

## **FINDING OUT IF SOCIAL CARE PERSONAL BUDGETS ARE IMPROVING THE LIVES OF ADULTS WITH LEARNING DISABILITIES IN WANDSWORTH**

### **An Enter and View Study**

### **Executive Summary**

#### **What is the study about?**

We did this study to find out how adults with learning disabilities in Wandsworth are getting on with using Personal Budgets for arranging their social care rather than relying on fixed services provided by the Council. Are they enjoying a wider range of stimulating activities? Are the supporting financial arrangements working properly?

#### **Who did we talk to?**

We spoke in depth to 13 people with learning disabilities and to the family carers of most of them. They covered a range of age, level of disability, gender and ethnicity. We observed them at some of the activities in their weekly schedules and talked to support workers who know them well.

#### **Are Personal Budgets improving people's lives?**

We found that nearly all the service users we talked to are enjoying busy weeks packed with diverse things to do. They and their families are very pleased that having a Personal Budget, often with an element of Direct Payment, has led to increased variety and stimulus in their lives, in some cases leading to less frustration and better quality of life. We came across excellent services that are stretching people with a wide range of disabilities.

We did not find anyone with significant gaps in their plans – but our need to rely mainly on providers to put forward candidates for our study may explain this.

#### **Are there any drawbacks?**

We found that that the big improvements in outcomes for our service users do come at a high price. Family carers are left with an enormous and bewildering burden of paperwork. Many remain confused about the Council processes and appear to get very little advice and support – for example on how to make changes to their son or daughter’s programme. They are very aware of the increased responsibility they are carrying, particularly if they are managing Direct Payments.

Other carer anxieties relate to Council cuts in respite and the high turnover of both services and workers funded by Council contracts – personal assistants employed directly tend to be more reliable.

Carers seemed to rely heavily on informal networks and contacts to achieve a range of activities for their son or daughter. The need for individual persistence and luck in finding someone at the Council who can help them was mentioned too often for us to conclude that the current system is either fair or sustainable.

### **What do we recommend?**

Social workers are clearly under tremendous pressure with large numbers of young people lined up to move into adult services in the next few years. But if service users or carers, often getting older themselves, are increasingly encouraged and expected to take more and more responsibility for managing complex packages of care, they need stronger support in understanding and finding their way around the system.

Our specific recommendations cover:

- Making improvements to the basic administration of the new system, adopting a customer service ethos – the Council should do what it says it will do in terms of providing written eligibility outcomes, care plans and Personal Budget information. The Council should set targets for when written information is sent out at each stage and for completing the process. It should monitor its adherence to these standards and publish the results.
- Streamlining ways for service users and carers to achieve changes to care packages, also setting standards of performance that are monitored.
- Introducing new approaches to supporting service users and carers through the processes – the Council’s stated plans to provide support planning and brokerage as

a separate process to assessments by social workers should be implemented as soon as possible, learning from carers to get it right.

- Direct Payments should be seen as a free choice and not pushed explicitly or implicitly onto service users and carers by the Council. If they are taken up, carers need particular support such as named contacts, exceptional payments for administration costs and guidance on the use of personal assistants which gives reasonable flexibility.
- The Council's comprehensive Transition Protocol should be supported by sufficient staff resources and should be monitored for its application in practice alongside other processes.
- More facilities are needed for respite care and more information should be issued about entitlement. Particularly where services are being restricted because of budget cuts, the Council's approach should be transparent and even handed.
- The Council should take a clear lead in seeking further improvements in the quality and range of services and should consider facilitating a carers' noticeboard for the exchange of useful information of service availability and quality.

We conclude from this study both that there are some real successes for individuals using Personal Budgets and that their carers are remarkably resilient and prepared to play their part despite the uphill tasks they experience on a daily basis – but they do need to get more consideration and support.

## **PEOPLE WITH LEARNING DISABILITIES: EXPERIENCE OF PERSONAL BUDGETS DRAFT REPORT OF ENTER AND VIEW PROJECT 2012 -13**

### **Introduction**

Over the last few years, in line with national policies, there have been significant changes in the way care is provided for people with learning disabilities in Wandsworth. Using the national Fair Access to Care (FACS) criteria, support has been focussed only on those whose needs are assessed as critical or substantial. Following a strategic review of services for people with learning disabilities in Wandsworth, the Better Days programme has been developed, which involves moving away from the former large day centres exclusively for people with learning disabilities (to which attendance had been declining) to smaller sites called hubs and community bases with the emphasis on greater social inclusion and the aim of supporting people to become part of the community they live in, be with friends or take part in specific activities they enjoy. Finally, the Personalisation agenda has been introduced on a national basis to ensure that every person receiving support should have choice and control over the shape of that support in all care settings. The main instrument of Personalisation is the system of Personal Budgets for social care and support.

### **Why we did our study**

We wished to find out from service users and their carers how these changes had affected them in order to follow up concerns that had been raised with LINK (now Healthwatch).

Some carers of people with learning disabilities had expressed concerns to LINK about the new regime. The familiar Atheldene Day Centre, a large purpose built centre, attended by many people for many years, and originally fought hard for by the now older carers, is to be closed. Questions were raised as to whether the range of new resources was adequate and

reliable enough to replace the Atheldene. The four replacement local Bases are in rented Community Halls. For some people the process of being allocated a Personal Budget and the changes to the care arrangements had been unsettling.

There were concerns that some people who had done so before were no longer receiving services.

There were also anxieties expressed by service providers that some valued services would not survive if they had to rely solely on payments from Personal Budgets without any block funding.

LINK had already undertaken some research on Personal Budgets with older people and people with mental health issues and identified concerns about the process.

## **The Proposal**

We planned to make case studies of 10-15 people with learning disabilities receiving packages of support via Personal Budgets. We wanted to find out how the service users themselves and their carers thought the new arrangements are working, identifying what they considered were the good and less good features.

We decided to interview and observe the service users, their carers, and key workers on visits to their homes and the activities that were part of their support packages so we could build up a picture of whether the service users were enjoying and benefiting from the new services.

Although we could study only a small proportion of the 366 people with learning disabilities reported to be receiving community services from Wandsworth Adult Social Services via a Personal Budget, we considered that these studies and the general research from interested parties would adequately reflect the sort of services people were now able to access and provide a flavour of typical issues arising.

The proposal to carry out an Enter and View study was approved by the LINK Executive in May 2012.

## **The Enter and View team**

The team members were Martin Haddon, Jenny Purkis, Alison Tomlin, and Peter West. We shared the research tasks and reported back at regular meetings. In order to assist with the interviews we recruited four additional volunteers with a special interest and experience in Learning Disability to work alongside us as Associates. They were Pat Billington, Penny Bradford, Pam Hall and Edna White. This ensured we could have two people on almost every visit.

## **How we went about it**

Firstly, we needed to know a lot of background: how the system for assessment and payments worked, the range of providers, what particular issues were troubling people. We attended meetings and also spoke individually to a wide range of people including family carers, providers, and Wandsworth Borough staff. A full list of the meetings and people we spoke to either face to face or on the telephone is in appendix 1.

We obtained information from Wandsworth Adult Social Services regarding the number of adults under 65 years with learning disabilities receiving support in the community and in residential care and how much money is spent. In March 2012 of the total number, 724, who received a service, 466 were currently receiving community services and 258 in residential or nursing care. In 2011-12 the annual expenditure on services for all adults with learning disabilities (excluding the £21M spent on Nursing and Residential Care) was approximately £16M.

We also read widely, both local and national information. See appendix 2 for the list of the main documents we looked at in our preparatory work.

We used the issues raised from these sources as the basis of what we wanted to find out in our case studies.

## **Finding people to interview and observe for our case studies**

We wanted the interviewees to reflect a range of age groups, ethnicity, living arrangements and degrees of disability. We included people attending and using a wide range of services including the new Bases and informal, personally tailored, activities using their own personal assistants. We did not attempt to interview people who were in long term Residential and Nursing Care placements.

