

Circles of Support and Personalisation: exploring the economic case

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Personal Social Services Research Unit
PSSRU Discussion Paper 2882
August 2014
www.pssru.ac.uk

Personalisation and Circles of Support: exploring the economic case

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Running title: A mixed methods study of community capacity-building in action

Key words: Circles; disability; personalisation; community capacity-building; economics

Accessible summary

We looked at Circles of Support for people who have a disability. Our paper tells you about:

- how Circles help someone with a disability to live a good life in the community
- what sorts of things people on the Circle do to help the person live well
- Whether Circles can be a good idea for other people with disabilities.

Summary

We used predominantly qualitative methods to investigate how five people with disabilities were supported by a Circle of Support to live well in the community. Face-to-face interviews were conducted with Circle members: the person with disabilities (where possible), a primary informant (usually a parent) and another Circle member to find out how and why the Circle was set up and how it supported the person with disabilities to have as full and independent life as possible in the community. Circle facilitators were also interviewed to understand their role in providing the planning tools to enable the Circle to best support the person with disabilities. Quantitative data on recent health and social care service use were collected to develop 'economic pen pictures' of the five Circles. Informants considered the Circle had impacted positively on the individual's quality of life. Circles supported care packages which appeared to provide successful alternatives to residential care. Commissioners may wish to explore further how Circles can be an additional approach to personalisation to support people with disabilities to live as independently as possible in the community.

Acknowledgements

The research on which this paper was based was funded by In Control and the National Institute for Health Research (NIHR) School for Social Care Research (SSCR). Views expressed in the paper are those of the authors and are not necessarily those of In Control, SSCR, the Department of Health, NIHR or NHS. We are grateful to Martin Routledge and Helen Sanderson for their tremendous support, and to the members of the Circles who participated so generously in the interviews.

5647 words excluding appendices

Introduction

Circles of Support were developed in Canada and introduced to the UK in the mid-1980s (Circles Network 2014; Skills for people 2014). They are groups that meet regularly to help people with disabilities accomplish their personal goals in life when they are unable to achieve such goals on their own or ask others for help. Each Circle contains a facilitator with responsibility for maintaining focus on those goals. They are based on the belief that the community is a place where everyone belongs (Circles-of-support 2014). A Circle aims to create a comprehensive portrait of the person and support them to plan new developments in their lives ranging from everyday activities, like going shopping, to moving to a new house (Foundation for People with Learning Difficulties 2014). It brings together people who are important to the individual, including family, friends, neighbours, support workers and other professionals. A central characteristic of Circles is their adoption of person-centred planning - a process of life planning for individuals, based around the principles of inclusion and the social model of disability (Dowling et al 2006; Circles Network 2014).

Supporters of the Circles model view it as a powerful way of empowering disabled and disadvantaged people to contribute more effectively to decisions about their lives, and see it as an example of personalisation in action (Neill and Sanderson 2012): 'a deeply practical way of building social and community capital and of harnessing 'social productivity'. Circles bring together people to think and plan in a way that organically builds the capacity of communities to welcome people with disabilities' (ibid p4).

We describe a small-scale study of Circles for people with complex disabilities. The research was conducted as part of a wider study to assess the economic case for community capacity-building initiatives, located in the context of national policies emphasising fiscal austerity and 'localism'. The latter aimed to strengthen civic society by developing and harnessing resources within communities, partly as an alternative to traditional services whose continued funding might no longer be sustainable.

Our aims were to (a) examine the economic case for Circles as mechanisms enabling people with disabilities to have greater choice and autonomy in meeting their needs; and (b) describe, through case studies, the ways in which Circles have been used, the outcomes achieved and costs incurred

Methods

To address the research aims we sought to understand why members become involved in each Circle and their roles within them. We also explored how each Circle expected to help the individual and their family, what difference was made, and how the situation might have differed if the Circle did not exist. We used a mixed-methods approach.

