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## **Circles of Support and Personalisation: Exploring the Economic Case**

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### **Abstract**

Circles of Support aim to enable people with learning disabilities (and others) to live full lives as part of their communities. As part of a wider study of the economic case for community capacity building conducted from 2012-2014, we conducted a mixed methods study of five Circles in North West England. Members of these Circles were supporting adults with moderate to profound learning disabilities and provided accounts of success in enabling the core member to live more independent lives with improved social care outcomes within cost envelopes that appeared to be less than more traditional types of support. The Circles also reported success in harnessing community resources to promote social inclusion and improve wellbeing. This very small scale study can only offer tentative evidence but does appear to justify more rigorous research into the potential of Circles to secure cost effective means of providing support to people with learning disabilities than the alternative, which in most cases would have been a long-term residential care placement.

### **Introduction**

***There is a growing interest in England, as elsewhere, in personalised social care and support emphasizing choice and control, including funding models for community-based initiatives. This interest in the field is reflected, for example, in the Think Local, Act Personal (TLAP) partnership between central and local government, the NHS, the provider and voluntary sectors together with people with care and support needs, carers and family members. (TLAP 2016).. One such innovative approach is through Circles of Support for people with disabilities.***

Sanderson (2015) defined **a Circle of support** as ‘a small group of family, friends and staff who come together to support a person, helping them to identify what they would like to do or change in their life and then supporting them to make this happen’. Circles assist people with disabilities to accomplish their life goals when they are unable to do so on their own. A Circle therefore aims to support people 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 Disabilities, 2014).

A central characteristic of Circles is the 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). A range of planning tools is used to help people make purposeful and meaningful choices in their life. (PUSH, 2001; O'Brien and Forest, 1989; Pearpoint, O'Brien and Forest, 2001) 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 (Neill and Sanderson, 2012).

Circles are not, however, a new intervention; nor are they confined to learning disabilities. The approach was first recorded in Canada as enabling someone with disabilities, to move from a nursing home to their own apartment (Forest & Snow 1983, Pearpoint, 1990). In England, they have been used to support older people (Macadam et al 2009), people with dementia (Macadam and Savitch 2015), people with learning disabilities (Burke 2006) and in offender management (Nellis 2009, Thomas et al 2014). They have also been developed in Scotland (PUSH) 2001 Germany and India (Knust-Potter, Potter and Stukenberg 2006) as well as Canada Pearpoint 2002 and the USA (Novak et al 1990).

***Very little economic analysis of Circles has been conducted in any field of policy, nationally or internationally. For example, in their extensive review of evidence about the operation of Circles for offender management, Thomas et al 2014, p.35 identified limited evidence about costs and cautioned that generally reported positive experiences were not necessarily the same as ‘impact and efficiency’. McCartan et al’s (2014) review for the Ministry of Justice similarly emphasised the***

***absence of 'large, long-term and independent evaluations that have investigated the impact of (Circles)... in the UK or elsewhere'.***

Few circles for people with learning disabilities exist in England but their expansion might be consistent with the current policy context. The concept supports policy objectives such as community capacity-building, person-centred care and support, and self-directed support. Neill and Sanderson (2012) have highlighted their potential to couple

‘the control over resources that personal budgets in health and social care offers....with the practice of building a supportive network of allies around a person (to create) a powerful mechanism for implementing change in that person’s life, change in the way services interact with that person, and a fundamental change in the way communities receive and regard people who require support’.

