

‘It’s about respect’: People with learning difficulties and personal assistants.

Full version

Introduction

This report is about the second stage of our research study, **Skills for Support**. It is an inclusive project, which is carried out by a team including two researchers with learning difficulties. We are based at a Centre for Inclusive Living, an organisation run by disabled people, and the research is funded by the Big Lottery. Norah Fry Research Centre is a partner in the project. Our aim is to find out more about what makes good support for people with learning disabilities, particularly those who use direct payments or have one-one support through organisations or agencies. We wanted to learn more about these personal assistants (PA’s), their backgrounds, training needs and work practices. The first stage of our project included a survey of personal assistants of people with learning difficulties throughout the UK. The findings were reported in our first report.

In the second stage of our project, we aimed to visit six direct payment schemes, to carry out group and individual interviews with people with learning difficulties, their personal assistants, and with the scheme managers. In the event, the group interviews took place in:

- One People First (self-advocacy) group, with members who used DP.
- One support provider organisation
- One social services department
- One day centre

The fifth place we visited was a direct payments support service, who introduced us directly (without a group) to individuals using their service. With the exception of the support provider organisation, these organisations all introduced us to people with learning difficulties who used direct payments. In two of the areas, we were also able to interview DP support service managers. Our two self-advocate researchers were central to all these interviews; they developed the questions for the interviews, and one or other of them led every interview apart from two.

The people with learning difficulties we interviewed had various levels of independence skills, ranging from one person with profound and multiple (complex) needs through to people who could communicate and organise their lives very effectively. All, however, needed support with aspects of their life, their independence and their communication. They had all been deemed eligible for support by their social services departments.

One important methodological point was that we only met PA’s in the company of the person they were supporting. In consultation with our steering group members, we felt that this was the most ethical approach, as we did not want to approach PA’s and talk about people with learning difficulties behind their backs. The present report is based on the group, individual and pair interviews, and the various people who participated are detailed in Table 1.

Table 1
People who were interviewed in Stage 2

People with learning difficulties	19
Personal assistants or support workers	14
Managers of DP support schemes or provider organisations	9
Parents or carers	8
Total	50

Following the interviews, the aim of Stage 3 of our project is to make videos of PA's working with people with learning difficulties. From this, we will learn more detail about the things PA's do, and the communication that goes on between them and the people they support. In the present report, we will discuss simply what people said about the support they have, and what PA's themselves said.

The past v. the present

All the people we talked with had one-one support, for periods ranging from 2 hours per week to 24 hours. One person had two-one support. Most of the people we met lived in rented accommodation, though there were also other arrangements (see Table 2).

Table 2
Where people lived

Rented flat	7
Family home	5
Rented house (couple)	2
Unknown	2
Own house (shared ownership)	1
Temporary hostel	1
Family placement	1
Total	19

We were interested to know whether they preferred 1:1 support to what had happened in their lives before, and in fact they all rated their personalised support well above their previous experiences of care. Clearly, for many these statements were also linked to their new experience of living more independently. Many people had previously lived in residential homes:

In River House we had to be in bed by ten and during the weekends you had to be in at 11pm and I said to myself 'It's about time I moved on and do something else.'

When people talked about their past lives, they often mentioned the strict routine which was ruled by the staff. They felt that they had had little control over their own movements, and by contrast, they valued above all their new freedom and independence. Staff in residential care were remembered as being inapproachable. They did not communicate as equals:

If you don't talk to them you won't get no sense or anything. If you argue where I used to live, you don't get a chance to talk to them, all they do is ignore you.

One of the problems of life in a residential, or group, home was that individual preferences were often overlooked. Staff had to organise their activities according to the needs of the whole group, and individual people had to just fit in:

I was used to people coming in and saying 'get up, come on Sam, get your coat on and go to Tesco's. That's where we're all going'. I was quite glad to see the back of the place, we all lived in Tesco's.

For some, the memories were much worse than this. They included instances of punishment (getting locked in your room) and being 'told off' like children';

Other people we spoke with had previously lived at home with parents. One person mentioned that she had looked after her mum for the last four years of her life. None of the people we met in our interviews were now living at home, but for many, their parents still had a heavy commitment to them and their care. Parents were aware of the positive difference the move from residential care had made, and had frequently been involved in supporting the move. One set of parents talked about the problem of staff changes in residential care, which 'stops it being a home, and makes it an establishment'. Personal assistants also spoke positively of the move towards greater independence, on behalf of the people they supported:

Luke has never lived independently before. He's gone from residential home to residential home, and this is what he has always wanted. He's so, so pleased that he's living here independently, that it's a pleasure to work with him. He's so happy all the time!