Our principal data collection tool was face-to-face, semi-structured interviews with key members of five Circles of Support. Quantitative data were collected using the Client Services Receipt Inventory (CSRI)(Beecham and Knapp 2001), to capture details of recent care and support arrangements, and the Adult Social Care Outcomes Tool (ASCOT) (Netten et al 2011) to gain an understanding of social care-related quality of life of the individual at the centre of each Circle. ASCOT is a widely used measure of outcomes that ranges across the domains of control over daily life, dignity and respect, nutrition, personal hygiene and home cleanliness, social participation and occupation. We adopted an interview version of ASCOT that gathers information from a relative or staff member about the SCRQoL of the person across these domains and then asks what the impact would be if the service (in this case the Circle) did not exist. SCRQoL scores are then produced for both circumstances measured from 0 to 1: a score of 0 means high needs in all domains whereas a score of 1 means that the person was in an ideal state in all domains. Respondents are asked to state on a scale from 1 to 3 how far their social care related needs are met where 1 refers to an optimal state and 3 to high needs. We collected this information from a parent in four cases and informal carer in the other. Qualitative and quantitative data were combined to develop 'pen pictures' of individuals and the support provided through Circles.

Families were approached on behalf of the research team by intermediaries working with Circles or in the wider personalisation field who either knew the families personally or knew of them through close colleagues. A researcher (MP) then contacted the family to arrange interviews. In four cases, interviews took place in the home of the individual with disabilities; in the other, where the individual chose not to be present, the interviews took place in a key informant's home.

A primary informant was identified for each Circle, usually a parent but, in one case, another long-standing close carer. In all cases, interviews sought to involve the person at the centre of the Circle but the degree of disability in two cases (minimal understanding and lacking verbal capacity) left them unable to participate in their own right.

The interviews provided narrative descriptions of individuals' lives, how and when Circles were set up, how they worked and what 'presenting issues' they had been established to address. Interviews also covered the roles of Circle members, their views on each Circle's impact and what might have happened in its absence. Altogether 15 formal interviews were conducted, supplemented by informal conversations with other family members of one person. Interviewees also included friends, personal assistants (PAs) and the Circle facilitator. Each person was interviewed at a location of their choosing. Ethical approval was obtained from the Social Care Research Ethics Committee (reference 11/IEC08/00).

Unit costs for services were taken from the PSSRU volume (Curtis 2013) and are at 2012/13 price levels.

Findings

Individuals in the study

Two of the five were aged under 25, two were between 30 and 40 and one was nearly 50. In four cases, legal responsibility was held within the family as a 'suitable person' under the Mental Capacity Act 2005, as a deputy under court of protection or as a benefit appointee. Further details are provided in Box 1 (and see Appendix 1 for fuller information).

Role of Circles

The Circles had been in place for between 18 months and 15 years; some had evolved naturally from contacts with friends, often with experience of caring for their own disabled child. In all cases, the primary informant described the key motive for creating the Circle as their wish to give the person at its centre a life as close as possible to those of others in their communities of similar age and without disabilities. Triggers for their establishment were sometimes specific changes in the individual's life. In one family, the Circle was set up eight years ago when the individual was approaching transition to adult services. For another family, the driving force was to enable the individual to have their own house and mortgage. Another reason was to establish longer-term support arrangements as parents aged.

It is important to emphasise that, as well as being parents or carers, all principal informants were professionals working in the field of disability or a related field with direct experience of social care, health and education. In addition to knowledge gained through their caring role, they had much contextual knowledge and experience of statutory services. One informant had been an independent living adviser, while two were employed in national disability societies. Such characteristics need to be borne in mind and may not, of course, be universally reproduced.

Other Circle members were friends, family members or close acquaintances of the family, including former work colleagues. Some had professional knowledge in the field of disability, and some were Personal Assistants who had known the individual from school days. While membership of the Circle varied over time, each had a small core of regular attendees, including the individual (where possible) and the parent(s) or other principal unpaid carer.

Circles usually met relatively frequently when established, perhaps bi-monthly, but meeting intervals increased to perhaps three or six months and even annually as the individual's care and support stabilised. However, the Circle could be called more immediately if urgent issues arose such as funding or staffing.

Support provide by Circles

Interviews with primary informants showed how Circles made significant contributions to their own emotional support as well as the individual's. Some said they might have been unable to continue caring without the Circle and suggested their caring role had strained their mental health 'to the limit'. Nonetheless, while each informant welcomed the fact that they could share the burden and anxiety of care more widely, the 'best interests' of the individual remained the key focus of each Circle.