At the same time, however, such objectives are being pursued simultaneously with the largest real cuts in the history of adult social care (Fernandez et al, 2013). Inevitably, this context reinforces the demand to evidence the benefits from new services and investments, ***a demand for which, as we have noted, the current evidence base can do little to meet.***

***This paper begins to provide such evidence about the contributions of Circles of Support for people with disabilities by reporting on a small-scale, exploratory study undertaken as part of a wider study of the economic case for community capacity building (Bauer et al 2015). We studied five Circles of Support in North West England organised around adults with moderate to profound learning disabilities.*** More specifically, and adopting a mixed-methods approach, we aimed to:

- (a) examine the economic case for Circles as a means to give people with disabilities greater choice and autonomy in meeting their needs; and
- (b) describe, through case studies, how each Circle was expected to help the individual and their family, together with perceptions of what differences Circles actually made and how the situation might have differed if the Circle did not exist

## Methods

### *Individuals in the study*

#### **Box 1 Pen Pictures of Individuals in the Study**

**Person 1** is 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 20s, with 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 when 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 using his DP to provide book keeping and management oversight.

Case studies were conducted of five Circles (see *Box 1*). *The individuals at their centre varied widely in terms of type and level of disability. Two of them were aged under 25, two between 30 and 40 and one was nearly 50. Three were male and two female. Two were supported in work for a short time each week; two were unable to work gainfully because of their level of disability. One attended university, with support. In four cases, legal responsibility for the person's affairs was held within the family. Three of the individuals were unable, or did not wish, to take part in interviews.*

### **Membership of Circles**

Other Circle members included friends, family members, personal assistants or close acquaintances of the family. Some had professional knowledge of disability and had known the individual from school days. The core members (see below) attended each meeting and others were brought in to advise on particular issues e.g. legal matters around special education.

### **Core Members**

Circle 1: focus person; mother; a friend with a disabled child; friend (also local vicar); facilitator

Circle 2: focus person; parents; a friend with a disabled child; personal assistant; facilitator

Circle 3: principal unpaid carer; a friend (with employment experience of Direct Payments); a friend with a disabled child

Circle 4: focus person; parents; sibling; facilitator

Circle 5: focus person; parents; personal assistant; sibling; facilitator.

### **Instruments employed in data collection**

A mixed methods approach was used to understand the ways in which Circles had impacted both on the life of the individual at its centre and on others in the Circle.

For the qualitative data, our principal data collection tool was face-to-face, semi-structured interviews with key members of five Circles of Support, including (where possible) the person at its centre. *A topic guide was developed to gather information on individuals' lives, how and when Circles were established, how they worked and the issues they were set up to tackle. Interviews also covered the*

***roles of Circle members, their views on each Circle's impact and what might have happened in its absence.***

Quantitative data were also collected from principal interviewees using the Client Services Receipt Inventory (CSRI, Beecham and Knapp 2001) and the Adult Social Care Outcomes Tool (ASCOT, Netten et al, 2011). The former captured details of recent care and support arrangements using unit costs from Curtis, (2013) at 2012/13 price levels.

ASCOT is a widely used measure of outcomes ranging 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 to gather information from a relative or staff member about the social care-related quality of life (SCRQoL) of the person at the centre of each Circle across those domains and then explored perceptions of what the impact would be if the Circle did not exist. We collected this information from a parent in four cases and unpaid carer in the other. Qualitative and quantitative data were combined to develop 'pen pictures' of individuals and the support provided.

### ***Procedures***

Families were identified and initially approached by intermediaries working with Circles or in the wider personalisation field who knew the families personally or through close colleagues. One of the authors (MP) contacted the families to arrange interviews including with the person at the centre of the Circle. In two cases, the person's degree of disability meant they were unable to participate in their own right and, in a third, the individual chose not to participate. ***Information sheets were provided to potential interviewees and interview and participation secured through forms.***

***Fifteen formal interviews were conducted with Circle members including friends, personal assistants (PAs) and the Circle facilitator. Each person was interviewed at a location and time of their choosing. Interviews lasted around an hour and a half. In two cases the individual at the centre of the Circle participated with the support of a principal carer.***

Ethical approval was obtained from the Social Care Research Ethics Committee (reference 11/IEC08/00).