Getting one-one support

Having had largely bad experiences in past residential care, or bad support from agencies while living in their parents' home, how did people change to a more individualised type of support? In three of the group interviews, people talked about a person-centred planning process.

I'm trying to work with my support staff, to try to aim myself on. By looking at my ELP, and what I want changed in my life. I've got friends and support when I want it.

This question was followed up in the individual interviews, and parents also talked about the value of a process which involved them, other family members and friends:

We had a three day course where we took Mary and her person centred plan was set up and then since then we have had meetings on a regular basis where the people that work with her at the day service, the people that have her when she goes on short breaks, her old friends and then family like myself and my husband but also her sister which means that you get another line of thought, so all of the people ... and also the nurse that has looked after her as her community nurse also comes, so we also have her health link. So yes, all of the people involved.

Other people told us about meetings that were not designated as 'person-centred planning', but which took place with family members, with the person themselves and sometimes with social services staff. Seven of the people we interviewed had had a person-centred plan of some sort, and all of these were from three of the places we visited (a day centre; a group of service users

from a specific 1-1 support service organisation; a group of DP users whom we accessed through a social services contact). Getting a person-centred plan seems to depend on which area you live in. Of the other people, one in particular talked to us with his parents present. He could only recall being 'told' that he was ready to move out into independent living by his residential care staff. It seemed to him that he had to pass a test of some sort, and then he was allowed to be released!

The actual arrangements which people used to obtain their 1-1 support were rather varied (see Table 3)

Table 3
Arrangements for getting 1:1 support

Direct Payment: person recruits and employs PA	5
Direct payment paid to an agency or support organisation, who supply PA	4
Direct Payment support organisation arranges PA	4
Support provider organisation provides PA	3
Direct Payment managed by family	1
Former residential home provides PA	1
Not known	1
Total	19

Given this variety of models, it was not surprising perhaps that some people tended to be confused about the way in which the arrangement with their PA had come about. More worryingly, one man seemed to think that the direct payment was a special gift, which could be withdrawn at any point:

When we go to college (...) we had a man come to talk about direct payments, and they said if they did stop it, to write a letter to them, and ask them why they stopped it, and keep on to them.

How many people had actually chosen their own PA? Surprisingly, this did not match entirely the pattern of direct payment/ non direct payment. The three people who used a support provider organisation, for instance, had interviewed and 'tried out' their PA's before taking them on. Conversely, those who bought into an agency seemed to have little control over who was allocated to them. In one case, the person had told us in the group interview about his dissatisfaction with the current PA. In another case, the person had several different PA's, and appeared not to know them all very well.

Of those who had had a degree of choice over their PA, two had chosen members of their own family. In one case, this was someone with high support needs, whose family members had in effect decided that her sister could be paid as part of her support team. In the other case, someone had taken on his own mother as a PA, and said that she was very good at

separating out the two roles! Other people almost universally preferred someone they knew already. The following comment was typical of people's account of finding a PA:

She's a friend of a friend, so me and mum's friend.
...We both knew her as a friend anyway, so that's how I
know she's OK.

Where people had access to a good DP support scheme, people had advertised and interviewed for their own PA, and recalled that the process had taken a long while. Also, people reported problems in some cases with the PA they had first chosen. In one case, this was because the DP scheme had encouraged them to advertise for a student, and this person moved on. In another case, the first PA had taken advantage of the person they were supporting, and had misused finances.

PA's accounts of how they came to their present job matched the accounts by people with learning difficulties. Often, they had known the person through personal or through other professional routes. One PA had worked in a garden centre scheme, where she had met the person she now supports. Another was a nursery nurse who had worked with the younger siblings of a man with learning difficulties, and so was well known to the family.

Two main messages seemed to come from this small sample of people using 1:1 support.

- Where the support worker is employed by a 3rd party (an agency or a support organisation), this can work well for the person needing support. However, it seems most popular to have a 'try-out' period, and to make sure that the person can decide and say 'no' to someone they don't get on with.
- Where the DP user recruits and employs their own member of staff, people often chose the safety-net of employing someone they already knew.

