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'Circles of Support/Friends'

Exploring the notion of relationships, intimacy, friendship and support.

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***Abstract:** This paper raises concerns and challenges the deficit interpretations and descriptors such as: 'vulnerable', 'learning difficulties', 'oppressed', 'lack reciprocity'; of people who have come to be associated with the 'Circles of Support/Friends' approach. The argument here, is that the notion of relationships is much more complex than how they are being presented in the 'Circles of Support/Friends' literature. This argument is evidenced through the experiences of the participants who shared their personal identities; identities such as: impairment, racial identity, sexual orientation, gender and age. This paper uses a 'Relationship Map' with a difference. A difference that challenges deficit assumptions and suggests that relationship choices are affected by influencing factors and that the notion of uncertainty affects all relationships.*

Introduction

The purpose of this paper is to raise a number of considerations and concerns as to the way 'circles of support/friends' is understood and applied in practice. The paper begins by exploring 'circles of support/friends' as an approach that attempts to illustrate informal and formal social networks. This paper adds to the view that illustrating and understanding issues related to relationships, intimacy, friendship and support is problematic and much more complex than is being presented in the 'circles of support/friends' literature. Initially, this paper begins with the work of Falvey *et al.*, (2003) and Mount (1988) which offers different approaches to illustrating social networks. However, there seems to be at least two confusions. One of the confusions relates to the use of the terms 'circles of support' and 'circles of friends' since at times they are used interchangeably. For Falvey *et al.*, (1993, 2003) one distinction is that adults prefer to use the term 'support' whilst young people prefer to use the term 'friends'; although there are examples where adults have adopted the term

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'circles of friends'. The second confusion relates to why and for whom 'circles of support/friends' is used.

Literature on 'circles of support/friends' is scarce and there seems to be little critical discussion as to their merit and in terms of how they relate to theory and practice. One of the concerns in this paper is the association that the 'circles of support/friends' approach is being assumed to encompass the sole experience of disabled peoples' relationships as though relationship, intimacy, friendship and support issues do not affect non-disabled people. Another concern with using the 'circles of support/friends' as a 'social scan' is the issue of placing individual's in relation to their 'closeness' and the assumption that individuals who are paid in a person's life is assumed to be 'less than' meaningful than not having individuals who are paid.

Drawing upon the contribution of participants the findings in this paper present three themes for consideration. Firstly, that informal and formal social networks based upon a deficit assumption about an individual's identity; is in danger of becoming 'circles of charity/entrapment'. Secondly, individual choices are affected by influencing factors such as: biological, cultural, economical, functional, geographical, personal, political, psychological, religious, social, and spiritual; amongst other possible factors. These influencing factors are not necessarily in any order as such; the recognition is that these factors influence the way individuals interpret relationships. The third consideration is the emerging illustrative representation in this study, whilst adopting the term 'Relationship Map', shifts the focus of attention from the individual and provides a 'social scan' that places the focus on highlighting barriers to and within relationships.

Literature

Forest, Pearpoint and Snow (Falvey, 2003, p.87), who are co-authors, suggest that 'circles of support/friends' is *'part of a tool box of person centred planning strategies'* and state that *'Circles do not belong to any one author. They are an ancient concept of building community and relationships in a modern context'*. In a chapter from this book, Forest and Pearpoint point out that there has been some confusion as to the process and explain that:

*In the past, people have confused the exercise with the actual building of Circles which is a life long practice...The circle exercise is a powerful consciousness raising tool to **start** a process that might lead to building relationships in anyone's life.* (Forest and Pearpoint, 2003, p.92) [emphasis in original]

Falvey *et al.*, describe the illustrative exercise as a 'social scan' and explain that:

It will give a quick picture of who is in your life. It is very useful to gain clarity about who might be involved in certain activities, or circles that need to be filled. We recommend it personally and consider it an essential preventative health check for students, teachers and citizens. The hidden key question is: "Who loves this person?" (Falvey *et al.*, 2003, p.6)

The authors use four concentric circles to illustrate this 'closeness' and term the process 'circles of support/friends' (Fig 1, below). The concentric circles are presented in relation to their 'closeness' to the individual and from the centre outwards are referred to as: intimacy, friendship, participation and exchange; although the work of Newton and Wilson (1999) refer to these circles as: anchors, allies, associates and those who are paid.

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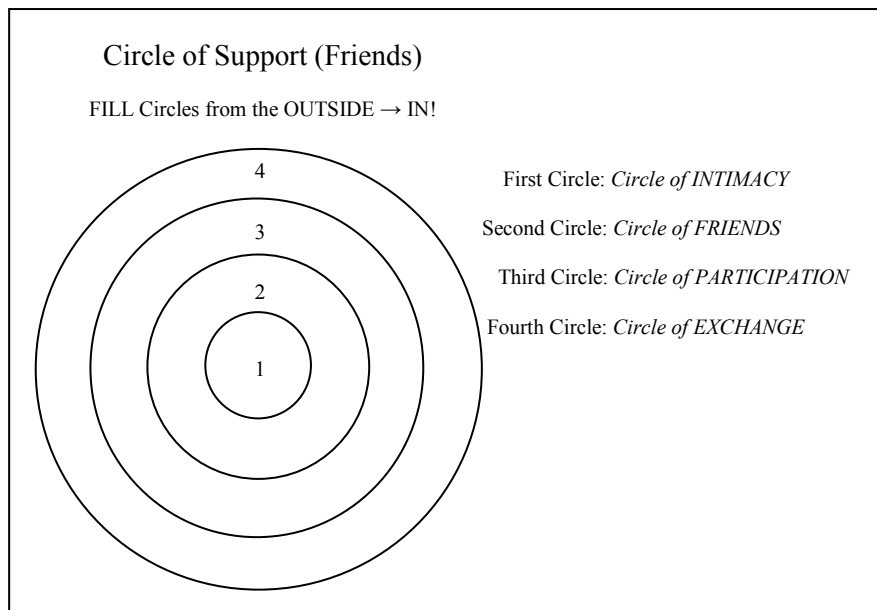


Fig.1: Forest, Pearpoint and Snow (2003)

The authors also make an additional note to the instructions and state that *'People can be in more than one circle. Example: your doctor or teacher could also be a very close friend, a deceased parent/friend or even a pet, might be an intimate personal supporter, etc'* (Falvey et al., 1993, p.6).