Circles also enabled task and skill-sharing to help address complex issues, such as financial management of support packages involving several funding streams, or attending review meetings to negotiate care packages and their costs. Such meetings required careful preparation of figures and arguments to justify the package requested. Concerns about negotiating the next care package with statutory agencies seemed ever present. Circle members also took on tasks such as staff training, managing direct payment returns, presenting accounts, or simply making tea and providing food for meetings. For one primary informant, their long-standing Circle was 'like family now'. On occasions, people with specialist expertise known to Circle members might be invited to offer advice, for example on legal aspects of special education.

Care arrangements

Care arrangements in place for each individual were personalised and underpinned by innovative financial arrangements not generally available to other families. These arrangements involved several funding streams and required time and effort to establish. All five individuals had received care packages for many years variously funded by, for example, the Independent Living Fund (ILF), Direct Payments (DPs) and more recently, newer funding streams such as Individual Budgets (IBs)

Each Circle was the key vehicle for ensuring that the agreed care package was tailored to the individual's needs and circumstances as specified in their care plan, while also reflecting their wishes and 'best interests'. For example, informants emphasised the importance of carefully selecting Personal Assistants who could understand and react to changing mood or behaviour. Other care and support needs were met with additional input from family, friends and others such as a cleaner, fitness trainer or gardener.

Primary informants reported that care packages negotiated through the Circle were flexible enough to take account of how each family functioned so that everyone's needs could be met more responsively and naturally. One family had a second disabled child and the package covered the needs of the family as a unit, making it possible for each child's needs to be met flexibly from the single pot of money. As one respondent said, 'there is no one size fits all. Local authorities need to be flexible over systems and management processes...and not just workout packages on the basis of hours and regular time slots'. The needs of the individual sometimes changed suddenly and the Circles permitted timely responses without repeated local authority assessments. For example, one

Circle used the person's direct payment to fund a home visit from a speech therapist for £25 rather than go through the longer and more costly process of commissioning it through Adult Social Care.

Flexibility was secured in another case by funding an independent provider to manage the whole care package, so that difficult discussions with staff to ensure the individual exercised choice and control were handled by the provider in consultation with the Circle, relieving the parent from that responsibility.

Relationships with local authorities

Relationships with education and social care professionals were described as being very difficult, protracted and stressful for some families, and the Circle was an essential source of support. One primary informant described how it enabled them to 'go to services with the solution and ask for funding not for help with the problem'. Despite an annual 'battle', the individual's care package and funding seemed to be successfully negotiated each year through the Circle. Indeed, after many years, local authorities were mostly reported to have confidence that families could manage the packages. However, while one informant considered the authority trusted them to spend the money wisely, another emphasised the need, 'for all parties ...to work together and to treat families like commissioners, not idiots.'

Some respondents reported that personalisation and flexibility in funding and delivering care packages was still not well understood in local government, especially among those with financial responsibilities. They also reported concerns that, where care arrangements were working well, the council might seek to withdraw part of the package as no longer required. Specific difficulties included one case where the authority advocated a managed care package rather than a direct payment, and another where agreement for a personal assistant to sleep over and for the individual concerned to have their own house had been difficult to secure.

Mental health consequences of caring

All primary informants reported experiencing considerable stress from long-term caring roles. Three reported their mental health had suffered greatly from receiving, in their view, inadequate support and understanding of what they wanted for their child. One described receiving one night's respite per week and feeling she was 'holding on by her fingertips at that time'. By contrast, 'the Circle has taken away constant stress of being a carer 24/7 and that monumental responsibility for someone's life'. Having felt suicidal and requiring long-term counselling, she now described herself as living a 'normal' existence because the Circle supported her as much as her child. Another who had feared the stress of caring would cause a heart attack said, 'now, my life isn't about (my child) anymore; I can be a normal Dad because of the support from the Circle and what it has enabled to happen for (the child).'

All key informants referred to the impact of care on employment among family members. Full time work was difficult and flexible working patterns were needed to organise their caring responsibilities. Career paths had been affected with key family members unable to secure promotion for example because they wished to avoid moving the family and negotiating support arrangements in a different authority. One parent highlighted the positive psychological and financial results of being able to work full-time when the Circle enabled their daughter to move into her own flat. The Circle's impact was described as, 'huge, incredible really. It gave me my life and it gave (child) hers.'