The most important issue was that people felt they were 'in control' of the choice of PA. In practice, this often meant and this gave them a greater sense of being in control of their whole life.

The needs of personal assistants

With the 14 personal assistants we interviewed, we were able to follow up some of the issues that had arisen in our survey. Chief amongst these were the issues about supervision and training. In our survey (Report 1), the results showed a surprising number of PAs who had professional backgrounds in residential care and elsewhere. These people, in the main, brought a background of professional training to their job as a PA. However, throughout our research project, people with learning disabilities and their PAs (for instance in our focus groups) have alerted us to the lack of training offered.

There was a great difference between supporters and PAs who worked for support organisations, and those who worked directly for the person with a direct payment. Those in support organisations benefited from a high level of supervision and training. For instance, in one group interview people talked about a system where problems and issues could be taken back to a supervisor. This system appeared to work well, because it also involved the person with learning difficulties directly. They too had access to the supervisor, to raise any concerns they might have over their 1-1 support worker.

PAs who worked for agencies or support organisations appeared to have a wide range of training on offer. Most of them talked about the training they had done about general issues such as Health and Safety or risk management:

I've done my Health and Safety training, and First Aid. At the moment I'm doing my NVQ3 in Care. I'm on the waiting list to do an autism course.

One of the DP schemes we visited also offered training directly to PA's, so that they had a whole pool of 'trained' PA's for their direct payments users.

What was notable about all this training, however, was how little the people with learning disabilities themselves knew about it. It was seen as something which the PAs did, for their own benefit, and outside their job as a PA for the individual person. One person had 'inducted' his new PA, by inviting him in along with someone who had experience of supporting him. In another instance, it was felt that the parent had a key role in providing training about her own son. She invited the new PA into her own home, to learn about her son, before formalising the job.

However, no-one had a good system for continuing to provide support and supervision for their own PA. People with learning difficulties in one of the areas we visited felt that it would be very useful to have a joint system, where PAs and people they supported met together for joint training sessions. This is an option which we will return to at the end of this report.

The new job of personal assistant was often seen by our respondents as a positive and challenging new opportunity to really have an influence on people's lives, to support people in taking control, and in 'getting a life'. Most felt excited and privileged to be a part of this. However, the down side of this exciting opportunity was that PA's could become over-involved with supporting a person and with being able to draw the line between work and private life. In effect, PA's were often sharing their own lives with the people they supported, and the whole issue of professional boundaries was one in which most PA's felt that they needed support and supervision.

Parents and carers

The topic of parents and carers deserves a section of its own. Unexpectedly, we did meet a large number of parents and carers (8) during our visits to people's homes. This happened despite the lack of any particular requests for parents to be present, but it was a tribute to the amount of input and involvement they obviously had still with their son or daughter.

Five people we interviewed still lived in their parents' home, but even for those who had moved on, parents and other family members were still key people. One person with high support needs had assistance from his parents at every step, in managing her person-centred planning, and deciding about the direct payment, the personal-assistant and the type of support. Another person had had a lot of support from his parents in moving into a shared-ownership house, and because the official support he could access appeared to be very limited, his parents were effectively backing him up by supporting him at other times. Another man had rented his house from his brother, and several people had brothers and sisters involved – either as part of their support team, or simply in giving them general family support. In most cases, this came across as a real interest in supporting greater independence, and a better life for their family member with learning difficulties.

However, it seemed occasionally that family members had taken over some of the decision making. One man who had a direct payment said that the DP support organiser had never 'come up to see me. My sister sorted that out with them'. In another two cases, where the DP user lived at home with family, everyone seemed extremely supportive, but also very confused about what a direct payment actually meant. One family asked the interviewers if there was any other option apart from a direct payment, as this had obviously not been explained properly. Since this family spoke English as an additional language, there may well have been unmet communication needs.

The only family members who spoke to us about worries over safety were the parents of one woman who had support supplied by her former residential home. As this did not seem sufficient, and the support workers kept changing, the parents were probably quite justified in their concern. On the whole, though, parents and other family members were very positive about the increased quality of life which had been offered to their son or daughter through direct payments. The views expressed by this parent were echoed by others:

I don't feel so guilty about leaving her (with her PA) and I think it is nice for her because it means she spends quality time with a friend who does lots of different things with her that mum and dad would probably be a bit more...how can I say, wrap her up in cotton wool.

