The role of Supported Employment in promoting positive health behaviour of people with learning disabilities in work

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A dissertation submitted to Cardiff University in accordance with the requirements for award of the degree of Doctor in Philosophy (PhD)

June 2015

Author's declaration

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This thesis is the result of my own independent work/investigation, except where otherwise stated. Other sources are acknowledged by explicit references. The views expressed are my own.

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Summary

This mixed method research study originally contributes to understand the role covered by Supported Employment Agencies (SEAs) in promoting positive health behaviours of employees with learning disabilities.
Employment is rarely experienced by people with learning disabilities. Supported Employment Agencies provide a service to facilitate the employment experience for people with learning disabilities, through supporting in finding, keeping and maintaining a job. While many studies on employment have highlighted health benefits for the general population in employment, data is lacking for people with learning disabilities.
This study wants to understand if and how Supported Employment Agencies support the health of their clients with learning disabilities.
The quantitative phase of this study involved managers of Supported Employment Agencies completing a web-survey to understand the strategies used by Supported Employment Agencies preventing health risk behaviours and promoting health.
In the qualitative phase of this study Grounded Theory Method was used to discover the role played by Supported Employment Agencies in supporting the health of their clients with learning disabilities. For this purpose interviews with mangers and job coaches of Supported Employment Agencies and interviews with employees with learning disabilities were held.
Results from this study reveal Supported Employment Agencies to influence the health of employees with learning disabilities in several ways, both informally and formally. Indeed, health was a key element in all phases of supported employment, even if Supported Employment Agencies were not formally committed and funded to promote health.
The thesis highlights the potential for SEAs to capitalise on their role as employment mediators to promote health outcomes and healthy lifestyles for employees with learning disabilities.

Acknowledgements

I would like to express my deepest gratitude to my supervisors, Dr Stephen Beyer and Prof. Michael Kerr who strongly supported me throughout my PhD with their knowledge and patience. I am grateful to Dr Stuart Todd from the University of South Wales, who joined the supervisory team for the second phase of the project. My deep gratitude to Dr Meirion Evans, Dr Fiona Wood and Prof. Paul Kinnersley for monitoring my progress year by year, and for giving me suggestions on how to progress in my studies.

I wish to thank Supported Employment Agencies contributing to this study taking part to the survey. I am grateful to managers of the selected supported employment agencies who organized interviews and actively contributed in this study. I want to thank job coaches and employment consultants who decided to share with me their views on supported employment and health. Finally, I am extremely grateful to employees with learning disabilities who took part to an interview with me. I wish them all the best for their future careers.

I want to thank the Welsh Centre for Learning Disabilities and Clinical Epidemiology IRG for funding my project and Cardiff University for offering useful workshops that helped with my knowledge development.

A big thank to my parents Rita and Giovanni, my parents in law Alessio and Rina, aunt Luciana and uncle Gianni who travelled to the UK or to conferences to look after my son Alessio while I was studying. My deepest gratitude to my friend Marina, who loves me as a sister and supported me and my family in this difficult time.

Finally, I want to thank my husband Matteo, for supporting and encouraging me despite the hard moment in our lives. Finally my children, Alessio and Lorenzo who are the most precious gifts in my life.

In memory of my mother in law, Rina,

always in our prayers and in our hearts

List of Abbreviations

ASEA	Association of Supported Employment Agencies (Wales)
BASE	British Association for Supported Employment
BOS	Bristol Online Survey
BMI	Body Mass Index
CANTAB	Cambridge Neuropsychological Test Automated Battery
CBA-H	Cognitive Behavioural Assessment forma Hospital
CCGs	Clinical Commissioning Groups
DDA	Disability Discrimination Act
DES	Disability Employment Service
DH	Department of Health
DLA	Disability Living Allowance
DWP	Department of Work and Pension
ESA	Employment Support Allowance
ESF	European Social Fund
EUSE	European Union of Supported Employment
GP	General Practitioner
GTM	Grounded Theory Method
IB	Incapacity Benefits
IPA	Interpretative phenomenological approach
JC	Job Coach
JHWSs	Joint Health and Wellbeing Strategies
JIS	Job Introduction Scheme
JSNAs	Joint Strategic Needs Assessments
NI	Northern Ireland
NIUSE	Northern Ireland Union of Supported Employment
OSI	Open Society Institute
PIP	Personal Independence Payment
SDA	Severe Disability Allowance
SE	Supported Employment

SEA	Supported Employment Agencies
SF36	Short Form 36 health survey questionnaire
SPSS	Statistical Package for the Social Sciences
SUSE	Scottish Union of Supported Employment
TMT	Trail Making Test
UK	United Kingdom
VEN	Valuing Employment Now
WHO	World Health Organization

List of Conference Proceedings

- Vigna, E. et al. 2010. The role of supported employment agencies in promoting health of people with ID. *Journal of Applied Research in Intellectual Disabilities* 23(5).

- Vigna, E. et al. 2012a. Supported employment agency as mediator for people with intellectual disabilities health: Results from a qualitative study. *Journal of Intellectual Disability Research* 56(7-8).

- Vigna, E. et al. 2012b. Cross cultural study on the role of supported employment agencies in promoting the health of People with intellectual disabilities: A comparison between the UK and Spain. *Journal of Intellectual Disability Research* 56(7-8).

List of Conferences

- IASSID 2012: 9-14 July 2012, Halifax (NS). World Congress: A World of Potential. Presentation: Vigna E., Beyer S., Kerr M. “Supported employment agency as mediator for people with intellectual disabilities health: Results from a qualitative study”.

- BASE 2011: 7th and -8th September 2011, Cardiff (UK). Annual Conference British Association for Supported Employment. Presentation: Vigna E., Beyer S., Kerr M., “Supporting Health Outcome through employment: the role of supported employment agencies in delivering the health benefits of employment for employees with learning disabilities”.

- IASSID 2010: 20-22 October 2010, Rome (Italy). 3rd Europe Conference: Integrating Biomedical and Psycho - Social –

Educational Perspectives. Presentation: Vigna E., Beyer S., Kerr M., “The role of supported employment agencies in promoting health of people with ID”.

List of Seminars

- PLUSS Supported Employment Agency (2013): Supporting health outcomes through employment: the role of supported employment agencies.

- University of Salamanca (2011): Supported employment and its role in promoting the health of people with learning disabilities: results from a web-survey in the UK.

List of Posters

- IASSID 2012: 9-14 July 2012, Halifax (NS). World Congress: A World of Potential. Presentation: Vigna E., Kerr M, Jordan de Urries B., Verdugo M., Beyer S. “Cross cultural study on the role of supported employment agencies in promoting the health of People with intellectual disabilities: A comparison between the UK and Spain”.

- Postgraduate day conference 2012 (Cardiff University): Supported employment agencies mediating the health of people with intellectual disabilities: results from a qualitative study.

- Postgraduate day conference 2011 (Cardiff University): Cross cultural study on the role of supported employment agencies in promoting the health of people with learning disabilities a comparison between the UK and Spain.

- Postgraduate day conference 2010 (Cardiff University): The role of supported employment agencies in promoting the health of people with ID.

Contents

Figures

Tables

Introduction

My original contribution to knowledge in this thesis is the description of the role covered by supported employment agencies in promoting positive health behaviour of employees with learning disabilities. Employment for people with learning disabilities is an important, but rarely experienced, opportunity. Supported employment agencies provide a service to facilitate this experience, helping people with learning disabilities during the process of finding, keeping and maintaining a job. The aim of this study was to understand the role Supported Employment Agencies play in protecting and promoting the health of their clients with learning disabilities, recognising the health inequalities they experience compared with the general population.

This research adopts a mixed method approach; the topic was first investigated using a quantitative approach through a web survey, and secondly investigated using qualitative approach through Grounded Theory. The research is based primarily on contributions from employees with learning disabilities, managers and job coaches of Supported Employment Agencies. The thesis is divided into 9 chapters.

Chapter 1 describes the theoretical background for the study based on the relevant literature and the search criteria adopted. It starts with a definition of learning disabilities and is followed by the description of key elements in health promotion. The health inequalities experienced by people with learning disabilities, their health status and health risks, and access to health care are discussed. This is followed by the analysis of the link between employment and health in the general population and how some companies approach health in their employees. A description of supported employment, how it works at present and the relation between employment and people with learning disabilities is given. Finally, some

future options for Supported Employment Agencies in promoting the health of people with learning disabilities are discussed.

The second chapter describes the research design step-by-step, focusing on research questions and analysing choices faced during the course of the research. Both quantitative and qualitative methods are detailed, with a description of the instruments used for this research, research ethics committee approval procedures and ethical issues.

In the third chapter results from the web survey are presented together with potential bias and their implications.

The fourth chapter describes my approach to qualitative methods, how the sample was selected for this part of this study and how participants where approached.

The fifth chapter provides a detailed description of the Grounded Theory process for this study.

The sixth chapter reports how the theory emerged from the analytic process from the contribution of employees with learning disabilities.

The seventh chapter reports how the theory emerged from the analytic process from the contribution of managers.

The eighth chapter reports how the theory emerged from the analytic process from the contribution of job coaches.

Finally, the ninth chapter provides discussion and conclusions for this study.

1 Background

People with learning disabilities are mainly unemployed, and individuals in employment are likely to be employed in part-time positions. Supported employment plays a key role helping individuals with learning disabilities entering and keeping employment. The aim of this study is to investigate if and how supported employment plays a role in protecting and promoting the health of employees with learning disabilities. This is because we know people with learning disabilities experience health inequalities compared with the general population. Employment can improve health and longevity for employees with learning disabilities. This study is looking at a small, but still significant, portion of individuals with learning disabilities who are employed. This study is also looking at the impact of employment on the health of with learning disabilities.

Considering the over mentioned key facts and the starting assumptions for this study, the literature review has been developed following several directions:

1. Investigating the relation between employment and people with learning disabilities;
2. Investigating the role of supported employment for perspective and existing employees with learning disabilities;
3. Investigating the health inequalities experienced by people with learning disabilities compared with the general population;
4. Investigating the health status and health risks for people with learning disabilities.

This chapter describes the background literature for this research including:

I. An overview of the search strategy and results for each topic of interest for this research;

II. A historical introduction to the concept of learning disabilities contextualised within the UK society,

III. A historical introduction of the concept of health and health promotion, and a description of health and health promotion is given.

IV. A discussion of the health risks and health behaviours of people with learning disabilities.

V. A discussion of health inequalities and a discussion of how the health care service and health promotion services are accessed by people with learning disabilities.

VI. A discussion investigating the link between health and employment, with references to the current employment and health debate.

VII. A discussion of Supported Employment (SE) and employment, how it works and future potential for SE and health.

1.1 An overview of the searching strategy

The systematic literature search was carried out using several databases, providing a comprehensive and multidisciplinary citation search.

The following databases were searched:

- PsycINFO
- Allied and Complementary Medicine Database (AMED)
- Excerpta Medica Database (EMBASE)

- Medline
- Pubmed
- Web of Science

Google and Google scholar were also searched to access other resources of knowledge such as for example White Papers, reports and any relevant grey literature. A search of references within papers, and article titles, led to the inclusion of other papers that may be relevant to the topic.

Systematic literature searches were carried out combining the following truncated terms with the truncated terms “intellectual disabilities”, “learning disabilities”, “mental retardation” and “learning difficulties”.

- Obesity;
- Overweight;
- Smoking;
- Alcohol;
- Substance abuse (“substance abuse” was used instead of “drug” to avoid the inclusion of results related with medication drugs);
- Health risks;
- Health inequalities;
- Supported employment;
- Employment.

Search results were compared and duplicates were excluded. References have been managed using Endnote Web.

The searching criteria have been reported in flow chart diagrams, based on standards given by PRISMA (Preferred Reporting Items for Systematic Review and Meta-Analyses), (www.prisma –statement.org). Diagrams are reported for each section discussing the topic.

The search criteria included journal article and review of the literature in English, including articles up to 2013.

1.2 Learning disability

The label “learning disability” describes a heterogeneous group of people who have a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) and with a reduced ability to cope independently (impaired social functioning) which started before adulthood and which has a lasting effect on development (DH 2001 p.14). The definition includes adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average or even above average intelligence – such as some people with Asperger’s Syndrome (DH 2001).

The British Psychological Society (2000) defines a person with learning disabilities to be an individual whom:

1) presents a significant impairment of intellectual functioning;

2) has significant impairment of adaptive/social functioning;

3) presents the impairment before adulthood (BPS 2000).

People with learning disabilities constitute a heterogeneous group having different diagnosis, personal backgrounds, and specific health needs. Therefore people with learning disabilities may present similarities related with an impaired intellectual, adaptive and social functioning, but

individuals also present significant differences (Fletcher et al. 2003). A further description of the diagnostic classification is given in Appendix C.

The number of people with learning disabilities who are known to learning disability services are estimated to be in England (2011) 1,191,000 cases, 286,000 children and 905,000 adults (Emerson et al. 2011b).

People with learning disabilities began to be considered and included progressively in the society after the Second World War. In the sixties institution based services were criticised because they were causing isolation for people with learning disabilities. Government in the UK stated the rights of people with learning disabilities and set up services for them within the community (Race, 1995).

The UK Government is now committed to improving the life chances of people with learning disabilities during their lifespan, and providing support to their families. Government policy is that people with learning disabilities should be treated with dignity and respect and should be leading their lives like any other person, with the same opportunities and responsibilities. This principle can be translated to promoting inclusion, particularly for those who are the most excluded, and empowering people with learning disabilities to make decisions and shape their own lives (www.dh.go.uk). Indeed, the White Paper “Valuing People Now” (DH 2001) stated a three year government strategy, based on the assumption people with learning disabilities are people first. Employment was at the centre of this strategy, as a possible source of independence, empowerment and inclusion for people with learning disabilities. This is one of the rationales for this study, because employment may be a way to live healthier lives.

Since then many milestones have been met to integrate individuals with learning disabilities into the society as equal citizen, but for individuals with learning disabilities some rights are still denied, such as unequal health care opportunities and job opportunities (MENCAP 2007; 2013). This contributes to support the rationale for this study.

1.3 The concept of health and health promotion

The World Health Organisation (WHO) first defined health as "*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*" (WHO 1948 p.2). This statement extended the meaning of health to psychological and social aspects rather than just physical. However, it is clear that it is unlikely a person will achieve a complete and permanent state of well-being. Therefore, in 1986 the WHO amended the definition, considering health to be *"a resource for everyday life and not the object of living*. "

In the same years, Lalonde, the Canadian Minister of National Health and Welfare, elaborated a new concept of health. Lalonde (1981) introduced the "*health fields concept*", where health and illness were assumed to be the results of the interactions of several elements such as human biology, environment, lifestyle and the impact of health care organisation input. Since then more attention had been paid on researching the basis of human biology and on how to improve the natural environment in conjunction with the development of a new understanding of "self-imposed risk" due to negative lifestyles (MacDougall 2007). Hence, investing in health promotion was synonymous with investing in better nutrition, physical activity, preventing sexually transmitted diseases and abuse of drugs, alcohol and tobacco (Lalonde 1981). This new concept of health is now widespread in Western Countries, where the concept of health moved from a culture of treatment to a culture of prevention.

Health promotion therefore became a popular concept in society, aiming to prevent diseases and death through several models. The medical approach to health promotion aims to reduce morbidity and early mortality through primary, secondary and tertiary prevention. Primary prevention aims to prevent diseases through educating people. In the UK several campaigns are in place to prevent certain high risk behaviours or to advise

people on how to reduce these risks, as for instance the Change 4 Life programme (www.nhs.uk/change4life/). This programme covers many topics that could represent hazards for the population such as poor diet, lack of exercise, smoking, excessive use of alcohol and immunisation. Secondary prevention can be seen as a second step, aiming to prevent or monitor the progression of a disease through screening and diagnosis. Screening tests are carried out on a segment of population that is at risk of developing a specific disease. Therefore, this segment of population is tested for it as a measure of secondary prevention. If an individual experiences symptoms, secondary prevention is important for detecting an illness through an early diagnosis that may reduce the effect of the disease. Finally, tertiary prevention aims to prevent and recover from damages that have already been done, through rehabilitation for example.

The educational approach to health promotion aims to inform the individual and provide the skills to make informed decisions. Another approach involves encouraging people to adopt healthy lifestyles through behaviour change (Naidoo and Wills 2000). Health promotion can be accessed through empowerment. In other words individual or community needs are identified and knowledge and skills are taught to help people control the health aspects of their lives (WHO 1986). Finally, health promotion can also be achieved through social change targeted to a group or a population at risk to help them to achieve better lifestyles (Naidoo and Wills 2000).

People with learning disabilities are clearly members of our society and, as in the society they belong to, they are a heterogeneous group of people with different characteristics, dissimilar needs and peculiar health conditions. Thus, services must consider the health disparity of people with learning disabilities in comparison with the general population and the difficulties those people may experience in accessing primary health promotion activities. Health inequalities among people with learning disabilities have been generally highlighted and addressed (Emerson and

Baines 2010; Emerson et al. 2011a). People with learning disabilities are often hindered in accessing health care due to personal problems such as difficult mobility, sensory impairments, behavioural and communication problems (Kerr 2004). They are also hindered due to barriers thrown up by poor professional practice such as time constraints on staff affecting their ability to give people with learning disabilities the time they need, repetitive ways of working and stereotypical concept of learning disability (Shaughnessy and Cruse 2001).

The Government White Paper *Valuing People* stated that people with learning disabilities have the right to access mainstream health services, through being registered with a general practitioner (GP), having a health facilitator who could help and to have the opportunity to complete a personal Health Action Plan (Kerr 2004). People with learning disabilities may need support to avoid or abandon unhealthy behaviours (Crawley 2007) and also to acquire awareness on how to live healthy lives. Furthermore, some people with learning disabilities are not able to express their needs and problems and so may need an advocate to represent them in this respect.

1.3.1 The health and health inequalities of people with learning disabilities

The following key words have been searched to investigate the topic of health inequalities:

- (health* ineq* AND int* disab*), (health* ineq* AND learn* disab*), (health* ineq* AND mental retard*), (health* ineq* AND learn* diffic*).

Searches for health inequalities yielded 55 results, 34 of these were duplicates. Hand searching yielded 15 results. Finally the screening process resulted in the inclusion of 19 papers (Figure 1.1).