Quality of life impacts

Other Circle members universally said they produced major social, psychological and practical outcomes for the individual and their family. The same interviewees also identified Circles as positive influences on their own feelings of being able to provide support. One described the Circle's impact as 'massive' for a person with complex needs who now knew that 'people are looking out for her'. This person could take part in activities that would not have been open to them without the Circle and was seen to be much better integrated into the local community and able to be involved in activities in the same way as people without disabilities. Another Circle was increasing social participation and confidence: the individual was involved in a book group and engaged in conversation more: 'It is a remarkable event that is happening. It would be purgatory for the person if he was in residential care.....I forget he is disabled...he just has a different set of abilities'.

Three of the five people at the centre of the Circles were living in their own accommodation with 24-hour support from personal assistants and family. One was attending university supported by a personal assistant; two worked half a day per week. Unfortunately, we could not directly secure the views of most of the individuals with disabilities, either because they did not participate in the interview through choice or because of their disability. However, one did say she would be a 'heap on the floor' without the Circle.

Facilitators

Interviews with Circle facilitators helped us understand how Circles operated in practice. Each had a professional background in the disability field, extensive knowledge of personalisation and had been known to the family for some time through previous personal and professional contacts. One primary informant described the Circle facilitator as 'the ideas person' who saw the big picture and understood personalisation, providing an authoritative link between family, Circle and local authority or provider.

Facilitators saw Circles as a safe space for exchanging ideas on how to tackle current problems or those likely to arise in future. Several informants reported that, 'the Circle enables people to say things they would not have said before; nothing in the Circle is off limits'. Facilitators described the need for mutual respect and honesty in the Circle, using an approach where everybody's voice was equal and heard. Circle members were passionate that individuals should fulfil their potential. One facilitator described the process as creative and not formalised, where the constant question was whether a course of action was in the best interests of the individual. Facilitators brought planning tools to the Circle which helped focus discussion on 'what is the best way of achieving X and to give people life they want.' They also helped achieve compromise where different views arose in response to such issues.

Where the individual had capacity, his/her views were heard and of prime importance, but where someone could not speak for him/herself, the Circle had 'huge power' to provide solutions to problems. One facilitator described Circles as natural, using the important people in the person's life and the networks that Circle members have as a form of community capacity-building, drawing on wider community networks as resources for finding solutions.

It was acknowledged that there was often a grey area between support for the individual and for key carers, as their lives were closely intertwined. At the same time, the Circle could support a course of action which the key carer, usually a parent, might not themselves have supported. However, facilitators felt Circles could be seen as 'fringe' activities by professionals for whom budgetary considerations were always to the fore. Similarly, facilitators felt that statutory services did not always fully appreciate the extent to which Circles could benefit disabled people and their families. Finally, they reported that there was ongoing debate about whether facilitators should be paid. One

view was that, as personalisation becomes more central to care and support, personal budgets might fund a selected facilitator from a range of community organisations.

Service receipt, costs and outcomes

Interview data were supplemented by information on services received by each individual, their costs, funding sources and changes in reported social care outcomes.

i) Care package costs

Each individual received a care package to meet their day-to-day care and support needs, together with additional services and a range of grants and benefits (Table 1). Care packages provided the basic support, such as personal assistants and social activities, needed to enable each person to live independently in the community. Some packages were very substantial (including 2:1 and overnight care) with annual costs ranging from £7,000 to £80,000 (mean £51,000). By contrast, the weekly cost of residential care in a fully-staffed setting for someone with severe learning disabilities could cost £139,308 per year (Curtis, 2013, p74). It is possible that the costs of residential care for individuals 2, 3 and 5 would have exceeded that figure given the severity of their needs.

The other two individuals (cases 1 and 4) would not have required such high levels of care in a residential setting. If we assume they might have been placed in a group home with a care package, the annual cost based on people with mild to moderate levels of learning disability) would be £72,852 (Curtis 2013, p73). This figure is substantially greater than the total costs we identified of the funding and support negotiated for these individuals through their Circles (Table 1).