A similar approach can be found in the work of Mount *et al.*, (1988), based in Connecticut, USA, who rather than using concentric circles use a rectangle sectioned into three areas (Fig.2, below). In their representation the authors use three categories to describe this 'closeness' and refer to the illustrative exercise as a 'relationship map' who describe the method thus:

A relationship map is simply a drawing of the people who are important to the focus person. We usually group these people into three categories; family members, friends and associates, and paid human service workers. (Mount, et al., 1988, p.4)

Although in their illustrations, using 'match-stick' figures, the authors use the categories: 'Friends', 'Family' and 'Support/Resource People'.

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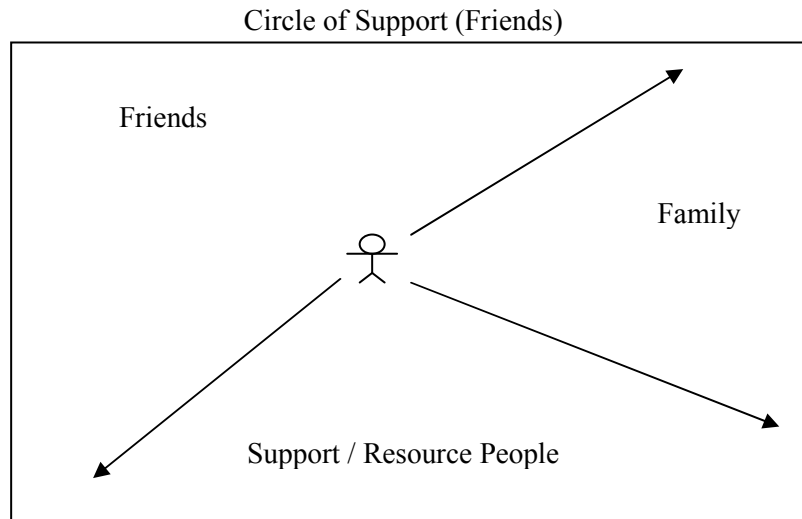


Fig 2: Mount *et al.*, (1988)

For the building of 'circles of support/friends' Falvey *et al.*, (1993; 2003) and Mount *et al.*, (1988) describe the process in similar ways. The authors note that the process involves a range of individuals, primarily: an individual referred to as the focus person, a facilitator; who co-ordinates the group, and circle members. The work of Whitaker *et al.*, (1998) recommend that there be six to eight circle members who may consist of peers, parents/carers, teachers and volunteers. As to the role of the facilitator, Newton and Wilson (1999) advocate that the facilitator's role is to co-ordinate the group, and to '*encourage mutual support, trust, honesty and openness among the group members*'. The focus person for who the 'circles of support/friends' is intended is described in various ways and is a point of contention in this paper.

A call for a discussion as to the value of 'circles of support/friends' had been noted by Deborah Gold who stated that:

The debate about the value of 'circles of friends' as a support-providing and friendship-making strategy must go on, for it is only in this kind of theoretical and practical discussion that we will continue the struggle toward more inclusive community.... (Gold, 1994, p.451)

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Whilst no illustrative representation was made, the work of Gold focused on one group of five adults, in Ontario, Canada, who formed a 'circles of friends' for Leslie a 26 year-old woman described as having a '*developmental disability*' (Gold, 1994, p.435). The work of Gold suggests that the value of the group was an emotionally supportive and problem-solving apparatus and noted that circle members were friends before they became involved. The paper discusses a number of findings into the way the group struggle with: being a 'friend', doing 'support', 'acceptance' and 'caring'. Gold also makes reference to work that is critical of the 'circles of friends' approach and suggests that these sceptics:

...fear circle-building as just one more human service technology, and warn against seeing circles or any other such approach as the answer to the complex problems of stigma and devaluation...They are particularly sceptical about an unnatural friendship-making tool which derives from human service thinking, and thus brings such construction into the minds of peers without disabilities, and into the community at large. (Gold, 1994, p.437)

Although some 11 years have passed since Gold's comments, the concern here is to engage in a critical discussion as to the merit or otherwise of 'circles of support/friends' with and through the participants' experiences of informal and formal social networks.

Examples of 'circles of support/friends' within the literature from a UK context is scarce and what does exist, in part, appears confusing and contradictory. Assumptions tend to suggest that the individual for the 'circles of support/friends' approach are perceived as though they '*do not have a great variety of relationships,*' '*spend majority of their time with their close family, that is parents/carers and siblings, and others who are paid to spend time with them on a professional basis...*' (Whitaker, *et al.*, 1998; Newton and Wilson, 1999; Jay,

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2003). The respective authors attribute the origins of 'circles of support/friends' to North America and describe what 'circles of support/friends' is, as:

It offers a means of including vulnerable and marginalised youngsters into the school community by harnessing its creativity and commitment.
(Whitaker, *et al.*, 1998, p.60)

Circle of Friends (sometimes known as 'circle of support') is a tool for inclusion. It works by creating the intention to build relationships around the individuals who are vulnerable to exclusion because of their disability, difference or because they face a crisis in their lives.
(Newton and Wilson, 1999, p.13)

They are a powerful tool that gives a young disabled person with high levels of support need the best possible chances to live a valued and inclusive life alongside the rest of society. (Jay, 2003, p.28)

Posing the question: 'For who circles of support is *for*?' The authors present a number of descriptors such as: 'vulnerable,' needing a 'high level of support,' 'marginalised youngsters,' 'social interaction difficulties,' 'emotional difficulties,' 'learning difficulties,' 'profound and multiple learning disability' (PMLD),' 'highly challenging,' 'oppressed people,' 'physical disabilities and/or autism or mental illness,' 'lack reciprocity' are found. Posing the question as to why the authors suggest using 'circles of support/friends'; responses such as: 'importance of friendship,' 'limited opportunities for relationship-building to take place,' 'do not have a great variety of relationships,' 'more involved in community life,' 'supporting an individual to live a more inclusive and meaningful life'; to name but a few emerge.

Whitaker *et al.*, (1998), who are members of an 'Outreach Team', use the term 'circles of friends' which they seem to interpret as a behaviour modification approach and

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make reference to seven '*youngsters with autistic spectrum disorders*'. Six of the '*youngsters*' attended a mainstream school, whilst '*one in a school for pupils with moderate learning difficulties*' (Whitaker, *et al.*, 1998, p.61); which appears contrary to the work of Newton and Wilson who suggest that '*circles of support/friends*' is '*to promote the acceptance of pupils with disabilities in mainstream schools*' (Newton and Wilson, 1999, p.12). With respect to this issue Newton and Wilson suggest that:

Circles is about looking deeper, looking behind the behaviour and finding the person. It does not involve looking for deficits in people and attempting to 'fix' them (Newton and Wilson, 1999, p.14).