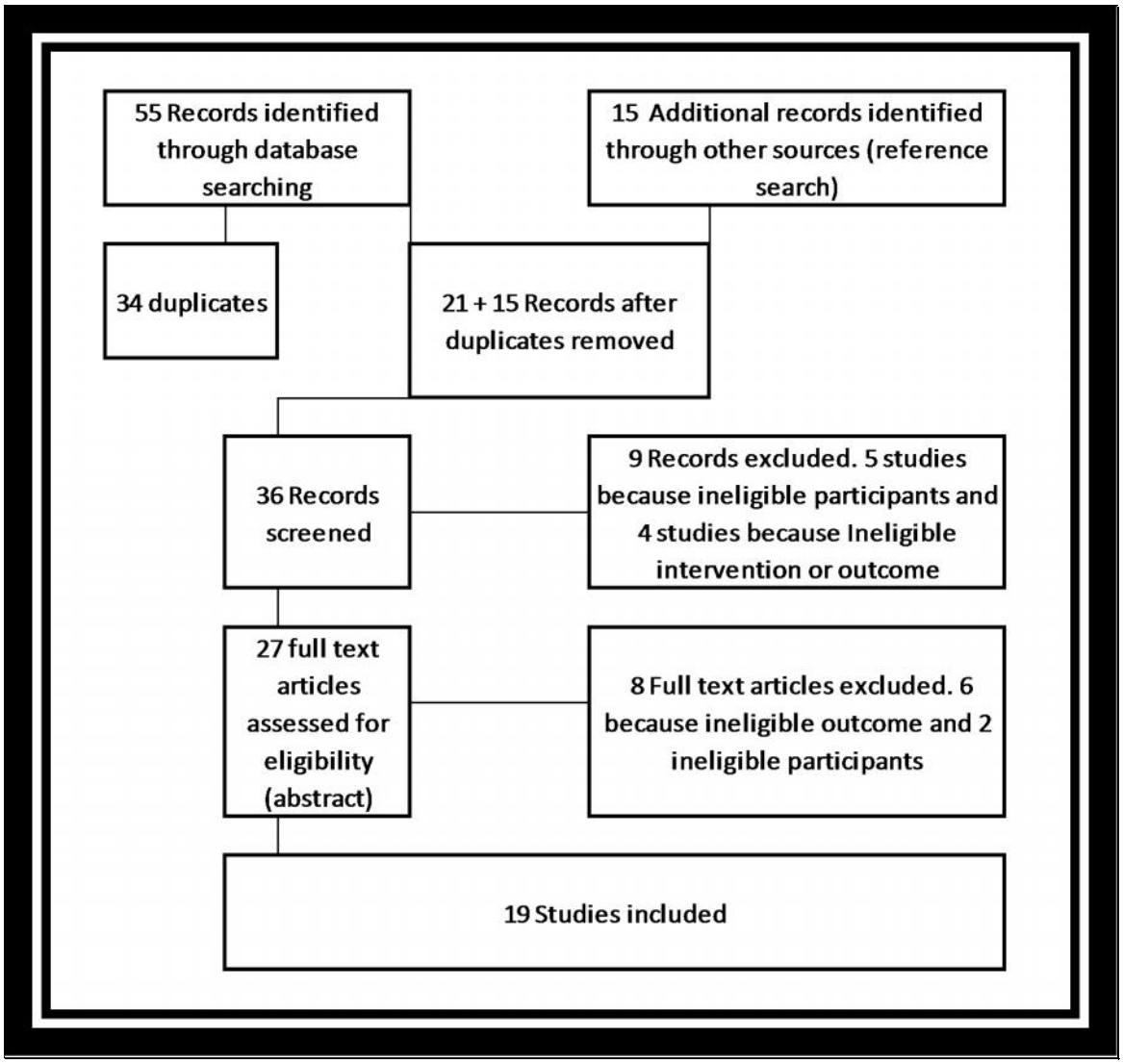

Figure 1.1: Flow chart for health inequalites searches

People with learning disabilities are more likely to experience health inequalities in comparison with the general population as underlined by the Department of Health in a recent document on health inequalities (Emerson and Baines 2010; Emerson et al. 2011a). Health inequalities for this group are due to complex multi-factorial reasons. Several health problems may not be directly related with the cause of the learning disabilities (Turner 2001), but more frequently linked with living condition, exposure to negative social determinants such as poverty, poor housing conditions and unemployment (Emerson and Baines 2010). People with learning disabilities also have poor bodily awareness and many have

limited communication skills and health literacy, which contribute to their poor health. One example of attempting to reduce health inequalities came from the Scottish government where people with learning disabilities and their supporter were recruited as expert patients to become members of a national review team (Campbell and Martin 2010). This was to empower people with disabilities who generally had few or no chance to express their feelings on their experience of the health service. Learning disabled reviewers received one day's training that at the end of the study was found to be not effective in an evaluation. However, the overall initiative was a success leading individuals with learning disabilities to become active reviewers of their health service.

Many researchers have investigated the health status of people with learning disabilities. A recent and well documented study, the POMONA project, produced and tested a set of health indicators for people with learning disabilities (van Schrojenstein Lantman-de Valk et al. 2007). The health status indicators reported the prevalence of health conditions for a sample of 1269 people with learning disabilities. Half of this sample reported their general health to be very bad, as compared with 20% that consider their health status to be very good (POMONA 2008). In addition, 12.5% of people with learning disabilities reached caseness for a psychiatric disorder. Furthermore, 28% of the sample has been diagnosed with epilepsy and 20% experienced a seizure in the last five years (POMONA, 2008), with a higher prevalence in less able people (Perry et al. 2010). Other health issues have been highlighted by POMONA: 21% of the sample reported pain in their mouth, 39% used a visual aid, 15% reported hearing difficulties and 26% reported mobility difficulties (POMONA 2008).

People with learning disabilities have twenty times higher prevalence of epilepsy, which is often resistant to treatments and heavily affecting their quality of life and mortality (Branford et al. 1998; Kerr and Bowley 2001; Amiet et al. 2008; Matthews et al. 2008; Emerson and Baines 2010).

Overall, life expectancy for people with learning disabilities is lower than the general population (Morgan et al. 2001: Kerr 2004). Risk factors increasing mortality for this group are: severity of their disability, reduced mobility, feeding difficulties and a diagnosis of Down's syndrome (Strauss et al. 1998; Van Allen et al. 1999; Kerr 2004). Furthermore, mortality for people with learning disabilities is still linked with infections, being 8-10 times higher than the general population (Turner 2001). Specifically, respiratory disease is still the leading cause of death for people with learning disabilities (Puri et al. 1995; Hollins et al. 1998; Emerson and Baines 2010). Coronary heart disease is also a frequent cause of death for people with learning disabilities (Hollins et al. 1998; Emerson and Baines 2010). This is due to increased longevity and community lifestyles, which represent added risk factors especially for people with Down's syndrome who are more likely to be affected by congenital heart defects (Martin et al. 1997; Emerson et al. 2011a).

1.3.2 Health risks for people with learning disabilities

The following key words were searched to understand the health risks for people with learning disabilities:

- (health* risk* AND int* disab), (health* risk* AND learn* disab*), (health* risk* AND mental retard*), (health* risk* AND learn* diffic*).

Database searching for health risks produces 33 results, 14 of these were duplicates. Hand searching yielded 11 results. Finally the screening process results in the inclusion of 12 papers (Figure 1.2).

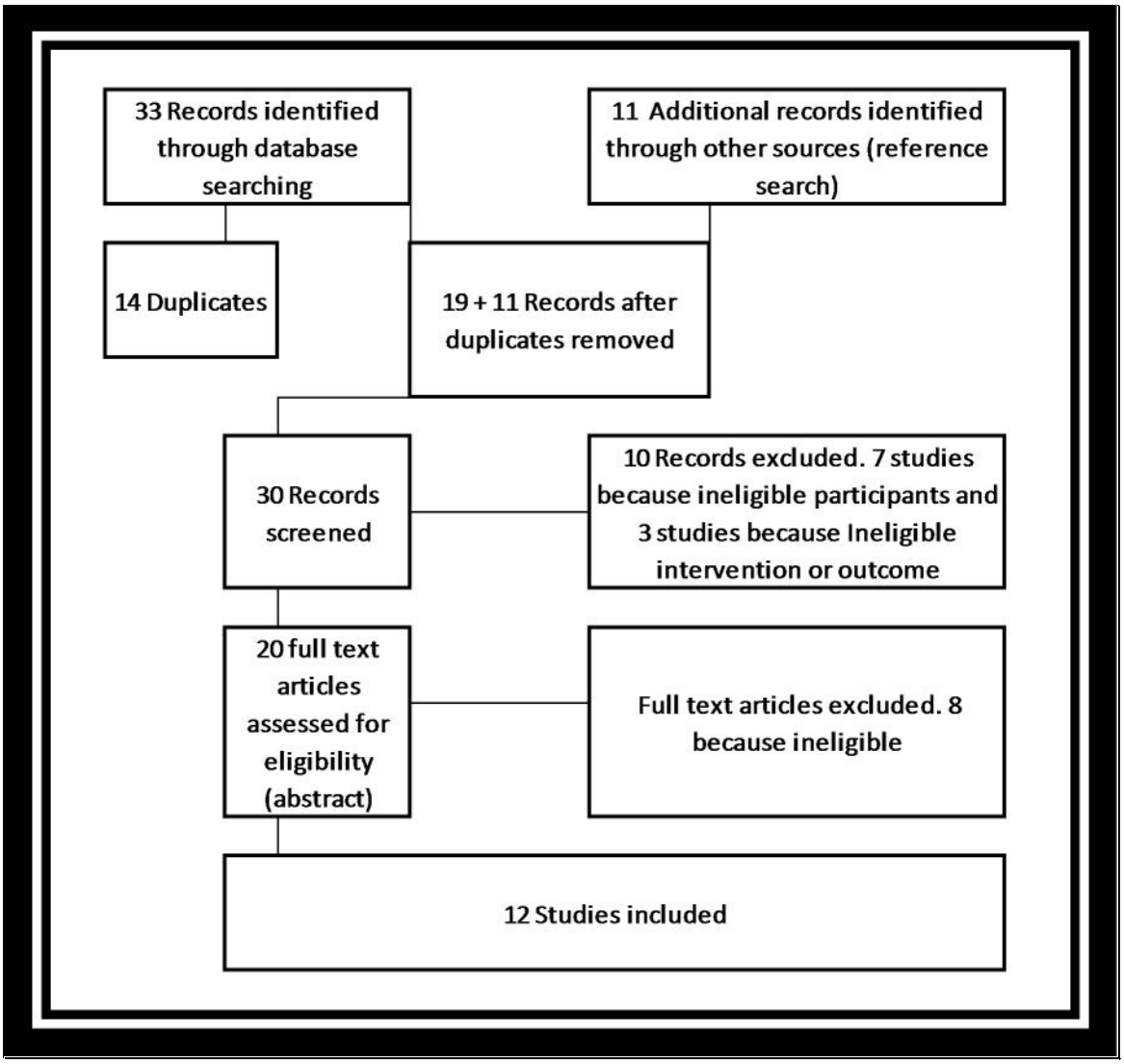

Figure 1.2: Flow chart for health risks searches

The 12 studies selected were related with general health risk such as smoking, substance abuse, alcohol use and weight disorders, which have been also specifically searched and discussed in the following paragraphs.

1.3.2.1 Overweight, obesity and underweight

The search keywords for weight disorders are described below:

- (obes* AND int* disab), (obes* AND learn* disab*), (obes* AND mental retard*), (obes* AND learn* diffic*);

- (overweight AND int* disab), (overweight AND learn* disab*), (overweight AND mental retard*), (overweight AND learn* diffic*);
- (underweight AND int* disab), (underweight AND learn* disab*), (underweight AND mental retard*), (underweight AND learn* diffic*);

Database searches for obesity, overweight and underweight yielded 566 results, 153 of these were duplicates. Hand searching yielded 22 results. Finally the screening process resulted in the inclusion of 11 papers (Figure 1.3).

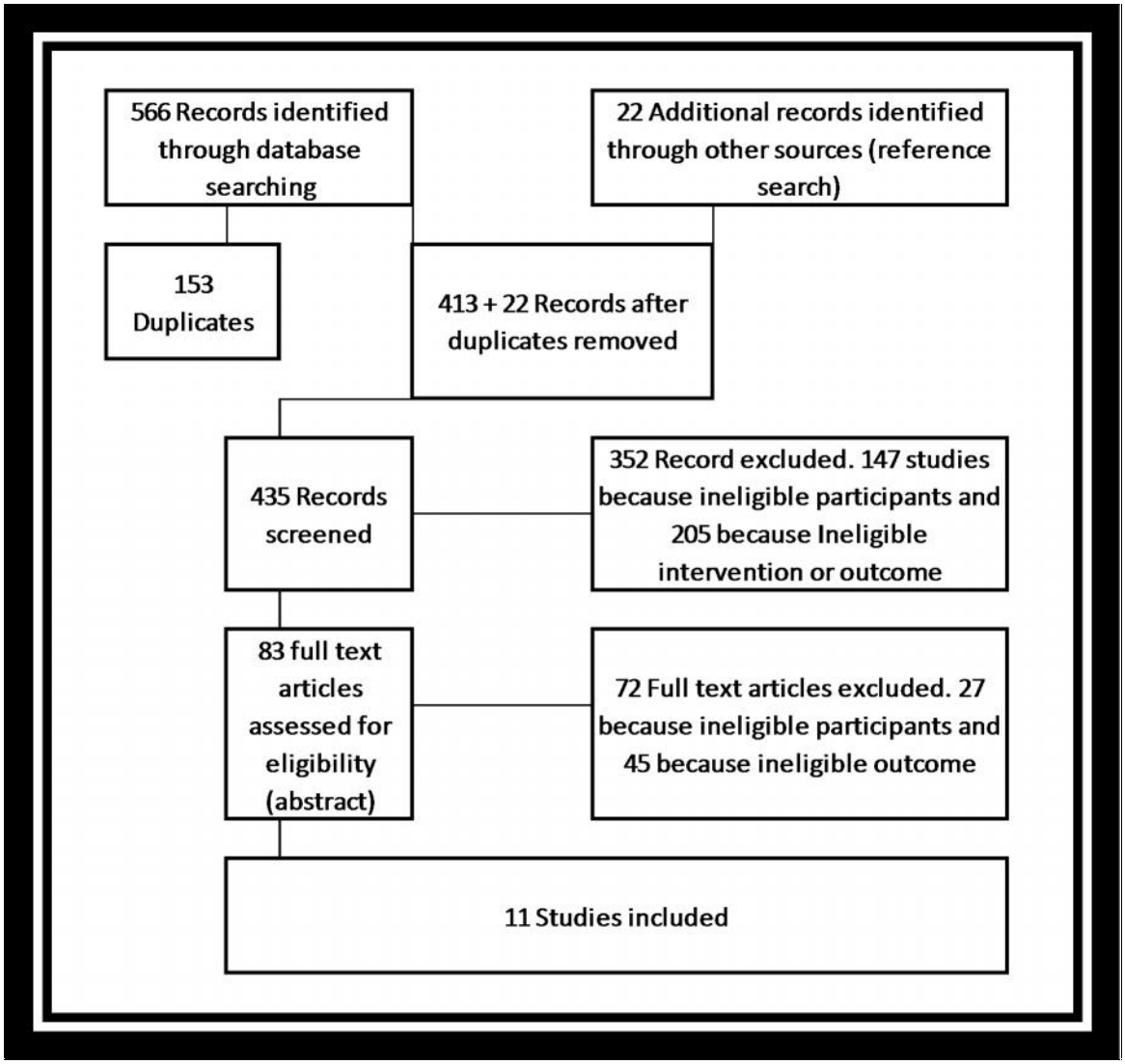

Figure 1.3: Flow chart for obesity, overweight and underweight searches

Obesity is a condition already described by Hippocrates in ancient Greece, together with the value of dietary restrictions, physical activity and lack of sleep. In history obesity was generally associated with a personal moral weakness. Following the discovery of fat cells, obesity was then associated with the concentration of too many fat cells and familiar factors were then discovered (Bray 1990). Obesity is becoming a growing problem in the Western Societies where the food habits and lack of exercise of people in general are increasing the risk of their developing overweight and obesity.

Being obese (defined as an abnormal or excessive fat accumulation able to impair health) and being overweight, (defined to be a increment of BMI equal to 25 and up to 29.9) are widely found among people with learning disabilities (A full definition of overweight, obesity and underweight can be found in Appendix B).

There are higher rates of obesity for people with learning disabilities than in the general population (Hove 2004; Holcomb et al. 2009). A cross-sectional postal questionnaire to investigate health habits disclosed that 68% of 157 participants with a learning disability were overweight or obese (McGuire et al. 2007). This study involved carers of people with learning disabilities in both residential and family settings, which may represent a limitation of this study. Carers in residential settings may not be aware of all the health behaviours of the individual with learning disability and the questionnaire did not ask about the length of the relationship with the individual with learning disability. Furthermore individuals with learning disabilities were not directly involved in this study, the reports being third party only.

Within the population of people with learning disabilities women are more likely to be obese or overweight than men (Robertson et al. 2000). Robertson et al. study looked at the risk factors for people with learning

disabilities in different residential settings including 540 people randomly selected. A questionnaire was given to carers, and therefore no individuals with learning disabilities were directly involved in the study. This was a limitation of the study because carers may not be fully aware of diet and exercise habits of the people concerned. However, when comparing women with learning disabilities living in residential settings with women from the general population, Robertson et al. (2000) found that women from the first group were more likely to lead inactive lives.

Overweight and obesity are common among people with Prader-Willi syndrome and they are widely found among people with Down syndrome (Prasher 1995; Crawley 2007). However, it seems that at least for men, obesity and overweight were not linked with these conditions, but with lifestyle factors (Melville et al. 2005; Crawley 2007). People living in a less restrictive environments, such as group homes or semi-independent living, and people of higher ability are at increased risk of obesity (Emerson and Baines 2010). This is most probably due to more independence in what they buy and eat in these living arrangements. This is based on recent evidence from the UK on the health status of people with learning disabilities.

Fewer people with learning disabilities have a balanced diet, with the right intake of fruit and vegetable (Emerson and Baines 2010). Furthermore, people with learning disabilities can lead a physically inactive life (Melville et al. 2007) and this represents a risk factor for cardiovascular disease, high blood pressure, high cholesterol and diabetes.

Furthermore, obesity is diagnosed at a younger age among people with learning disabilities, and it is found in areas of high socio-economic deprivation (Valdez and Williamson 2005; Melville et al. 2007). Thus people with learning disabilities may be dependent on others and, consequently, they may perform low levels of physical activity (Horvat and Franklin 2001; Melville et al. 2007). People with learning disabilities are at

risk of over consuming food to fight boredom and social isolation (Melville et al. 2007).

Being under a healthy weight (Appendix B) is generally widespread among people with severe learning disabilities, living in supported accommodation. A study involving 1,542 adults with learning disabilities living in supported accommodation found that 14% were underweight (Emerson 2005; Crawley 2007). Being underweight was generally associated with immobility and feeding difficulties; and being underweight was generally experienced as a longstanding condition and not recognized by staff of supported accommodation (Crawley 2007). Being underweight is a serious problem associated with increased mortality, thought to affect from 35% to 72% of people with severe learning disabilities (Gravestock 2000; Crawley 2007).

The health assessment of people with learning disabilities through classic measures, such as BMI and waist measurement, is not completely appropriate for this group (Appendix B). Indeed, some people with learning disabilities can present physical characteristic typical of a specific syndrome, which can quite different from the general physical features found in the general population. For example, at present there are no correction factors for the use of BMI for people with Down's syndrome, who tend to be shorter than the general population. Nevertheless waist measurement is not the best way to determine personal status especially if the person uses medicines that cause a variation in their body shape. It is good to take these measurements as a guide, but in general, it is worth keeping in mind that there are no standard validations for people with learning disabilities as yet (Crawley 2007).