## Findings

*This section presents the main themes that emerged from the interviews together with the results of the costs analyses.*

*In order to develop the initial pen pictures of each Circle, interview data were analysed thematically drawing on the key issues described by participants on the purpose, development, structure, functioning and perceived outcomes of the Circle. **They are summarised below according to the main themes that arose from the interviews.***

### **Role of Circles**

The Circles had existed for between one 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 others in their communities of similar age and without disabilities. Triggers for their establishment were sometimes specific changes in the individual's life such as the transition to adult life, to enable an individual to have their own house and mortgage and to establish longer-term support arrangements, as parents grew older.

Significantly, all principal informants also possessed atypical levels of contextual knowledge and experience as they worked in disability or related fields and had direct experience in social care, health and education.

Other Circle members were friends, family members or close acquaintances of the family. Some had professional knowledge of disability and had known the individual from school days. While membership of the Circle varied over time, regular attendees included the individual (where possible), parent(s) or other principal unpaid carer. Circles usually met frequently when first established, perhaps bi-monthly, and less frequently as care and support arrangements stabilised.



### ***Support provide by Circles***

Circle members identified two key tasks: supporting the individual to live well in the local community and assisting the management of their care package. Individuals were supported in their chosen social activities, including attending a gym, music classes or socialising with friends. The Circle also helped with the financial management of support packages and attended review meetings to negotiate them. Sometimes Circle members might invite people they knew with specialist expertise to offer advice.

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 support of the Circle. Nonetheless, while each informant welcomed being able to share the burden of care, they saw the 'best interests' of the individual as the key focus for each Circle.

### ***Care arrangements***

Care arrangements had been developed through the principles of person-centred planning 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, funded by, for example, the Independent Living Fund (ILF), Direct Payments (DPs) and, more recently, Personal Budgets (PBs). Each Circle was the key vehicle for ensuring that the agreed care package was tailored to the individual's needs and wishes as specified in their care plan.

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 work out packages on the basis of hours and regular time slots'.

### ***Relationships with local authorities***

Relationships with education and social care professionals were described as very difficult, protracted and stressful for some families, and the Circle provided 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', this individual's care package and funding seemed to be successfully negotiated each year through the Circle. Indeed, local authorities were mostly reported to have confidence now that families could manage the packages, although one informant emphasised the need, 'for all parties to work together and to treat families like commissioners, not idiots.'

Some respondents reported that personalisation and the need for flexibility in funding and delivering care packages was still not well understood in local government, especially among those with financial responsibilities. Specific difficulties included one case where the authority wanted 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. By contrast, the Circle had 'taken away the constant stress of being a carer 24/7 and that monumental responsibility for someone's life'. Having felt suicidal and requiring long-term counselling, one parent described herself as living a 'normal' existence because the Circle supported her as much as her child: 'it gave me my life and it gave (child) hers.'

### ***Quality of life impacts***

Circle members universally said they produced major social, psychological and practical outcomes for the individual and their family. One described the Circle's impact as 'massive' for a person with complex needs who now knew that 'people are looking out for her'. She could now take part in activities in the same way as people without disabilities and was much more integrated in the local community.

The social participation and self-confidence of another individual were said to have increased through involvement in a book group: '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'.

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.

All key informants described the impact of care on employment: full-time work was difficult and flexible working patterns were needed to accommodate caring responsibilities. Some family members had been unable to secure promotion because, for example, they wished to avoid moving the family and negotiating support arrangements in a different authority.

### ***Background and role of Facilitators***

Each facilitator had a professional background in the disability field, extensive knowledge of personalisation and had been known to the family for some time through 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, local authority and providers.

Facilitators saw Circles as a safe space for exchanging ideas on how to tackle current and anticipated problems. One facilitator described the process as creative and not formalised, where the constant question was in the best interests of the individual. Facilitators brought planning tools to the Circle to help focus on the best way to give 'people the life they want.' They also helped achieve compromise when differences arose.