The work of Jay (2003) refers to the CREDO Project which is based within a national voluntary organisation '*that practices and teaches others to build inclusive communities through the development of 'circle of support'*' (Jay, 2003, p.24). This work focuses on individuals who '*are commonly described as having a 'profound and multiple learning disability' (PMLD)...*' and suggests that '*...young people with high level of support need are arguably among the most marginalised and oppressed individuals in society today*' (Jay, 2003, p.25). The work describes the experience of Jonathon, a disabled young person who also appears in a video with the title '*Hello You*'. The video begins with Jonathon's father recollecting the accident his son was involved in (*Hello You*, 2001). In this paper Jay, who is CREDO Project co-ordinator, comments as to Jonathon that '*...eight years previously he had experienced an acquired brain injury and was continuing to relearn many skills*' (Jay, 2003, p.27). With regards to the earlier work of Mount *et al.*, (1988), Jay makes reference to completing a '*relationship map*' which also included '*people who are important*' and commented that:

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After completing a relationship map whereby Jonathan's relationships with all the different people involved in his life were mapped out, Jonathan's true 'allies' were identified and invited to come together and help map out his future. (Jay, 2003, p.27)

In the paper Jonathon's parents comment that they '*strongly recommend the process*'. However, in addition to previous comments regarding the description of the process being a 'powerful tool' Jay concludes by stating:

Circles of support are not always the solution and they are not a 'magic wand' that provide a quick fix to a situation. (Jay, 2003, p.28)

Another emerging feature of the 'circles of support/friends' literature is concerned with the role of individuals who are paid by formal services an issue that is raised by Newton and Wilson who comment that:

Children with disabilities and those in care will tend to have higher than usual numbers of people in Circle Four and this skewing of relationships is a serious barrier to their participation in ordinary community activity. (Newton and Wilson, 1999, p.9)

As an explanation to this 'skewing of relationships' the authors make reference to a 'Western' taboo; that of maintaining a 'professional distance' and comment that:

...individuals in this circle are unlikely to become close friends or allies of the focus person. The individual in this circle also have their own agenda as far as the focus person is concerned and it may not always be the agenda he or she would have chosen. (Newton and Wilson, 1999, p.9)

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The work of Jay adds to this view and specifically makes a point as to the issue of payment and support, suggesting that *'Circles are in the main made up of those people who are not paid to support an individual but, rather, truly care about their wellbeing and their future'* (Jay, 2003, p.25). The inference drawn from such comments seems to suggest that the authors question individuals who are paid and whether they 'truly care'.

Each of these examples of 'circles of support/friends' provides a range of approaches and interpretations as to how, why, for whom and in what context 'circles of support/friends' is used. Indeed, one of the overarching views from the work of Forest and Pearpoint is the position they refer to as the 'Golden Rule', which they state:

The driving force behind Circles...is the ethic of the Golden Rule. This sounds simple, but is profound and difficult in its application...[that is] not to practice these tools on anyone else until you have gone through the exercises yourself. (Forest and Pearpoint, 2003, p.91)

With respect to this issue none of the authors: Whitaker, *et al.*, (1998); who are members of an 'Autism Outreach Team', Newton and Wilson, (1999); who are educational psychologists, and Jay, (2003); who is a project coordinator, do not state whether they had gone through the exercise themselves.

Method

The period of investigation was over 17 months in the field. A consideration for engaging in the field related to the issue of consent and being sensitised to the issues raised in the emancipatory disability research literature concerning accusations of 'using' participants; issues that have been explored by Kikabhai (2003). The approach was to develop a research relationship that was transparent and which made clear these hesitations as to why these issues had arisen. A resolution to such issues involved building a mutual relationship that

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was based upon concepts such as; mutual trust, openness, honesty and transparency. Fundamentally, the process required a commitment to the Social Model of Disability (Rieser, 2000). Further an opportunity to turn the tables arose where a fellow research colleague was asked to be part of a process where Navin, as the researcher, was questioned about support, and informal and formal social networks.

Interviews were conducted using an open-ended semi-structured approach. At the end of the interview participants were asked to illustrate their relationships using two 'circles of support/friends' templates. The first template was used to illustrate a previous point in time and a second template to illustrate the participant's current relationships. The findings, at this stage, emerging from the interviews and 'circles of support/friends' templates, also led to creating an alternative relationship map.

The method of analysis was conducted with the aid of NVivo a qualitative software programme. Initially, the process involved transcripts being returned for participants to make amendments for clarification and coherence; and to ask whether participants would want to withdraw their consent.

Participants

Although no specific details of the individual's identity were asked for; the participants could be described in the following way. The group consisted of three females and six males, the age of the participants ranged from 15 to 68 years of age. Of the group, 7 of the participants would be considered to be disabled people. The cultural and ethnic identities of the group could be described as being: Pakistani, Jewish, Indian, and British. The younger, Qurban, was attending a 'special' school for children labelled as having 'severe learning difficulties' and was interviewed with his mother Kishwar who also described her experience as a disabled person. The older participant, Sunil lived in warden 'controlled' accommodation

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and first came to England from India in 1967 and found work in a local textile mill. Sunil described one of his impairments and also gave an example of attempting to write a cheque, he said *'it's like shaking [shaking his arm]...sometimes all the time, the leg sometimes, no sign properly. Last time we, a chequebook, signed, but they returned back so problem'*. Hilary and Jacob were both 16 years of age, and like Qurban were interviewed with family members. Hilary and Jacob both use 'facilitated communication' (Biklen and Cardinal, 1997). Iram was in her mid-20s and described her previous experience of being a student on a Post-16 teacher training course. Mathew was 36 years of age and was living *'in supported accommodation for people with mental health problems'*. Graham, in his mid 40s, was employing his own staff through the Direct Payments¹ scheme. Navin was joint researcher and had been interviewing the participants and when interviewed described his understanding and experiences of formal and informal social networks, particularly in relation to his dad.

Findings

In general listening and engaging with the participants lived experiences was disturbing and contentious with regards to formal and informal social networks. In part many of disturbances relate to the discrimination and prejudicial attitudes that many disabled people continue to experience. Overall, there was a consensus amongst the participants about their experiences of formal social networks; in that much of it was negative and in some instances would be tantamount to discrimination. All the participants interpreted aspects of their relationships that would have been illustrated to be in more than one of the four concentric circles: intimacy, friendship, participation and exchange.

¹ Direct Payments is a payment from a Local Authority under the Community Care (Direct Payments) Act 1996 which came into force in 1997 and enables people to purchase their own services.