As shown in Table 1, some cost data are missing. However, on the basis of available data, total costs of the most expensive care packages appear to be well within the nearly £140,000 annual unit cost of residential care for people with severe learning disabilities (which may themselves have been insufficient to meet the needs of the three people with high level needs: persons 2,3 and 5). This is also the case for the other two cases had it been necessary to admit them to a group home with an associated care package.

ii) Further services

'Other service costs' in Table 1 refers to services received over the previous six months that were outside the care package agreed through each individual's Circle. With the exception of case 5, those costs (annualised) were modest. This finding provides evidence that the care packages are providing a relatively complete substitute for residential and specialised hospital services which some of the five people had used previously. We do not know whether they have been able to access all the additional services they require, though the ability of Circles to secure large and innovative care packages tends to suggest that such access problems would have been picked up by the Circle facilitators.

iii) Benefits and grants

Table 1 also shows the not insignificant support obtained in welfare payments and grants, ranging from £6800 to £27020 annually. These totals are not complete in the case of persons 2, 3 and 4. Support for interest payments for part ownership mortgages is interesting since it suggests that some costs (though limited in total) will be effectively self-liquidating over time. We cannot be certain what difference the inclusion of missing costs would have made to the overall cost of the care and support provided to individuals 2, 3, and 4. In addition we did not cost support from local

authority personnel and financial systems (against which the substitution effect of the unpaid facilitator role would need to be considered). However, it is relevant to note that the level of the equivalent benefits and grants received by others among the five cases (Appendix 2, Table B) were relatively modest and unlikely to exceed the difference in the cost of residential care options.

iv) Social care- related quality of life

The results from the ASCOT showed that informants considered the Circle had impacted positively on the individual's quality of life and that it would have been substantially worse across most domains if the Circle had not existed. Indeed, the group as a whole had a reported score of 0.82 compared with an estimate of 0.21 without the support of the Circle. Thus, the reported gain in overall SCRQoL was the substantial level of 0.61.

Discussion

Our study of economic aspects of Circles of Support used a mixed-methods approach to look at the experiences of five people with disabilities and their families. We relied predominantly on evidence collected in semi-structured interviews with key people involved in each Circle. We would caution against generalisation from this evidence to other Circles. Moreover, the absence of a comparison group means we do not know what would have happened without the Circle, and it is possible that there are other more or less (cost-)effective ways of supporting such individuals. Also, given the small sample, the value of the quantitative data is limited and hard to generalise. Nonetheless, our findings suggest that five Circles studied have promising dimensions which commissioners might think merit more extended study. The evidence does offer indications that:

- The Circles offered an effective and personalised way of supporting people with disabilities to have good quality of life. They were seen by all respondents as the key factor enabling the five individuals to live well in the community while also enabling their principal carers to continue their caring roles.
- Each individual had packages of financial support in place from multiple funding streams, including housing, employment and welfare benefits. Significant challenges had to be overcome before authorities agreed to such packages. Such processes were time-consuming and involved Circle members in demanding negotiations.
- Circles had developed and harnessed community resources which promoted social inclusion and improved wellbeing for all relevant members. Local communities knew the individuals well and expressed concerns if they witnessed something untoward.
- Circles were, themselves, an expression of community capacity-building through which skills and expertise of individuals, families and wider networks could be pooled and developed over time to produce creative care and funding solutions outside of the 'default' and standardised options previously available through statutory agencies.
- We identified some economic consequences of Circles:
 - The cost of care packages, while substantial in some cases, was lower than the cost of the specialised residential settings three individuals would otherwise have required or the care packages plus group home places which seem the relevant comparator for the other two individuals. Although there were gaps in our cost data (e.g. for local authority staff and financial systems support, benefits and grants), such sums seemed likely to be relatively modest and unlikely to exceed the costs of the residential care alternatives, though we cannot be certain this was the case. Circles provided opportunities for all five

individuals to live a much enhanced quality of life, as shown by the ASCOT results obtained from principal carers. Circles supported care packages which appeared to provide successful alternatives to residential care and which were reportedly effective in delaying or averting need for further health and social care support.

