9 'I' For Identity: Reflections on Ageing with a Disability

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Introduction

One of the first things that should be made clear in respect of this paper is what it is not. It is not a psychological examination of identity formation or maintenance, neither does it relate to growing older and becoming disabled by the effects of ageing. It is also not about reaching a specific age or having a specific disability but is about the <u>process</u> of ageing through some consideration of the variety of roles and identities experienced and negotiated by those living with a disability as they become older. It is a 'snapshot' focused on the initial results from doctoral study which, as a 'work in progress', may provide additional insights as the thesis nears completion. The initial focus of the thesis was not on identity, however, and a short rehearsal of the methodology used is needed to show why this emergent theme is regarded as important.

Preliminary Considerations

In broad terms, contemporary social theory and resulting policy maintain that:

- Identity is fluid and under individual control.
- 'Disability' and 'age' are socially constructed.
- Demographic change means both acceptance of an 'ageing population' and a longer working life.
- Diversity and difference are to be embraced.
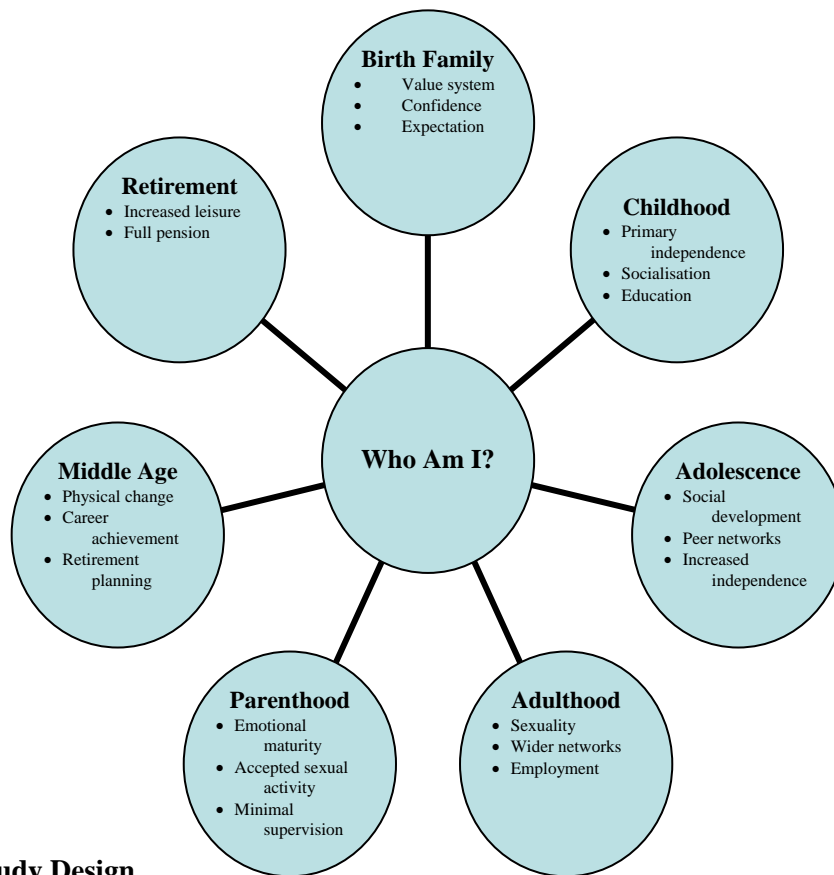- Those who are 'different' are also 'normal'.

These concepts are apparent in both tangible and intangible ways but the question is whether and how they are translated into 'everyday life'. Legislative changes over the last decade[1] mean that anyone involved in service industries, education or other public services will almost certainly be aware of the fundamental concepts of discrimination and 'reasonable adjustment'

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[1] Starting with the Disability Discrimination Act in 1995 and progressing through various amendments and additions since.

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(Barnes, 2000; DDA, 1995). Whether greater recognition of the 'social model' (Oliver, 1990) negates the 'personal tragedy' model and has substantial impact on the everyday issues affecting many disabled people in reality or whether it, more accurately, reflects a climate of 'political correctness' is, however, a matter for conjecture.

The points in Fig. 1 are drawn predominantly from the literature around lifecourse and identity formation. They are, however, broad descriptions intended to indicate the major influences and assumptions attached to each 'stage' of the lifecourse rather than any discussion of the theories or processes involved. The diagram is designed to show what contributed to the framework used for the semi-narrative interviews conducted.