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Hilary did try using 'circles of support' and a family member commented that *'I felt it was quite structured and I find it really hard to ask people for help and it was really weird and it didn't feel comfortable at all'*. Hilary's mother also added that:

I think the circle of support at school was initially to get Hilary out of the room that she was in at the time...because she wasn't included in class...she was in a room with two teaching assistants...she was in that all day except for lunchtime. (Hilary)

Asking the family about formal support they commented:

...they're barriers...they want an easy ride...well, I think it's like let's get them in bed...they write everything down, which I feel is violating Hilary's rights. Nothing about the support is Hilary centred...its not support, it hinders, it's more work than it is support, it adds to the stress...it doesn't take it away...anything for an easy ride. (Hilary)

Mathew was asked of his opinion of an organisation where 'circles of support' is used, he commented they're: *'supposed to help and give circles of support to people with mental health problems'* and added:

No I don't see them as support...They're supposed to help me live a normal life, instead of helping me they've cut off my support from a social worker, from an alcohol and drug's worker, and the main office have totally cut me off from any support whatsoever, except for the duty officer team that they use...supposed to be a place for people with mental health problems. (Mathew)

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There appeared to be a general reluctance to ask for support and for the participants this related to the issue of trust. Mathew shared his experience of having a daughter who he has been trying to locate over the last 9 years, and added:

It causes a hell of a lot of pain, people don't understand it, they tell you to get on with your life but I want to know how Mandy is. I want to know how she's getting on at school and what she's doing at school.

(Mathew)

When asked whether he has received any support during this search, Mathew stated:

I've no support at all now, I found my last support worker...a two faced bastard. I thought I could trust him with all the stuff I'm going through, he's not done, he's had every word that I've said to him documented put on files and it's gone against me, not for me. (Mathew)

There appeared to be a cultural and geographical factor that determined the choice of support, in that individuals from Jewish, Indian and Pakistani cultures preferred to ask relatives and family members and individuals with a shared culture within their immediate communities; whereas, individuals who were British did, although with some hesitancy, seek support from outside their family networks and advertised outside their geographical location. Graham, being on Direct Payments, passed comment as to the dangers of attempting to recruit staff formally, and said:

...if they came from a newspaper add and I didn't know them there's always a chance that actually while I'm in bed they could ransack my house and then go. I forgot that kind of danger that I could put myself in, even if they'd done a couple of shifts and double cover with people, you still don't get to know people well and it takes up to 6 months to get to know them. (Graham)

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Graham's previous experience of formal support was through a social services agency. Graham needed assistance with personal care but would often ensure he would be washed and ready before staff had arrived, and explained:

...because I didn't want them coming in the bathroom and seeing me naked and just helping me...it was just degrading and when I approached those services and said that and the agencies said, 'they are trained, they do know what they are doing,' but I'm not trained in doing that, you can't, you can't suddenly like, I expect a stranger to come in and see you naked. (Graham)

All the participants choice of support was influenced by a functional factor in that they expected support staff to act upon their request for support. For the younger participants Qurban, Hilary and Jacob age was a factor that influenced their choice of support. For Hilary gender was an influencing factor and for Qurban and Jacob their respective cultures and religions were also influencing factors. Qurban enjoyed being with his cousins and said he particularly enjoyed 'bowling' and 'swimming'. Kishwar, Qurban's mother explained she had in the past relied on formal support from agencies and expressed concern with the service and later decided to apply for the Direct Payments scheme, and commented that:

With Direct Payments I am in a position to get my own, sort of, people to work with Qurban as long as they have been, sort of, police checked and everything. His cousins can work with him as well. At the moment, I did use an agency initially but I felt that people, even though, I felt that people who were working with him were quite a bit older than him, they were in their 40s from the support agency. I want Qurban to be with a younger person.... (Qurban)

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During discussion Kishwar explained that she with Qurban had gone to Hajj, a pilgrimage, and shared her religious belief about having a disabled son:

...the fifth pillar of Islam. So we went there, and I was just praying for him there and I thought if God had wanted him to go to mainstream school he would have given him to me as a normal child, so he wouldn't of had the problems that he has now. So I decided that I'm going to try a special school for him, which I'm glad I did because the staff there were very very supportive. (Qurban)

Asking Qurban whether he enjoyed attending the 'special' school he indicated no and said *'No shouting, no hitting, no hitting, no pulling'*.

For Sunil his decisions about support were influenced by an economic factor and related to his retirement status as an older person. Grahams' relationships were influenced by a range of factors; biological, functional, personal, psychological, and social factors which related to his sexuality. Similarly, Mathew's relationship choices were affected by a range of factors and were particularly related to the issue of trust, and the feeling of entrapment. For Mathew a description of a formal social network was given in terms of his experience of trying to attend college. Mathew explained that:

...at the moment, I'm going to need as much support as I can and, I've seen things like if you have trouble with this, that or the other phone this number at certain colleges. And they do that to trap you... To see how good or clever you are. (Mathew)

and continued by adding:

I'm going to be straight and I'll say it in my words... At...College, they have what is known as a retard squad and these people single out

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people who are trying to get on courses they want to get on, and they are spending most of their time saying 'come on, come to this one, this is a special one for you'. And these people I have met about five or six times at colleges.... (Mathew)

Iram's relationships were influenced by personal, religious and cultural factors. Iram described her formal social networks in terms of being a student on a Post-16 teacher training course during 2002 to 2003. Iram commented that *'I didn't really enjoy going to be quite honest with you...I just felt that if I needed help I didn't really get the help, or if I was stuck or something, academically, through my work I thought well, who do I ask?'* Iram had been failed and informed to submit her assignment the following year in June 2004, she recalled:

...I handed my assignment in and I thought that would be it because I made the amendments that they told me to do, and the next thing I know...she found something else which annoyed me because I thought why didn't she find them in the first place and tell me all at once rather than telling me now...it was just going back and forth and it was getting a joke really, it was frustrating and getting me down and depressed.
(Iram)

Before the course Iram had experienced two bereavements in 2002 and found it difficult to confide in the tutor about her personal experience, *'...I didn't feel comfortable talking to her...I just couldn't tell her even though her being my tutor and then I realised my work was suffering and then I had to tell her. I approached her and told her, and she said 'oh well'.*

Support for Navin may be understood to have been influenced by personal, spiritual, social and cultural factors. Navin explained that he would help his dad to get ready for dialysis and on one occasion recalled observing a support worker shaving his dad and commented:

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He had hold of the razor and he started to shave my dad and I was watching him shave my dad and there was something about it, and this is about me this, feeling uncomfortable that somebody else doing that for my dad and it was interesting for me on reflection that when he had finished shaving I thought he missed a bit. He's not done it like I did it, and I don't know where that comes from. But I think what I'm trying to say is that when he's shaving he's not doing it with love, when I'm shaving I'm doing it with love even though I might miss a bit....(Navin)

The experience of asking for support was an issue raised by all the participants. General comments included individuals feeling a sense of unease with asking 'strangers' for support. One of the reasons given by Hilary's family was related to the issue of reciprocity and Hilary's father commented that: *'when you ask people for help it's difficult because you don't know whether they're going to reciprocate in the way you want them to...'*.