- We have no evidence about the future sustainability or otherwise of the existing care arrangements. However, some had been in existence for over 10 years and, over the previous six months, none of our sample had made substantial demands on additional services.
- Unless individuals had significant unmet needs, our evidence suggests that the five care packages were capable of meeting almost all the current needs of the individuals concerned.
- We have no independent evidence about the health and social care needs or quality of life experienced by other Circle members. However, our interviewees consistently reported reductions in demand for mental health services and improvements in mental health status, especially among primary informants associated with support from their Circle.
- If, as part of the roll out of Circles, facilitators were funded from Personal Budgets and recruited from local community and user-led organisations (Neill and Sanderson, 2012), they could further contribute to building community capacity and local economies.
- We did not systematically study the value and quality of employment provided through the Circles model, but its potential for making a positive contribution to the wellbeing of employees as well as recipients is a highly relevant topic for any further studies.

In view of its limitations, it is important to re-emphasise that our study does not demonstrate that the outcomes described above could be achieved by other Circles of Support or that they would not have been achieved for these five individuals in the absence of their Circle. However, it is also important to acknowledge that our interviewees were unanimous in attributing the five individuals' current quality of life to the role and support of their respective Circles.

Conclusion

Proponents of Circles understandably wish to demonstrate how they could be rolled out more widely. We have rehearsed above the study's limitations in this respect. We have also identified features of the Circles studied that would probably make them atypical. First, the parents and other unpaid carers all had unusually high levels of relevant skills, knowledge and networks which were not only important to their success but were unlikely to be available to many families. Second, Circle members generally had a powerful vision and a strong value commitment both to personalisation and the Circle's over-riding purpose of securing the best life possible for the individual at its centre. Third, the facilitators were charismatic personalities with established reputations for promoting personalisation. They carried the credibility with statutory agencies necessary to negotiate innovative and largely untested approaches. To the extent that these factors were essential to securing Circles' outcomes though, wider roll out would be correspondingly problematic. It is essential, therefore, to understand the special characteristics of pathfinder innovations in order to determine how or whether they can be reproduced or compensated for in mainstream practice.

Ultimately, the expansion of Circles depends on local authority commissioners and practitioners accepting their potential as another way to provide more personalised support to help people with complex disabilities to live richer and more fulfilled lives in their local communities. Rolling out

Circles more widely should not be regarded as an end in itself but a possible vehicle for delivering high-quality personalised support. In our view, the evidence from the five cases justifies a closer look at this model of service delivery to establish more certainly how far it is or can become fit for the purpose we have described. It is possible that there are other innovative and (cost-)effective mechanisms for producing similar outcomes for people with similar disabilities but their assessment awaits further research alongside the continuing study of Circles. We end, however, with a different reflection. Notwithstanding their knowledge and expertise, key informants and facilitators experienced substantial difficulties engaging local commissioners in a delivery model which was unfamiliar and did not correspond with 'usual' processes and procedures, especially for finance. Although more economic evidence is necessary, it may not change such cultural barriers. The extension of Circles is also likely to be influenced by the kind of narratives produced from our interviews. Notwithstanding the caveats we have placed on our findings, they support a continuing commitment to understanding the potential of Circles to provide an effective tool to improve outcomes for individuals with complex needs and their families. Most families in this study described having lived difficult and complicated lives for many years before their Circle of support was established. It is important to ascertain on behalf of other individuals and families in similar circumstances how far this and other delivery models can produce similar changes in their lives.

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Box 1: Pen Pictures

Person 1 is described as being at the high-functioning end of the autistic spectrum. He does not have learning disabilities but has great problems with social participation and social inclusion. He was able to attend mainstream school when younger. He is now at university.

Person 2 is in her early 20's described as having autism and learning disabilities. She was described as having 'challenging behaviour' in the past. She lacks understanding and has little language. She can get anxious and needs lots of preparation for new situations. She lives in her own accommodation purchased with a mortgage through a 50:50 joint ownership arrangement with a Housing Association.

Person 3 is middle-aged with a complex of intellectual and physical disabilities. He has cerebral palsy, epilepsy and severe learning disabilities. He is non-verbal although his regular carers can understand his reactions and interpret his wishes. He needs full personal care and has lived for many years in the home of his main carer whom he met as a resident of a hostel where she worked. The Circle is set up as a Board of Trustees.