The route to getting a PA was certainly not straightforward for most of the people we met. This matched well with a previous study (Gramlich et al.,

2002) where we found that people with learning difficulties needed many different kinds of support in obtaining and managing their direct payment.

Using one-one support: the views of people with learning difficulties

What were the experiences of people with learning difficulties once they had a PA? We will divide this section into three main areas which were discussed in the interviews and groups. These were: a) independence and control; b) things people did with their PA; c) what people felt about their PA.

a) Independence and control

We were interested to know whether people with learning difficulties using 1:1 support felt that they were 'in control' of their lives. We specifically asked them about who makes decisions, and what was the 'best thing' about having 1-1 support. In the survey (Report 1) we had found that these questions were mostly answered by people saying they 'talked about things' with their PA. In other words, decisions were jointly negotiated on a day-to-day basis.

From the interviews, it seemed that the concept of 'independence' meant two different things to people, and it is perhaps important to separate these out. On the one hand, independence meant doing more things for yourself. This included being able to get out more, but it was also about managing household tasks unaided, and being 'left alone' to get on with things. The following comments illustrate this theme:

It's much better. I can get out a lot more, and do more for myself.

Another thing I do, I do the ironing myself, I do my bedroom, I do my friend's washing and ironing. Last night I did four hours of ironing.

This type of new-found independence, of course, could be simply because people are getting less hours of staff contact than they had previously had access to in residential care. However, many respondents were both very proud of their achievements, and also felt that they did not want staff unnecessarily 'telling them what to do'. They liked being left to get on with things unaided when possible. One person even said that his 'best experience of support' was:

When I go on holiday every year, and we don't have to have the staff with us.

On several occasions, in joint interviews with people with learning difficulties and their PA, people spoke more about how this kind of independence happens. For instance, one man had always liked to go to football matches, and had done this with his support staff. His PA had deliberately supported him to become more independent in managing the bus route, getting his own ticket, and going to matches on his own. He is now very proud of being able to

do that. The skill of being able to step back is a key one for personal assistants, and is often part of a longer process of supporting and ensuring that the person is safe.

The second aspect of 'independence' which people talked about was more to do with the relationship with their PA. Many people talked about 'team work', where they felt they had a more equal relationship with their PA than with previous staff. Where previously they had felt that their staff always told them what to do, they now are taking more control over who does what. This was often in the context of day-to-day activities, so that when the PA came to the house, they could decide what to do, and ask the PA what to do for them. In many cases, people admitted that there was a type of routine, with certain tasks which had to be done. This was particularly so where PA's provided support with domestic chores or with aspects of personal care. However, where the PA was employed to assist with social or leisure activities, people could have much more choice.

Who decides where to go, if you are going out?

Me, I think!

So if you're coming to a pub, who decides how long you're going to stay here, or what you're going to drink?

Sometimes, most times I do.

Many of the PA's we talked to felt that they did 'offer choices' to the person they were supporting, but that phrase still implies a degree of control by the PA. By contrast, people with learning difficulties seem to be taking the reins more into their own hands by finding their own solutions to their support needs. For instance, one man showed us a good example of how he had developed his own system for recording his shopping needs, which was a laminated list of possible items that he could use as a checklist.

One very interesting role that the PA may have is to negotiate matters with the outside world, on behalf of the person being supported. In the survey, we found that 'going out' was the activity most often done with the support of a PA, and we also asked about whether the PA spoke up for the person they were with. The survey results showed that overwhelmingly, supporters and PA's answered that they *did* speak up for the person, but that this *did not* disempower them. From the comments we had in interviews, people with learning difficulties were more aware of occasions when they spoke up for themselves. PA's also gave examples of how the person they were supporting interacted directly with officials or members of the public (e.g. when buying tickets, or ordering food). It will be interesting to find out more about how these things actually happen from our video data.

The most important theme in the relationship with the PA seemed to be the feeling of being 'in control', and this could simply mean that the PA had a very clear and detailed knowledge of exactly what works for the individual. Even the person with profound and multiple needs was said to be able to show clearly if she did not feel 'in control', as she tended to switch off and go to

sleep. For other people, the feeling of being 'in control' was also about being allowed to change their mind, or simply do nothing. They did not want staff who constantly required them to stick to a plan or to carry out planned activities:

It's about respect. It's like - the fact that my support workers can accept that I like to do my own thing, I don't have a routine as such. I like doing my own thing, because I'm a very chilled person.