1.3.2.2 Smoking

The following key words were searched for the smoking topic:

- (smok* AND int* disab), (smok* AND learn* disab*), (smok* AND mental retard*), (smok* AND learn* diffic*);

The search yielded 61 results, 34 of these were duplicates. Hand searching yielded 6 results. Finally the screening process result in the inclusion of 10 papers (Figure1.4).

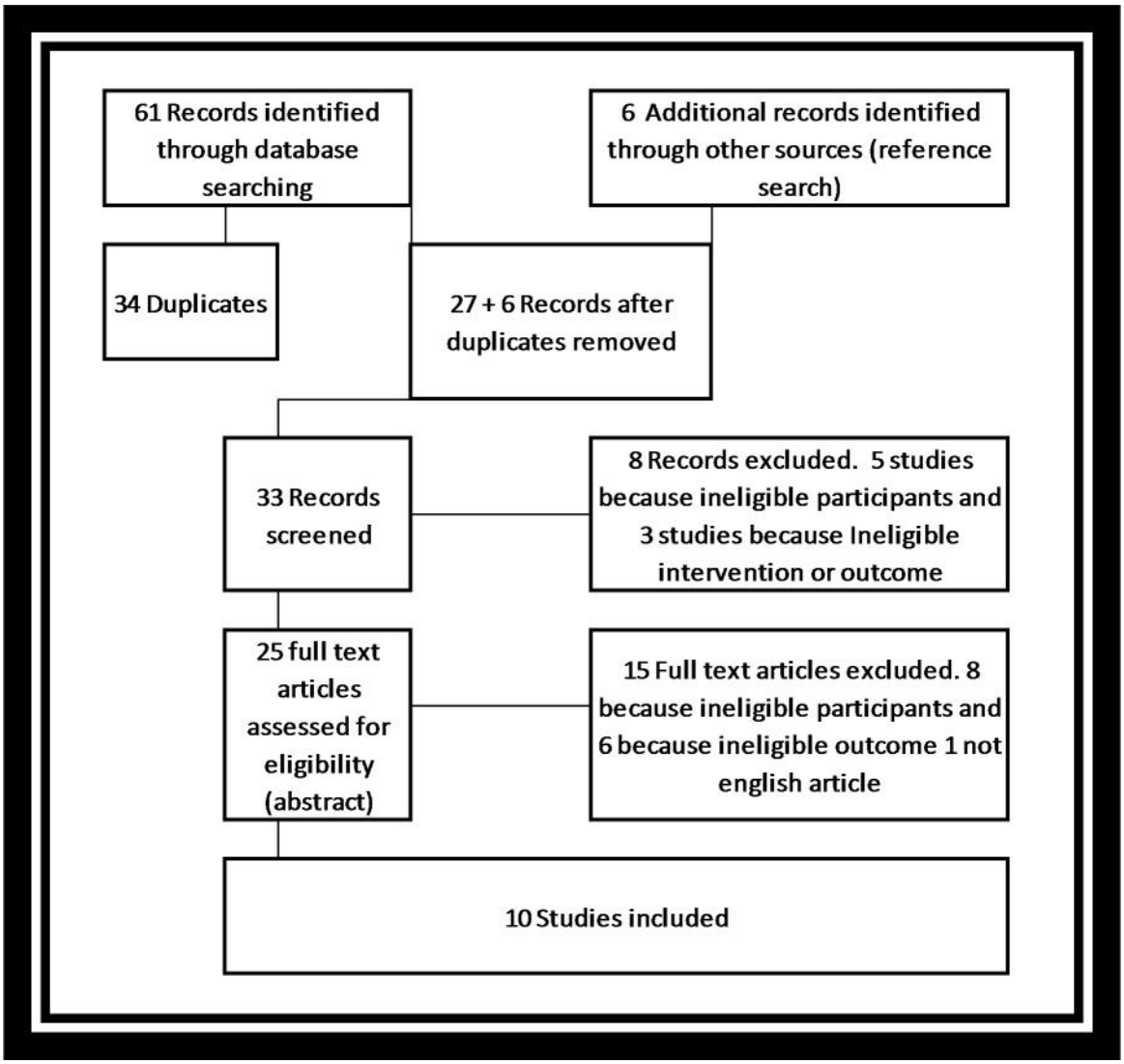

Figure 1.4: Flow chart for smoking searches

Smoking represents a negative health behaviour that has been the object of many public health campaigns as described in Appendix B. Negative effects of smoke on individual health, and specifically with lung cancer, were already highlighted in 1929, but remained a taboo subject until the

1960s. Several public health campaigns were developed that have contrasted smoking behaviour in the general population.

Research on smoking behaviour for people with learning disabilities is inconclusive at this stage. People with learning disabilities who smoke are usually “high functioning”, male, and live in a less restrictive environment, such as group or semi-independent housing (Steinberg et al. 2009). These findings are based on a review of the literature, which did not highlight the proportion of smokers within the population of people with learning disabilities. Therefore, future studies on the topic should investigate smoking patterns for this population more specifically, including the rate of smoking, and quitting, behaviours.

However, levels of smoking have been reported to be lower than for the general population at least for individuals with learning disabilities living in residential settings (Robertson et al. 2000). Other studies of adolescents with learning disabilities have found that rates of smoking are higher in comparison with their peers, probably as a consequence of the acquired independence (Maag et al. 1994; Cosden 2001; Emerson and Turnbull 2005; Emerson and Baines 2010). Other studies emphasise that people with mild learning disabilities are more likely to smoke in comparison with people with severe disabilities (Taylor et al. 2004). Indeed, people with a mild degree of learning disability are more at risk of becoming smokers. However, living arrangements do not appear to be related to smoking in Taylor’s study: specifically, people living independently were not more likely to develop smoking behaviours (Taylor et al. 2004). It is generally agreed that people with learning disabilities need to lead an independent life. However, staff supporting them have the duty to inform and educate people at risk of developing smoking behaviours (McMillan 2009).

A recent study carried out in the UK, revealed an association between smoking, increased body mass index (BMI) and asthma. Indeed, a large proportion of people with learning disabilities diagnosed with asthma were also smokers and obese (Gale et al. 2009). This innovative study identified

a representative sample from primary care patients with learning disabilities diagnosed with asthma. However, researchers noticed there was a gap in data collection because some information on BMI were missing, which may have influenced the results.

1.3.2.3 Alcohol use

The following key words have been searched to investigate the literature to date on this topic:

- (alcoh* AND int* disab), (alcoh* AND learn* disab*), (alcoh* AND mental retard*), (alcoh* AND learn* diffic*);

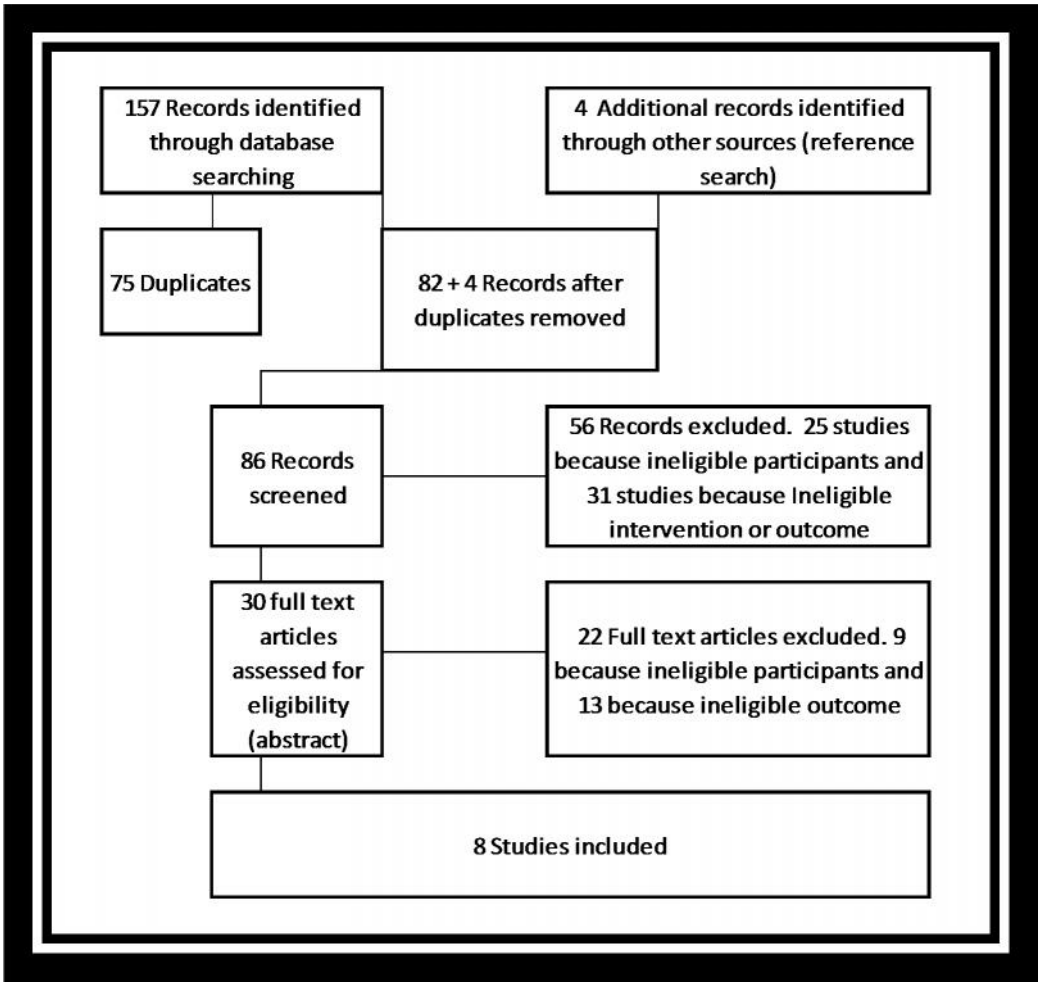

Figure 1.5: Flow chart of alcohol use searches

The search yielded 157 results, 75 of these were duplicates. Hand searching yielded 4 results. Finally the screening process resulted in the inclusion of 8 papers (Figure 1.5).

Alcohol has always been highly valued in history to be a source of nourishment, a source of relaxation and a factor helping in socialisation. However, alcohol misuse can lead the individual to adverse social behaviour and ill-health. Alcohol misuse is an ever-growing problem in the UK (Appendix B). The literature on people with learning disabilities and alcohol use is limited, but a high level of abstinence has been found (Robertson et al. 2000; Barrett and Paschos 2006). Hypothetically Barrett and Paschos highlighted several factors which may increase the risk of a person with learning disabilities developing adverse drinking habits. These are discrimination, low self-esteem, peer pressure, desire for social acceptance and loneliness. There are no empirically validated study on that, but it is worth investigating how and if employment may impact these factors and the subsequent attitude to alcohol use among employed people with learning disabilities.

However, Robertson and colleagues found that participants in their study never exceeded the government's recommended safe level for units of alcohol (Robertson et al. 2000). Robertson et al. included individuals from residential settings, therefore people living independently or with their families were excluded. Alternatively, a survey carried out in Ireland with carers of people with learning disabilities looked at the health behaviours of a sample of 157 individuals. They found that 10% of the sample regularly consumed alcohol, this being a relatively low rate if compared with the rate of 74.3% for the general population taking part in the same survey (McGuire et al. 2007).

Risk factors such us a family history of alcohol abuse, low socioeconomic status and psychiatric disorder, together with availability of alcohol in the

living context and a general positive social attitude to drinking, may act as relevant factors for people with learning disabilities to start drinking (Cocco and Harper 2002; Barrett and Paschos 2006). Common cognitive aspects that may be present in people with learning disabilities are a lack of social skills and social isolation, self-identity difficulties and inadequate reasoning. These conditions alone may lead to develop a alcohol related problem (Sturmey et al. 2003; Barrett and Paschos 2006). Indeed people with learning disabilities who have alcohol and drug related problems are likely to have many other problems such as economic, social, forensic and health; therefore a multi-model approach is requested for intervention (Barter 2007).

1.3.2.4 Substance abuse

The following key words have been searched to investigate the literature to date on this topic:

- (substance* abuse AND int* disab), (substance* abuse AND learn* disab*), (substance* abuse AND mental retard*), (substance* abuse AND learn* diffic*);

The search yielded 27 results, 4 of these were duplicates. Hand searching yielded 3 results. Finally the screening process results in the inclusion of 5 papers (Figure 1.6).

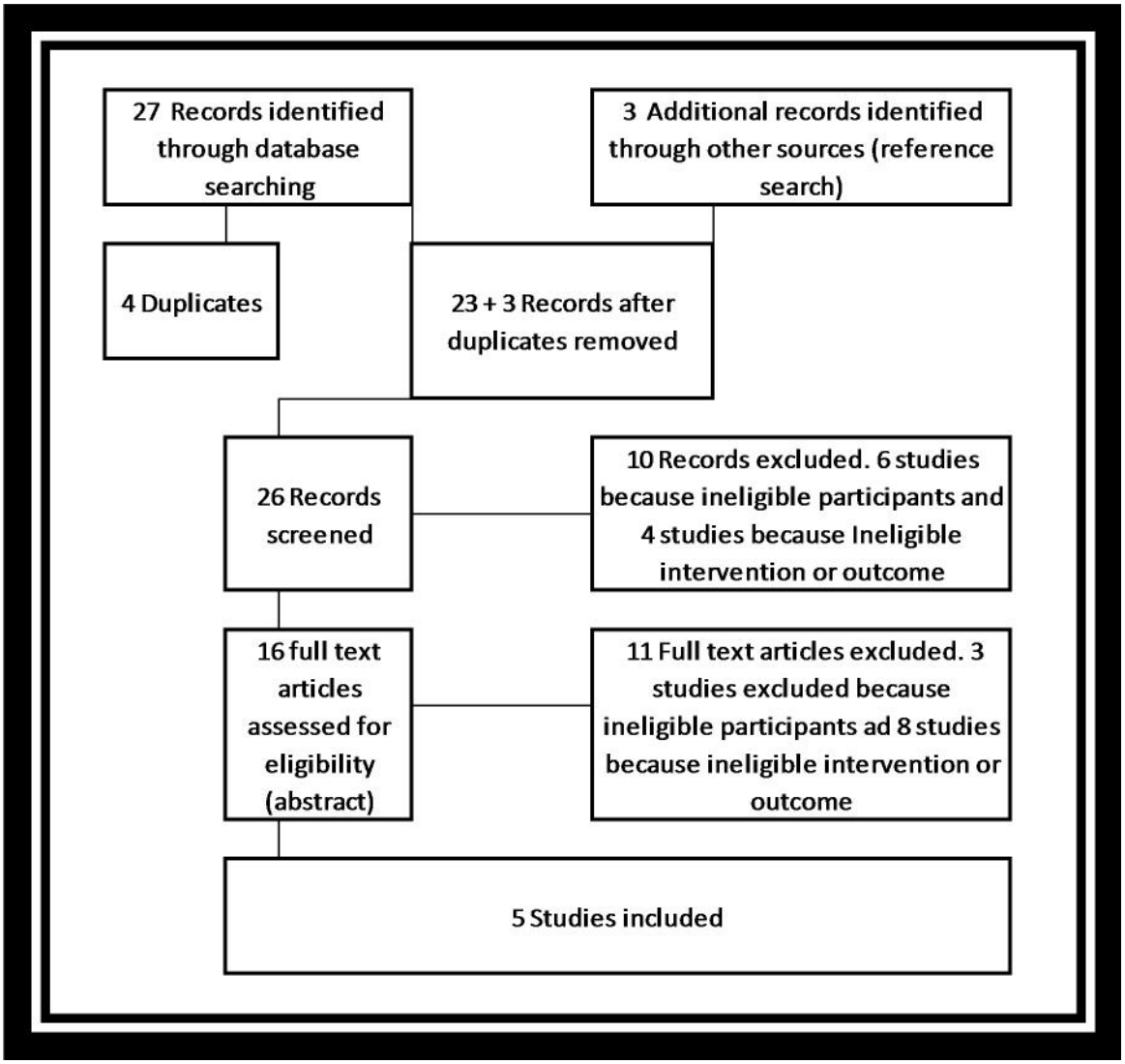

Figure 1.6: Flow chart for substance abuse searches

There are few studies investigating substance abuse among people with learning disabilities because it does not appear to be a widespread problem for this population. However, it is worth considering the following acting as risk factors for individuals with learning disabilities. Common reasons for individuals with learning disabilities to consume drugs could be:

a) used as a solution to reduce depression, anxiety or hyperactivity and

b) used to allow the creation of a peer group, by following their behaviours by trying illicit drugs (Katims et al. 1996; Cosden 2001).

A study reported adolescents with learning disabilities to be at increased risk of developing substance abuse disorder, but having similar rates of substance abuse and substance consumption levels to adolescents without disability (Beitchman et al. 2001). While looking at substance abuse this study also included alcohol abuse. A review of the literature on adolescents with learning disabilities and substance abuse highlighted that most individuals with learning disabilities do not abuse drugs (Cosden 2001). However, another study identified adolescents with learning disabilities to have higher rates of marijuana use than adolescents without a learning disability (Maag et al. 1994; Cosden 2001). Possible explanations are the negative influence of peers who used drugs themselves. However there is a gap in the literature around the reasons why people with learning disabilities may start to use drugs, what their background is, or any risk and protective factors that need to be addressed in future studies.

1.3.3 Access to health care and health promotion

The level of access to health promotion for people with learning disabilities is inadequate considering their health status and the potential risks to their health.

Felce et al. (2008) found out that people with learning disabilities consulted a GP or another member of the primary care team 5.4 times per year. The figure is higher than the rate in Wales for the general population which is 4.4 times per year. However, this may be low when the general level of co-morbidity suffered by this population is considered. A recent study including 200 adults with learning disabilities investigated the number of consultations they asked for with their GP. From this study women were consulting GPs or nurses more frequently than men (Turk et

al. 2010). However, this female consultation mean rate is a half, if compared with figures for the general population at the same age, therefore the consultation rate is generally lower than the general population. This study did not take into consideration the consultation made to A&E services or other specialist consultations, therefore further research may be required.

A review of primary care and people with learning disabilities, reported low levels of health promotion for people with learning disabilities, that are unlikely to be related to the number of consultations with people with learning disabilities which is almost equal to the general population (Jacobson et al. 1989; Beange et al. 1995; Welsh Office 1995; Kerr et al. 1996; Lennox et al. 2007). Another paper highlighted that GPs and primary care staff do not always recognize and address the health problems of people with learning disabilities (Jansen et al. 2004), and that they often are not trained to understand the needs of people with learning disabilities (MENCAP 2007). One of the main issues is that there is not a clear definition of the health problems experienced by people with learning disabilities in Jansen review. It is suggested in a MENCAP report (2007) that primary care staff did not diagnose health problems because these are felt to be a feature of the underlying disability. This represent an obstacle in recognising the health problem and consequently in tackling it.