Figure 1   Identity Formation – Influences on 'Normal' Lifecourse

Birth Family
- Value system
- Confidence
- Expectation

Childhood
- Primary independence
- Socialisation
- Education

Retirement
- Increased leisure
- Full pension

Adolescence
- Social development
- Peer networks
- Increased independence

Who Am I?

Middle Age
- Physical change
- Career achievement
- Retirement planning

Adulthood
- Sexuality
- Wider networks
- Employment

Parenthood
- Emotional maturity
- Accepted sexual activity
- Minimal supervision

Study Design

The initial research questions were posed in the context of employment and premised on both personal experience and on Zarb's (Zarb, 1993) classic reference to a perception of disability as 'premature ageing'. The overall aim being to see how the experiences of this group this compared to 'normal' lifecourse perceptions as identified in Fig.1.

Fundamental to the methodology was that participants be drawn from a population who were not defined solely by the nature of services accessed, equipment used or medical categories. It is very much a study of the 'everyday' and the 'ordinary' as it exists for people categorised elsewhere as 'special needs'. Participants were thus not only a 'hidden' population (Gilbert, 2001) but essentially invisible as there was no common central point at which those falling into the desired 'category' could be found. The sample was drawn up around the age group 45-65, included physical or sensory impairment and consciously excluded disability rights groups; cognitive or learning disabilities and those in sheltered employment. It therefore excluded those who were likely to be highly aware of disability issues through a level of personal politicisation but included participants who were 'old enough' to have a working-life history and 'young enough' to either still be in employment or to have left it only recently.

One major observation is that despite a mixture of non-medical approaches being used to access participants none of them were highly effective. Access was attempted through public social routes such as local large employers, internet resources and public libraries as well as 'snowballing' via informal contacts. It became obvious that the obstacles not only included the familiar 'gatekeeping' activities but the fact that individuals operating in a 'normal' world were unwilling to self-define as disabled. This unexpected dimension provided additional, methodological questions and it was decided to investigate this aspect further through the interviews with members of a newly-formed local group of polio survivors in addition to the small number of participants who responded to a set of open questions by email.[2]

Data Collection & Analysis

Interviews began with a short discussion about educational background which was followed by a very wide central question which requested participants to tell me about their working life – "Tell me about the jobs you've done." This basic, open question allowed me to use a literature-based framework as an aide-memoire to explore a variety of aspects but also allowed me to identify

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[2]   There were some concerns that this might skew the data but, in fact, the difference in research tools provided a level of triangulation which would otherwise have been difficult to achieve in a sample of this size.

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the importance participants' attached to them through examination of the language used and the 'stories' employed. Using N-Vivo allowed an iterative process to be established based on themes identified from the literature and expanded as analysis progressed.

It should be noted at this point, however, that there is a cohort effect to acknowledge. Data shows, for example, not only intrinsic gender differences but also those differences in life aspirations and assumptions about potential dictated by historical context. If individuals are considered as 'objective beings' simply because they fulfil one category of description eg. have a particular disability then it is easy to ignore some of the more general life effects that operate on them. Acceptance of life events cannot, therefore, be simplistically regarded as a negative 'internalisation of oppression' (Barnes, Oliver and Thomas, 2001) but can also be seen as a perfectly logical result of a series of life events which provide the cohort with a different perspective.

Initial Findings

For the purposes of the initial analysis I have accepted the 'everyday' meanings commonly attached to descriptors by participants. The statements shown as sub-headings represent the main themes from the data as illustrated by some typical ways that participants gave expression to description and discussion of themselves.

1. - "I don't really think of myself as disabled"

One of the difficulties in accessing the sample was due to the need for participants to 'self-define as 'disabled' - a requirement which emerged as contradictory to individual self-image. It could be referred to as 'denial' but, in context, is more akin to what Biggs (1999, p.88) refers to as '*masque or masquerade…[which] at one and the same time protects … and maintains a form of connection to immediate social milieux*'. The participants effectively broke this 'protective' barrier through group membership but indications are that they would not have volunteered as individuals. Their self-concept was of 'having had polio and having to use a *[calliper;stick;wheelchair]*' rather than as 'disabled'.

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2.   - "I'm the sort of person who just gets on with things"

A demonstration of pragmatism and instrumentalism – the common sense statement of 'fact' which participants often employed to mask feelings of inevitability about their daily lives. It was often said in conjunction with a 'story' about some event in the workplace or expression of frustration about an aspect of the individual's life. It acknowledges some lack of control over external influences but at a level which is acceptable.