Person 4 is in her early 30s, with Down's syndrome and has lived for several years in her own flat purchased with a mortgage through a 50:50 joint ownership arrangement with a Housing Association.

Person 5 is severely disabled intellectually and receives care 24 hours, 7 days per week. He is in his 30s and for the past three years has lived in accommodation purchased with a mortgage through a 50:50 joint ownership arrangement with a Housing Association. He needs support on a 2:1 basis during the day, with one Personal Assistant sleeping overnight. He needs support with all activities of daily living. A parent is employed full-time to provide book keeping and management oversight.

Table 1: Annual costs of care and support (£, 2012/13 prices)

Person	Total package cost	Other service costs	Grants and benefits	Total
1	7000	412	21,764	29,176
2	80,000	252	12,420 ¹	92,672
3	70,000	496	6,800 ²	77,296
4	20,000	1502	13,764 ³	35,266
5	80,000	58	27,020	107,078
Mean cost	51,400	244	16,333	68,297

¹ Excludes Housing Benefit, cost not known

² Excludes Housing Benefit and Employment and Support Allowance, costs not known

³ Excludes Access to Work grant, costs not known

Words to this point: 5645

Appendix 1: DETAILED PEN PICTURES

Person 1 is described as being at the high-functioning end of the autistic spectrum. He does not have learning disabilities but has great problems with social participation and social inclusion. He was able to attend mainstream school when younger. He is now at university.

The package of care comes as part of a unique Family budget of £18000pa through an agreement between local Adult Social care and Children and Families departments. The package for the person is, by local agreement, administered through the In Control budget held in the local Mental Health Trust. This provides for the assessed needs of the whole family – the person and his disabled sibling- and the assessed needs of the parents who are involved in meeting the needs of the two disabled siblings.

This person has a support worker who accompanies him to university and stays with him throughout the day. The person receives Disabled Student Allowance which funds the support worker for 20 hours pw over 30 weeks of the university term. The person receives DLA at middle level care and lower level mobility (£3,764).

The other support he needs during the day is provided by his parents. These tasks include: overseeing personal care, safety, providing food, overseeing clothing, transport. It is estimated that each parent provides 10 hours pw unfunded care and support for the person out of university term time. He has minimal independence so the challenge is to increase his independence and social participation.

Person 2 is in her early 20's described as having autism and learning disabilities. She was described as having 'challenging behaviour' in the past. She lacks understanding and has little language. She can get anxious and needs lots of preparation for new situations. She lives in her own accommodation purchased with a mortgage through a 50:50 joint ownership arrangement with a Housing Association.

The Circle commissions a local independent provider to deliver her care package. She has lived in her own flat for 3 years and receives 24hour support, 7 days pw. One person is on shift at all times including overnight. There is a team of four support worker and a senior manager from the local independent provider who oversees the staff. The staff helps the person to have many social activities, such as going to the cinema, shopping, cycling, art class, walking and attending music festivals.

The person's package of care comes through an Individual Budget of £80,000 pa which pays for the staff and the costs and support services delivered by the provider. The provider holds the budget in an Individual Service Fund. In addition the person receives Employment and Support Allowance (ESA). The flat was purchased through a 50% mortgage and 50% Housing Association scheme with the interest element of the mortgage covered through Income Support. The person also receives the highest levels for DLA at both care and mobility components.

Person 3 is middle-aged with a complex of intellectual and physical disabilities. He has cerebral palsy, epilepsy and severe learning disabilities. He is non-verbal although his regular carers can understand his reactions and interpret his wishes. He needs full personal care and has lived for many years in the home of his main carer whom he met as a resident of a hostel where she worked. The Circle is set up as a Board of Trustees.

This person's package of care comes from three funding streams: Supporting People, the Independent Living Fund and an Individual Budget, taken as a Direct Payment, held in trust by the Trustees, totalling £70,000pa. Three part time staff provides 1:1 care for the person on a rotational basis supplemented by the principal informal carer. Sometimes the person needs 2:1 care. Staff may sleep over when needed; otherwise the principal informal carer provides support. The care package funds the person's weekly art class, gym (2x pw), swimming (3x pw) and music activities.