Jansen et al. (2004) reported a lack of education for doctors or GPs on specific requirements and communication skills for people with learning disabilities in the Netherlands. Even in the UK the proposals for improving the education for GPs received a negative response (Ineichen & Russell 1987; Lennox & Kerr 2007). A large primary care research study compared people with and without learning disabilities accessing primary care screenings in the UK. The results showed people with learning disabilities have fewer recorded screening tests for cervical cancer, breast cancer, prostatic specific antigen and faecal occult bloods compared to the general population (Osborn et al. 2012). This study does not take into

consideration the level of learning disabilities because it was not clear from the GP health records. This does not allow comparison between people with mild and severe learning disabilities. A review of the literature highlights that when a health condition is diagnosed, people with learning disabilities have few health checks afterwards (DRC 2006; McGrath 2010). Indeed, health checks have an important role because they identify unmet health needs, therefore a standardised tool such as the Cardiff Health Check has to be used.

Knowledge of health status and risk factors for people with learning disabilities, together with regular health screening are fundamental for the improved health of this population (Baxter et al. 2006). Baxter et al. (2006) showed 51% of a Welsh sample of people with learning disabilities had one or more health needs identified during a structured health check. The paper also underlines further evidence of the importance of health promotion, such as reduction of cardiovascular diseases after obesity treatment (Rimmer et al. 1994; Wells et al. 1997; Baxter et al. 2006) and prevention of further deterioration if a sensory and mobility problem is tackled early (Evenhuis 1995; Baxter et al. 2006).

Finally, follow-up study results on the Baxter et al. study underlines the importance of repeated health checks for the group of people with learning disabilities (Felce et al. 2008), highlighting the utility of an annual check. A previous study highlighted that standardized health checks for people with learning disabilities are extremely important to detect health risks such as obesity and lack of exercise in a population at higher risk (Martin et al. 1999). Indeed, the main purpose of health checks is to contribute to improve health and quality of life (Martin et al. 2004; McGrath 2010). A large study evaluating health checks for people with learning disabilities showed improvement in measuring blood pressure, recording smoking status and current BMI. The health checks were based on the Cardiff Health Check protocol (Baxter et al. 2006; Felce et al. 2008), which also

included health risk questions related to disability (hearing, visual, behaviour, feeding).

Results from a confidential enquiry run by the University of Bristol and funded by the Department of Health, showed that approximately 1,200 people with learning disabilities die needlessly every year because they do not receive appropriate care from the NHS system. Indeed, 37% of deaths were reported avoidable with better care, prompt diagnosis and treatment (MENCAP 2013).

In conclusion people with learning disabilities are more at risk to experience health inequalities, unequal health opportunities and health care. This is due to health disparities in accessing health promotion activities and the primary care service. These evidences lead to the need of increase health check for this population. Thus, there is a need to increase the awareness of the needs of people with learning disabilities there are needs to increase both in primary and secondary care, but also among wider services, acting in safeguarding roles, such as employment.

1.4 The links between employment and health

Evidence from a review of the health of Britain's working age population has shown that being in work has a positive impact on personal health (Black 2008). People in employment spend 60% of their waking hours at work, therefore the workplace is a good place to promote health and well-being (Black 2008).

However, many jobs may have direct relationships with hazards like handling toxic or chemical products or carrying out risky duties such as lifting loads (Naidoo and Wills 2000). At present approaches are generally more concentrated on the risks linked with being at work and on the health and safety procedures to avoid mishaps in the workplace. The link between employment and health is complex, but it is evident that

employment helps people to pursue better health and well-being in different ways.

Being employed contributes to well-being through increased income above welfare benefit subsistence levels. It allows people to access goods and services and to improve their material quality of life. There is a strong correlation between income and health; higher income allows access to better housing and environmental conditions. Health inequalities within the population are generally associated with socio-economic hardship. Higher income also offers a greater resilience to traumatic financial events, together with lower levels of stress in “making ends meet” contribute to reach better health and well-being. A study using a self-reported health scale helped to understand the difference between having a professional job or a managerial position and being an unskilled worker. Skilled workers reported a better health status than unskilled ones (Black 2008). Several studies have highlighted how health and disease are socially driven with people at the top socio-economic classes living longer and with a better health than people from the bottom of the socio-economic scale (Benzeval et al. 1995; Acheson et al. 1998; Naidoo and Wills 2000). Nevertheless, families and society in general benefit from employment as there is a correlation between a lower parental income and poor health in children. In this sense the principal objectives of the government are the prevention of illnesses and promotion of health and well-being, achievable through designing and maintaining healthy workplaces.

The second goal of healthcare in the workplace is intervention and assistance when an employee develops a health condition, focussed on incentivizing recovery and return to work (Black 2008).

Being employed is central to meeting people’s psychological needs, and building up personal identity as the individual experiences a specific role and enhanced status in society (Jahoda 1982; Nordenmark and Strandh 1999; Dodu 2005; Waddell and Burton 2006). Employment status does

have an impact on mental health; people without a job are more likely to experience depression and psychosis compared to those who are employed (Black 2008). Researchers have suggested that an adequate level of stress leads to a happy state of fulfilment and job satisfaction (Edwards and Cooper 1988; Waddell and Burton 2006).

In certain situations stress may become harmful when the demand is too high for the individual and the locus of control over the situation is too low (van der Doef and Maes 1999; Waddell and Burton 2006). Job insecurity may cause ill health and psychological strains for the individual (Green 2003; Waddell and Burton 2006). Stressful situations and poor mental health may cause increased incidence of physical injury. Indeed the incidence of heart attack among manual workers is higher than in other strata of society (Tones and Tilford 2001).

The first Conference on Health Promotion in the working world held by the WHO in 1986, considered the evolution of new scenarios within society (www.who.int). Forecasts saw society divided into two groups, the employed and the unemployed. The former group had to face stressful working conditions such as shift work, job overload or under load, role conflict or insecurity, promotion blockage and lack of opportunity. Those conditions could cause high and harmful level of stress, so it is necessary to find how to reduce stress levels. The other part of the society had to face the consequences of unemployment (Tones and Tilford 2001).

Long term unemployment can also have a detrimental effect on health, as it can raise the level of personal dissatisfaction and stress that consequently increases the risk of developing a health condition. People unemployed for more than 12 weeks are from four to ten times at higher risk of developing depression and anxiety. Furthermore unemployment is associated with higher suicide rates (Lelliott et al. 2008). Lately, in post-industrial societies the reduction of the working week, the presence of part time options and early retirement are widespread, requiring people to be

extremely flexible in adapting their personal skills such as flexibility, resilience and productivity.

Whilst health and well-being improvements from employment have been identified for the general population, there is no evidence as yet that similar benefits, or in fact other benefits, are experienced by people with learning disabilities. This is primarily because people with learning disabilities have been largely excluded from the labour market in most countries. It is likely that further support may be needed for people with learning disabilities if they are to reap the same health benefits from being employed. Such “reasonable adjustments” are seen as crucial across health care delivery to this population (MENCAP 2004).

1.4.1 Company approaches to health

The recent report “*Health, Work and Well-being*” (2010) reported that employers are becoming more aware that work is linked to health and well-being and that they have a responsibility to encourage employees to be healthier. They are also becoming more aware that having a healthy workforce is good for business (DWP 2010). This awareness has helped many companies to invest in promoting health at work: as a result they have highlighted important savings after the introduction of health orientated initiatives. A number of case studies have reported both employees and companies benefiting after the introduction of these initiatives (DWP 2009). Fitness opportunities, healthy eating options, health assessment, staff training, pre-employment health screening and activities to encourage staff to meet up socially are some examples of activities introduced for health promotion by these companies (DWP 2009). The consequences of those actions are cost savings for companies and fewer mental health issues, greater happiness and well-being for employees. The implications for employees with learning disabilities are

unknown because few of them are employed, and even less are employed in large organisations which are more likely to have set such scheme.

1.4.2 Outcomes of the employment and the health debate

A significant issue in the current negative economic climate is how to promote the health of employees when reductions of cost are more popular than new investments, especially for medium and small businesses.

The Dame Carol Black report played an important role in helping the Department of Work and Pensions to develop new initiatives to promote health at work (Sainsbury et al. 2012). Firstly, new funding was designated to *Health, Work and Well-being Co-ordinators* in Wales, Scotland and 9 English regions. Co-ordinators are people coming from different backgrounds and experiences around health, work and well-being and they have several responsibilities:

- co-ordinate health, work and well-being activities in local areas;
- create partnership and networks
- create a profile for the health and well-being agenda.

Secondly, a *Challenge Fund* was established to finance initiatives in small and medium firms toward developing initiatives in the workplace to promote the health and well-being of their employees. A research study (Sainsbury et al. 2012) revealed the overall positive impact of the *Health, Work and Well-being co-ordinators* and of the *Challenge Fund* on employees. While co-ordinators improved the partnership between employment and health, they showed a lack of experience in dealing with mental health and engaging with employers about health, the Challenge Fund has been used to promote many activities. Some activities were designed to promote the health of a single employee and some used to

promote initiatives for groups of employees. These included measures such as physical exercise and mental health initiatives. The fund was useful to help firms implementing activities, developing ideas, and 60% of the firms which benefited from the challenge funding were expected to carry on activities after the eligible period (Sainsbury et al. 2012).

In the last year public health has been the subject of change in England. Indeed, the responsibility for public health has been relocated from the NHS to Local Authorities, providing new opportunities for linking health and well-being with employment. This has been developed through the creation of Health and Well-being Boards, which have "*the purpose to promote the health and wellbeing of the local community and reduce inequalities for all ages"* (DH 2013, p.4). Figure 1.1 shows how the Health and Wellbeing Boards act in practice. New powers and duties have been introduced for the Boards though the Joint Strategic Needs Assessments (JSNAs), assessing current and future needs that could be met by local authorities and new Clinical Commissioning Groups introduced through mainstream NHS reforms. The assessment of community needs varies across different ages, disadvantaged groups, and vulnerable individuals including people with learning disabilities. Therefore, Clinical Commissioning Groups might highlight the need of connecting health and employment also for people with learning disabilities, and therefore promote initiatives in this respect.

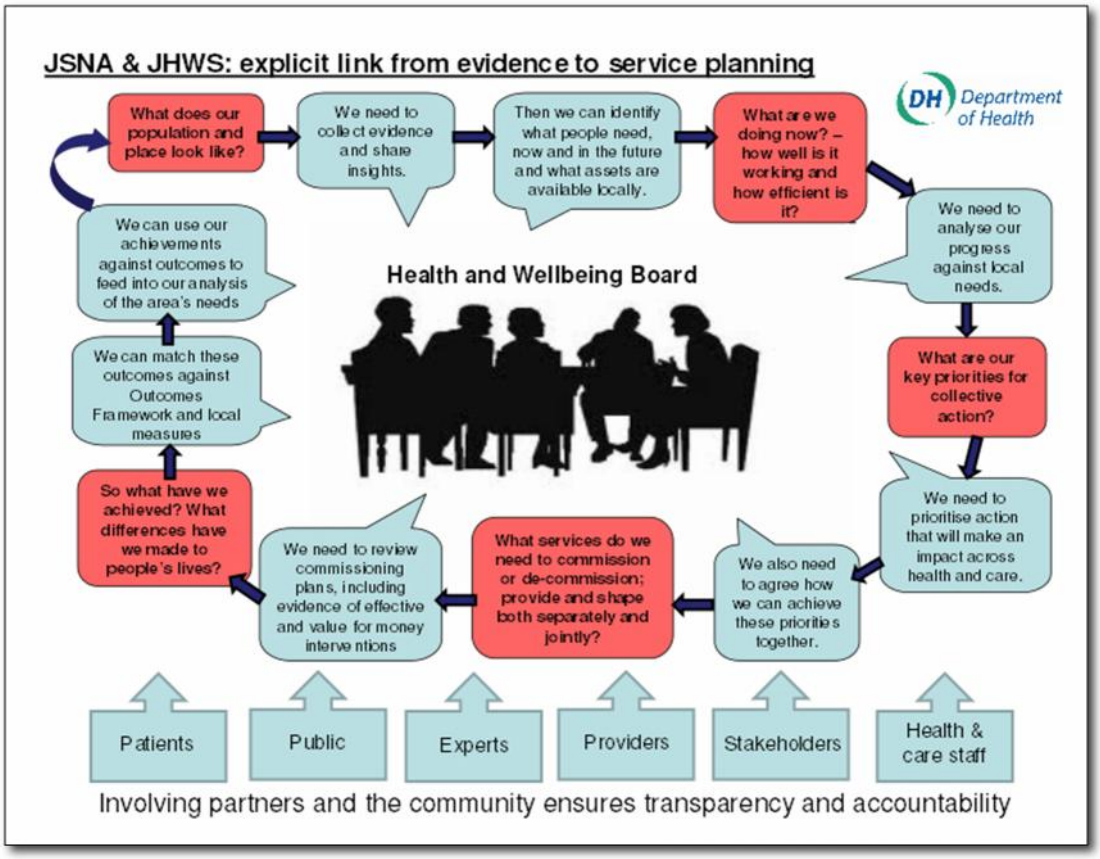

Figure 1.7: Health and Wellbeing Board activity (www.dh.gov.uk)

Local authorities deliver appropriate services and make decisions to suit the community health needs, but they are supported by data, interpretation and evidence coming from Public Health England. The board reviews its' operations to see if they efficiently meet the community needs. Overall, the assessment carried out is to support the vision of the government that communities need to be more active in order to achieve better health and wellbeing.

Local authorities are in a position to understand what is already on offer, improve it, commission it and help the community to learn about it. This is part of the Joint Health and Wellbeing Strategies (JHWSs), intended to be strategies adopted to meet needs identified in JSNAs (DH 2013). In this process members of the community and partners need to be involved in the consultation, as guarantee of transparency and accountability.

Local authorities might be of help for people with learning disabilities promoting and funding health initiatives for people with learning disabilities in employment and in supported employment, but at this stage a deeper knowledge of the employment and health topics is needed.

1.5 An overview of Supported Employment

Key words searched for the Supported employment and employment topics are the following:

- (support* employ* AND int* disab), (support* employ* AND learn* disab*), (support* employ* AND mental retard*), (support* employ* AND learn* diffic*);

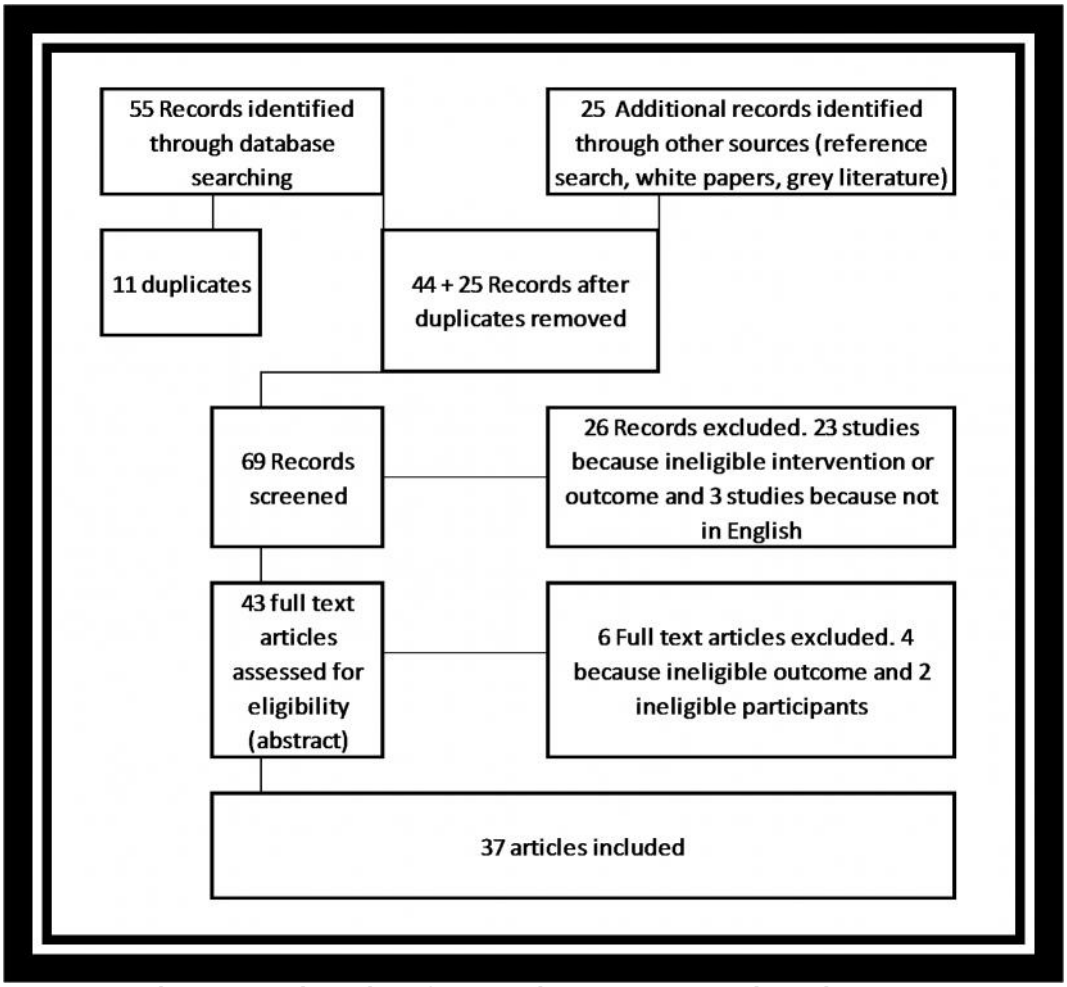

Figure 1.8: Flow chart for searches on supported employment

Searching for supported employment and employment yielded 55 results, 11 of these were duplicates. Hand searching yielded 25 results. Finally the screening process resulted in the inclusion of 37 papers (Figure 1.8).

Supported Employment (SE) “is an evidence-based and personalised approach to support people with significant disabilities into real jobs, where they can fulfil their employment aspirations and achieve social and economic inclusion” (DH 2010a p.2). Supported employment was developed in the United States in the seventies to meet needs of individuals with learning disabilities who may be employable also in ordinary settings.

SE is a successful system for supporting disabled and disadvantaged people in finding and maintaining a job (DH 2009). The success of this system has been measured in several ways including the level of employment and the number of job maintained (Beyer et al. 1996; Beyer and Robinson 2009). The main feature of SE is that it is tailored to the individual, who is conceived to be unique, with specific interests, preferences and life background (EUSE 2009).

People with disabilities in SE, and consequently in employment, can access a wide range of benefits. Supported employees with learning disabilities experience better emotional well-being, objective quality of life, work environment and community involvement than employment enterprise workers and day service attendees (Beyer et al. 2010). In this study there was no significant difference in subjective quality of life, as perceived by the individual. Overall, supported employment appears to be the best service model as supported employees are reported to be happy with their lives, have higher productivity and better emotional well-being when in work. This study also compares supported people with learning disabilities with non-disabled people, finding the firsts to be less productive, having less material well-being. This study is of great interest, but further studies, involving a large number of services may further help understanding benefits coming from the supported employment experience.

An Australian study investigated the impact of employment on the quality of life of people with learning disabilities (Eggleton et al. 1999). Eggleton et al. compared a group of employed people with learning disabilities with a group of unemployed people, finding out the first group experienced better quality of life than the second group. This study's main limit is that participants were from a single supported employment agency, therefore findings are difficult to generalise and further studies involving more agencies are required.