For the participants informal support consisted of individuals who were generally known, or recommended through existing contacts, who generally were not paid; although some were employed. Words used included: 'trust', 'friend', 'love', 'family members' and 'relatives' were commonly used. Asking Hilary's family about support, comments such as 'being there', 'rely on' and 'genuinely caring' were made. For Hilary support meant *'being in contact with good people'*. Their recollection of informal support was when a family friend had recommended an individual, Hilary's mother commented:

...effective support was about four summers ago when June supported Hilary. June was a young woman of 18 and Hilary must have been 12...we decided we had to have somebody to help us over the summer. So we hired June...and everyday from 10 to 2 she took Hilary to the park and Hilary did Hockey, Gymnastics, Athletics...she did a full week block of all those things. And facilitated with her right from the

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beginning and kept a summer journal of all the things she did and all the positive things and that was really really wonderful.... (Hilary)

Graham shared his experience of informal support from family members and also expressed the restrictions, stating that:

...my brothers would take me out for a drink and I'd try going for a swim when it fitted in with them. So everything revolved around the family support and without that I couldn't of managed.... (Graham)

For Graham in reflection, since employing his own staff, it was intimate personal care that would be difficult to ask his family members and commented:

That's were it really became an issue that I didn't want my brothers to do that for me. I mean, they did and that was fine, it wasn't fine it was just something I had to accept. The personal stuff like that I didn't feel comfortable for my brothers to do. Its like, to be really personal, when I'm having a shower I need to wash under my foreskin, I would never ask my brothers to do that, but because the staff support me and I recognise that and that's their job and personal care like that I need doing. Once I get to know them I feel comfortable then that's something they've got to do but I think if I was getting support off my family now my brothers I would never ask my brothers to do that because it wouldn't feel comfortable. Stuff like that the very personal stuff that it feels ok once I've had people working for me for a month and then to say, 'I need this doing'. (Graham)

For Navin the theme of personal care was also raised and recounted an experience of receiving a phone call from the dialysis unit asking him go to the hospital, he explained:

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I got a phone call to say, 'Navin, your father...' he soiled himself, he was on dialysis, he'd finished dialysis but he wouldn't want anybody to clean him up. So I rushed over got there and I said to my dad 'its alright' and for him not to worry and preceded to undress him took his trousers off and took his underwear off and that was the first time I'd ever seen him naked. There was blood all over the place and I cleaned him up... (Navin)

For Mathew, informal support consisted of 'friends', he commented:

At the moment there are two of my friends who are supporting me with my college stuff... they're friends that I've known for a couple of years...that's the only reliable support I have.... (Mathew)

Over the years Mathew had enrolled onto various courses and had experienced a number of barriers, and was currently getting support from an individual he described as a 'teacher' a 'family friend' and when asked whether that was somebody from the college, Mathew responded:

No, not from my college, he's a friend, he's a family friend now and he's giving all the support I need...I've known this person for a long time...Through a day-centre, that I went to...I didn't know how available he would be, but now I know that this person is available for me all time now. But I'm not asking the college for any support. (Mathew)

For Iram informal support was confiding in a fellow student and responded that:

Michelle, she was a friend, well I got to know her through the course...she was doing the PGCE, and she was in my group...she helped me to go to the Student Union, and told me to get a doctor's note and I did do, and through them they said we'll refer you and you've got a year to complete this assignment.... (Iram)

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Illustrating these relationship networks were particularly problematic, since placing people in terms of their 'closeness' did not reflect their personal experience. One of the emerging concerns was the way individuals are placed in relation to their 'closeness' and the value ascribed to this positioning. An example of this particularly dilemma is given by Graham's experience of using the 'circles of support/friends' as a 'social scan'. The year chosen by Graham was 1996 (Fig. 3, below). For Graham this was a time when he was primarily receiving support from his family and agency staff through social services.