It took time to obtain our sample. Over a period of about 6 months and with help from Generate, Day Care Services, Community Learning Disabilities Team, Odyssey Care, George Shearing Youth Club and carer’s networks we identified 13 service users who met our criteria and were willing to participate in our study. Most had a Personal Budget and some also had Direct Payment arrangements. All but two of our interviewees had family carers. We recognise that, given the practical limitations of obtaining our sample, we have not been able to identify people who did not receive services who may have previously benefitted from them.

We assured the 13 and their carers that their comments would not be attributed in our final published report and that they would have an opportunity to check the notes we made for accuracy. We visited most of the interviewees living with their families in their homes and one in a café. Where the family was less involved we met in the care providers’ base and the supported living home with the key workers. With their permission we then visited and observed most of them at the activities they attended. See appendix 3 for the full list of the facilities that we visited. We observed what the provision offered and how the individual got on in that context and discussed issues with their key workers.

Our interviewees were: 7 Women and 6 Men with the following distribution:

Age	Degree of disability	Ethnicity
Under 25 years 3	Mild 4	Majority white British , 2 Black or Black British, 1 Asian or Asian British 1 Other
25-30 years 2	Moderate 5	
30-40 years 4	Profound 4	
40+years 4		

## The questions we asked

We sought answers to questions in these areas; the interviewee’s experience of having a Personal Budget, how they decided to spend it, whether the right sort of activities were available, what was the process like, and what could be improved to make their life better. Refer to appendix 4 for more detail.

We returned to some interviewees and their carers a second time to follow up outstanding issues to see whether they had been resolved.

## **Communication**

Before we commenced the interviews we considered the problems of communication with people with learning disabilities who, either had limited language skills or, in some cases, were non-verbal. We took advice about how to phrase questions eg avoiding open-ended questions and the need to identify any tendency to echo opinions or say what is expected in answering. We found ourselves trying to observe mood, expression and engagement often as much as recording verbal opinions. We used carers and key workers for guidance about the best means of communication and capacity to understand and make decisions.

## **Records**

As part of the process of assembling the evidence for the report we gathered key information on our interviewees comprising; contact details, age, sex, ethnicity, degree of disability, living arrangements, services attended on what days, activities, support workers and travel arrangements.

When we made our visits we used a prompt list (see appendix 4) to ensure we covered the range of questions we wanted answered but did not use a questionnaire format.

Afterwards the written up notes of the visits agreed by the team members were shared with the service user and their carer so they could check for accuracy. We recorded the source of the written evidence, Service User, Carer, Worker or Observation. We then drew up an analysis summary sheet for each individual.

We do not include the individual records in our report for reasons of anonymity but they form the basis of our findings and recommendations below.

## **FINDINGS**

- 1. General impressions**
- 2. Setting up a Personal Budget: finding out available options and deciding**
- 3. Content of social care packages: activities**
- 4. Social networks**
- 5. Travel and transport**
- 6. Respite**
- 7. Access to Health Services**
- 8. Transition**
- 9. Process issues**

- a. **Assessment**
- b. **Other issues of clarity**
- c. **Delays**
- d. **Other Social Work issues**

## **10. Personal Assistants, One to Ones**

## **11. Administrative burden of Direct Payments**

## **12. Contingency and future planning**

## **13. Quality and monitoring**

# **FINDINGS**

## **1. General impressions**

We were impressed by the overall level of care which our interviewees were receiving, by the variety and creativity of the approaches taken to meeting their very diverse needs, and by the dedication of those, whether parents, family members or professional staff who implement these care arrangements from day to day. These care arrangements are supported by a complex system of assessment, administration and finance which, not without hiccups, delivers the good results we saw but which shows clear signs of under-resourcing and variability in performance, leading to unsatisfactory situations, in some cases glaringly so. Our interviewees and their carers expressed an overall level of satisfaction with the current care arrangements and clearly recognised the improvements resulting from recent policy changes under the banners of Better Days and of Personalisation.

Many of the carers managing Direct Payments, however, emphasised the heavy burden of administration they carry and some carers drew attention to the contribution they make in terms of personal effort, time and sometimes money to supplement, or make good perceived gaps in, the support provided. Some had concerns about lack of transparency or perceived unfairness in some of the financial arrangements. But even where there were glaring instances of delay, carers showed a to us surprising level of tolerance and long-

suffering, which we suspect may be socially reinforced within the community of those dealing with learning disability and its consequences. We consider it would be wrong to allow this long-suffering attitude to disguise systematic or individual shortcomings in service provision.

## **2. Setting up a Personal Budget: finding out available options and deciding**

Personalisation offers real opportunities to tailor care packages more closely to people's interests and needs, including development needs. We asked how people found out what they could do with a Personal Budget and made the decisions. Three of our interviewees seemed to have benefitted from the pilot scheme initially set up in 2009 with a dedicated social worker to start the process of moving people onto Personal Budgets. There are some indications that people dealt with under the pilot may have received more thought and attention in setting up their care packages than has been available to later comers when the pressure to meet the Council's targets has been greater. Others of our interviewees have clearly relied heavily on keyworkers from independent service providers (in particular Generate or Odyssey) or on directly employed Personal Assistants for help in identifying and deciding possible activities. In a significant number of other instances, where mainly younger adults were concerned their parents felt a distinct lack of officially provided information and of the opportunity to discuss things face-to-face and consequently found themselves relying (perhaps too much?) on word of mouth recommendations eg. from other parents in a similar situation who they met via Dolphins or Mencap. (The specific problems of Transition are dealt with separately below).

The question of individual choice, which features largely in the official discourse of Personalisation, is of course particularly problematic for people with severe learning disabilities. We were however impressed by the attention that generally seemed to be being paid to people's likes and dislikes. As a regular procedure people were taken to an activity centre (or a number of them) to see if they liked it before any decision was taken. People's expression particularly of dislike was often very clear and we came across several instances where people decided to stop attending a particular centre or respite provider without being able to verbalise the reasons. In other instances people's enjoyment and enthusiasm for a particular activity was clear to their carers or keyworkers. The system of annual reviews (to the extent that it functions) provides an important longstop in this respect. A

number of those we spoke to specifically identified greater freedom of choice as a benefit of the new system. We found some packages that involved staff going to considerable lengths to arrange genuinely 'personalised' programmes for example sampling activities and varying a programme over time, but it is likely, and, perhaps inevitable, that for some the range of provision is limited. At least three of our interviewees expressed an interest in activities that were not available to them. In general we have a worry that choice may tend to be limited to what is already provided locally without sufficient thought being given to creating new opportunities.

### 3. Content of social care packages: activities

We received generally very positive feedback about the amount, range and type of activities supported by our interviewees' Personal Budgets. A full list is at appendix 5. We cite some examples of those we visited in the text boxes. The activities we encountered can be categorised as: work experience (only one of our interviewees had found any paid work), education, including numeracy, crafts, drama, music, physical exercise (including cycling, dance/movement and swimming), and purely recreational and social.

"He was bored at the Day Centre but now shows off his achievements with pride. 'Everyone revolves around me!'"

To some extent these categories overlap: many of the activities serve an educational purpose in the wider sense and all give opportunities for social interaction and have an element of keeping safe. The majority of our interviewees had activities each weekday morning and afternoon and sometimes weekends too, depending on their circumstances, in particular the availability of family care and the degree of disability.

There were some instances, particularly involving younger adults, where we wondered whether parents could have secured financial support for more activities for their son or daughter had there been a fuller discussion of the options. A number of particular problems we encountered in relation to failure to support, or delay in supporting, particular desired activities are dealt with later as instances of issues with the process of administering Personal Budgets.

A number of carers mentioned that the variety of activities now provided across the week reduced boredom and frustration. Some were of a very high standard and improved motivation and development towards greater independence.

We were particularly impressed by this specialist craft workshop for adults with learning disabilities recently set up and run as an independent not-for-profit company by a team of craft tutors formerly employed at the Council's Atheldene Day Centre. The building was spacious and well-adapted, the craft facilities for ceramics, graphic work and woodwork seemed excellent, the staff were highly professional as well as understanding of the problems of learning disability, the atmosphere was calm, business-like and cheerful and the students we saw (they have about 70 students in all from Wandsworth and neighbouring boroughs) were well engaged and clearly enjoying the work.