The same results were found also in a more recent study, where people in open employment showed a higher quality of life, than people in sheltered employment (Kober and Eggleton 2005). Jiranek and Kirby (1990) showed that young people with learning disabilities employed in competitive jobs experience higher self-esteem than unemployed people with learning disabilities; they expressed greater job satisfaction, less boredom and they spend more time with people than unemployed people.

A Spanish study highlighted “typicalness” of employment (defined as the application for employees with learning disabilities of similar employment condition of co-workers without a disability) to be associated with a higher quality of life (Verdugo et al. 2006). This study did not highlight a difference in terms of quality of life when comparing people working in competitive and sheltered employment. A difference was highlighted in another study which reported higher self-esteem and job satisfaction in open employment (Griffin et al. 1996; Jahoda et al. 2008).

High quality of life ratings have been found among people employed in microenterprises in the US (Conroy et al 2010). This study included 27 individuals with learning disabilities employed in microenterprises that are small businesses operated by disadvantaged people.

Findings for the quality of life topic are at present inconsistent, and there is not a general agreement on what may be the best employment context for people with learning disabilities. It may be worth to consider different scenarios and experiences, from supported employment in competitive jobs and sheltered employment.

A study highlights that one of the most relevant outcomes from employment are positive feelings of being productive and becoming an active part of the society (Freedman and Fesko 1996). Focus groups were run with individuals with learning disabilities and their relatives to discuss job outcomes, job relationships, support, obstacles and expectations at work. Several themes came out and employees highlighted how disabled

people were able to access goods and services because they were earning a wage. In the focus groups it was found how people with learning disabilities increased their quality of life and were treated fairly and with respect by other members of society because in employment.

These are important outcomes, however the employment experience is a personal experience and many elements need to be analysed in order to understand its impact. The employment experience depends on several factors, for instance the level of welcoming and support found in employment, and this experience may be affected negatively by barriers experienced in employment (Stevens and Martin 1999; Jahoda et al. 2008).

Some authors argue that the most fundamental factor needed for a person with learning disabilities to enter into employment is personal motivation to work. This factor is the most important, determining whether a person will obtain employment (Beyer and Kilsby 1997). The motivation to work of people with learning disabilities has been assessed using a single scale evaluation (Rose et al. 2010) and focus group approach (Andrews and Rose 2010). The focus group revealed people with learning disabilities to be motivated by monetary gains, social aspects and perceived competence. Indeed, Andrews and Rose's study showed how making friends and making family happy because a person was in work increased the motivation of people with learning disabilities. Being bullied by co-worker and being judged in an interview acted as deterrents to employment instead. In addition, the individuals' awareness of personal difficulties, such as not being able to hand paperwork, influenced individual motivation toward office jobs (Andrews and Rose 2010).

Hensel et al. (2007) investigated psychological factors associated with obtaining employment for 60 individuals in supported employment. The study highlights that people with learning disabilities who report being less satisfied with life, are also those who are more motivated to change these adverse circumstances by starting employment (Hensel et al. 2007).

Employment carries important benefits for people with learning disabilities. Cognitive improvements have been highlighted following people with autism in SE. A study involved 44 supported employees with autism, working for more than 20 hours a week and earning competitive wages. Their cognitive abilities, specifically memory and executive functions, were evaluated using the Cambridge Neuropsychological Test Automated Battery (CANTAB) and using a paper and pen cognitive test, the Trail Making Test (TMT). Participant cognitive performance improved following 30 months of employment for people enrolled in the SE programme, showing the SE programme had a positive effect on cognitive abilities of people with autism (Garcia-Villamisar and Hughes 2007). Further studies investigating a wider range of cognitive abilities in a sample including not just people with autism, but also people with learning disabilities would be necessary.

SE can enable the individual with learning disabilities to achieve greater social inclusion through employment. Work is an important life context where social contacts can be nurtured. A study of 400 people with learning disabilities moving from institutionalisation to community care, showed that people with learning disabilities had an aspiration for paid employment and to have more friends (Forrester-Jones et al. 2002). The level of inclusion of people with learning disabilities was the result of the influence of several factors as shown in a small qualitative study by Fillary and Pernice (2006). In the Fillary and Pernice study, 16 New Zealand people with learning disabilities were included. From this study, the presence of a strong workplace culture, that is described as a high level of social inclusion at the workplace and formal and informal support form co-workers, fostered a sense of belonging to a team experienced by people with learning disabilities (Fillary and Pernice 2006).

Another study investigating features of the relationships in a group of people with learning disabilities supported by a SEA, showed an increment in their social network size, with a real opportunity to meet people not

associated with the learning disability surrounding (Forrester-Jones et al. 2004). Comparisons of social interaction across service settings have shown that people with learning disabilities were interacting more at the day centre than in employment. However, those in employment were spending more time interacting with people without a disability and users of the service (Kilsby and Beyer 1996). Lately, work has been recognised to be a social activity, positively influenced by support based on assistance and relationship naturally available in the workplace (Rogan et al. 1993; Jahoda et al. 2008). Indeed, natural support offered by co-workers was important in promoting social integration. Co-workers were trained to promote social integration following different approaches, among those there was a job coach model and a mentor model. In this study co-workers were training employees with severe disabilities and employees without disabilities on how to approach with employees with disabilities. The mentoring model was found to be the one that facilitated reciprocal interaction among co-workers (Lee et al. 1997; Chadsey and Beyer 2001).

Overall certain work settings promote social integration more than others. A natural support workplace culture, that is translated in typical support patterns during job acquisition, work roles etc., was linked with high level of social interaction among people in SE (Mank et al. 1997; Chadsey and Beyer 2001).

Loneliness is a key negative factor for people with learning disabilities in employment. Findings from a study confirmed loneliness to be present but not to be a widespread feeling among workers with learning disabilities (Chadsey-Rusch et al. 1992). However, as long as a few employees experienced this feeling at work, further investigation will be required to find out the reasons (Katz and Katz 2002). A study comparing the experience of people with mild learning disabilities employed in real jobs with those working in sheltered workshop found that the level of loneliness was higher in a community job than in the sheltered workshop, suggesting

the frequency and nature of interactions with no-disabled co-workers are different than interactions experienced with people with disabilities (Gascon 2009) and to be generally work related interactions (Lignugaris-Kraft et al. 1988; Chadsey-Rusch et al. 1989; Storey et al. 1991; Ferguson et al. 1993; Gascon 2009).

A small mixed methods study held in Australia involving 31 people with mild learning disabilities from one SEA showed how job satisfaction was negatively correlated with loneliness, therefore a satisfied worker with learning disabilities felt less lonely (Petrovski and Gleeson 1997). This is a relevant finding, however it is of difficult generalisation because of the small sample and its particular features. Further studies should consider the influence of co-workers on the job satisfaction and loneliness of workers with learning disabilities.

1.5.1 Employment and people with learning disabilities

Having a job represents a normal challenge for an adult entering employment age (Hendry and Kloep 2002). However, obtaining employment is not a normal challenge for people with learning disabilities. They experience more difficulties in getting a job initially and, in general, it represents an important challenge, as only 6.4% of people having learning disabilities are currently employed, compared to 48% of disabled people generally and 78% of those in the general population (DH 2011). The reasons for this are multi-factorial, involving both the cognitive impairments of people with learning disabilities, the poor response from society to their support needs and discrimination.

In the UK, research suggests that the majority of people in employment have mild learning disabilities and therefore low support needs (Beyer et al. 1996). While data is poor on hours people work, in the recent past many people with learning disabilities only work part-time, paying a low

amount of tax and retaining welfare benefits (Beyer et al. 1996; Beyer 2008; Melling et al. 2011).

People with learning disabilities experience more difficulties in learning new information and tasks; they need more support in the learning process, and are heavily dependent on local contexts. In many cases it is difficult for them to generalise learning from one setting to another (DH 2001). Also they can experience “adaptive deficits” affecting communication and creating difficulties in making new relationships (WHO 1992). Learning a new job involves facing new tasks that, for a person with learning disabilities, could be a source of stress and anxiety. They may also experience difficulties in relationships with colleagues, employers and clients, communication being a general weakness for the group. A qualitative study underlined how work can be a source of negative experience for people with learning difficulties, reporting episodes of misunderstanding or exclusion, leading to unpleasant situations (Di Terlizzi 1997). Poor social situations can lead to a decrease in well-being, higher levels of stress and a worsening in health.

The UK government defined guidelines on how to support people with learning disabilities with the document “Valuing employment now: real jobs for people with learning disabilities (VEN)” (DH 2009). The document set out an ambitious goal for every SEA to progress the employment condition of people with learning disabilities. The main idea was that people with learning disabilities need the same fulfilling lives as everybody else. They are entitled to realize the same aspirations, dreams and to enter employment as other people do. This document aimed to ensure that all the organisations involved (school, employment agencies, job centre plus, NHS, local authorities etc.) in providing the right support. VEN underlined the importance of a lifelong change that involves culture in school, where more positive messages must be given to parents of children with learning disabilities. Children with learning disabilities were encouraged to think about which job they were going to do when they become an adult. In

support of this, the transition from school to employment had to be planned to make “getting a job” be seen a real opportunity for people with learning disabilities, through the creation of a personal pathway to work.

SE is a service that should be used from the age of 14, to help increase the presumption of employability among individuals with learning disabilities, their parents and others stakeholders (Melling et al. 2011), this aim being supported also by the Department of Health (DH 2009). Employment has to become a real option for young people who do not intend to carry on their studies at college.

The main goal of UK government is that in adulthood most people with learning disabilities should be employed in full time jobs or self-employed (DH 2009). A popular employment setting for people with learning disabilities is a social enterprise. The most robust version of a social enterprise in business terms is social firm. This is a type of social enterprise and that must employ at least 25% of people with disabilities among their employees (Melling et al. 2011). A recent study compared 40 individuals with learning disabilities employed in broad social enterprises setting with 40 individuals with learning disabilities attending social centres. The results showed social enterprises to be a good training setting for future employment, but not as good in promoting social inclusion as alternatives (Forrester-Jones et al. 2008; Melling et al. 2011). A novel option for people with learning disabilities is self-employment. There have been some good examples in Canada, where social purpose businesses have been successfully operated by people with learning disabilities (Owen et al. 2012). At present, however, self-employment is a rarity among people with learning disabilities in the UK (Melling et al. 2011),

Valuing Employment Now represented a challenge to SEA to improve the quality of their services, especially job coaching, and for commissioners to find stable ways to fund SE. It is therefore important to understand the key stages and key figures in SE.

1.5.2 Key stages of SE

SE has been often called the “place, train and maintain” approach and is intended to be an effective model of vocational rehabilitation (Rusch 1993; Jahoda et al. 2008; Beyer and Robinson 2009; Banks et al. 2010). The SE process is composed of several key stages, which are extremely important for this system to succeed (Wehman and Kregal 1985; Trach and Rusch 1989; O’Bryan and O’Brien 1995; Beyer and Robinson 2009). These are commonly reported to be:

- vocational profiling;
- job finding;
- job analysis and placement;
- job training;
- follow-along services.

SEAs work in parallel with clients with learning disabilities and the employer as presented in Figure 1.9.

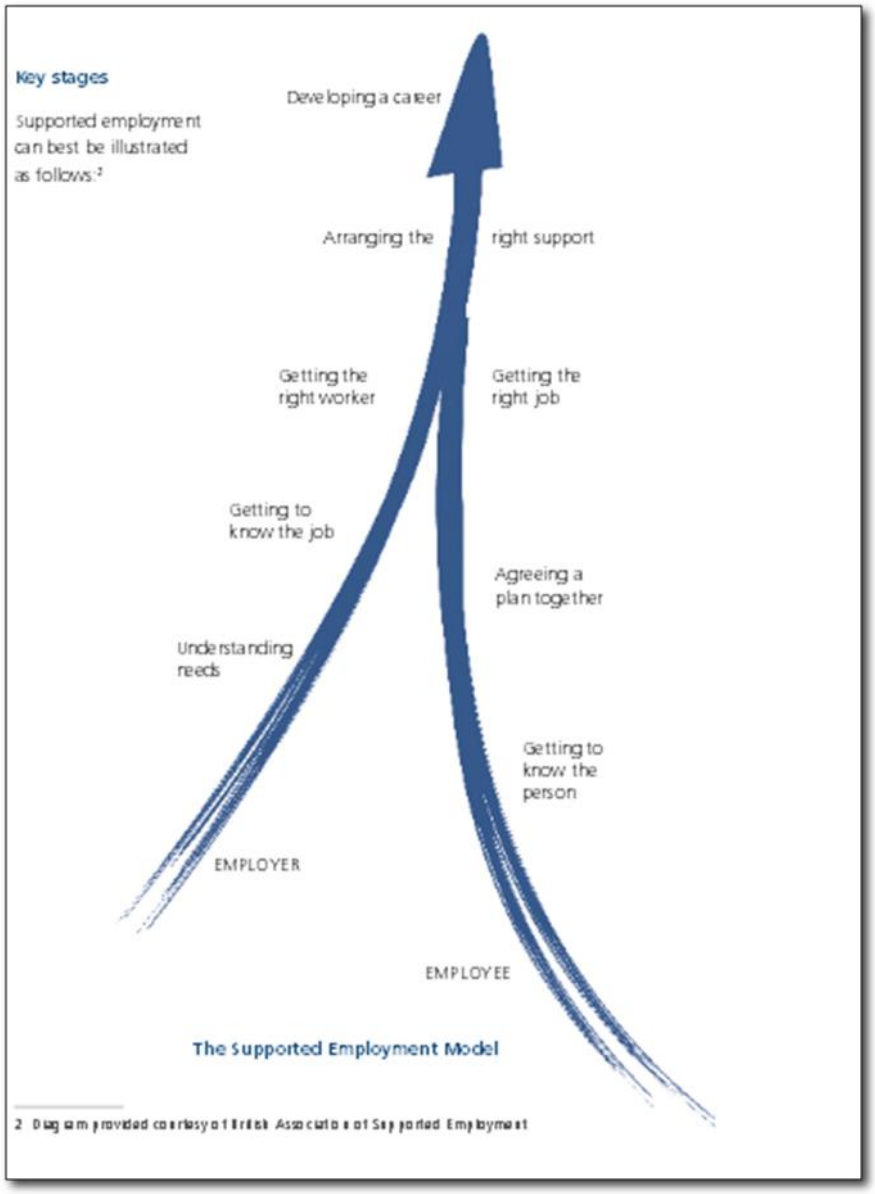

Figure 1.9: The SE model (www.base-uk.org)

The first step is mapping out employment paths for each individual with learning disabilities, starting from a person centred approach. A personal pathway through employment for people with learning disabilities is achievable starting with a good assessment or vocational profile in order to discover individual skills and interests, and matching the right job with the right person. General support in employment is gained from family, carers and community support, to confirm that a certain job aspiration is achievable. The SE system must ensure the client with disabilities is an

active and motivated participant in this process of support, agreeing an employment plan together (DH 2010a).

Meanwhile, SEAs carry out research on the labour market and on job availability to match individual job seeker requirements. Some employers are available to employ people with disabilities, offering an appropriate job and work environment, and therefore they agree to receive the support of SEAs.

SEAs also analyse employers' needs and they draw on a personal profile of the job seeker with a learning disability, in order to match the right person with the right job. The correct matching is followed by the application for the job and eventually by the job interview. SEAs offer a service in supporting the activity of writing a CV, filling out an application form and preparing the interview with the client with learning disabilities. SEAs also help employers to modify these entry procedures where they disadvantage disabled job seekers, providing "reasonable adjustments" under the Disability Discrimination Act (2005).

Employment is followed by training in the matched workplace, including learning job tasks and practicalities, social support, support for health and safety and travel to work (Beyer and Robinson 2009). This is achievable using the services of a job coach who works to teach the job to the employee. Beyer and Kilsby (Beyer and Kilsby 1998) and Beyer et al. (1996) have shown that job coaches spend significant amounts of time vocationally profiling people with learning disabilities and subsequently in supporting and training people in the workplace. When the job coach is task training the client with learning disabilities, the task is often broken down to simple steps and then taught with the aim to promote workers' independence using "Systematic Instruction" techniques (Beyer and Robinson 2009).

SEAs guarantee periodic and ongoing support and also additional support by co-workers and employers is provided through negotiation. Ongoing

support is important to avoid common reasons for job loss (Beyer 1995) which are often related to difficulties establishing social relationships rather than an individuals' ability to do the tasks of the job. Indeed, the current SE system is the result of evolution of this system over the years as detailed in Appendix A.

The central figure in this system is the job coach or job trainer. The job coach is the person in charge of training the employee with a learning disability in the workplace. The strength of job training is that it takes place in the workplace, since every job is different and employers' have specific requirements that are difficult to replicate in training environments. Contextualised learning also allows people with learning disabilities to familiarise themselves with specific social demands of that particular workplace. This overcomes the general difficulty people with learning disabilities face in generalising learning from training to real environments (Beyer and Robinson 2009). Training in the workplace is usually broken into different and easy to understand steps, based on stimulus/response chains, where the end of one task becomes the stimulus for the beginning of the next (Beyer et al. 2010). In this way the person with learning disabilities can learn without being dependent on other people, for instance their employer (Freedman and Fesko 1996). The training may provide suggestions on how to cope with possible social difficulties due to becoming a member of a working group. Through workplace training and ongoing support, people with learning disabilities become progressively more independent in their tasks and have problem solving available to them from their job coach if required.

The job coach will also negotiate reasonable adjustments to allow the employment to be a feasible and a positive experience for the individual with learning disabilities. Such reasonable adjustments are negotiated with the employer. Therefore the job coach's role is ideally situated to address the integration of health and well-being within the overall context of the workplace.

Some studies have highlighted the importance of job coaches teaching social skills during their training in the workplace directed to promote social integration. Chadsey-Rusch et al. defined social skills to be dependent on the context and rule-governed, and therefore difficult to generalize (Chadsey-Rusch et al. 1999; Beyer and Robinson 2009). However, Chadsey and Beyer (2001) identified two different approaches to developing social skills. The first involves changing the social behaviour of the person with learning disability using social skills instruction, role play activities, problem solving strategies, self-management or self-monitoring. The second approach involves co-workers who in addition to training people in the workplace also assist clients with learning disabilities in bonding with other colleagues, with the aim to increase social integration (Chadsey and Beyer 2001; Beyer and Robinson 2009).

Hence, a successful job placement is a combination of a good training to learn the task and minimizing social distance between workers. This is possible thanks to good support from the job coach and thanks to the creation of the right advocacy. Advocacy is a part of job coach activity and could be defined as the support given by an advocate that provides support in terms of information and representation with the aim of empowering the advocate partner. Sometimes the job coach helps a person with learning disabilities to speak in a difficult situation, where the person with learning disabilities voice might not be heard (Townsley et al. 2009). An example could be the support performed by some agencies during the interview with the employer. The advocate provides information and advice about health promotion or social relationship. The help could also involve resolving problems and issues linked with work demands or personal well-being.

Furthermore, the job coach has a role in positively supporting the family of the client with learning disabilities who is engaging in work (Freedman and Fesko 1996). This recognises the central role many families play in the lives of people with learning disabilities.

To my knowledge this is the only study investigating how job coaches may influence employees' health. Results from this qualitative study on the factors associated with high levels of physical activities for people with learning disabilities (Temple 2009), highlighted the importance of job coaches teaching people to be physically active when at work. The same study evaluated travel training as a chance to enable people to be more active, being also a source of low cost physical activity.