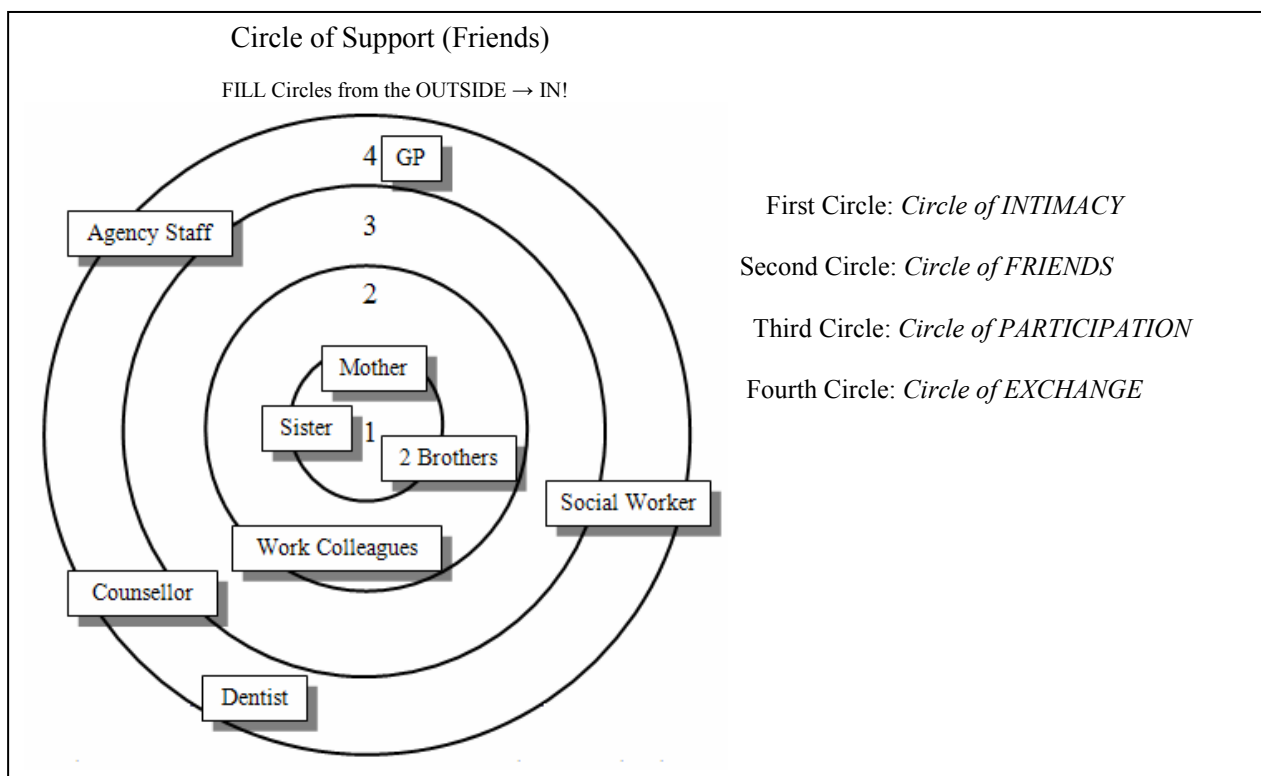


Fig.3: Circle of Support/Friends – Graham 1996

For Graham this had been a time of frustration. During this time Graham shared his weekly routine which consisted of:

...out to work during the day, I would go back to my mums for my evening meal, I then came back here and then sat here basically till

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about 11 o'clock and then tried going to bed. I'd get bed myself, and the next morning I'd do exactly the same, and that's Monday to Friday. (Graham)

Graham had been working 9 to 5 in a solicitor's office working locally until he had to travel *'quite a distance, I was struggling then and, fortunately, I got a job a bit nearer...'* Graham was finding it difficult to live in his own house and asked social services for more support, he explained:

...it was really difficult to keep living here on my own I asked social services for more support and I was offered the home care agency support at the time. That was the thing they could offer me, apart from going in to a residential home...it wasn't a possibility there. I would have just ended up dying there unhappy, I'm sure because I wouldn't have been able to put up with it...to be suggesting going into a residential home was rather upsetting, you know, that was very upsetting. (Graham)

Graham added:

I did write a suicide note and I was ready to commit suicide because of the pressure of living independent or trying to live on my own and being pressurised into accepting going home or being safe in a residential home. The only alternative to that was to get agency staff in to assist me getting up, well it wasn't ok, because I had no choice on that, that was agencies who would send somebody round and they would give anyone a key to my house, come round and mostly the staff, all the staff were elderly females who had no idea of what kind of support I needed...I was very specific in what kind of support I needed. I remember saying to social services, 'I need someone like my brothers', in that they treated me normally and just supported me...it

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was a big issue about what kind of support I needed if things went wrong. (Graham)

The second template is dated 2004, the year Graham was interviewed (Fig.4 below). This representation suggests that 8 paid support staff had been placed in the circle of intimacy with his mother and sister.

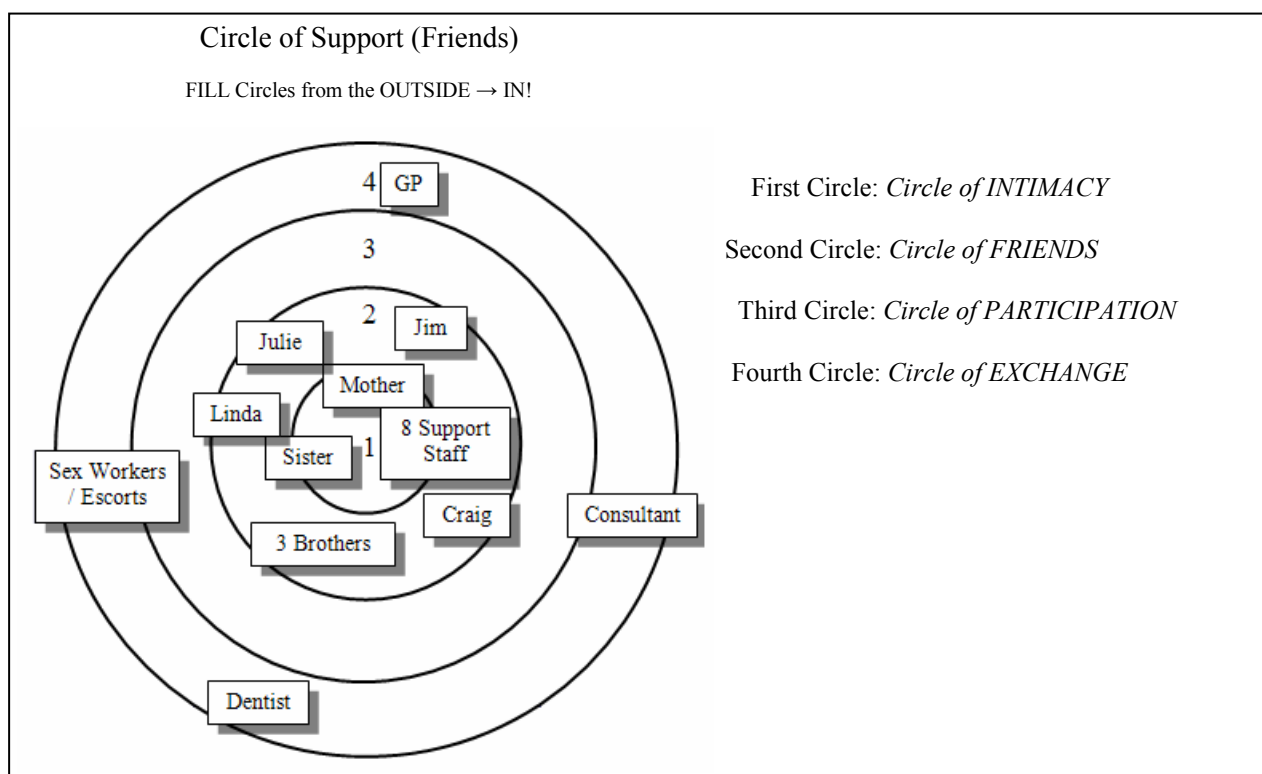


Fig.4: Circle of Support/Friends – Graham 2004

Confusion with this process is related to the meaning ascribed to Graham’s interpretation between the paid support staff and family members. Graham had shared his experience of the way support from family members was meaningful to him; different from his paid support who he described as ‘friends’ yet where not placed in the circle of exchange. Graham was employing 3 full-time, and 5 part-time staff, who work on a rota providing 24 hour support, and added:

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...I'm in control of everything...so everything I do from the minute I wake up, well even while I'm asleep I'm in control of what happens and basically live a life I want to with some restrictions I suppose. But a life of my choosing, I do have total control and feel that the support workers are not just people who work for me, they're friends.
(Graham)

In the following relationship map Graham's relationships are reconfigured with an attempt to reflect these relationships rather than a focus on 'closeness' (Fig. 5, below). During the interview, Graham shared that it was one of the support staff who was particularly supportive with issues of his sexuality and the experience of employing a sex worker. The relationship map attempts to differentiate these relationships and recognises that Graham does have a paid relationship which is intimate and was affected by a number of influencing factors. The relationship map for Graham also recognises that he has paid support that he considers to be his 'friends'. In this representation it is the relationships that is under the 'spotlight' and the way they are interpreted.