We observed excellent music tuition which included composition and guitar working towards a performance. But the group was only just financially viable because of the small numbers attending.

One interviewee had a programme which involved a different activity each day of the week and "had never been happier"; "its made a great difference to [their] behaviour", according to the carer.

The question of the value of the various activities in developing skills and abilities is clearly a

We chanced to meet one of the interviewees out shopping with a colleague new to their project. Given the responsibility for supporting someone else, handling the bill and so on there was no obvious disability: the interviewee was a shopper like any other.

tricky  
one  
and  
accou

nt needs to be taken of the particular abilities and potential for development of the individual concerned.

But we did feel on reflection that, while the developmental quality of what we saw or heard about was sometimes clearly excellent, it sometimes seemed to fall short of an individual's capabilities. We felt that this might reflect a variability in performance, whether at the assessment stage or in service delivery, but that there could also be systemic issues here such as the need for better communication and sharing of good experience both between professionals and with family carers. It also raises the wider question of quality assurance which we return to below.

#### 4. Social Networks and Informal Advice

We encountered conflicting evidence as to whether personalisation has increased or decreased supportive social networks for both the interviewees and their carers. There is a risk that people (carers/Personal Assistants as well as the people with learning disabilities) may become isolated and lose opportunities for support, information and for developing new ideas and ways of working through contact with their peers.

On the one hand some interviewees missed the large group activities, for example Green Bus journeys, and familiar faces. On the other hand some had also widened their range of contacts: they met a wider variety of other people with learning disabilities, as well as using 'mainstream' facilities, including leisure centres, helping at a charity shop, public transport and eating out and so meeting more of the general public.

We saw one of our interviewees travelling as part of a group by bus to a gym, exercising amongst mainstream gym members and thoroughly enjoying choosing and collecting their meal from the public cafeteria.

And the development of individual real relationships with long term P/A or One-to-one carers should not be underestimated.

For carers, however, the Day Centre was no longer serving as a focus for support and information. Carers were finding their support from diverse groups such as Dolphins Swimming Club, Mencap, the Carers Centre, and even the Borough consultation groups, some of which are financially fragile.

One carer said "Mencap is my first point of call" - Another "I've been coming to Dolphins for years and I never miss a week."

This fragmentation will make it more difficult for carers to speak with a united voice over matters of concern. The Personal Budget system does not naturally support small self- help and voluntary initiatives such as Dolphins, Gateway and Tooting Tryers (which are in fact examples of co-production, a policy promoted by Social Services) and we are concerned that without the capacity to manage larger cash flow such groups may be threatened by the removal of the relatively small contributions they receive in the form of help with transport and rental costs.

One carer had "no idea about social workers, they change so often."

Also previously the Day Centre offered a first level of expertise for identifying abnormal behaviours, psychiatric problems

etc and referring to the appropriate agency. Most interviewees or their carers we spoke to could identify someone whose expertise they respected to whom they would go if there were a problem but not all. It was frequently a manager of a service that they had used in the past. Some of our interviewees when asked who they would go to if worried were vague and referred to workers who had now left the department.

This suggests that there is an issue here to be addressed. The ideal would be an allocated social worker for each person with learning disabilities eligible for social care but we recognise that this is unrealistic. But we do think it is important, when a person's needs are assessed or subsequently reviewed, that the question is explicitly addressed where the person or their carer can readily go for advice if concerns arise – whether that be a member of the social work team, or an agency manager or a Mencap worker.

## 5. Travel and transport

The wider range of activities now being offered to people with learning disabilities and the attempt to overcome social exclusion puts more emphasis on people's need to be able to travel safely and freely to access the increased number of venues. Three of our interviewees now regularly travelled to activities independently on public transport. We were impressed by the number of solutions being used by the others: one person with mobility problems has their own Motability car for their PA and other keyworkers to drive them around in; some of our interviewees employ PAs who escort them on public transport; one uses a Travel Buddy scheme, which can have the added merit of giving employment to people with milder disabilities; some have regular taxis provided, if necessary with an escort as well as a driver. Without collective transport some interviewees had achieved the skills to; walk to specific places independently, travel on certain public transport routes and behave reliably on public transport when necessary.

Clearly some modes of transport involve greater risk of various sorts of breakdown than others. We heard a number of anecdotes about problems with cabs and with unfamiliar and unreliable Travel Buddies. Some taxi firms can provide trained and CRB-checked drivers, others do not. But we did not find any systemic problems. Collective transport is still being provided by some of the centres which people with learning disabilities attend and this is

likely to be cheaper and more reliable but on the other hand less flexible, usually with long pick up and drop off routes. Some of this transport is provided or part-funded by the Council and there are reports that cutbacks are in prospect. In at least one instance, the Dolphins Swimming Club, a longstanding facility for children and adults with learning and other disabilities organised and run by local people with financial support from the Council and other sources and attended by a number of our younger interviewees, there is a fear that the loss of Council transport could threaten the viability of the Club - as it already has precipitated the closure of the Rainbow Art Club. This would be a serious loss and needs to be avoided. (See above issues regarding vulnerable self-help initiatives)

## **6. Respite**

People with learning disabilities and their carers both need breaks from their usual routine. Carers of people with learning disabilities can also badly need time off, either away or at home, from the often physically and emotionally demanding routine of care. From what we heard, the Personal Budget system does in principle recognise these needs but the rules do not seem to be very clear and the availability of suitable respite arrangements in practice does not seem to match the potential demand. The Council's recent decision to reduce entitlement for some people with learning disabilities had affected some of our interviewees adversely.

We encountered a number of types of holiday or respite (but this may well not cover the whole field). One is the independent holiday, not financed directly out of personal budgets: we met some people who have been fortunate enough to be able to go away for holidays with their families and at least one who has no family but has been able to finance periodic holidays with the necessary support staff out of other available income. The second is group holidays away from town organised and staffed by a service provider like Generate – in some instances these seem to have been paid for out of Personal Budgets, in others not.

Then there are established residential facilities offering respite care within or outside the Borough which people are able to use out of an allocation in their Personal Budget. The largest of these, Hartfield House in Roehampton Lane, operated by the Southside Partnership under a contract with the Council, was mentioned to us a number of times but more often than not as a place that someone did not like or would not go to again. We understand that the Council consider Hartfield House as no longer fit for purpose in the long term and are planning to replace it shortly with a newly refurbished but smaller building

under the same management in Wardley St SW18. In addition there is a further respite care scheme, called Shared Lives, also operated by Southside Partnership under a Council contract, which involves placing people with learning disabilities in the family homes of paid carers. This seems originally to have been intended as a basis for long term placements but the potential for a short term respite scheme has been recognised and is apparently being developed. One of our interviewees has been spending one weekend a month with a Shared Lives worker, overlapping one night with a friend. A similar scheme on which at least two reported very positively involved breaks in Norfolk staying at the home of a previous manager of Hartfield House. Direct payments enabled other ways of providing respite. One parent carer was able to pay her daughters to come to stay and take over whilst she was away. And one hoped to find a suitable companion for one of the interviewees so two of them could go on holiday together and share care costs.

We encountered general concern about respite provision within the community of people involved in the care of people with learning disabilities. In particular in relation to our 13 interviewees, the lack either of funding or of suitable facilities or both was mentioned as a problem of greater or lesser significance in the case of 7 of them and in 1 further instance, a young adult, there was apparently no current provision for respite but the family seemed to accept this situation. In another instance a young adult was receiving 52 days respite care but from a children's provision which would not continue to be available to them in the longer term.

Some carers concerns about availability of suitable respite provision related to their worries about future care if a time came when they were unable to continue.