1.5.3 Supported Employment's current funding system

SE in the UK is funded from different sources according to the European Union of Supported Employment (EUSE). In England, the main sources of funding have been Local Authorities, the Health Service, the Government's *Work Choice Programme* and in part, the European Social Fund (ESF). Northern Ireland SE is not mainstream funded, and funding comes mainly from Europe through the Department for Employment and Learning or the Department of Health and Social Affairs, supported also by Lottery funds or by utilizing the Government's *Disability Employment Service (DES)*. It delivers an introduction on work through the *Job Introduction Scheme (JIS)*, *Workable NI* and *Access to Work (NI).* Scotland is in a similar situation, having the *Work Choice programme* and a variety of Local Authorities and voluntary sectors sources used for developing SE. In Wales, the situation is again very similar to England. In addition, SEAs use the Government *Work Choice programme* and *Access to Work Programme* for people with learning disabilities (EUSE 2010) as well as Local Authorities funding.

1.6 Aims of this study and research questions

The literature review provides a discussion about the relevant topics for this study. There are several gaps in the knowledge I would like to

investigate in this study, in order to discover what role SEAs have in promoting positive health behaviour for employees with learning disabilities.

The key facts emerging from the literature reviews are the the following:

- People with learning disabilties should be treated with dignity and respect, learding their lives:
- Employment is a source of independence;
- Employment can be a way to live healthier lives;
- There is a risk of unqual health opportunities for people with learning disabilities;
- There is a risk of unequal health care for people with learning disabilites;
- People with learning disabilieties may experience health disparities in accessing health promotion activities;
- There is a lack of consultations of primary care services for people with learing disabilties;
- Primary care staff may not always recognise people with learning disabiltis needs;
- There is a need to increase health check for people with learning disabilites;
- There is a lack of understanding about health checks for people with learning disabilties;
- There is a lack of understanding of benefits for employees with learning disabilites from health initiatives offered by employers;
- Quality of life may increase for people with learning disabilties while in employment;
- Cognivive funcions may increase for people with learning disabilties while in employment;
- Social inclusion with no-disables people improves for people with learning disabilties while in employment;

- Loneliness in employment for people with learning disabiltieis should be furthere investigated.

Furthermore the SE system can potentially deliver positive health through the process of enabling people with learning disabilities entering employment. As discussed previously, work is good for health, but at present little is known about the SE system possible role in health promotion for people with learning disabilities.

AIMS AND OBJECTIVES:

There is a lack of studies investigating the relation between health and employment and supported employment for people with learning diabilites. **My aim is to discover if SE services play a role in maintaining and/or promoting the health of people with learning disabilities. I hope to explain the quality and the nature of the SE provision in relation to health.**

In the literature review I described the features of SE, which may help in finding different ways to protect and improve the health of employees with learning disabilities while at work. Every job presents a sequence of tasks that vary from one context to another. Job coaches are asked to examine tasks and they have the potential to identify features of jobs and tasks that are capable of promoting health. Job coaches are the ones who negotiate the job, and they could potentially be more interventionist in promoting healthy behaviour and well-being or be more conservative while negotiating employment task with employers. There is a gap in the literature related with this topic. **Therefore my aim is to describe strategies used by SEA to support health and/or prevent risky behaviours for employees with learning disabilities.**

I would like to understand if job coaches consider themselves to have a role influencing employees with leaning disabilities' health, considering the

lack of study on this topic. **Therefore my aim is to understand if and how job coaches may influence the health of employees with learning disabilities.**

Job coaches have promotion of inclusion within the workplace as a key goal. They will spend time analysing the social ecology of the workplace and either help the person with the micro-social skills needed to fit in, or to help them connect to workplace mentors who can help them integrate. **My aim is to investigate if and how co-workers may influence the health of employees with learning disabilities.**

Furthermore employers, especially large ones, may have company based health promotion schemes that may touch on these areas, such as quit smoking campaigns, sport offers, or healthy eating campaigns as reported in the literature. **I want to understand if job coaches play any role in helping to adapt employer led health promotion programmes or information gained from them, so that people with learning disabilities can better access them.**

Overall the evidence to date suggests that employment can have an impact on health and access to health promotion for people without a learning disability. People with learning disabilities experience a poor health status and poor access to health promotion. SE represents the most important mechanism for people to get jobs and thus access the potential health gain of employment. If people with learning disabilities are to experience the same level of health gain by being in employment it is important to better understand this system and how it may mediate health behaviour.

RESEARCH QUESTIONS:

Overall the research questions for this study are:

1) **How do managers and job coaches of Supported Employment Agencies (SEAs) perceive their role in supporting the health of their clients with learning disabilities?**

2) **What are the views of people with learning disabilities, on the ability of SE and employment to increase their health and well-being?**

2 Study design

It is well established in the literature that people with learning disabilities experience employment difficulties (DH 2009) and health inequalities (Emerson and Baines 2010; Emerson et al. 2011). Therefore, it is relevant in this study to discover how SE and employment help increasing the health and well-being of individuals with learning disabilities in employment, and what role managers and job coaches play in this respect. Furthermore, the topic has not been explored extensively so far as supported by a recent review of the literature (Fine 2011). Hence, the following research has the objective of providing an analysis of the problem and providing the basis for future studies and/or interventions.

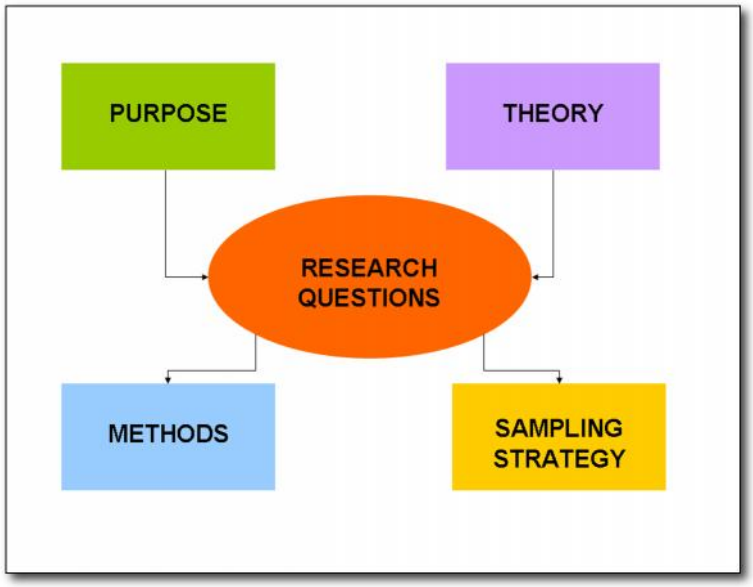

Figure 2.1: Framework for research design, p.82 (Robson 2002)

The research designed was planned step by step using the five components proposed by Robson (2002) (Figure 2.1) and described in relation to this research in the following paragraphs. The mixed method rationale is described in detail and is followed by an in-depth examination of the quantitative and qualitative methods used in the study. Finally, sample selection and arrangements for ethical approval are described.

Overall this chapter describes how the research evolved. Figure 2.2 illustrates how the research design was intended to operate and how it was scheduled across the duration of the PhD course (Figure 2.2).

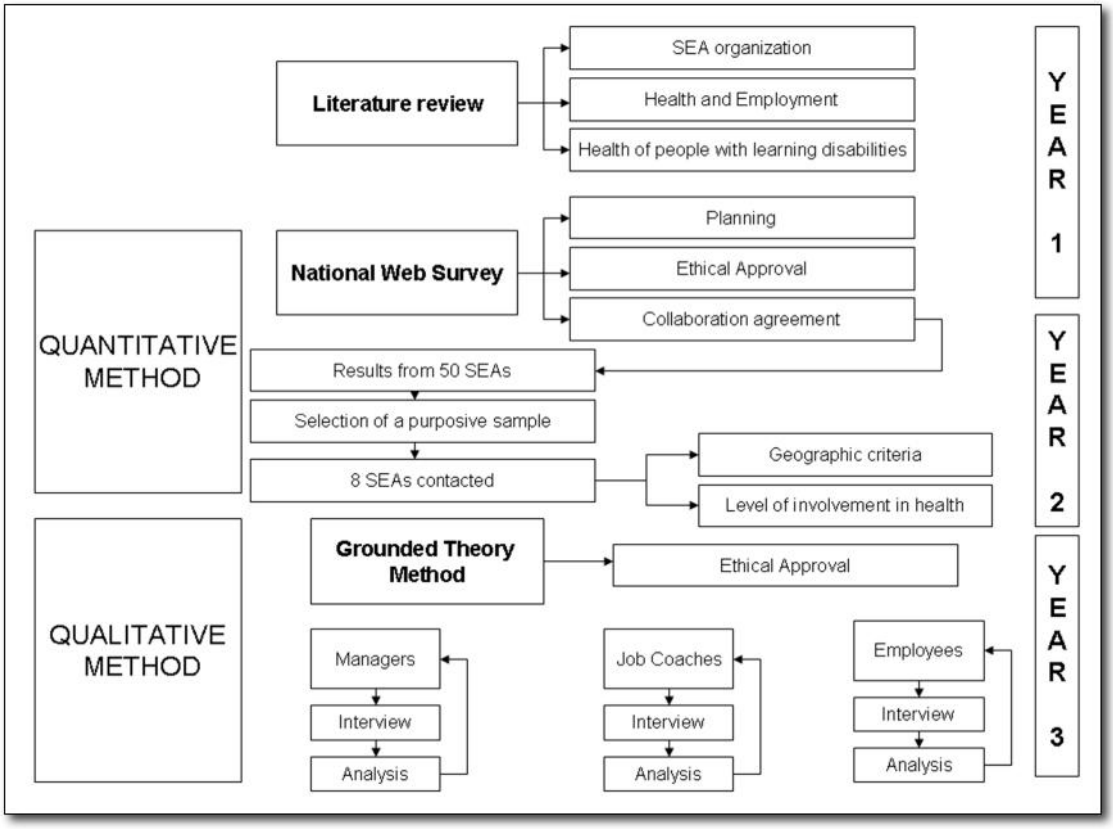

Figure 2.2: Research design

2.1 Methods

2.1.1 Mixed-method study rationale

A mixed method approach was considered to be the most appropriate way of exploring the role of SEAs in supporting the health of their clients with learning disabilities. There are no previous studies focusing on the role of SEAs in supporting the health of people with learning disabilities. Therefore, I developed a questionnaire to understand the SEA's service outcomes in the UK on this topic.

The strategy adopted was non-experimental, my aim being not to modify the situation, but to understand the awareness of the managers of SEAs of the topic. Furthermore, I wanted to understand how the practice of UK SEAs' may influence the health of their clients. The best choice was using a questionnaire survey because it allowed me to gather data from a wide range of SEAs in a manageable period of time within the overall project timetable.

The results obtained from this quantitative part of the study would also enable the sample selection for the second, qualitative, phase of the research. In this second phase, the research sought to understand the processes underpinning health outcomes and the quality of the SEAs' provision in relation to health. For this reason interviews with managers and job coaches allowed them to further describe their experiences and to find out more about their practice and awareness of health in their work. Moreover, interviews with employees with learning disabilities strongly contributed to explaining any ability of SE to increase the health and well-being of their clients.

In deciding on the best method, I took into account the debates scholars have had on the weaknesses of using both quantitative and qualitative methods for the same study. The first objection was that quantitative and qualitative methods carry different epistemological commitments, the first inspired by positivism and the other by phenomenology. Therefore, qualitative and quantitative methods may be considered as two different paradigms, "*in which epistemological assumptions, values, and methods are inextricably intertwined and are incompatible between paradigms"* (Guba 1985; Morgan 1998; Bryman 2012, p.629). The general purpose of quantitative methods is to measure a phenomenon and generalize results from a sample to a population. Alternatively, qualitative methods aim to understand a phenomenon from participants' thoughts, motivations and actions.

After decades of debates around this topic, scholars have highlighted similarities between quantitative and qualitative methods of research. Indeed, they both use empirical observations (Johnson and Onwuegbuzie 2004), constructing explanatory arguments for the study (Sechrest and Sidana 1995; Johnson and Onwuegbuzie 2004) and they both attempt explanation around human beings in their real life environments (Biesta and Burbules, 2003; Johnson and Onwuegbuzie 2004). Nevertheless, a researcher adopting a mixed methods approach must be aware of the epistemological differences, constraints and limitations in the use of that mixed method approach.

It may be considered ambitious for a single researcher to conduct a mixed method study. The researcher must learn, plan and conduct the study to a high standard using both approaches (Johnson and Onwuegbuzie 2004). However, one benefit of using mixed methods is the reduction of *inappropriate certainty,* which is common when researchers use a single method, trying to find the right answer (Robson 2002). Robson (2002) argues that answers coming from the use of two different methods facilitate the construction of more robust knowledge. However, the researcher may focus more on one paradigm rather than the other, providing an unbalanced and unintegrated picture.

Overall, this study benefited from the use of mixed methods because I gathered a more complete picture of the topic. The results from the questionnaire provided me with the knowledge basis to select the sample for the qualitative study and formulate the interview for the participants.

The decision-making process for a mixed method led to draft Figure 2.3, setting out how the research worked within two different paradigms. The figure shows two parallel processes, the first leading to understand the outcomes of SE in relation to health, and the second leading to describe processes involved.

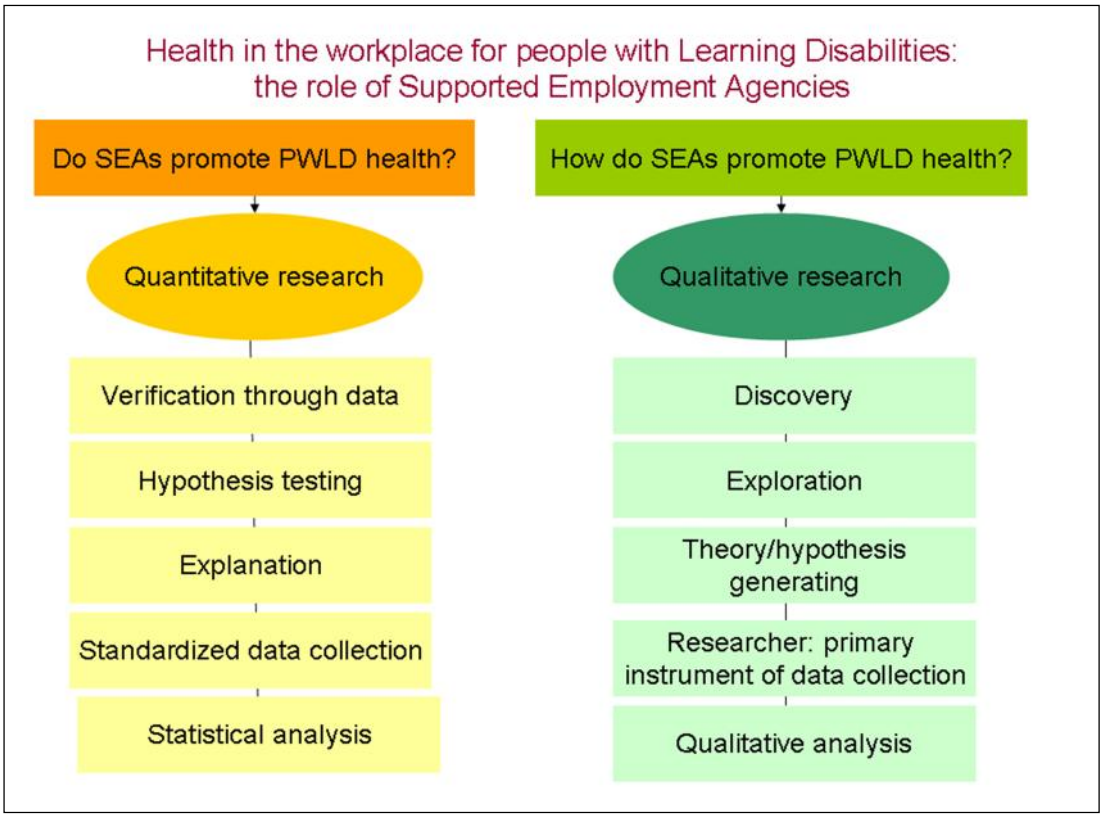

Figure 2.3: Steps into research, inspired by Johnson and Onwuegbuzie (2004)

2.1.2 Quantitative research

The quantitative approach is inspired by the idea within positivism that all social events may be reduced as empirical indicators (Sale et al. 2002). Scottish philosopher David Hume (1711-1776) a well-known empiricist, and later British philosopher John Stuart Mill (1806-1873) established the fundamentals of positivism science (Neuman 2011). Their philosophy inspired scientists, scholars and researchers over the years.

The epistemological position supported the application of methods used to study from natural science to social science (Bryman 2012). The ontological assumptions of this position are that in the social world there are patterns and regularities and researchers need to discover them (Denscombe 2010).

Data collection is standardized and data confirm the hypothesis throughout the use of statistical analysis. The ontological position of this approach assumes there is only one truth about the object of analysis and that it is independent from human perception (Sale et al. 2002).

2.1.2.1 The choice of a Web questionnaire

The idea was to create a questionnaire to be completed by managers or senior staff of SEAs supporting people with learning disabilities, enabling them to provide their self-reported experiences of SE and it relationship to health. The questionnaire was titled *Employment and Health* (Appendix E).

I decided to administer the questionnaire as a web survey. The choice was dictated by the intention to reach as many UK SEAs as possible. A web-survey is fast and inexpensive (Neuman 2011), and appropriate for respondents who are used to operating using the internet. Face to face, telephone and paper based questionnaires were rejected as methods, primarily because we did not have direct access to UK SEAs' addresses and telephone numbers. The web-survey was the only instrument able to reach the majority of the agencies through the email membership networks of the Associations and Unions of SE in the UK. We targeted the organisation for SE around the UK, with the aim of reaching a difficult to reach population through other channels (Wellman 1997; Garton et al. 1999; Wright 2005). Moreover, a study comparing web and postal surveys identified a similar response rate for people who have web access (Kaplowitz et al. 2004). We need to consider that UK Associations and Unions of SE did hold more than one email address for some organisations (Wright 2005), and so several respondents could be from the same agency. The study discounted responses from multiple respondents, using only one.

2.1.2.2 Questionnaire development

The questionnaire structure was inspired by the literature review on SE and the health behaviour of people with learning disabilities carried out for the study. I consulted POMONA questionnaire (Health indicators for people with intellectual disabilities) used in a previous research study in my Institution (POMONA 2008). My previous knowledge of other questionnaires such as Short Form 36 (SF36) – Italian version (Apolone et al. 1997) and Cognitive Behaviour Assessment Forma Hospital (CBA-H), (Zotti et al. 2010) represented an asset in developing the formats of the questionnaire and how health conditions were targeted in these questionnaires.

I had the chance to informally visit two SEAs in Wales, to meet the managers of these agencies and to ask questions about their practice, with the aim of discovering more about their awareness of health and actions relating to health within their SE's. This helped to identify relevant questions alongside the literature review.