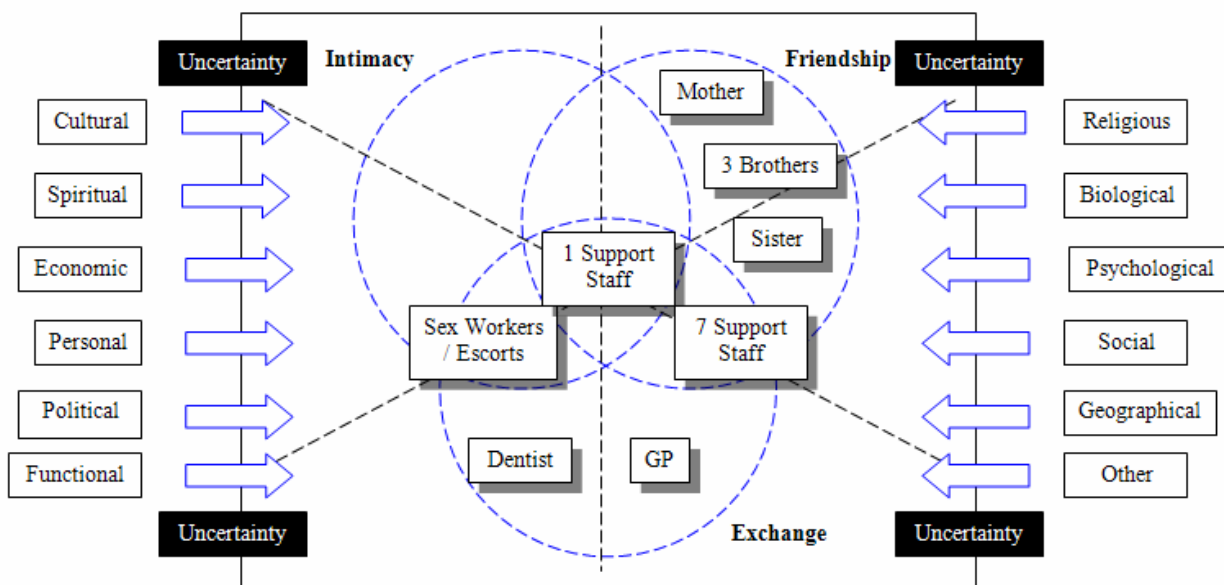


Fig.5: Relationship Map - Graham 2004

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In this representation, Graham employs a sex worker who is intimate which also differentiates the support from family members. Although Graham has 8 paid support staff who he considers to be 'friends', there is one individual in particular who is supportive in facilitating his sexual identity.

The process involved to complete a relationship map begins by considering one of four zones that is: Intimacy, Friendship, Participation and Exchange, and is explained by Kikabhai and Whittaker (Appendix – Relationship Map). The process may not necessarily utilise all four zones and is entirely based upon the person's interpretation. The 'open' circles attempt to reflect the changing context of relationships which recognises that interpretations will shift from one zone to another dependent upon the context of the person's interpretation. For example, what may occur is that a family member may provide paid intimate support, or that support staff may leave, or shift from zone to zone. In this sense, all the participants' experiences of relationships were affected by uncertainty and were related to the way relationships were interpreted and experienced.

Discussion

Taking a philosophical perspective as to the concept of friendship raises some important and useful considerations, particularly as to how these are understood in relation to the interpretations given by participants in this study. In books VIII and IX, for example, of *'The Nicomachean Ethics'* by Aristotle who whilst being attributed to the phrase *'O friends, there is no friend'* suggests that there are three types of friendship. For Aristotle these are friendships based upon: mutual moral good, sexual attraction or usefulness. For Aristotle the 'perfect' friendship is that which is based upon mutual moral good, and argues that:

Only the friendship of those who are good, and similar in their goodness, is perfect. For these people each alike wish good for the

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other qua good, and they are good in themselves. And it is those who desire the good of their friends for the friends' sake that are truly friends, because each loves the other for what [s]he is, and not for any incidental quality. (Aristotle, 2004, p.205)

In this sense friendship and love are inextricably linked and was evidenced in this study through a comment made by Jacob who suggested that for him *'the best support is either friendship or just love'* and when asking whom he loved and trusted without question, Jacob responded by naming his mother, father, sister, brother and his facilitator. Taking Aristotle's interpretation and the possibility that friendships are based upon utility, sexual attraction or moral good as separate and not overlapping does accord with Graham's experience when he shared his identity in terms of his sexuality and the issue of paying for a sex, he commented:

...James only a couple of weeks ago agreed that he was happy for me to get an escort around if I wanted an escort around. But he recognises that kind of stuff and he's very supportive in that kind of stuff. If I wanted to go and have sex with another bloke, he wouldn't have a problem, he would make sure everything was sorted...But, to a certain level I don't think they have a problem with it...I'm more happy with their support, not happy but will relinquish the intimacy with another bloke to maintain the support I've got. I'd rather be happy with their support. But in itself that does create problems because you might be sexually attracted to your staff and it can always lead to indecent proposals I suppose.... (Graham)

Graham's experience seems to suggest that paying for sex and paying for support are mutually exclusive. That is for Graham, he is unlikely to develop a sexual relationship with support staff; he would *'relinquish the intimacy'* to maintain the support which in Aristotle's terms would be a friendship based upon utility. Since, according to Aristotle *'the same*

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people do not become friends for pleasure as well as for utility, because incidental qualities are not often found in pairs' (Aristotle, 2004, p.207). However, Graham did say as to his sexuality that *'I do suppress my sexuality but that's because that's my choosing I think because I choose to employ heterosexual lads...'*

The notion that friendship being inextricably linked to love is also discussed by Montaigne who commented that:

...what we normally call friends and friendships are no more than acquaintances and familiar relationships bound by some chance or some suitability, by means of which our souls support each other. In the friendship which I am talking about, souls are mingled and confounded in so universal a blending that they efface the seam which joins them together so that it cannot be found. If you press me to say why I loved him/her, I feel that it cannot be expressed except by replying: 'Because it was him/her: because it was me'. (Montaigne, 2004, pp.9-10)