## **7. Access to health services, therapies and equipment**

Although not all directly related to the content of personalised social care packages, this seems to be the place to mention what we heard about health issues and access to health and related services. First, nearly half of our interviewees suffered from physical disabilities or long term health problems and at least two others had needed significant dental or other treatment. We got the impression that at least for the most part health services had been sensitive in their handling of these vulnerable patients. Secondly, it was clear that people's health needs, particularly the need for exercise, were being given appropriate consideration in the design of their social care packages.

But, thirdly, we encountered two specific shortcomings, one of which seems to us to be serious. This is the apparent failure of the Wheelchair Clinic at Queen Mary's Hospital to recognise the need of a profoundly disabled young person of 18 who has simply outgrown their existing wheelchair. The need for a replacement seemed clear to the (unqualified) members of our team who visited. His parents say they pressed for a replacement at the last annual assessment but were not listened to. The special school have tried to make the wheelchair serviceable but believe it should now be condemned. But they seem fatalistic about the prospects of persuading the Clinic in advance of the next review. We feel that the decision of the Clinic if sustained could potentially be viewed as abuse of a vulnerable adult.

The second shortcoming, although less dramatic in its effect seems to be systemic and therefore worthy of attention. One of our younger interviewees, now 19, who has both physical and learning disabilities, used while still at school to benefit from physiotherapy, speech therapy, occupational therapy and hearing and visual impairment services. Despite what they were told at the school, these services are not available at the mainstream college now being attended. They have asked Connexions for a referral to the therapy services in the Community Learning Disability Service at the Joan Bicknell Centre but nothing has transpired. They have been told that OTs at the Joan Bicknell Centre are not taking new clients. This situation does not seem satisfactory and seems to point to a systemic problem eg under-resourcing.

## **8. Transition**

The above findings mainly concern the content of personalised social care packages. We have a number of findings to report on people's experience of the process of operating Personal Budgets. But before moving on to the generality of these, we would like to focus on the particular issues arising from people's experience of the Transition stage. This is the term used specifically to refer to the transfer of responsibility for someone with learning disabilities from the Disabled Children's Service to Adult Social Services. This transfer formally takes place when someone reaches the age of 18 but the process of preparation for this and the subsequent putting in place of adult care arrangements is described as Transition. This is inevitably a period of some anxiety and stress for the young people and their carers and the processes involved need careful handling, not just because children's services are free and adult social services involve a financial assessment. Adult Social Services have established a Transition team within the Community Learning Disability Team

and in February 2011 they issued a Transition Protocol setting out in some detail the various stages of the Transition process and the actions which should be taken, starting some years before someone's 18<sup>th</sup> birthday. The main actors in the process, apart from the young person and their carers, are the school, the Connexions advisory service and Social Services themselves. The issuing of this protocol represents at least a tacit admission that things have not always been handled correctly in the past and the experience of a number of our interviewees and their carers continues to bear this out.

For recent experience of Transition we can only look to four of our interviewees: three aged 18 to 19, two of whom were identified for us by the Transition team, and one aged 25 identified for us by the Council's Youth Service. The evidence from this small sample suggests that problems with the Transition process are yet to be ironed out. The youngest interviewee, who is severely disabled, has so far had a good, if limited, experience of Transition, being still at a special school for one more year and able to attend the George Shearing Centre's daytime programme in the holidays as well as a residential respite centre for disabled children. For this young person there has therefore so far been no real change. The family have been looking at the choice of a specialist college for next year but this will have to be outside the Borough. They have very little information at this stage about other local services that the young person might need to access while at college, eg for respite, or after the expected three years there.

The two 19 year olds have had less happy experience. In one instance the family, although attending Transition reviews at the special school

'This has taken up my life for the past year.' 'The social worker knew less than I did,' said a carer commenting on a lack of timely and appropriate support from the transition team.

and receiving advice from Connexions, were either steered or allowed to choose a mainstream college, which when it finally (and perhaps belatedly) saw a full statement of the young person's needs declared themselves unable to provide the necessary support. The consequence was that the young person lost a term of their education (autumn 2011) and the family were left making shift as best they might to provide support and activity at a very difficult time in their lives, until a place was found at a special college outside the Borough. This strikes us as a very serious failure of the system, although we have not heard all sides of the story.

The other instance reveals a variety of gaps and problems in the Transition arrangements, none of which in itself has had quite as serious consequences: but the whole process has

accounted, according to the carer, for “taking up my life for a year” and two complaints to Social Services. One of the factors seems to have been an excessive turnover or discontinuity of social workers. In consequence for much of their last year at special school (ending July 2012) this young person with multiple difficulties, having passed out of the responsibility of the children’s services had no access to adult services for respite or activities out of school hours, (A particular problem about access to therapies is dealt with above). Only with major efforts by the carer, it seems, was a satisfactory package put in place in time for the young person leaving school and starting college four days a week.

In looking at these young people’s experience of Transition we became aware that the initial transfer to adult services was often only a first stage, with college often replacing school and with continuing attendance at familiar youth clubs and activities. A further important transition takes place when a young person “moves on”, leaving college and outgrowing youth clubs, which tend to have an age limit of 25. The Council’s Youth Service kindly identified such a person for us to interview. This was a severely disabled young person of 25 who had had 3 years at a specialist college at a variety of sites outside the Borough and had finished there in July 2012. Some 6 months later, the person was finally settled at a day centre 4 days a week and receiving some additional one to one support from an independent provider at weekends, but the formalities of establishing the Personal Budget were apparently not concluded and it was due to return to a Panel. The intended support plan included part-time college attendance but no suitable place was available. No residential respite had been received since 2010 when an incident at Hartfield had led to admission to a psychiatric hospital. The parent’s experience of the process was not good. Social workers had changed fast and family got more help from the day centre and independent provider staff. An advocate had been appointed after the hospital admission but had proved unreliable. Clearly this was a complex and difficult case but it serves to emphasise that the problems of Transition do not end at 19 and that preparation for the further transitional stage needs to start earlier than currently seems to be happening.

One of the problems has clearly been under-resourcing. We were told that the Transition team had been strengthened to a complement of three social workers and was now fully staffed but we remain concerned that under the present system the team will find it difficult to cope with their potential caseload, which we were told, had already reached about 172. It is to be hoped that the Council will ensure that adherence to the essential requirements of the Transition Protocol is enforced and monitored by Social Services management. On this, we were not much reassured to be told by the head of the Transition team that even with their increased complement it was not possible to attend all the Transition reviews held

annually under the Protocol. This means that social workers will know little of the people they are dealing with at Transition and the Adult Services perspective will not be fed in until a late stage in the process.

## **9. Process issues**

We were given oral information about the process of setting up and operating Personal Budgets at our various meetings with Adult Social Services staff and members of our team attended regular meetings of the Advisory Board set up by Adult Social Services in March 2012 as part of “The Future, Today,” a wide-ranging review of social care arrangements. We also received from Adult Social Services and from some of our interviewees a number of relevant documents, included in the list of reading matter [appendix 2]. We have not attempted to carry out a systematic audit of the process but we did note some significant discrepancies between the official account and individuals’ experience. We have dealt above with the specific issue of Transition and the following sections focus on other issues arising.

### **a) Assessment**

The formal process of setting up a Personal Budget starts with an assessment in which a person’s needs for social care and support are identified, using a Personal Needs Questionnaire. If the identified needs pass the Council’s threshold for support under a national set of criteria known as FACS (Fair Access to Care Services), then they are entered into a computerised valuation system devised by the Council, known as the Resource Allocation System, which produces an Indicative Budget within which in theory the person’s support plan is supposed to be constrained. Provision is made for cases where the support plan cannot realistically be so constrained to be referred to a special Panel who determine the financial envelope on a case by case basis. In practice, as the Council have now recognised, the existing Resource Allocation System is not fit for purpose, since too high a proportion of cases, particularly for adults with learning disabilities, have needed to be referred to the Panel. This, although it means that many decisions are taken on an individual basis, is a costly and time-consuming business and has undoubtedly added to the pressure on social work resources and the consequent delays (of which we found evidence described below). The Council are currently procuring a new Resource Allocation System (called FACE)

from an independent provider, which has been in use elsewhere and has a better track record. It is to be hoped that this and other changes which the Council are proposing to make under their review will speed up processes connected with the setting and operation of Personal Budgets. But it must be recognised that if the revised arrangements allow greater reliance on automatic systems there may be a greater element of “rough justice” in some of the decisions taken. The Council will need to monitor the impact of the changes very carefully.