As a result of interest in the research from one of the two agencies, I was invited to spend 2 days with them, attending job seekers and basic skills courses with clients having learning disabilities. I had the chance to look at assessment papers and develop a greater understanding the agency procedures in practice and how their work was financed. I attended a meeting with a job coach who visited two employers and a client. Finally, I had the chance to visit two workplaces and see how clients worked in different environments. This experience, in conjunction with the literature review, helped in designing a valid questionnaire.

The questionnaire to SEA managers (Appendix E) covered the following areas:

- **Employment service offered:** Multiple choice questions were asked to identify the sort of employment service the agency

provided. An open question was asked to allow the participant to better describe the agency's work in relation to employment. These questions were relevant to understand what the SEA general approach was. A further question was asked on the agency size with the aim of eventually exploring differences in practice related to health in small, medium and large SEAs.

- **Training provided:** A question was included on the provision of training in the workplace for the client to understand the extent to which this practice was offered by agencies. This was also relevant to understanding if the job coach spent time with the client in the workplace and therefore had an opportunity to influence health outcomes.

- **Assessment process:** SEAs were asked if they carried out assessments of their clients and what the questions were included in these assessments. The categories explored were inspired by the assessment documents consulted during previous visits to SEAs. SEAs were also asked about the characteristics predictive of success in people getting employment to understand what factors were considered to be obstacles.

- **Activities to support the client:** SEAs were asked questions on the activities they provided to generally support the client. This question was asked because a well-supportive environment might be positive for the social inclusion of clients with learning disabilities (McConkey and Collins 2010).

- **Health and safety procedures:** information was requested about the health and safety advice the SEA offered.

- **Awareness of health initiatives promoted by employers:** The link between SEAs and employers was investigated. I wanted to understand if SEAs were aware of any health promotion activities

offered by employers, and if clients with learning disabilities were included in these.

- **On-going support offered by SEA:** SEAs were asked questions to understand if they offered support in the period after initial placement and the characteristics of this support if it was offered.

- **Assessment of health:** Several questions were asked about SEA's assessment of clients' health before entering employment. This was important to understand if health was a central aspect or not for SEAs.

- **Actions toward health:** A section was dedicated to understanding the actions SEAs took when facing health issues or health concerns that individuals with learning disabilities had. These questions were based on the literature review and related to weight problems, smoking, use of alcohol and illegal drugs, even if some of these behaviours have not been widely found among people with learning disabilities.

- **Obstacles promoting health:** Questions were included about obstacles Job Coaches and SEAs commonly faced in promoting clients' health. These questions were inspired by pre-study informal meetings with SEA managers and job coaches.

- **Health gains after employment:** Open-ended questions were included on whether health gains had been seen among SEA's employed clients and what these had been.

- **Practical help:** My pre-study visits to SEAs also inspired a question on what types of practical help were given to clients by job coaches (e.g. in life domains outside employment, such as housing, referrals to health professionals).

- **Staff training:** A question was asked about any training SEA staff had received, and whether it involved in some way the health of clients.

- **Social skills development:** Considering a holistic approach to the person, it was relevant to know what kind of social skills development the SEAs provided.

- **Support for traumatic life events:** The final question was inspired by my personal experience, from a background in health psychology and by the literature review. I asked about any support provided by staff to clients with learning disabilities in coping with a traumatic event that may affect the physical and/or mental health of the client (Hulbert-Williams and Hastings 2008; McEvoy et al. 2010).

- **Interest in taking part in the qualitative study:** SEAs were also asked if they would be interested in taking part in the qualitative follow-up study, if selected for the sample.

Questions included multiple choice, dichotomous (yes or no) and Likert scale format questions. Open-ended questions were also included to gather more information on SEAs, and these were useful in understanding the variety of services that were being provided. Open-ended questions were used to provide a clearer idea of any health gains identified among employed clients and these are reported more fully in Chapter 3.

2.1.2.3 Questionnaire testing

Prior to beginning fieldwork, a pilot test was conducted with managers or key staff of 4 SEAs to test whether the questionnaire was understandable and easy to respond to. Completion time was found to be about 20-25 minutes. The questionnaire was tested on a paper version before the web

version was finalised. Another two people who were not in the supported employment field reviewed the questionnaire and provided feedback on the wording and structure of the questionnaire rom a lay-person's perspective.

The web-survey was addressed to a named member of the agency staff (usually the manager) and completed by them. This was a strength because it is usually the manager who knows best how the SEA is run and what processes are in place. However, different people within the same organisation may have different points of view.

However, the survey was a good instrument to get to know the reality of SEA practice and to start a collaboration with the agencies in the second, more detailed, stage of the research. The survey also aroused interest in the research among respondents.

2.1.2.4 Contacting participants

The team negotiated collaboration with the Associations and Unions of Supported Employment for each UK country:

- British Association of Supported Employment (BASE);
- Scottish Union of Supported Employment (SUSE);
- Association of Supported Employment Agencies in Wales (ASEA)
- Northern Ireland Union of Supported Employment (NIUSE).

All agreed to collaborate in the quantitative element of the study by sending an email invitation to their member SEAs urging their participation in the study and containing a link to the web-survey.

The collaboration with the national Associations and Unions for SE had its positive and negative sides. It was positive because a SEA receiving an

invitation by the Association or the Union the agency is a member of may increase the manager's motivation to take part to the study. On the other hand, it may be negative as the Association or the Union may send a considerable amount of communications, newsletters and other mail which can sometimes be ignored by the staff of SEAs, and this may lead to failure to engage with the invitation to the study. A second reminder email was sent 3 weeks after the original invitation by the Associations and Unions.

Contact details of participants were retained by the researcher to enable future contacts with some of the SEAs that might be selected on their responses as a part of the sample for later stages of the study.

2.1.2.5 Bristol Online Survey

The survey was hosted by Bristol University through the Bristol Online Survey (BOS) system (http://www.survey.bris.ac.uk/). The software, developed by the University of Bristol and licensed to Cardiff University is accessible online. Bristol Online Survey allowed creating, sharing, delivering and analysing surveys. The survey was structured in 6 sections.

The survey included the logo of Cardiff University. The benefit of this tool was that respondents were able to save the survey and come back to it later on. The major weakness of this tool was that it was not allowed to go back to the previous section in order to review the answers. I had to deal with 3 respondents who wrote me asking to amend questions on the database, and this was facilitated.

The software allowed then export of the database using an Excel spread sheet. The data was subsequently transferred to IBM SPSS 16 for further statistical analyses.

2.1.2.6 Data analysis

The data was analysed using SPSS 16 for Windows. The data were checked before the beginning of the analysis to exclude duplicate entries for the same SEA and any missing or inconsistent answers. SEAs were followed up to clarify problem entries and some edits were made to the data as a result.

Descriptive analysis was used to give an overall understanding of the results. The analysis had to deal mainly with ordinal variables, dichotomous variables and several nominal variables. The first round of analysis included the description of the data using frequency. The analysis of **frequencies** offered numbers and percentages of SEAs for each category of the variable. Frequency tables were provided by SPSS outputs and diagrams were plotted in Excel.

In order to determine a relationship between two variables, contingency tables were used. They allow us to simultaneously analyse two variables and produce a non-parametric test, the **chi-square** test, when the variables in question are nominal or ordinal. Chi-square is used together with an indicator of the level of confidence showing the probability of being significant differences between the two variables and it is based on the difference between the actual and the expected values (Bryman 2012). Chi-square is also associated with a level of statistical significance, reporting the chance that any difference is due to chance factors (Neuman 2011).

2.1.2.7 Multiple-indicator measures

Looking at a single indicator may be reductive during data analysis. The answer to a single question may incorrectly classify the view of an individual. A single question is usually very specific and does not give a general description of a wider concept. Instead, considering a multiple-

indicator measure representing a concept is certainly helpful to highlight the outcomes of the study (Bryman 2012).

As I was interested in more general concepts, several items were brought together to create indicators to describe particular aspects of SEAs provision related to client health. A range of scores helped summing answers to different questions. Likert scale items, and the score attached to them, allowed me to bring together groups of responses with the aim of summarizing and producing an index value. The score represents the sum of the scores for each item of the characteristic described below. The internal reliability of the index, that is the measure of coherence within the items constituting the index, is reported in Appendix F.

Health assessment: This includes 9 items concerning the information collected by the agency on the client health and if the SEA asks (using a three point Likert scale: always, sometimes, never) about whether:

a. a client smokes
b. a client's alcohol intake is higher than government policy limits
c. a client's use of drugs
d. a client's usual diet
e. a client's level of physical activity
f. a client's height and weight
g. a client's impairment(s)
h. a client's medical condition
i. a client's psychological condition (depression, phobias, anxiety etc.)

The minimum value of the scale is 9 and it means the agency never asked about all of the listed clients' health aspects and the maximum value is 27 and it means the agency always asked about the listed clients' health aspects.

Diet and weight action: This includes 7 items agency provision if a client is overweight/obese or underweight (three point Likert scale: always, sometimes, never) and SEA:

a. suggests a healthy diet
b. suggests more physical activities
c. provides easy to read leaflets relating to healthy eating
d. builds a plan with the client and employer to make positive changes to diet in the workplace
e. makes a healthy eating plan with the client
f. makes a healthy eating plan with family or carer
g. involves appropriate health professionals in treatment and any plan

The minimum value is 7 meaning the agency was not active in promoting the clients' health and the maximum value was 21 when the agency was active in promoting client health.

Support to stop smoking: This includes 6 items about the agency staff behaviour when the client smokes (3 point Likert scale: always, sometimes, never) and the SEA:

a. gives verbal advice
b. provides easy to read leaflets relating to reducing or quitting smoking
c. builds a plan with the client and employer to make positive changes to reduce smoking in the workplace
d. plans actions with client
e. plans actions with family or carer
f. involves appropriate health professionals in treatment and any plan

The minimum value is 6 when the agency was not active in helping the client with smoking and maximum value is 18, indicating the agency was active in helping the client with the smoke habit.

Support to reduce alcohol use: This includes 6 items about the agency staff behaviour when the client uses alcohol to excess (3 point Likert scale: always, sometimes, never) and the SEA:

a. gives verbal advice
b. provides easy to read leaflets relating to reducing or quitting alcohol
c. builds a plan with the client and employer to make positive changes to alcohol consumption
d. makes a plan with the client to reduce or quit alcohol
e. makes a plan with family or carer to reduce or quit alcohol
f. involves appropriate health professionals in treatment and any plan

The minimum value is 6 if the agency does not intervene if a client abuses alcohol, and maximum value is 18, indicating the agency was active in supporting the client reducing or quitting alcohol consumption.

Verbal advice: This includes 5 items (3 point Likert scale: always, sometimes, never) and the SEA:

a. suggests a healthy diet if the client is overweight/obese or underweight;
b. suggests more physical activity if the client is overweight/obese or underweight;
c. gives verbal advice if the client smokes;
d. gives verbal advice if the client abuses alcohol;
e. gives verbal advice if the client abuses drugs.

The minimum value is 5 meaning the agency never gave verbal advice for any health problems and the maximum value was 15 meaning the agency was active providing verbal advice for problem listed above.

Outsourcing (health information): This includes 4 items related with the agency behaviour in front of a client health problem (3 point Likert scale: always, sometimes, never) and the SEA:

a. involves health professional if a client is overweight/obese or underweight;
b. involves health professional if a client smokes;
c. involves health professional if a client abuses alcohol;
d. involves health professional if a client abuses drugs.

The minimum value is 4 when the agency never contacted health professionals, and maximum value is 12, when the agency always contacted health professionals for the over mentioned problems.

The scores described helped in:

1. Selecting the sample for the qualitative part of this study.
2. Performing secondary analysis based on continuous variables. This included the analysis of variance test (ANOVA) and correlation between two variables.

2.1.2.8 Analysis of variance

The one-way ANOVA is a robust test used to determine if there are significant differences between the means of two or more groups. The assumptions for this test are:

1. The dependent variable must be continuous;
2. The independent variable must be categorical and with independent groups;
3. There must not be a relationship between observations;
4. The dependent variable must be approximately normally distributed. The test is robust, meaning there is a level of tolerance

as the normality assumption can be partially violated without invalidating the test. The distribution can be checked using the Shapiro Wilk test. This test has an associated p-value, therefore we can accept or reject the hypothesis that the distribution is normal.

5. The Levene test needs to be performed in order to check the homogeneity of the variances in several groups.

The ANOVA test produces an F score associated with a p-value which is used to test whether the null hypothesis should be accepted or rejected.

- Null hypothesis: the means of the groups studied are the same, and any differences are due to chance. This is the interpretation when the p value associated to the F value is < 0.05 (level of confidence).

- Alternative hypothesis: the means of the groups studied are different and differences are significant, not due to chance. This is the interpretation when the p value associated to the F value is > 0.05 (level of confidence). Post-hoc t test are performed to understand what groups are statistically different. Some form of correction should be applied to reduce the risk of Type I error (reject null hypothesis when it is true).

2.1.2.9 Kruskall-Wallis test

The Kruskall-Wallis is a non-parametric test that can be used instead of the ANOVA when the distribution is not normal. The Kruskall-Wallis test can be used if the following assumptions are respected:

1. The independent variable must be categorical and groups should be independent;

2. The dependent variable should be continuous;

3. The observations must be independent;

4. The distributions of each group have to be the same shape and therefore similar variances. This assumption has to be checked in order to correctly interpret the Kruskall-Wallis test. If the distribution has different shapes, the test can be only used to compare mean ranks.

2.1.3 Qualitative research

The philosophy inspiring qualitative research is phenomenology, founded by Edmund Husserl (1859-1938) which considers personal experience and the meaning of it as a source of knowledge. Arguably the richness of this approach is that findings are created within the context of study and in which the researcher is actively involved. The data collected and analysed according to qualitative data analysis constitute the base of the discovery of a theory or hypothesis generating.

The application of this philosophy to social science means opening the door to naturalistic research accessible through interactive methods of research such as interviews, focus groups and observations. Therefore, the researcher's aim is to discover the social meanings of social facts which are emerging in the interaction between the researcher and the participants (Bowling 2002). The researcher understands the social world studied through the participants' words. The strength of the qualitative method is that the researcher has the chance to gather quality data in the field. It allows the drawing of a complete picture of the processes leading to any outcomes. Furthermore, the qualitative methods entail the interaction between the researcher and the participant, with the clear advantage of asking further information to understand the experience.

This method has different characteristics (Crosby et al. 2006), which apply to this study and are detailed below:

1) ***Naturalistic:*** data collection takes place in a natural context of life. The surrounding context itself provides important information and plays an important role in research. In this research the workplace or the SEA premises are naturalistic contexts were data are gathered.

2) ***Descriptive data:*** data have different forms, for instance words, pictures, video, and document records. In this study transcribed narrative and a diary constitutes the set of data.

3) ***Process-focused:*** the research focuses on the process, rather than the outcomes (Bogdan and Biklen 1998; Crosby et al. 2006). In this research the process is the one allowing the delivery of health and well-being to employees with learning disabilities, through the SE pathway.

4) ***Inductive Approach:*** the process of qualitative research is inductive as the data collected generate patterns and themes, which can become hypotheses for the sample considered.

5) ***Finding meaning is the objective:*** the aim is finding the meaning of processes linked with the object of study according to the viewpoint of participants. In this research we wish to find out:

    a. The managers' and job coaches' perception of their role in supporting the health of their clients with learning disabilities;

    b. The perception of employees with learning disabilities on the ability of SE and employment to increase their health and well-being.

c. Understand the role of other stakeholders such as employers and co-workers who may influence the health of employees with learning disabilities.

2.1.3.1 Choice of a qualitative methodological approach

I have chosen the most appropriate method to fulfil the research aims and objectives of this study. There are a number of options and the strengths and weaknesses of these in relation to the study's aims and objectives are considered in turn:

1. case study
2. biographical or life history research
3. ethnographic study
4. interpretative phenomenological approach (IPA)
5. grounded theory (GT)

Case study: this approach is usually used when a case or a small group of cases has to be explored in depth and probably followed over time (Bowling 2002). It means the researcher wants to study a phenomenon within its real life context using multiple sources of data. The researcher first describes the strategy, beginning with details on a specific physical setting. Many debates arise from the science of case study, because it refers to a particular case, explaining peculiarities of a particular situation. The object of the study could be analysed in this way focusing on antecedents, contextual factors, perceptions and attitudes preceding a known outcome. The results from this approach are important to highlight causes, determinants, factors, processes and expertise. Another possible option for a case study is for a set of individuals to be studied considering the same features (e.g. personal attitude toward something). However this method is also used when studying a particular community, group, or organisation in order to describe relations among their members,

behavioural patterns etc. Finally, particular events, roles and relationships could be investigated in this way (Robson 2002). A researcher would chose this method if the aim is to find the holistic and meaningful characteristics of real life events (Mason 2002; Yin 2012). The case study approach involves a deep investigation of a phenomenon in a real life context, using multiple source of evidence (Robson 2002; Yin 2012).

This was not a suitable approach for this research as it concentrates on one or a small number of cases and a range of SEAs and client circumstances were needed to answer the research questions fully.

Biographical or life history research: this approach could be considered as a particular kind of case study to investigate a person's story, where interviews are used in conjunction with documents and records (Robson 2002).

The research aim was not to investigate a personal story, but the experience of participants of SE, employment and health. For this reason this approach is not appropriate for this research.

Ethnographic study: this approach provides an interpretation of a culture or a social structure of a particular social group. It is widely used in anthropology, where the researcher has been involved in that particular culture, as a member of the group. Geertz (1973) underlined the importance of understanding the culture from the inside (Geertz 1973). The main instrument is participants' observation, where the researcher observes the context from the inside. No particular methods of collecting data have been elaborated. It is worth considering possible influential factors, first of all the presence of the researcher in the group (Robson 2002).

The aim of this study was not to observe how job coaches support the health of people with learning disabilities at work. Furthermore, in the SE environment this is difficult to carry out. The main reason is that this would

also involve the employer and the work context (kitchens, offices etc.) where other people work and where there are different policies and regulations in place. Hence, health behaviours may not be routinely seen in the research settings, with influences spreading out into health behaviours in other life contexts.

Interpretative Phenomenological Approach (IPA): this approach focuses on the subjective experience of the individual studied and it is based on the philosophy of Heidegger and Husserl. IPA is the application of this thought stream where a particular "phenomenon" is observed, described and studied. Larkin et al. (2006) emphasized in his article two commitments the research must follow to get good data using this approach:

1. the phenomenological requirement to understand and "give voice" to participants;

2. that the interpretation to makes sense from a psychological perspective.

IPA is usually used when the aim of the study is to get an intensive and detailed analysis of the topic of interest for a small number of participants. Instruments that particularly fit this approach are semi-structured interviews, focus groups and diaries, which produced patterns of meanings (Larkin et al. 2006).

IPA concentrates mainly on making sense of a particular experience and/or understanding of a phenomenon (Smith et al. 2009). This method was not appropriate for this research because it does not help the researcher to explain how employment may influence health.

Grounded Theory (GT): This empirical approach focuses on discovering theory from data obtained in social research through qualitative research and analysis (Clarke 2003). It has been developed by the American sociologists Glaser and Strauss (1967) in order to allow researchers to

generate their own theory, based on reality and not on other pre-existing theories when they are hard to come by (Glaser and Strauss 1999). In their book, *The Discovery of Grounded Theory* (Glaser and Strauss 1967), Glaser and Strauss explained systematic strategies to conduct a qualitative research on the experience of death and dying in hospital. The authors defined a very well-structured approach of GT to the context of study, adopting an inductive process to discover a theory from data (Pidgeon and Henwood 2009).