3.   - "Of course I'm a…"

… Very independent person
An individual who accepts no more help from those around them than anyone with whom they identify. The nature of the 'help' and whether it can be 'justified' becomes an integral part of this internal discussion. These statements often reflected those made under the previous section about 'getting on with things' and so included aspects of resignation as well as a mixture of frustrations and strong statements of self-reliance.

… loyal worker
The person as worker is, in the context of this study, also integral to the sense of self. In every interview, however, some defensiveness was shown about the perceived value of that role to others, often expressed by providing evidence of loyal behaviour. Equally, these expressions regularly revolved around reports of behaviour that could also be construed as exploitative or even abusive and certainly marginalised the individual. Richard, for example says,

> They all used to be able to go downstairs to lunch but of course I couldn't get…so I was there to answer the phones in the dinner hour – it wasn't really my job but that was OK, they were very good to me there.

What is interesting is that this is still apparent in those interviews where the person also presents as a 'maverick' in some way and provides evidence of rebellion or sabotage. John told me,

> …so the Queen was coming and they wanted all the long-serving staff to meet her and they just said of course you'll need to be in the front row 'cos of your wheelchair, John and I said but I don't want to go and they said don't be silly….so I took a days holiday to show them!

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4.   - "I'm just a …"

The choice of words for this section was interesting as 'just' essentially diminishes the reported roles while the descriptions of them made it obvious that they were core to participants' sense of self.

… Father/mother/grandparent/husband/wife/partner
The qualities associated with these roles is comparative – participants' own behaviours and activities being measured against the traditional eg. the father as breadwinner, the mother as carer. For most of the participants the identity associated with these roles was fundamental to their understanding of their 'social position' and also to their expression of relative self-worth. This is not unusual, of course, but the relationship between private, domestic role and public, employment role was often expressed as exceptionally important in the context of the person as 'disabled'. One participant, for example, stated quite clearly that her main aspiration has been to be a '*good wife and mother while still being independent*' which indicates some ambivalence about her perception of what constitutes either '*good wife and mother'* or '*independent'*. She says,

> …it was like, when [my daughter] was little … I was always scared she would run off and I wouldn't be able to catch her. So Mum used to come with me all the time.

… son/daughter
The role of child was often problematic for participants who indicated that they could identify a number of points for frustration or tension in the relationship which would not have occurred had they not had a disability. Most participants indicated that their parents had encouraged them to be independent but also that the role of the parent was maintained for longer than for participants' peers. For others, parental influence remained into adulthood. This generated guilt within the participant out of their frustration and resentment of intended assistance and support which resulted in limitation and restriction.

> …. they've told me that its for me when they don't need it any more, that's why they built a bungalow, for me. Trouble is, its too big! … I'm much better here … and I know they won't understand that I don't want it but I'll have to tell them …

… sibling
Siblings were often reported as having protective roles within participants' lives. This role was usually an expectation imposed by parents but, again, varied in degree although all of those interviewed reported that their family

members displayed some level of protective behaviour. In some cases, the participant reported that this behaviour was problematic,

> …and they told my brother he always had to make a job for me…and he thinks I should work for him even though I don't want to.

As they both get older, this ongoing source of conflict is likely to disappear, though, as they get to an age where retirement is acceptable to the family.

4.   – Tensions

The opportunity for choice was often mentioned as a site of tension and brought together some of the aspects discussed already. In employment, this was particularly clear as participants rehearsed their recollections about what occupation they wanted to follow and whether they had been able to do so. Some of these tensions came out of assumptions made about ability both on an individual level and on a social level, eg. the limitation within this cohort when special schools provided qualifications of lesser value in the labour market. Others came from some form of recognition of limitation imposed by their disability whether this occurred at the start of their working lives or part way through, perhaps with the onset of Post Polio Syndrome (PPS).

5.   – Fears

One female participant is married to someone quite a lot older and the quotes that follow show a degree of what I will term 'reflected age' which does not always equate with her chronological age.

> He's full of energy for his age but he does get tired sometimes and that's easier for me, I suppose. When we were younger I found it hard to keep up at times so him being older works out, really.