These findings about greater independence and control must be seen in the light of the great weight of institutional thinking which still persists with many people with learning difficulties. Even amongst this sample of people using 1:1 support, there were some telling comments, which reminded us of the fact that many people still assume they are dependent on others to make decisions for them. This man was talking about the decision to keep in touch with a woman he had known previously:

I did ask about one girl, a great big special one, and they agreed that I could have her. Just to visit here. And it's been going on for years - and that's how I got her.

Moving towards greater control and independence has to be done as a joint effort, and we must remember that new skills and attitudes may need to be fostered both in people with learning difficulties and in the staff who support them.

b) Things people did with their PA

From our survey, we knew that in general the most frequent activities which people did with their PA were:

- Going out
- Shopping
- Money management

The information from interviews in general supported this picture. However, we were able to probe a little bit further in interviews, and we asked people quite specifically 'what do you need support with?'

The areas of money management, shopping and going out all appeared to be linked activities. In more than one instance, the most sensitive aspect of support was seen as assisting a person to budget and to manage their money effectively. One person had had support from his PA to keep money for essential food items - instead of buying a vast stock of CDs. Another person regularly sat down and worked out exactly how much money his food shopping would cost; the PA then helped him to budget by giving him just the money he would need each day. When people are going out to the shop with their PA, then, it is not so much physical or communication support which they are getting. It is far more to do with selecting and buying items which fit into the budget!

In general, the activities and support needs covered in the survey were the same ones that came up in the interviews. However, there were one or two unexpected supported activities. One was holidays (which we had not asked about specifically in the survey) and the other could broadly be subsumed under 'emotional support'. The area of emotional support was interesting, since it was interwoven with many of the other activities which people talked about. In effect, emotional support happens inevitably at every stage, but for some people, it seemed to be an explicit matter. One man said:

We chat about how I feel about things, don't we? I tend to get stressed. I tend to get a little bit stressed - it can't be helped, can it?

When first asked about what they had support with, most of our respondents talked about simply 'going out' with their PA. We then asked people why they had a PA with them – what did the PA enable them to do, which they could not do by themselves? An interesting observation was that many people saw their PA as providing company and friendship. One man who lived on his own found that the regular visits of his PA gave him structure to his week, and helped him to manage his life in general. Others who went out with their PA socially saw this as a chance to be in public spaces with another person for company. In one case, we asked the person with learning difficulties if he could have managed to go out by himself, and it turned out that he did indeed go to pubs, cafes and shops by himself. However, the PA added a social element to his life, not just with his own presence, but also because of his own social circle. The pair often met up with friends of the PA, had a game of pool or a drink together in the pub. All this helped the person with learning difficulties to feel far more a part of his local community.

For people with learning difficulties, a PA can be a vital part of their role in the community, and the PA often helped them negotiate problem areas in their life. In more than one instance, PAs had been involved in negotiations with police (in one case, because of a mistaken identity; in the other case, because of becoming a victim of physical abuse). In other instances, PAs helped with personal issues within the family or with friends. Often, however, people simply had support with the mundane matters of everyday life, sorting out letters, forms, banks and officialdom.

c) What people felt about their PA

Finally, we move on to what people said about their relationship with their PA. This was sometimes in answer to: 'what is good about having 1-1 support?', but it was also about specific factors in the relationship which made people feel they were more in control of their life than previously.

The first theme that emerged here was the theme of trust. As noted above, people often had 1:1 support workers or PAs whom they had already known in their lives. Even when this was not the case, it was felt important that you

could get to know the person well, and develop a degree of trust. In the words of one of the PA's:

I think we had quite a good rapport together. We got on quite well, and I think it helped Brian initially, in that when I did come to work for him as a PA, he already knew me. Which is - you know, a lot of the problems isn't it?

Secondly, the theme of mutual friendship and equality was important. People with learning difficulties themselves talked particularly about a relationship of equality, where there was mutual understanding and a bit of 'give and take'. One person said that when they go to the pub, he buys his PA a drink. Another said:

It's about them understanding you, and you understanding them, isn't it?