It may be of interest to note that in the course of our interviews, while we obtained a significant amount of evidence about lack of clarity, delays and other difficulties in the process of establishing Personal Budgets, we heard only two comments on the initial assessment process as such. One of our interviewees was allocated a personal budget after an assessment conducted with the family carers over the telephone; the social worker had not met the individual or carers. The budget would have covered around half the cost of their existing services. This was corrected following an intervention by staff at Generate. The other family reported that it had taken a prolonged series of case conferences and input from a care support organisation that already knew them to identify the disabled person’s full needs.

But the assessment process does not seem to be sufficiently transparent: one of our interviewees, who, being in a higher ability range than most, was managing some of their own Personal Budget in the form of Direct Payments, clearly found it hard fully to grasp that the support package was intended to meet specific assessed needs and showed some frustration at the limitations thereby imposed on what the money was allowed to be spent on. A similar misunderstanding had arisen with a carer in another instance about which we heard. The concept of “Outcomes” seemed little understood and no one offered to show us their support plan.

“I think I have got a support plan somewhere” said one carer, but they could not find it.

## **b) Clarity in relation to Personal Budgets**

The other end of the initial process is the allocation of a Personal Budget for a person’s social care arrangements. According to the official account, this also involves offering the individual or their carer the option of taking some or all of the budget in the form of Direct Payments (ie monthly payments into a dedicated bank account which the individual, carer

or other responsible person can use to meet the cost of the specific care arrangements agreed). It should also involve a financial assessment of whether the individual is liable to meet part of the costs from their other income (whether from benefits or otherwise).

In the case of 6 of our interviewees Direct Payments were being received for all or part of the person's care arrangements. Typically the elements provided by Council services such as the Atheldene day centre or the "social bases", were understood to be being administered by the Council. In a further four instances, the family carers or (in one case) the responsible housing manager were clear that a Personal Budget for the individual in question had been established or was in the process of being established and being wholly administered by the Council.

But in the case of three out of our 13 interviewees the individual's main carers, in each case the parent or parents, said that they were unaware of or totally unclear about the existence, let alone the details of a Personal Budget. None of them had apparently been offered the option of Direct Payments. In two of these cases there had been demands from the Council for a sizeable financial contribution (one of which had apparently been withdrawn, the other had been renegotiated to a more manageable regular amount) which suggests that the process of establishing a Personal Budget may well have been completed at the Council's end, but without adequate notification of the outcome to the carer. In the third case the parent was not aware of any financial contribution having been assessed and believed that they were still waiting for the completion of the Personal Budget, some two years after the arrangements had effectively been put in place. Whether or not this last instance is indeed mainly or partly due to excessive delay in completing the paperwork, these examples do seem to us to attest to a lack of clarity in the system and in particular a failure on the Council's part to communicate effectively with carers.

### **c) Delays**

In addition to the last-mentioned case, we heard complaints of apparently excessive delay in finalising Personal Budgets in two other instances: one of our interviewees had been waiting at least 11 months for the final outcome, another (one of the Transition cases mentioned above) over 6 months after leaving college, the preparatory work presumably having started some months before that date. In both cases the delay concerned the final approval of the budget. It did not significantly affect the individual's actual access to the services which were already in place, but delayed increase or change to the provision. But such long delays even when of limited practical significance seem to us evidence of a system under strain and can be stressful for family carers.

More serious in their practical impact can be the obstacles and delays, about which we also heard, in making changes to Personal Budget arrangements after they have been agreed. The need for such changes can arise for a variety of reasons and we have been told by social services management that people needing minor changes need only make a phone call to the Finance Dept or to the relevant social work team and that only where an increase in the Personal Budget is required does the issue lie outside the competence of a single finance officer or social worker to settle. In practice we encountered the following 4 glaring instances of delay or obstruction among our 13 interviewees.

*"Changes take ages" said the mother of one severely disabled young person who was originally intended to go to college on a*

A young person who left school last summer hasn't been able to go the specialist gym sessions provided for in their support plan because the gym was incorrectly named in the support plan. The money is piling up unspent; getting the wording changed has defeated a determined but increasingly embattled parent.

An older interviewee who, despite having mobility problems as well as learning disabilities, has clearly benefitted from the new arrangements which provide opportunities to go out and about with one-to-one support, was effectively "grounded" one day a week after deciding for their own reasons to stop attending one of the Council's centres. The independent provider which manages the house where the person lives has suggested swapping the funding to allow house staff to take them out for part of the day. An arrangement has been proposed which would actually involve a small net reduction in the budget – but nearly five months later the social worker had still not agreed the switch, apparently maintaining it will need to go to a Panel. Meanwhile so far as we know the person continues to sit at home one day a week in front of TV programmes which they do not really watch.

After a number of years without a review, a social worker at the 2012 review had encouraged the family to think of more demanding activities for their bright but disabled 26-year old. Shortly afterwards an opportunity arose for the young person to attend an extra class. This would have cost more than the equivalent amount of one-to-one time already provided for. When approached, the social worker said that the change could not be considered until the next annual review. For nearly a year the family put up with this and found the £35 a week for the class out of their own pockets. At the 2013 review in February a different social worker said that the Council was unlikely to agree to an increase given the current expenditure position but suggested the family ask again in the new financial year.

This last example seems to suggest that the difficulty of getting changes made to Personal Budgets is not just a result of excessive pressure on social work resources (of which we heard other evidence – see below) but may be being used by the Council as a tactic to cut work and limit expenditure. Such a policy would be at odds with the Council’s published information and would in our view be hard to justify. [There is, as we found, quite a widespread fear of impending expenditure cuts impacting on current social care packages: if policies of austerity are indeed to be pursued in relation to the support needs of vulnerable people, then this needs to be done transparently and even-handedly, not arbitrarily and by stealth.

#### **d) Other social work issues**

Under the current arrangements Council social workers play a key role in deciding and sometimes administering aspects of personalised social care. We heard from a number of our interviewees the suggestion that decisions can depend unduly on the views of an individual social worker and that the performance of social workers varies. It should be noted that this was most apparent when a new social worker performed better or took a more favourable decision than their predecessor, which is at least in the right direction.

There were a number of comments (not only in the Transition cases but more widely) on the apparently rapid turnover of social workers which means that they may know little about the people whose needs they are assessing or on the difficulty of reaching social workers or social work managers when something needs doing.

One carer was not sure who she could go to now “because things are changing”

A number of our interviewees mentioned that when they have needed help in getting support arrangements set up or changed they have relied on Council day centre staff or staff of independent service providers who have sometimes provided advocacy and support well beyond the terms of their contract.

We were told how a service manager known over a number of years, “stood up for \_\_\_ in pushing his case”. But the carer was not sure what the formal advocate was supposed to have done.

We take all this as further evidence of the current strain on social work resources. It was noteworthy that the parent of the only interviewee who appeared to have had an identifiable allocated social worker for a significant period of time seemed to have the least difficulty with administrative aspects of the system.

#### **e) Brokerage and support planning**

We understand that the Council are currently considering in their wider review the possibility of separating the role of needs assessment, which arguably demands the skills and judgement of a qualified social worker, and those of assisting people in identifying the available options for meeting their support needs, introducing them to suitable providers and negotiating detailed arrangements with them, which almost certainly do not. Scarcity of social work resources seem to be the main pressure at the moment and the idea of re-allocating part of the present process to a potentially less scarce and less expensive category of staff seems to us to be a worthwhile one to pursue. Brokerage provides an opportunity to provide a valuable source of information and support to families independent of, but complementary to, the social work role. We heard on one of our visits to an independent provider operating on the edge of the Borough that neighbouring Boroughs whom they also serve make more use of this kind of brokerage. Their experience is that specialised brokers of this kind can indeed smooth and expedite the process of setting up practical support arrangements. It seems to us that this support planning and brokerage function does not need to be provided solely in-house by the Council but should be susceptible of outsourcing to established independent providers on a cost-effective basis. Indeed the evidence above suggests that some individual provider staff are already making a (not fully acknowledged) contribution in this area.