Housing Benefit covers the person's rent. He also receives DLA at the highest level for both care and mobility components. The person receives Employment and Support Allowance (ESA). The principal informal carer is paid for 20 hours pw out of the budget (although contributes around 50 hours pw in practice).

Person 4 is in her early 30s, with Down's syndrome and has lived for several years in her own flat purchased with a mortgage through a 50:50 joint ownership arrangement with a Housing Association. She has lived there for several years.

Funding for the package of care comes from an Individual Budget (IB) of £20,000 which pays for a small number of hours of support from a co-resident family member (for cooking and overseeing safety). The IB also funds a job coach (once a week) to work on her website on her CV and job applications; a fitness instructor (four hours pw) to assist with mobility problems, a cleaner (5 hours pw) and occasional PA (2 hours pw), who is predominantly a friend, to accompany on outings.

In addition, the person receives Employment and Support Allowance which covers interest payments on the mortgage element of the flat purchase while Housing Benefit covers the rental. She receives DLA care component at middle level and mobility at lower rate. She has a regular one day a week job which meets the Access to Work funding.

The person's package of care supports her many social activities such as meeting friends, helping the person negotiate local public transport, help at local drama class for other disabled people.

Person 5 is severely disabled intellectually and receives care 24 hours, 7 days per week. He is in his 30s and for the past three years has lived in accommodation purchased with a mortgage through a 50:50 joint ownership arrangement with a Housing Association. He has care 24 hours, 7 days per week. He needs support on a 2:1 basis during the day, with one Personal Assistant sleeping overnight. He needs support with all activities of daily living. A parent is employed full-time to provide book keeping and management oversight.

The person's package of care totals £80,000pa drawn from DP, ILF and Supporting People funding streams. It comprises a DP of £54,000pa; ILF contributes £15,000pa and Supporting People provides £7000pa. The funding supports the employment of four PAs. It also enables the person to take part in various local activities supported by his PAs such as swimming, walking, seeing friends. It also enables the person to be supported in a regular one hour a day local job. Ten people are employed in total including a weekly gardener (2hours pw); a cleaner (2hours pw); and an occasional handyman.

The person receives benefits of £18000pa. This is made up of Employment and Support Allowance (ESA) of around £10,000 pa with interest on the mortgage (£1200pa) paid on top through the income support component of the ESA. In addition, the person receives DLA at the highest levels of both care and mobility components (£6800pa). Housing Benefit pays the rental element on the person's property (£2,600 pa).

Appendix 2: Details of Additional Services and Funding Received

Table A: Annual costs of services (£, 2012/13 prices)

Person		
1	Service	Cost pa
	Hospital dietician	£ 32
	Dentist	£ 36
	GP	£ 344
	Total	£ 412
2		
	Specialist dentist	£ 194
	GP	£ 58
	Total	£ 252
3		
	Neurology	£ 128
	Dentist (home)	£ 108
	GP	£ 172
	Occupational Therapist (home)	£ 44
	Physiotherapist (home)	£ 44
	Total	£ 496

4			
	Ophthalmologist	£	366
	Endocrinologist	£	732
	GP	£	344
	Physiotherapist	£	60
	Total	£	1502
5			
	GP	£	58
	Total	£	58

Table B: Other benefits and grants received

Person and Total	Benefits and other grants claimed pa
1 £21,764	Student loan (£6000) DSA (£12,000) DLA (£3,764) for middle level care and lower level mobility.
2 £12,420	Income based ESA (£5620) which also pays the interest element on mortgage HB (for rental element of property purchase) (sum not known) DLA (£6,800) for highest level care and higher level mobility
3 £6,800	Income based ESA HB (sum not known) DLA (£6,800) for highest level care and higher level mobility
4 £13,764	Income based ESA (£10,000) which also pays the interest element on mortgage. DLA (£3,764) for middle level care and lower level mobility Access to Work grant (sum not known)

<p>5</p> <p>£27,020</p>	<p>Income based ESA (£5,620) which also pays the interest element on mortgage (£1200)</p> <p>HB (£2,600) for rental element of property purchase</p> <p>DLA (£6,800) for highest level care and higher level mobility</p>

DSA= Disabled Student Allowance

ESA = Employment and Support Allowance

HB = Housing Benefit