies to mitigate risk for PB holders included adult protection training, audit trails, improving complaints procedures and 'beefing up' advocacy services to support people in decision making.

Key themes from the research

The evidence reported is derived from empirical studies about the uptake of PBs and safeguarding referrals in England using in-depth analysis of national data covering 152 Councils complimented by analysis of 2,209 individual referral records obtained from three purposively selected study sites.

[16] A Risk Enablement Panel provides a forum for full and frank discussion and resolution of serious concerns relating to the management of identified risks highlighted in an individual's Support Plan. When there is a significant or perceived substantial risk, it provides a forum for a shared decision making process where the outcome will lead to the Support Plan being agreed as ensuring that the individual will be enabled by the support described to remain healthy, safe and well, and where the local authority will be seen to have discharged its legal duty of care.

[17] Evaluation of individual budget pilots, Chpt 11 Risk and risk management. Accessed at http://www.lse.ac.uk/LSEHealthAndSocialCare/pdf/IBSEN.pdf18 June 2017

The analysis of national data demonstrated no relationship between the level of uptake of PB in general and DPs in particular and the level of financial, physical, emotional abuse or sexual abuse.

However, the study found indications of increased level of financial abuse in more deprived areas, especially rural areas potentially pointing to a link between poverty and financial abuse, although in the means tested UK system, in poor areas there will be more people with disability eligible for council funded social care compared to more affluent areas.

In addition, the analysis of national data demonstrated no relationship between the level of uptake of DPs and abuse by care workers, primary carers and by other family members. Of interest is the fact that very few councils reported any referrals where alleged abusers were workers employed by PB holders.

Mitigation Strategies

For persons organising social care, the results highlight the importance of balancing enablement and risk through a continuous process of support and review when PBs are offered.

The development of infrastructure to support PBs including support from care managers through MPB and the evolution of third sector organisations such as Centres for Independent Living allayed some of these fears.

Systemic safeguards developed include adjustment to Adult Safeguarding policies and practices to reflect PBs, the development of risk enablement panels, the dissemination of information and training to PB users, other agencies and the public, support for planning staff to identify risk management issues in the planning phase and monitoring proportional to vulnerability and experience in the use of PB.

For PB holders, mitigation strategies include access to information and training in relation to safeguarding issues and free criminal record checks.

Implications for the NDIS

Tactical and evidence based risk management strategies are critical to the successful implementation of self-management to enable participants to experience positive risk safely.

Strategies to enable self-managers to experience positive risk safely include:

- support for community partners undertaking planning to identify risk factors

- support to build personal safeguards[18]
- the development of systems to support self-management as outlined in Appendix 1
- monitoring of self-managing participants proportional to level of vulnerability and experience in self-management

[18] This was recommended by the IAC in its 2015 advice Enhancing personal safeguards and approved by the Board in 2016. It has not yet been implemented.