In other words, this is not just a one-way relationship, with the PA developing skills to support the person they work for. The person with learning difficulties is also part of that interaction, and successful support seemed to depend on a degree of familiarity developing between the two parties. People often talked about their PA as a friend, and said they were 'good company'. However, they also felt that the PA enjoyed their company, and that the relationship was mutual. With the person with high support needs, family members were aware that her PA was important to her because she was the same age, and provided her with a friend who would have age-appropriate interests. Both in this case, and with one other person, the PA sometimes included their own young child in activities such as shopping trips or even in social outings. Both the people with learning difficulties appeared to enjoy being part of their PA's family

A third theme that came up here was about people wanting a PA who was proactive on their behalf. They liked people who could actually sort things out for them, as this man said:

I like staff who are quite forward in getting on with things. Not too up front, but just trying to get things sorted out for me.

Given the importance of staying in the background, and not making decisions on behalf of the person you are supporting, it is a delicate task to get this right. As mentioned above, PA's did often provide a kind of interface with the community, and they certainly helped the person they were supporting in getting new activities. One man described this as 'extending my life a bit more'. In the end, the level of activity of a PA has to be determined by the individual relationship with each person with learning difficulties. As another man said:

I do like the subtle touch.

A good PA, then, is someone who is trusted, is friendly, and who can get the balance right between being proactive and standing back. With good 1:1 support, people with learning difficulties told us that they had achieved many of the dreams which they had in the past. These were not exotic or unrealistic goals, but the ordinary achievements of being an adult in today's society. Understanding and sharing the vision which a person has for their own future is surely at the heart of the skills for a good PA, and we will finish this section with some of these 'dreams achieved':

It's a really nice feeling, all my life I wanted to do some work, and when I was young - they said 'you'll never be able to live in a house on your own, you'll never be able to keep a job'... I have proved them wrong.

I do keep my own money, though. I go out and sort it out, and keep it with me. In the olden days, I had somebody to look after it all the time for me. But I don't now...other people can't take nothing away from me.

The grey areas

Towards the start of **Skills for Support**, the team produced two photo-story booklets about 'good support' and 'bad support', showing what it meant to our self-advocate researchers to be in charge of their lives. When we started to interview people and lead focus groups, we generally showed them these books. This was a way of leading in to the topic of the 'grey areas' in between 'good' and 'bad'. In essence, it is simplistic (although not always achieved!) to say what we mean by 'good support'. However, we know there are sensitive areas, where PA's strive to provide empowering support, while managing issues which can be far from empowering.

Three main areas were mentioned:

- Money matters
- Risk
- Giving advice in general (e.g. behaviour, communication, how much to drink!)

a) Money matters

The most common issue mentioned by people with learning difficulties and their PA was that of budgeting and money. Many of our respondents did need advice and guidance on managing their own money, so that they did not get into debt, and so that they had enough money left for the basic necessities of life. It was interesting to explore with these people how this type of support and advice worked for them. The person with learning difficulties was well aware, in each case, of the kind of support they needed. As one man said:

Susan helps me, sometimes, to make the right decisions.

It emerged that this man had had to be advised not to buy items he did not really need, as he was running into debt. Our interviewer pursued this topic

with him – how did it feel to have to take advice about managing your own money? The conversation went like this:

Q: Do you feel like they are taking your freedom away?

A: When I was in residential, that was like that. But now it's different.

So what exactly makes that important difference? How can a PA advise on money matters, for instance, without being controlling? This man's answers were all about the general context of his life. In residential care, advice over money matters was given in the context of overall control over his life:

Stopping you from going out, and stopping your friends coming round.

Now that he has his own place, this man said he feels more in control and more confident in himself. Given that new-found confidence, he is perhaps better able to accept advice on how to deal with his own money.

b) Risk and general advice-giving

Some of the managers we talked with specifically mentioned the issues about risk, which are understandably a key concern in providing 1:1 support to people who may be unused to living alone. For people with learning difficulties themselves, areas of risk mentioned included transport; managing new activities; dealing with people who did not understand them. They did not mention physical risks, but were more aware of the general risky nature of social life in general. One person, as mentioned above, had been in a potentially abusive situation in a pub, and another person had been mistaken by the police for someone else who had a detention order.

PA's also specifically mentioned areas of personal activity, in which they had had to advise people about how to behave with others, or how to communicate effectively with family members. There was also one person who had support to manage his own compulsions over various domestic activities. The conversation between him and his PA was interesting

PA: I've tended to get a little bit more - strict.