### **9. Personal Assistants/One –to-ones**

One of the principal changes that seems to have occurred in the provision of social care for adults with learning disabilities in recent years has been the growth in the use of personal assistants (PAs), sometimes referred to as “One-to-ones”. Such staff are employed by the Council in some of their day centres, by independent service providers and agencies, and directly by disabled people and their carers. They play an important role by accompanying the disabled person for significant parts of the day (including in the community and on public or private transport), ensuring that the person is kept safe and their needs are met,

and helping enrich the person's experience and promote the maximum degree of independent functioning.

It hardly need saying that this role requires the PA/One-to-one to form a relationship of mutual trust with the disabled person they are supporting. The great majority of our interviewees rely significantly on one, or in some cases several PAs/One-to-ones and in some cases their provision probably accounts for the bulk of a person's Personal Budget. We encountered a good deal of flexibility in how PAs/One-to-ones are used and the growth of this type of support seems to have contributed significantly to the improvement that some at least of our interviewees have noted in the overall quality of care arrangements in recent years. In one case a team of PAs had enabled someone to return to live at home after a long period of residential care.

"Anything \_\_\_ needs, her PA will fix" said a contented carer.

Direct payments have enabled people with learning disabilities and their family carers to directly recruit and employ PA/One-to-Ones of their own choosing as well as via agencies. We report the following positive comments. Known and trusted directly employed PAs were more flexible and it was easier to vary arrangements. They were longer term, some were, or had become, friends of the family. They could be trusted to take on greater responsibilities (such as accompanying an interviewee to hospital appointments). There were no longer problems of the interviewee having to relate to a stranger and the task of briefing a new one-to-one provided by an agency.

But we identified in the course of our interviews and visits a number of questions or issues which we need to bring to the Council's attention in the context of the wide-ranging review of social care arrangements in which they are currently engaged.

One concerns the qualifications or training of such personnel: we did not investigate this systematically but we became aware that the individuals that we met or heard about had had a range of previous experience and qualifications. Where the Council or an independent provider employs a one-to-one worker there are no doubt policies in place to ensure the suitability of staff employed. But a number of our interviewees use Direct Payments to employ Personal Assistants/One-to-ones directly or through some kind of agency. We were not told of any guidance issued by the Council about qualifications or previous experience of such staff. We would not necessarily favour restricting the ability of disabled people or

carers to employ people personally known and trusted but we think there might be a place for some guidance at least of an advisory nature.

Leading on from this, we became aware that a number of the one-to-one staff that we met or heard about had obtained their previous experience of such work within Council day services of the type which are now being dismantled or scaled down in favour of more personalised and socially inclusive systems of support under the banner of Better Days. The supply of trained one-to-ones is therefore benefitting, to some extent artificially, from the changes in the system. Our question is: how will the supply and training of such staff be assured in the future? Will it be sufficient to rely on the economic forces of supply and demand in a free market? Or is this something which the Council, or Government more generally, needs to be thinking about?

Supply and demand can perhaps be expected in the long run to regulate the price that needs to be paid for such work. But the Council has seen the need, presumably for the safeguarding of public expenditure, to set limits to the rates of pay for one-to-one work under Personal Budgets. We understand that in calculating Personal Budgets and awarding Direct Payments, the Council uses a basic hourly rate for PAs/One-to-ones with higher rates for unsocial hours, weekend and Bank Holiday working. We have the impression (but are not sure) that this does not prevent an individual employer choosing to pay “over the odds” in a particular case, which would presumably mean the employer finding extra money from elsewhere or obtaining fewer hours of care than the Personal Budget was assessed upon. We need to report that one of the carers we interviewed strongly believed that these arrangements were operating unfairly in that the Council’s recommended basic rate for directly-employed one-to-ones was lower than the rates paid for similar work by agencies or even by the Council itself in its day services. This carer had knowledge of this from the case of one of the one-to-ones she employed who had lost money by leaving the agency she was previously working for and coming to work directly for the family. She had apparently raised this issue at a recent meeting attended by the Director of Adult Social Services who had agreed to look into it but no response had so far been received. We are not in a position to pronounce definitively on this matter but it does seem to us likely to give rise to anomalies if the Council is prepared to countenance different rates of pay for individual care staff doing identical work depending solely on who is employing them.

Another issue which arose in our interviews concerns payment to PAs/One-to-ones for their meals and travel expenses. One carer reported difficulty because the Council would not allow such expenses to be reimbursed out of Direct Payments. This carer found it necessary

to pay such expenses out of the family's own pocket. Another carer whom we spoke to about this question, however, had no difficulty in expecting one-to-one staff to find their own meals and meet the costs of public transport (presumably using appropriate travelcards). There are no doubt arguments on both sides of this issue and there may be material differences in particular cases. But again what seems important to us is for the Council to be consistent in its policies: we wonder in particular whether staff performing one-to-one duties in the Council's day services are or are not able to claim out of pocket expenses for meals or transport?

## **11. Administrative burden of Direct Payments**

It was clear to us from our interviews that caring for and/or arranging the care of an adult with significant learning disabilities can be a heavy load in terms of time and effort as well as emotionally. Parents in particular can feel they have little choice but to go on supporting their grown-up disabled children for as long as they physically can. Some make this the centre of their lives, whether by choice or by necessity, and it is important that wider society should acknowledge this, as well as putting in place the support and care arrangements to lighten the load.

The new arrangements for personalised social care emphasise the importance of choice both for the service user and for carers. One intended instrument of greater choice is the system of Direct Payments which is supposed to put more freedom as well as more responsibility in the hands of service users and their families.

It may be true that, objectively speaking, the introduction of Direct Payments has in practice led to an increase in the range of options available to disabled people and their carers. An important finding of our study however is that in the experience of nearly half of our interviewees, the 6 out of 13 who have opted to take Direct Payments, the perceived balance between freedom and responsibility is very finely drawn. Given the need to limit expenditure of public funds to the specific purposes laid down, sometimes perhaps in too restrictive terms, in an approved support plan, the amount of day-to-day freedom and flexibility accorded to the recipient of the Direct Payments is not likely to be that great. On the other hand the administrative burden of making the correct payments and accounting for them as required on a monthly basis to the Council can be perceived as heavy. It is difficult to see how it could be made significantly less so without putting public funds at risk but we would encourage the Council to do what they can to simplify the requirements. The

proposal to introduce a special “smart card” for Direct Payments later this year may help some people.

To look at our evidence in more detail, for two of the carers we interviewed the administrative work needed for Direct Payments was seen to be beyond their effective capacity and they opted accordingly not to take this approach.

“Direct Payments are too much of a headache, I’ve not got time for accounts”, said one carer.

For several of those who had taken Direct Payments the work was seen as burdensome and/or a source of anxiety.

A carer described the increased anxiety she felt since taking Direct Payments: “many more things can go wrong”.

In one case it was in large part effectively delegated to the One-to-one who provided most of the care.

“I don’t understand the budget arrangements”, said the carer.

Only one of the carers who administered Direct Payments had no difficulty with the process [and we saw some significance in the fact that this was a retired person with commercial management experience. Some of the other carers had relevant skill and experience but had less time to spare].

The Council publicly seeks to promote the Direct Payments option. While none of those we asked would have wanted to go back on their choice of Direct Payments, we feel it is important to maintain a free and informed choice and not to put undue pressure on people to take Direct Payments.

It would not however be illegitimate to seek to tilt the balance a little further in favour of those who do take the Direct Payment option (and who thereby reduce the Council’s own administrative cost). One suggestion we offer for consideration is the possibility of including in all Direct Payment awards an automatic allowance to cover the recipient’s administrative costs. We understand that people can already claim an allowance for administrative costs but some have not done so and at least one of our interviewees said that the effort of keeping the necessary receipts etc for the small items involved made the exercise not worth pursuing. A “no questions asked” allowance would overcome this problem.