Where the individual had capacity, his/her views were of prime importance, but where someone could not speak for him/herself, the Circle had 'huge power' to provide solutions. The networks of facilitators and other members served as a form of community capacity-building, drawing on wider community networks as resources for finding solutions.

However, facilitators felt professionals sometimes saw Circles as ‘fringe’ activities, especially those whose budgetary responsibilities were paramount and did not always 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, with personal budgets being seen as a potential source..

## **Quantitative data**

### **Service receipt, costs and outcomes**

Interview data were supplemented by information **derived from administering the instruments described above** on services received by each individual, including 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 (PAs)** 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, however, the weekly cost of residential care in a fully staffed setting for someone with severe learning disabilities was £139,308 per year (Curtis, 2013, p74) but the costs of residential care for individuals 2, 3 and 5 could 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. 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 also substantially greater than the total costs of the funding and support we identified for these individuals (Table 1).

Although some cost data are missing, the available data show total costs of the most expensive care packages 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) This would also be true of the remaining 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 fell outside the care package agreed through each individual's Circle. With the exception of case 5, those costs were *in* Table 2. This finding suggests the care packages negotiated by each Circle were 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 were able to access all the additional services they required, though the ability of Circles to secure large and innovative care packages suggests Circle facilitators would have identified such access problems.

### ***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 cases of persons 2, 3 and 4 and, while we cannot be certain what difference the missing costs would have made, the equivalent benefits and grants received by others among the five cases (Table 3) were relatively modest and unlikely to bring the total costs above the relevant residential care options.

In addition, however, 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).

### ***iv) Social care- related quality of life (SCRQoL)***

The ASCOT results showed that informants considered the Circle had impacted positively on each individual's quality of life and that outcomes 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 at the substantial level of 0.61.

## Discussion

Our study of the five Circles used a mixed-methods approach but relied predominantly on data collected through semi-structured interviews with key people involved in them. The absence of a comparison group means we do not know what would have happened without the Circle and it is also possible that there are other more or less cost-effective ways of supporting these individuals. The small numbers also make it impossible to generalise from our findings. Nonetheless, they do suggest that these five Circles have promising dimensions which commissioners might think merit more extended study:

- Participants judged each Circle to be offering effective and personalised ways of supporting people with disabilities to have a good quality of life. They were seen by all respondents as the key factor enabling the five individuals to live well in their community and also supported principal carers to continue their caring roles.
- Each individual had packages of support 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 could involve Circle members in **difficult and/or** demanding negotiations.
- Circles had developed and harnessed community resources that promoted social inclusion and wellbeing for their 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 to produce creative care and funding solutions beyond those provided through statutory agencies.
- We examined some economic aspects of Circles. The cost of care packages, while substantial in some cases, was lower than the cost of the specialised residential settings that three individuals would otherwise have required, or the care packages plus group home places which seem the relevant comparator for the other two individuals (*see also Robertson et al 2004; McGill and Poynter 2012*)

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 of course we cannot be certain.

- **The ASCOT evidence showed that the Circles were perceived to have** provided opportunities for all five individuals to live much better quality lives by securing care packages which appeared to provide successful alternatives to residential care and which were reportedly effective in delaying or averting the need for further health and social care support. **The significance of these findings is underlined by the evidence of continuing shortcomings in the quality of the alternatives provided in hospital and residential care settings. For example, Emerson's (2012) analysis of unannounced Care Quality Commission (CQC) inspections conducted in 2011 and 2012 found that almost 50 per cent of the hospitals and care homes inspected did not meet national standards (see also CQC 2012). He also concluded that there was 'a notable similarity between these findings and those of the national audit undertaken in 2006 by the Healthcare Commission (2007).**
- We have no evidence about the future sustainability or otherwise of the existing care arrangements. However, some Circles in our study had been in existence for over 10 years and, over the previous 6 months, none had made substantial demands on additional services.
- We have no independent evidence about the health and social care needs or quality of lives of other Circle members. However, Circle members reported reduced demand on mental health services and improvements in mental health status, especially among primary informants.
- We cannot be sure from this small study that the substantial administrative burden carried by Circle members could be managed by members without their atypical mix of skills and expertise. We also do not know if sufficient resources exist or can be developed within local communities to support a wider rollout of the model.
- Neill and Sanderson (2012) have suggested that facilitators could be funded from Personal Budgets and recruited from local community and user-led

organisations. In some circumstances, suitably experienced volunteers might provide a further possibility.