He currently undertakes a lot of domestic duties which is appreciated by the participant as her health has deteriorated with the onset of PPS but it is a position which she identifies as making her vulnerable,

> It's a good balance now but it frightens me what might happen when he can't do these things. I'd probably manage but it would be very hard. He IS a lot older so it could all change very quickly which is why I don't push him.
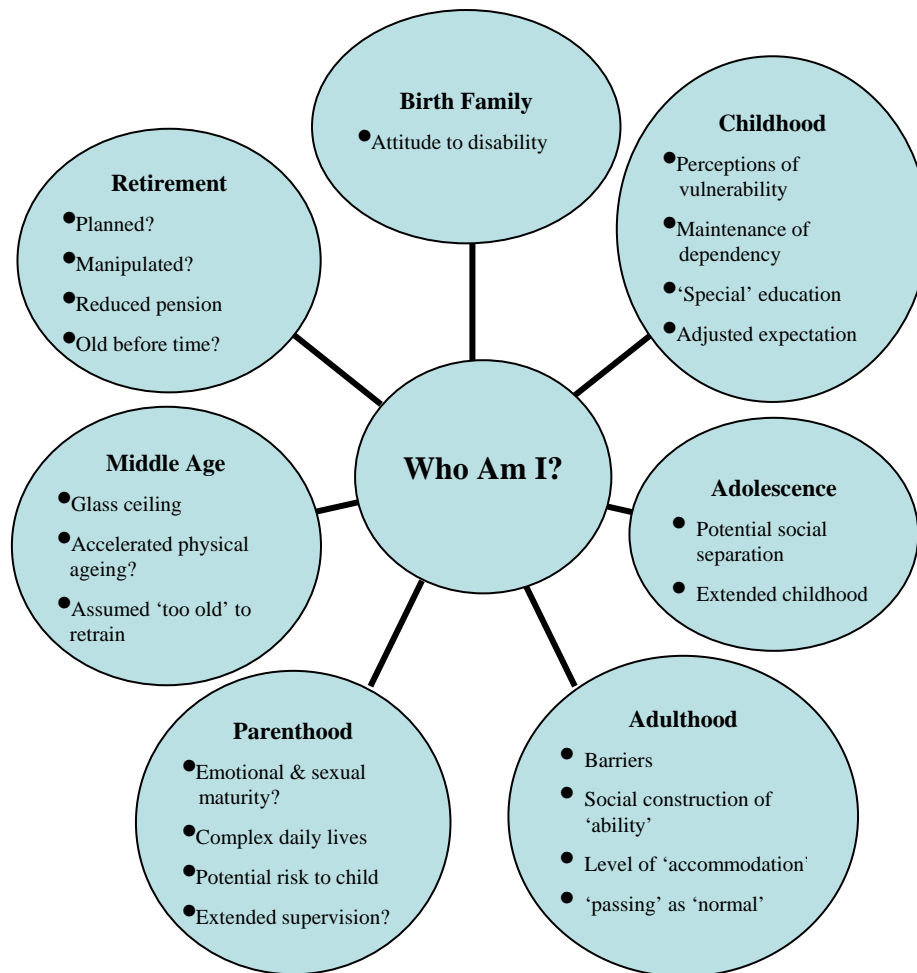
For many participants the fears often associated with the effects of increasing chronological age are increased by their existing level of dependence on others as they see not only the maintenance of the need for such support but a potential increase which conflicts with other notions of independence.

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Conclusion

The differences shown by the data are summarised in Fig. 2. The 'normal' diagram we looked at earlier (Fig. 1) is overlaid by the additional or differential aspects shown on this one. Where 'normal' means external acceptance and development, for example, in this there is questioning and maintenance. Although the original thrust of the study was around the experience of employment and much of the data does deal with that directly, the variety of roles which can be identified from the data in this context was unanticipated. Not only can roles be identified, however, but provide the basis for some very obvious differences and tensions in the identities attached to them.

The study included a variety of 'family types' and occupations, from those who had never married and had no children to those who had married several times and had large families. From those who had been in unskilled employment to those who held substantial and influential positions. From both the interviews and the email questionnaires, the basic themes of what I will call 'submerged' identities came through. No matter what the practicalities of their lives the people I spoke to all indicated that their disability had given rise to issues which either would not otherwise have affected them or affected them to a lesser extent and had changed their interaction with the world about them. We all have multiple roles and identities bound up within the 'rich tapestry of life'. Some of those will not be deliberately chosen roles or identities but for the people in this study that is exacerbated by living with a disability. Their identity is an amalgam not only of the outcome of deliberate choices but from major and ongoing inputs from those whose influence would normally wane across the life course. There are obvious effects on self-esteem and confidence from traumatic experiences, particularly in childhood and these were harrowingly described by one participant, but the resulting sense of 'who/what am I?' is surprisingly consistent. The outcome of a 'Disability history' composed of impairment, age at onset and effect actually had little influence on the emergence of the identities which people described.

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**Figure 2   Identity Formation: Differential/Additional Impacts for those
with Disabilities**

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