## **12. Contingency and Future Planning**

Some of the carers we interviewed admitted to anxiety about what would happen to the disabled person in their care if something happened to the carers themselves. We would guess that others suffer the same anxiety but disguise it more. We did in some cases, eg where a carer was elderly, ask specifically what thought had been given to future contingencies and there were sometimes answers, at least in outline.

Regarding future planning, in the case of two interviewees there was mention of seeking supported living placements in the longer term but there had been no encouragement to begin the slow process of looking at examples of what is available.

As we mentioned above it was clear that some carers' concern about the lack of respite were related to their worries about the longer term. It seems likely to us that the current pressure on social work and the limited respite resources means that not enough time or thought is being devoted to contingency and future planning of this kind and that any easing of the pressure and provision of additional respite resources should give an opportunity to think more about the longer term needs of people eligible for personalised social care.

## **13. Quality and Monitoring**

At least one carer raised with us the question whether enough is being done to monitor, maintain and improve the quality of the individual components of people's support packages. As already mentioned, we saw some excellent practice as well as some provision which could be described as "good enough" but with room for enrichment and improvement. We were impressed by some individuals' clear commitment to doing the best for the people in their care but saw little evidence of systematic quality assurance. More responsibility is being put on families to identify and manage tailor-made packages of care for their disabled members from a hopefully still expanding market of available options.

But it seems to us unrealistic and unsafe to rely solely on market forces to maintain and improve quality and provide training, particularly when there is economic pressure to cut costs. And what about people who have no family to manage things for them?

We do not know the answer to these questions but we think it is important to raise them and encourage discussion.



We have seen a recent paper on “Driving up Quality in Social Care” by TLAP which argues that responsibility is shared between a range of people but calls for discussion on what works in terms of raising standards. We believe that the Council should take up this challenge alongside the preparation of its Market Position Statement promised by the end of 2013, on the diversity and quality of local support services.

## RECOMMENDATIONS

In the light of our findings as set out above, we have the following recommendations for improvement in social care arrangements for adults with learning disabilities:

### 1. Clarity:

a. When an adult's needs are assessed under the criteria of eligibility for social care, the result of this assessment indicating their Support Needs and Outcomes should be communicated immediately in writing to the person concerned or their carer, with an indication of the further action to be taken.

b. All subsequent Support Plans, Personal Budgets, and amendments thereto, put in place to meet these needs, once agreed, should be immediately communicated in writing to the person concerned or their carer.

c. Where a request for a change in the Support Plan and/ or Personal Budget is received, whether orally or in writing, this should be recorded and a clear and reasoned decision thereon should be communicated in writing to the person concerned or their carer within a set deadline.

### 2. Timeliness:

The Council should, after consultation with service users and their carers, set target deadlines for the completion of new Personal Budgets and for making changes (or for communicating the decision not to agree a change) to existing Personal Budgets and should make arrangements to monitor and implement these (eg through the proposed new FACE system). In our view 6 months might be considered an acceptable target for new Personal Budgets and 6 weeks for changes in existing Personal Budgets. Performance against these targets should be published regularly.

### 3. Customer Service:

After the assessment stage, we have identified problems with access to Council services concerned with the setting up, subsequent modification and detailed implementation of arrangements for Personal Budgets (including Direct Payments). We believe that the Council

in its current reorganisation of services should follow a customer service model which would provide people with learning disabilities and their carers clear means of access to named individuals who are given sufficient responsibility and authority to initiate action on their behalf, including varying support plans and the consequent financial arrangements within the existing budget envelope or initiating the process for considering a change in the budget.

### **3. Support Planning and Brokerage:**

We support the Council's announced intention to establish support planning/brokerage as a separate function from that of needs assessment and we recommend that arrangements should be made to allow people to use independent agencies to carry out this function subject to appropriate reimbursement by the Council. Support planners could also play a role in monitoring service provision and identifying any gaps.

### **4. Direct Payments:**

a. It should remain a matter of free choice whether people choose to take their support in the form of Direct Payments or not.

b. Recipients of Direct Payments should be given a named contact in the Finance Department whom they can contact to discuss details of the payment arrangements.

c. In order to cover the inevitable administrative costs of managing Direct Payments, an appropriate supplementary allowance should be payable to all recipients without the need for proof of expenditure. It should remain open to people to make an exceptional claim for administrative expenses, to be supported by proof of expenditure.

### **5. Annual Reviews:**

a. We attach importance to the thorough implementation of the system of Annual Reviews for adults in receipt of social care and support. Efforts should be made to achieve the maximum possible continuity of the staff carrying out these reviews.

b. Particular attention should be paid to the variety and quality of the experience afforded to the individual by their social care arrangements, taking account of their abilities and potential.

c. Attention should also be paid to the need to provide for foreseeable future contingencies in the longer term and in the shorter term ensure that people with learning disabilities and their carers know who they can make contact with between the annual reviews, if they have worries about their mental or physical health or the services they use.

## **6. Transition:**

a. The Council should ensure that the recent improvement in the resourcing of the social work team responsible for young people with learning disabilities making the Transition to adult services is maintained and that the Transition protocol is observed in the spirit and the letter. In particular efforts should be made to ensure that social work staff get to know the young people and their carers concerned sufficiently in advance of Transition and are able to ensure that the adult services perspective is fed into Transition plans.

b. We also wish to draw attention to the importance of preparing young adults and their carers in good time for subsequent transitional stages such as leaving fulltime education and moving on from youth services.

## **7. Access to therapies:**

The Council in cooperation with the Clinical Commissioning Group should ensure adequate provision of specialist occupational and other therapies for adults with learning disabilities so as to avoid unreasonable delays in access to therapies.

## **8. Personal Assistants/One –to –ones:**

The Council should, in consultation with service users' and carers' representatives, review the terms on which it supports the employment of PAs/One-to-ones under the system of Direct Payments with a view to affording employers the maximum discretion on terms and conditions subject to the necessary protection of public expenditure. In its dual role as employer and paymaster it should avoid creating or perpetuating anomalies as regards rates of pay and other terms eg payment of expenses. It should in cooperation with the accredited Direct Payment support agencies issue a factsheet making clear the rules for employment of support staff under Direct Payments as well as providing guidance to service users and carers on issues of concern in relation to such employment.

### **9. Respite:**

The Council should publish a factsheet setting out the rules on entitlement to respite care and should continue, in consultation with suitable providers and with service users' and carers' representatives, to develop additional respite options for adults with learning disabilities.

### **10. Quality Monitoring and Assurance:**

The Council should initiate a process of discussion with service providers, service users and carers on arrangements for monitoring, maintaining and improving the quality of services provided to adults with learning disabilities in the light of the recent TLAP papers on Driving Up Quality in Adult Social Care. Such discussion could feed into the Council's Market Position statement.

### **12. Disseminating good practice:**

The Council should consider the need for further arrangements for disseminating information about available services for adults with learning disabilities and in particular about examples of good practice.

### **13. A Noticeboard for Carers:**

The Council should discuss with carers' representatives the feasibility of setting up an on-line noticeboard for local carers of people with learning disabilities to exchange information and support.

### **14. Other expenditure cuts:**

a) In making any necessary economies in the provision of social care and support the Council should make every effort to ensure that its decisions are clear, transparent and even-handed, recognising the special situation of the vulnerable people concerned and their carers.

**b)** The Council should ensure that any economies in provision of community transport do not undermine the viability of services or facilities of value to people with learning disabilities.

**c)** The Council should avoid using the introduction of Personalisation for the majority of social care arrangements as a reason for withdrawing support from small voluntary and self-help organisations which cannot afford the administrative machinery of charging on a full cost basis.