## **Conclusion**

In view of its limitations, it is important to re-emphasise that our study does not demonstrate that other Circles would achieve the outcomes described above for people with disabilities or with other needs; nor that the results described would not have been achieved in the absence of the Circles. However, interviewees unanimously attributed the five individuals' current quality of life to their respective Circle.

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 unusually high levels of skills, knowledge and networks of parents and other members, which were considered important to the Circles' success but unlikely to be available to many families. Second, Circle members generally shared a strong commitment to the values and goals of personalisation. 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 the Circles' outcomes, wider rollout might be correspondingly difficult.

Ultimately, any expansion of Circles depends on statutory sector commissioners and practitioners accepting their potential to help people with complex disabilities to live richer and more fulfilled lives in their local communities. In our judgement, the five case studies justify a closer look at this model to establish more robustly how far it might offer a cost effective mechanism for drawing on capacity within communities to extend opportunities for independent living and positive outcomes associated with them. At the same time, we are conscious that Circles can be viewed from the less benign perspective of the 'privatisation of risk' (for example Calhoun 2006). Without adequate public funding and the development of community capacity they could become an option available only to people with friends and families enjoying the kinds of expertise, confidence and authority shared by those in our five case studies. Moreover, even the 'sharp elbows of the middle



classes' could not produce the kinds of opportunities for independent living described here without access to sufficient public resources to make those opportunities real.

Even so, and notwithstanding the caveats we have placed on ***the findings from this small-scale and exploratory study***, they justify further research into the potential of Circles to provide an effective tool to improve outcomes for individuals and their families. ***Larger scale studies over longer time frames would help to establish how much confidence commissioners and providers might place on the feasibility, viability and cost effectiveness of adopting Circles in a range of contexts and settings.*** 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 with similar ***and different*** circumstances how far this delivery model can produce similar changes in their lives ***compared with the alternatives.***

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### **References**

Bauer A, Knapp M, Perkins M and Wistow G (2015), Building community capacity: the economic case in adult social care in England, Research Findings. London: School for Social Care Research. <http://www.sscr.nihr.ac.uk/PDF/Findings/RF50.pdf>  
Accessed 7<sup>th</sup> October 2015.

Beecham J and Knapp M (2001), 'Costing psychiatric interventions' in G.Thornicroft (ed) *Measuring Mental Health Needs*, Oxford University Press, Oxford.

Burke C. (2006), *Building Communities through Circles of Friends*. London: The Mental Health Foundation/ Foundation for People with Learning Disabilities

Calhoun C. (2006) 'The Privatization of Risk' *Public Culture* Spring 2006 18(2): 257-263; doi: 10.1215/08992363-2006-001

Circles 4EU (2015). [http://www.circles4.eu/default.asp?page\\_id=133](http://www.circles4.eu/default.asp?page_id=133). Accessed June 24 2015.

Circles Network (2014). <http://www.circlesnetwork.org.uk/>. Accessed 22 May 2014.

Curtis L (2013) *Unit Costs of Health and Social Care 2013*, Personal Social Services Research Unit, University of Kent: Canterbury

Dowling S, Manthorpe J and Cowley S in association with King S, Raymond V, Perez W and Weinstein P (2006) *Person-centred planning in social care, A scoping review*. Joseph Rowntree Foundation: York.