Person with LD: You're quite blunt over it, Jenny.

PA: And you're always pleased when I do, aren't you? You like to have boundaries.

The important feature of PA support in these difficult areas was that the PA communicated openly with the person they were supporting. Advice was not 'imposed' on the person, without consultation. In effect, the person with learning difficulties was an equal partner in the decisions about how best to provide support. This joint decision-making is perhaps one of the key defining features of empowering 1:1 support, and is well expressed by one of the PA's we interviewed:

I'd say ...that everybody comes up against tricky times, but as long as everybody works together, they can talk to each other - it can always be resolved, can't it?

Summary and discussion

This report has summarised many important issues raised by people with learning difficulties who have moved onto 1:1 support in various areas of their life. It has revealed the diverse and often quite complicated routes for getting 1:1 support which are used by people with learning difficulties, and also the extent to which continuing family support is important to many of these people. For many, their feelings of new-found freedom were tied up with new living opportunities, since they had also moved from residential care homes into their own tenancies. However, the 19 people we interviewed were almost universally positive about the opportunities that 1:1 support gave them in their lives.

We have discussed in this report how important it is for people with learning difficulties to feel 'in control' of their own support. Independent living often means to them that they can do more things without support, but it also means that they can choose exactly when to do something. People who had previously lived in residential care had experienced perhaps the greatest contrast between past and present living arrangements, and felt that they had achieved their dream of being 'free' and in charge of their own life. The particular things they liked about their 1:1 support were to do with good relationships and trust. They in fact appreciated a good deal of 'friendliness' with their PA, and many used PA support to increase their own social opportunities. In addition, people did like their supporters to be proactive on their behalf, and to 'extend their lives', without doing too much and taking over. They were aware that all this demanded subtle skills on the part of their PA and support workers, and that the best way was for them to talk things over together. Many PA's and people with learning difficulties emphasised the importance of team work.

The most difficult parts of the PA's job are, arguably, to do with risk and safety. Traditional support for people with learning difficulties has always assumed that the person is, to a greater or lesser extent, incompetent to manage their own life. Support staff have often tended to treat people with learning difficulties as children, with the assumption that they could not be relied upon to manage their own lives or make their own sensible decisions. One of our self-advocate researchers pointed out that the main skill which a good PA needs is to be able to treat the person they are supporting as an adult.

What, in effect, does it mean to be treated as an adult? It is hard to reconcile the idea of an adult-adult relationship with that of protecting the person from risks, giving advice on money matters, preventing debt, or giving advice on social or personal behaviour. To some extent, all these areas remind us that people with learning difficulties are often still 'learning' about how to improve their skills. The PA's role, then, becomes quite like an educator or a personal

tutor for the person, and the person with learning difficulties could become cast in the role of learner. This, again, provides a paradox; the teacher is often seen as the person who is in charge of the learning process, rather than the learner. Therefore, some of the skills for the PA will have to be around empowering and person-centred learning opportunities; these models do exist, particularly in adult and further education, and it is important that PA's are given the chance to explore how to facilitate learning.

The job of being a PA is a new and challenging one. While the PA's we met were all very positive and excited about this challenge, it was revealing that they were generally not receiving good support and supervision in their new roles. Many had previous training, and those working for support provider organisations had in-house training; there was clearly, however, a need to provide better training and support for those who were working 1:1 directly for someone with a learning disability. In particular, there was often a disjunction between the training offered to a PA and the actual person who was receiving support. One of the challenges will be to find ways for training and supervision to be individualised, and to be person-centred, with the person with learning difficulties directly involved. One of the groups we interviewed had thought about this question, and felt that it would be useful to have group training sessions that involved both parties – people with learning difficulties and their PA's. This would make a great deal of sense, since this report has shown how good support involves good communication and team work between the two parties in a support relationship.

The video phase of our project will reveal in far greater depth how interaction between the person with learning difficulties and PA actually works, and the possible strategies which PA's could draw on to provide empowering support. At the end of our project, we hope to develop some training resources, which we hope will help people with learning difficulties to take a direct role in training and supporting their own PA's.

In the words of one of our focus group members:

Good support is someone who listens.
But also working as a team, working together.
Respecting each other

We hope that the **Skills for Support** project will contribute towards the goal of working together and respecting each other.