Martin Haddon, Jenny Purkis, Alison Tomlin, Peter West

28th March 2013

## **Appendix 1**

### **Meetings and telephone calls**

As part of the background research and preparation we met or spoke to:

- individual carers of people with learning disabilities known to members of the team;
- Group worker Katherine Low Settlement and the Carers' Centre;
- Wandsworth Care Alliance Learning Disabilities Partnership project officer;
- Voiceability Wandsworth advocacy project officer;
- Operations Director, Generate, an independent local provider of support services for people with learning disabilities;
- the area managers of Odyssey Care, a local independent provider of housing and other support services for people with learning disabilities;
- Staff at Wandsworth Mencap, which provides support for carers and families of people with learning disabilities;
- Assistant Director of Adult Social Services (DASS), Wandsworth Borough Council;
- Day Services Manager for people with learning disabilities, DASS;
- Community Learning Disabilities Team, Transition, DASS.

We would like to thank the above organisations and individuals for their help with our study.

We are also grateful for the opportunity to attend a number of other meetings which were useful in our research and preparation:

- Better Days information meeting for carers of people with learning disabilities, organised jointly by Wandsworth Mencap and Day Services, DASS;
- the Annual General Meeting of Wandsworth Mencap;
- the Annual General meeting of the Wandsworth Independent Living Forum, a user-led organisation consisting of individual disabled people and disabled people's organisations;
- a number of meetings of DASS' Advisory Board, The Future, Today, an open consultative forum set up in connection with a wide-ranging review of social care arrangements.

## **Appendix 2**

### **Background documentation**

As part of our background research and preparation we studied the following main documentary material:

- Valuing People Now; a three year strategy for People with Learning Disabilities (Department of Health, January 2009)
- Wandsworth Borough Council's Guide for Direct Payment Service Users (May 2012) – information for setting up and managing Direct payments in FAQ format;
- Wandsworth Transition Protocol describing the roles and responsibilities of statutory agencies and other organisations, including the voluntary sector, at each stage of the transition process (2011-13) ;
- Moving On: an easy to read guide to transition in Wandsworth for young people with disabilities and special needs. Produced in association with the Transition Protocol;
- Wandsworth Direct Payments Factsheet;
- Stuck at Home, a report on the impact of cuts in day services (Mencap 2012);
- The National Charter for Inclusion produced by Giving Us a Voice, a joint project of Mencap, the British Institute for Learning Disabilities and the Association for real Change (2011);
- Report on Winterview Hospital (Department of Health Dec 2012);

- National Personal Budget Survey of service users and carers 2011, released by Think Local, Act Personal (June 2011)
- Charges for community-based services: Introduction to personal budgets London Borough of Wandsworth
- Getting it right! and Getting the right support. Foundation for People with Learning Disabilities;
- Making written information easier to understand for people with learning disabilities: Guidance for people who commission or produce Easy Read information. (Department of Health. 2010)
- What we do, statutory advocacy/independent mental capacity advocacy. (VoiceAbility, October 2012)
- We also found useful information in the records of the Wandsworth Learning Disabilities Partnership Board

### **Appendix 3**

#### **Services visited**

In the course of our study, mainly to see some of the services being used by the people we interviewed, we visited the following services and facilities, where we were kindly received and we wish to thank the staff and the service users who welcomed and assisted us:

- Atheldene Resource Centre, Garratt Lane SW18: the Council's largest day centre for adults with learning and physical disabilities, not considered fit for purpose in the longer term but closure awaits the completion of alternative facilities for people with the most complex needs.
- The Bridge, Falcon Mews SW12 : a cafe/meeting centre, operated by Generate (see below) which provides opportunities for people with learning disabilities to gain work experience and learn work related skills within a live business setting.
- Chilli Beans: a theatre-based activity group meeting at St George's Road Wimbledon SW19 4DP for people with learning disabilities run by Act Too, an independent local provider.
- Dolphins Swimming Club at Latchmere Leisure Centre SW11: a longstanding weekly swimming club for children and adults with learning and other disabilities organised and run by local carers with financial support from the Council and other sources.
- Generate, Summerstown Tooting SW17 Head office, meeting place and venue for Arts and Craft and music workshops.

- George Shearing Centre, Este Road, SW11: for young people between 13 and 25 with learning disabilities, operated by the Council’s Youth Service – evening youth club (which we visited) and day programme for young people during school/college holidays.
- Linden Lodge School, Princes Way, SW19: a special school for pupils with visual impairment and/or profound learning disabilities, which one of our younger interviewees was still attending
- Odyssey Care (now a subsidiary of the Brandon Trust): an independent local provider of Supported Living housing and community services for people with learning difficulties. We visited one of their group homes in SW17.
- Putney Community Social Base, Beverly Bridge SW15: one of the Council’s new bases offering a flexible programme of day activities with an outdoors emphasis for people with learning difficulties, based in a Sea Scout hut by the Thames towpath.
- Tooting Community Social Base, St Boniface Church Hall SW 17: one of the Council’s new bases offering day activities and outings for people with learning disabilities
- Wandle Leisure Centre Gym, Mapleton Road SW18 accommodates exercise-based activities for people with learning and other disabilities operated on behalf of Wandsworth Borough Council by YPD/HEART.
- Wimbledon Park Boating Lake SW19: a public watersports facility operated by Merton Council. One of our interviewees has a voluntary work placement there.
- Workshop 305, Weir Road SW19: an independent craft (including ceramics, woodwork and graphics) workshop for people with learning disabilities, set up as a Community Interest Company in 2009 by ex- Atheldene craft tutors.
- YMCA Gym and Sports Centre: Wimbledon High Street

## Appendix 4

### Prompts for questions/observations

Headline	Detail
<b>1. What is your experience of having a personal budget?</b>	<ul style="list-style-type: none"> <li>• Do you like it?</li> <li>• Who helps you if things go wrong?</li> <li>• Are the care / activities better or worse than before and how?</li> </ul>
<b>2. How did you decide to spend it?</b>	<ul style="list-style-type: none"> <li>• How did you find out what you could do?</li> <li>• How did you decide what to do? Did you have help deciding?</li> </ul>
<b>3. Are the right sort of activities</b>	<ul style="list-style-type: none"> <li>• Are you getting enough care/activity each week?</li> </ul>

<p><b>available for you?</b></p>	<ul style="list-style-type: none"> <li>• Which services do you like most and least? Why?</li> <li>• Do you have needs/interests not being met?</li> <li>• Do you get enough social interaction?</li> <li>• Are your health needs being met?</li> <li>• Are you getting help to improve your chances of employment?</li> <li>• How do you get around/travel – is it OK?</li> <li>• Do your carers get a break (respite)? Is this enough?</li> </ul>
<p><b>4. What is the process like?</b></p>	<ul style="list-style-type: none"> <li>• Are the rules clear?</li> <li>• Do they make sense?</li> <li>• Are there any practical difficulties eg with payments or paperwork?</li> <li>• How easy is it to get changes in budget/activities when you need or want them?</li> <li>• How well would arrangements cope with things that may happen?</li> </ul>
<p><b>5. What could be improved to make life better?</b></p>	<ul style="list-style-type: none"> <li>• Type of activity?</li> <li>• Frequency?</li> <li>• Getting around?</li> <li>• Other?</li> </ul>
<p><b>6. Anything else?</b></p>	<ul style="list-style-type: none"> <li>• Any issues about staff (qualifications, training, support)?</li> <li>• Any issues about family care and support?</li> <li>• Other comments/issues about care and support</li> </ul>

## Appendix 5

### List of supported activities reported by our interviewees

In addition to activities provided at and from the Council's day centre, hubs and bases or at school or college, our interviewees and their carers told us of the following activities supported directly or indirectly by their Personal Budgets:

- swimming and aqua-aerobics
- gym/exercise/movement groups



- massage
- cycling
- football and basketball
- kick-boxing
- gardening
- painting
- ceramics
- needlework
- music
- weaving and rug-making
- woodwork
- cooking
- drama groups
- youth clubs
- disco
- cinema
- concerts/gigs
- visiting museums and other places of interest
- shopping
- meals out with friends
- work experience
  - Wimbledon Boating Lake,
  - The Bridge cafe/meeting centre,
  - City Farm
  - Charity shops,
  - Old people's luncheon club