**Emerson E. (2012,) A Review of the Results of the 2011/12 Focused CQC Inspection of Services for People with Learning Disabilities. Durham: Learning Disabilities Public Health Observatory, North East Public Health Observatory. 2012**

Falvey M, Forest M Pearpoint J and Rosenberg RL (2000): *All my Life's a Circle. Using the Tools: Circles, MAPS & PATHS*. Toronto: Inclusion Press

Fernandez J, Snell T and Wistow G (2013), *Changes in the Patterns of Social Care Provision in England: 2005/6 to 2012/13*, PSSRU Discussion Paper 2867. London: Personal Social Services Research Unit, LSE.

Forest M, Snow J (1983) The Joshua Committee: an advocacy model, *Journal of Leisureability* 10(1) 20-23.

Foundation for People with Learning Disabilities (2014). <http://www.learningdisabilities.org.uk/our-work/family-friends-community/circles-of-support/>. Accessed 30 July 2014

**Healthcare Commission (2007), A Life Like No Other: A national audit of specialist inpatient healthcare services for people with learning difficulties in England. London: Commission for Healthcare Audit and Inspection.**

Inclusion Press (2015). <http://www.inclusion.com/circlesoffriends.html>. Accessed 24 June 2015

Indiana Resource Center for Autism (2015) <http://www.iidc.indiana.edu/?pageId=411>. Accessed June 24 2015

Knust-Potter E, Potter P, Stukenberg T (2006) Circles of Support in India and Europe: Community resource networks for people with disabilities and autism Summary report <http://www.transnational.evaluations.de/COS/pdf/5%20dortmund/dortmund%20summary%20report%20ekp%20pp%20ts%20.pdf> . Accessed 24 June 2015.

Macadam A, Bowers H, Easterbrook L, Smith C (2009) Using circles of support to improve well- being in later life, in Poll C, Kennedy J, Sanderson H (2009) *In community: practical lessons in supporting isolated people to become part of community*. Stockport: HSA Press.

Macadam A. and Savitch N. (2015) ‘ Staying Connected with Circles of Support’ *Journal of Dementia Care*, 23, 1.

McCartan, K; Kemshall, H; Westwood, S; Solle, J; MacKenzie, G; Cattell, J; and Pollard, A. (2014,) ***Circles of Support and Accountability (CoSA): A Case File Review of Two Pilots***. The University of West England, De Montfort University and the Ministry of Justice

**McGill, P. & Poynter, J. (2012) High cost residential placements for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 25, 584-7.,**

Neill M and Sanderson H (2012) Circles of Support and Personalisation

<http://www.helensandersonassociates.co.uk/media/75948/circlesofsupportandpersonalisation.pdf>. Accessed 30 July 2014.

Nellis, M (2009) *Circles of Support and Accountability for sex offenders in England and Wales: their origins and implementation between 1999 -2005*. British Journal of Community Justice, Volume 7, pp23-44

Netten A, Beadle-Brown J, Caiels J, Forder J, Malley J, Smith N, Trukeschitz B, Towers A, Welch E. and Windle K (2011) *Adult Social Care Outcomes Toolkit v2.1: Main guidance*, PSSRU Discussion Paper 2716/3, Personal Social Services Research Unit, University of Kent, Canterbury <http://www.pssru.ac.uk/ascot/>. Accessed 22 May 2014.

Novak Amado, A., Conklin, F. & J. Wells (1990) *Friends – A manual for connecting persons with disabilities and community members*. St Pauls, Minnesota: Human Services Research and Development Center.

O'Brien, J and Forest M (1989): *Action for Inclusion*. Toronto: Inclusion Press.

O'Brien J and Pearpoint J (2002): *Person-Centered Planning with MAPS and PATH. A Workbook for Facilitators*. Toronto: Inclusion Press.

Pearpoint J (1990): *Behind the Piano: The building of Judith Snow's unique Circle of Friends*. Toronto: Inclusion Press.