The notion that friendship being reflection of oneself – a mirror image – is particularly thought provoking and raises a question as whether individuals whether in this study or elsewhere would consider friends to be a reflection of themselves. Armstrong in an essay entitled *'the conditions of love: the philosophy of intimacy'* suggests that we don't actually need a *'looking glass'* and agrees that *'self-awareness depends upon the 'mirroring' of ourselves in other people'* and adds that *'something similar occurs with respect to the mind'* (Armstrong, 2002, pp.56-57). Armstrong further poses a series of questions with some responses such as: *'Why do I need another person? Because I cannot be happy on my own? For some people at least, this is too painful an admission. We sometimes avoid or need for love [friendship] because it casts us in a vulnerable role'* (Armstrong, 2003 p.69). Armstrong, who considers a number of perspectives, also suggests that cultural factors do

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have a role in how relationships are experienced and that *'love is 'merely' a social construct; it is 'simply' the product of economic and ideological factors'* (Armstrong, 2003, p.26). For Graham, he did have an opposing perspective and suggested that:

But ultimately I still say if everybody one needing support had a million pounds they'd choose someone who they felt sexually attracted to supporting them, without a doubt. I absolutely believe that.
(Graham)

However, for some clarification Montaigne does suggest that:

For the perfect friendship which I am talking about is indivisible: each gives [her]/himself so entirely to [her]his friend that [s]he has nothing left to share with another: on the contrary, [s]he grieves that [s]he is not two-fold, three-fold or four-fold and that [s]he does not have several souls, several wills, so that [s]he could give them all to the one [s]he loves. (Montaigne, 2004, p.15)

Since, in this sense, love is inextricably linked to friendship and the terms being used interchangeably it would be interesting to consider whether it is possible to have more than one friend. This point is considered by Aristotle who suggests that it is not possible to love more than one person at any one time; although it is possible to love more than one person if the 'friendship' is based upon utility or pleasure (Aristotle, 2002, p.210).

Another consideration as to the comments made by Montaigne is the notion that giving and receiving love is different. For Aristotle an element of friendship *'seems to consist more in giving than in receiving affection'* (Aristotle, 2002, p.213). Although, Aristotle draws upon the example of a parent's love for a child, to explain this difference, in that it is unconditional. Likewise too, Derrida in 'The Politics of Friendship' delivers a series

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of lectures based upon the phrase attributed to Aristotle's *'O friends, there is no friend'* and states that:

One can love being loved, but loving will always be more, better and something other than being loved. One can love to be loved – or to be lovable – but one must first know how to love, and know what loving means by loving. (Derrida, 1997, p.11)

These ideas are thought provoking and raise some poignant points in relation to a study of support particularly in relation to informal and formal social networks and the issues of friendship, intimacy and support.

Conclusion

We recognise that mapping social networks is challenging, problematic and contentious. Challenging because questions emerge such as: What is support? What do we mean by intimacy? What do we mean by friendship? Problematic and contentious because questions emerge such as: Is it acceptable to pay somebody you love? Is it acceptable to pay somebody to be your friend? Is it acceptable to pay somebody to be intimate? These questions, in a way, are no different to questions such as: Is it acceptable to lend or give money to somebody you love? Is it acceptable to lend or give money to a friend? Would you continue to consider them to be a friend if they charged you interest? What if they had said 'no' would you consider them to be a friend then? Would you ask a friend or a family member to give you a bath? Would you consider a 'family' pet to be a friend?

Answers to such questions raise moral and ethical dilemmas that requires a process of continuous reflection; a radical rethink as to how relationships are perceived and engaged into and no doubt will continue to be a contentious research field of study. Understanding these contentious issues need to be framed within a broader understanding of the complex

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issues that relationships entail and avoid the patronising view that non-disabled people are somehow 'experts' in relationships.

Such concerns are rooted in how individuals interpret concepts such as intimacy, friendship, and support. Take for example, a recent study entitled 'miserably ever after' in which 1,173 people were surveyed about living with a partner which concluded that:

...one in 20 people are financially shackled to their partner...nearly one in 10 people (9%) said that they would be more like to leave their partner if money was taken out of the equation, with 7% of respondents saying that they are unhappy with their current partner.

(Skipton Building Society, 2005)

What is interesting with these figures is that if the work of Aristotle, Montaigne and Derrida, hold any truth then friendship or love seems much more rare than is being currently presented which no doubt raises questions about how many of these relationships here were based upon mutual moral good, sexual attraction or utility.

The findings in this study suggest that there is a call for a re-think of how 'circles of support/friends' is understood in theory and practice. Previous interpretations were contentious and at times could be said to have been 'service led' which does raise some fundamental concerns as whether this support is one of charity and entrapment. The issue of individual's using 'circles of support' to avoid being trapped by services is a point that was raised previously by Forest *et al.*, who stated that:

...circles have often been built around people who have become trapped in the human service system or other forms of isolation. However, circles are change tools and are applicable to anyone who is vulnerable, isolated, or in crisis. (Forest, et al., 2003, p.87)

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Unfortunately, the 'circles' applicability criterion for Mathew was the basis of his 'entrapment' which was commented upon when Mathew was asked of his opinion.

The second theme for consideration presented in this study suggested that individual choices are affected by influencing factors. Examples of influencing factors were shared by the participants; one of the participants Graham shared his experience of relinquishing his sexuality for support (functional factor) with the staff he had.

The final consideration, then, emerging from the contribution from participants was a Relationship Map that accounts for and illustrates these experiences of formal and informal social networks, the influencing factors that affect relationship choices, and the recognition that uncertainty affects all relationships. What is important with these findings is the illustrative representations and how this attempts to reflect the relationships in a person's life. Through this relationship map emerged the feeling of *what is* and not *what should be* which shifted the focus of attention from the individual to the interpretation of the relationships. What was central to these contributions was the participant involvement and the importance of how each individual placed emphasis on the value or otherwise of their relationships on *their* terms. Their contributions were profound and were based upon a mutual trust, an openness to share their lived experience in a way that many would not find possible to do. In part, one of the key roles of this process is the role of a facilitator, and the issue of placing themselves through the process a point that had previously been made by Falvey *et al.*, (1989) referred to as the 'Golden Rule'.

Finally, as to the hidden key question: 'Who loves this person?' suggested by Falvey *et al.*, (2003); is a question that is in danger of positioning an individual for charity, entrapment and misinterpretation. Given the approach of 'circles of support/friends' within a broader acknowledgment of the oppression of disabled people it may be apt to conclude with the statement '*O friends, friends this is disability politics!*'

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