Pearpoint J, O'Brien J and Forest M (2001): *PATH: Planning Alternative Tomorrows with Hope. A Workbook for Planning Possible Positive Futures*. Toronto: Inclusion Press.

**Robertson J, Emerson E, Pinkney L, Caesar E, Felce D, Meek A, et al. Quality and costs of community-based residential supports for people with mental retardation and challenging behavior. *American Journal on Mental Retardation* 2004;109(4):332-44.**

PUSH (Perth and Kinross LTD) (2001). Circles project. Scotland.

Sanderson H. (2015) 9 reasons why I am excited about the potential of Community Circles to make a difference, Community Circles

<https://communitycirclesblog.wordpress.com/2015/09/21/9-reasons-why-i-am-excited-about-the-potential-of-community-circles-to-make-a-difference/>

Accessed 3<sup>rd</sup> October 2015

Think Local, Act Personal (TLAP).

[http://www.thinklocalactpersonal.org.uk/About us/](http://www.thinklocalactpersonal.org.uk/About_us/)

Accessed 21st January 2016.

Thomas, T., Thompson, D., & Karstedt, K. (2014), [\*Assessing the impact of Circles of Support and Accountability on the reintegration of adults convicted of sexual offences in the community\*](#) Centre for Criminal Justice Studies, School of Law, University of Leeds

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

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

<sup>1</sup> Excludes Housing Benefit, cost not known

<sup>2</sup> Excludes Housing Benefit and Employment and Support Allowance, costs not known

<sup>3</sup> Excludes Access to Work grant, costs not known

**Table 2: Annual costs of Additional Services Received (2012/13 prices)**

<b>Person</b>		
<b>1</b>	<b>Service</b>	<b>Cost pa</b>
	Hospital dietician	£ 32
	Dentist	£ 36
	GP	£ 344
	<b>Total</b>	<b>£ 412</b>
<b>2</b>		
	Specialist dentist	£ 194
	GP	£ 58
	<b>Total</b>	<b>£ 252</b>
<b>3</b>		
	Neurology	£ 128
	Dentist (home)	£ 108
	GP	£ 172
	Occupational Therapist (home)	£ 44
	Physiotherapist (home)	£ 44
	<b>Total</b>	<b>£ 496</b>
<b>4</b>		
	Ophthalmologist	£ 366
	Endocrinologist	£ 732
	GP	£ 344
	Physiotherapist	£ 60
	<b>Total</b>	<b>£ 1502</b>
<b>5</b>		
	GP	£ 58
	<b>Total</b>	<b>£ 58</b>

**Table 3: Annual costs of Additional Funding Received (2012/13 prices)**

<b>Person and Total</b>	<b>Benefits and other grants claimed pa</b>
<b>1</b>  <b>£21,764</b>	<b>Student loan (£6000)</b> <b>DSA (£12,000)</b> <b>DLA (£3,764) for middle level care and lower level mobility.</b>
<b>2</b>  <b>£12,420</b>	<b>Income based ESA (£5620) which also pays the interest element on mortgage</b> <b>HB (for rental element of property purchase) (sum not known)</b> <b>DLA (£6,800) for highest level care and higher level mobility</b>
<b>3</b>  <b>£6,800</b>	<b>Income based ESA</b> <b>HB (sum not known)</b> <b>DLA (£6,800) for highest level care and higher level mobility</b>
<b>4</b>  <b>£13,764</b>	<b>Income based ESA (£10,000) which also pays the interest element on mortgage.</b> <b>DLA (£3,764) for middle level care and lower level mobility</b> <b>Access to Work grant (sum not known)</b>
<b>5</b>  <b>£27,020</b>	<b>Income based ESA (£5,620) which also pays the interest element on mortgage (£1200)</b> <b>HB (£2,600) for rental element of property purchase</b> <b>DLA (£6,800) for highest level care</b>



	<b>and higher level mobility</b>

DSA= Disabled Student Allowance

ESA = Employment and Support Allowance

HB = Housing Benefit