Glaser and Strauss identified 7 components of GT (Glaser and Strauss 1967; Glaser 1978; Strauss 1987; Charmaz 2006):

1. Simultaneous data collection and analysis;
2. Use of data to construct analytic codes and categories;
3. Make comparisons in each stage of the analysis;
4. Develop the theory in each step of data collection and analysis;
5. Write memos to specify properties, describe categories, identify gaps;
6. Sample chosen with the aim of constructing a theory, not generalizable to the population;
7. Conduct the literature review after developing independent analysis.

GT was the object of further, sometimes controversial developments. While Glaser followed his methods for years, Strauss approached GT in a different way, developing concepts instead of theories (Bryman 2012). Strauss and Corbin moved to a method based on verification, more focused on technical procedures and less on a comparative method (Strauss and Corbin 1998). The acquired rigor of GT allowed it to be accepted in the 1990s by quantitative researchers. Several researchers adopted and modified GT for their work, to mix the rigour of the method with the multiple realities and contexts (Charmaz 2006). GT was the most appropriate design for this project as this particular topic had not been explained previously in the literature. Several studies involved the study of

health problems for people with learning disabilities but, at present, little is known about the role of SEAs in promoting health of people with learning disabilities employed in real jobs.

This approach did fit with the aims of this study, because it gives the chance to understand awareness of health outcomes among key players and whether, and in what ways, this is translated into decisions and actions as SE is offered. Furthermore, I was interested in how this was perceived by the recipients of SE and whether the process influenced the clients' views of their health and the impact of employment on it. There was no direct hypothesis being tested and therefore GT offered an ideal method for examining these issues in detail.

2.1.3.2 Grounded Theory procedure

Most of the concepts in GT are discovered from the data and from the relations between data. This theory works using induction and requires the researcher to follow a specific procedure. The main instrument used for GT is the interview, but it does not exclude the use of observation, analysis of documents or the inclusion of quantitative data. Hence, grounded theory is the process of building a new theory from gathered data. It may involve going back to the context of the study several times, and the analysis of data and coding have to follow the collection in order to exhaust or "saturate" categories (Robson 2002).

An important condition for GT is that the researcher has to start with the coding activities immediately after the collection of data. The process of coding begins immediately, in order to approach this method as a dialogue between interview and coding (Robson 2002). Categories emerge, are merged and are re-drawn until no new categories emerge and saturation occurs. Here are a few examples of GT studies and how they have been developed. A GT study inspired by the Glaser and Strauss approach was

conducted on the theme of deciphering chronic pain. The researcher compared two Pain Treatment Centres, structured similarly, but with a different approach to pain, one focusing on treatment and techniques for pain management, the second focusing on providing extensive, integrated care. Patients' consultations with the physician were observed over an 8 months period. Findings highlighted how the operational knowledge and decision-making process influenced the doctor-patient relationship. Indeed, medical theoretical knowledge worked like a frame, influencing the ways in which the two centres decipher the concept of pain. Medical knowledge was made operational in different ways, one centre considering the patient as spectator, the other considering the patient as actor in managing their own pain (Baszanger 1997; Strauss and Corbin 1997).

Another GT study investigated the process of recruitment of employees by employment search companies (Konecki 1997; Strauss and Corbin 1997). Twenty interviews with "head-hunters" were carried out and at least one authentic story of recruitment was reported. The coding paradigm by Strauss was adopted and the analysis led to the discovery of multifactor conditions that are influencing the recruitment story of perspective employees both positively and negatively. The multifactor conditions found in this study contributed to build a theory. Multifactor conditions were work circumstances such as hour and condition of work, organisation conditions of employer, interactional conditions with colleagues, market conditions and cultural conditions.

2.1.3.3 Instrument

Semi-structured interviews were carried out with:

- SEA managers;
- Employees with learning disabilities;

- Job-coaches supporting people with learning disabilities to get, learn and keep jobs.

The initial interview questions were carefully generated in brainstorming sessions within the research supervisory team. Questions had also been inspired by the survey results and from the research questions. We also formulated questions considering the participants' role and hypothetical level of understanding. Questions were kept at quite a general level, with the aim of not giving suggestion to respondents. However, several more focused sub-questions had been created to investigate issues in greater depth.

An introduction was given before starting the interview:

- Interview with managers and job coaches: "*In this interview we want to understand your agency's provision in terms of health promotion for people with learning disabilities. When answering the questions please think of your day practice and provide practical examples when you can. All personal details and names will not appear in any reports. Quotes may be used, but will be anonymised to respondents' role only (e.g. "a manger said" or a "job coach said"). The interview will be digital recorded and transcribed in order to best use the information you will provide. A report will be given at the end of the study as a feedback of our collaboration. I hope you had time to read the information sheet. If you have any questions I am happy to take them*."

- Interview with employees with learning disabilities: *"My name is Elisa and I work for the Welsh Centre for Learning Disabilities at Cardiff University. Your supported employment agency (name) is helping me with my project. We are running a research study on supported employment. We want to know if it helps make workers healthier. We want to understand your point of view on health at*

work. The interview will be tape-recorded and then written down so we can understand what you said. No personal information or names will be used. A report with the results of the whole study will be ready for you as a feedback in one year time. If you have any questions on this study, tell me at anytime. I will answer your questions. You can stop the interview at any time. If you want a break, feel free to take it. Before starting the interview we will go thought the information sheet again, if you want.

Examples of questions for managers:

- "How do you deal with the health of people with learning disabilities in your process of support?"
    - If not answered within the previous question: "What do you ask about health in your assessment/vocational profile?" or "How do you take health into account in your mentoring?"
- In your experience does having a job improve the health and well-being of people with learning disabilities?
    - If not stated in the previous question: "Do you have any example of ill-health after employment?

Examples of questions for job coaches

- Can you use any of your supported employment process stages to promote further health?
    - How?
    - Could you please give an example?
    - If not stated before: Have you ever modified job duties to influence health?

Examples of questions for people with learning disabilities:

Questions look simple, general but straightforward. A list of more specific questions have been planned if the individual was not talkative.

- What is your job?
- How many hours do you work?
- What do you have to do?
- Do you travel far to work?
    - How do you travel?
- What does being healthy means to you?
- Does your job help you to be healthy?
- Who do you work with?
    - Do you have good friends at work?

Full interviews content is reported in Appendix I.

2.1.3.4 Interview setting

In general, the researcher asked participating SEAs for a quiet room for the interview. The setting was laid out before the interview, when possible, preparing the setting as in Figure 2.4.

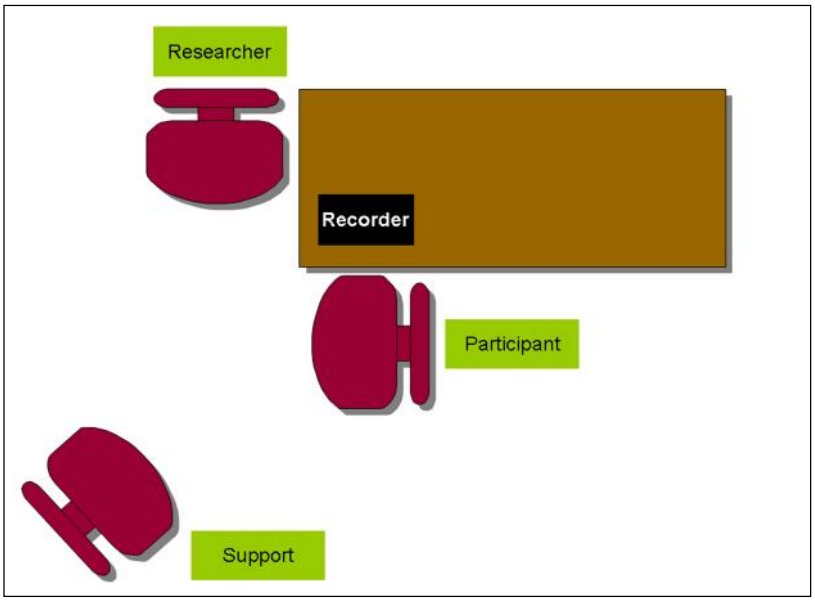

Figure 2.4: Preferred setting for the interviews

This room lay out allowed placing the participant and the researcher at the same hierarchical level. The desk did not represent a barrier, but only a support for the digital recorder. Other individuals (job coach, parent, carer) attending the interview where placed in the background (labelled as “support” in the picture), but not far from the participant, allowing them to act as a supporter or facilitator for the person, but not be in the position to respond on the participant’s behalf.

However, sometimes it was not possible to organise the setting before the interview. The majority of the interviews with managers, and sometimes with job coaches, were held in a setting showed in Figure 2.5.

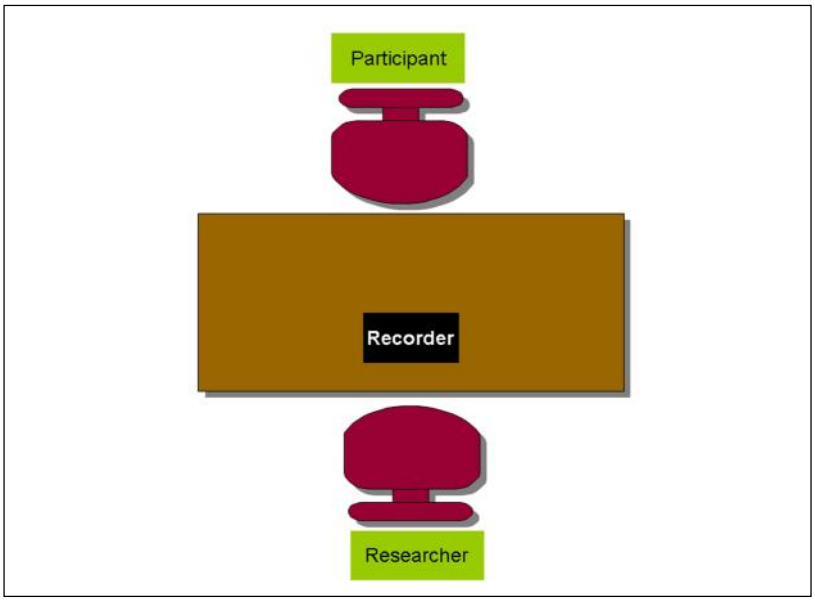

Figure 2.5: Usual setting for interviews with managers

When a meeting room was used, and there was no desk available or it was set on one side of the room, the setting was organised as showed in Figure 2.6. This setting arrangement was the best option for the participant. Any third person present in the room supporting the participant was always in the background.

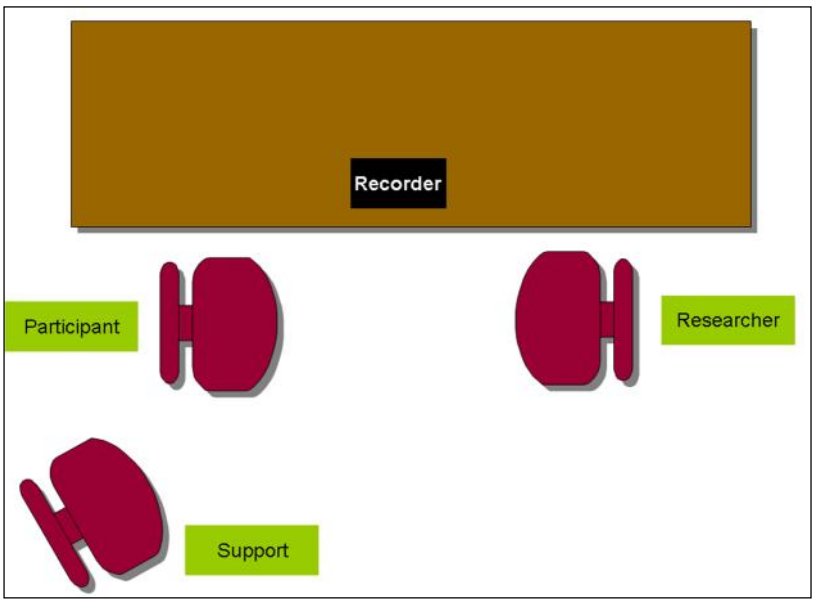

Figure 2.6: Third setting for interviews

2.1.3.5 Diary

I kept a diary to write my comments and my feelings on each interview immediately after it had been completed. The diary included information on my first impression of the agency, how the setting was organised and what the atmosphere was like. I wrote information about how I contacted the agency and any individual person I was meeting.

I then described my own interaction with the participant during the interview; in particular how I introduced the study and made the participant aware of what was the study about. I described the participant's behaviour as well as my own behaviour, in order to reflect on my work and to learn how to improve my interviews skills in this context. I also described how interview ended and what information I left with the participant at the end of the interview.

The diary was a fundamental reflective instrument for the interviews because it helped to give me a sense of the interview experience immediately after the interview. It represented an asset to help remember the interview and to help write memos on the experience during the GT analysis process.

2.1.3.6 Analysis

Interviews were recorded and transcribed following GT procedure, where the analysis of data follows the interview and directs future interviews. Analysis was supported by Atlas.ti, a qualitative analysis software. I had the chance to attend an intensive course on the use of Atlas.ti software (Di Gregorio 2004) in preparation for analysis. Names used in the analysis are not participants real names but pseudonymous.

2.1.3.7 Writing memos

A memo is a written record and a product of the analysis. Memos are not descriptive, but analytical and conceptual (Strauss and Corbin 1998). Memos have several purposes:

- highlight emerging concept;
- highlight a gap in the research process;
- highlight data connections;
- highlight differences between participants on the same topic.

In all cases memos must be titled, dated and refer to a part of data. Memos are fundamental in GT as they represent *a pivotal intermediate step between data collection and writing draft of papers* (Charmaz 2006, p.72).

2.1.3.8 Coding procedures

GT is generated for the study of a context and it involves four different coding modes:

1. **Initial coding:** this is used to create conceptual categories. Data are broken into discrete parts, closely examined and compared. Questions are asked about the peculiarities of the study object (Strauss and Corbin 1998; LaRossa 2005). Gerund[1] is used for this type of coding because it helps to detect processes (Glaser 1978). A peculiarity of GT is that data are grounded in the reality, it is not possible to apply pre-existent categories (Robson 2002). Initial coding may be structured word to word, line to line or incident to incident (Charmaz 2006). I decided to code incident to incident,

[1] Gerund is a form of a verb used as a noun also called the –ing form of a verb. An example: Infinitive form: to go → Gerund form: Going.

because it was the best option for comparing participants' experiences.

2. **Focused coding:** this is the use of the most significant or frequent codes to synthesize data.
3. **Axial coding:** this means that different categories are linked together. The format taken belongs to that particular research and it does not respect other pre-determined formats (Robson 2002). This particular type of coding involves the analysis of causes, contexts, consequences and conditions of the phenomenon under investigation. In conclusion this type of coding is about looking at phenomenon and explaining relationships between codes (LaRossa 2005).
4. **Theoretical coding:** abstract and sophisticated coding are introduced, specifying relationships between categories from the axial coding (Charmaz 2006). Theoretical coding is the most abstract level of coding, and it is based on the network emerging from the axial coding. When a Grounded theorist get to this level of coding, the theoretical framework can be draw and compared with the existing literature.

Data were coded using open coding procedures, where data were broken into discrete parts, closely examined and compared. Axial coding linked different categories together, while selective coding focused on the object of study in order to explain the overall picture.

This study sets out to generate knowledge on people's perceptions of the experience of promoting health delivered by the SE channel. Qualitative methods of research have the potential to answer the research questions.

2.2 Sampling strategies

The sample selected for a research needs to be representative of the population of interest. In this particular study, sampling strategies adopted are different considering different phases of the study.

2.2.1 Phase 1: selecting a sample for the quantitative survey

One aim of the research was to discover if SEAs play a role in maintaining or promoting the health of people with learning disabilities. The survey was directly addressed to managers of supporting employment agencies that have been invited to fill in the survey. The researchers' aim was to reach all the UK agencies and services for SE in the UK and therefore they were reached by seeking the collaboration of Associations and Unions for SE.

2.2.2 Phase 2: selecting agencies of interest for the qualitative interviews

A purposive sample of SEAs was selected, based on the results from the phase one survey. Both agencies actively looking at health issues and agencies apparently not involved in health issues were included. Criteria for agencies selection were based on:

Criteria 1: SEAs answers to the web survey questions

- Awareness of the health impact of employment;
- What health issues are raised at Assessment/Vocational Profile stage of the SEA process;
- Advice and interventions on health in work that the SEA provides;
- Use of partnerships to tackle health issues;

- Reported outcomes for health from the SE process used by the SEA.

Criteria 2: location of SEAs

A geographical criterion was applied and agencies from South Wales and South West England were contacted first with the objective of maximising resources both in terms of time and travel costs and to have the chance to travel back to the SEA if necessary.

The GT method did not impose a number of people to interview in the sample as it depended on information and the saturation of themes (Guest et al. 2006).

Managers of SEAs were contacted by post and by email; contacts details were asked while completing the web survey. A phone call followed the initial contact. If the manager agreed to the collaboration further information about the study was sent to the SEA for every participant. Job coaches were invited to take part in the study by their managers. The same procedure was used, starting with giving the briefing document on the research and seeking consent. Employees with learning disabilities were contacted by managers or job coaches. To be interviewed, the employee had to have the following characteristics:

- Mild learning disabilities and having the ability to take part in interviews.
- Supported by a job coach
- Trained in the workplace
- Employed at least for 1 year

The target group was people with learning disabilities who were in paid employment. The entry criteria for employment was generally that the people concerned required low levels of support and assessments used were such that only the most cognitively able people from this group

became eligible to enter employment. People must be able to understand and retain relatively complex instructions on manufacturing, retail and other work processes, and be able to give feedback on their work to supervisors. While this selectivity was itself a critique of current employment delivery, it did in practice mean that the people with learning disabilities working there were able to understand the notion of a basic interview, what will be done with the results of it, and to give informed consent.

Managers and job coaches selected the sample on my behalf therefore there may be an issue of them “cherry picking” participants. Nevertheless, employment for people with learning disabilities is a selective context itself because, at present, only the most able individuals are in employment, and most of the time people with moderate and severe learning disabilities are left out from employment.

2.3 Ethics issues

The researcher was committed to ensuring that the dignity, rights, safety and wellbeing of participants were the priority. Ethical implications were reviewed at regular stages in consultation with supervisors throughout the project. Ethical approval was gained for the quantitative and qualitative parts of the study from Cardiff University’s School of Medicine Research Ethics Committee without major amendments. The letters containing the approval for this study are presented in Appendix D. The School of Medicine Research Ethics Committee asked for prompt communicating of any negative reactions to the question asked during the interviews.

Information sheets explaining the characteristics of the research were produced for every group of participants in this study. Consent was received though a consent form approved by the School of Medicine REC (Appendix H).

Consent forms were given to participants, together with the information sheet, a number of days before the interview to allow people to decide whether they wanted to take part in the study. In those cases I gave time for the participant to go through the information sheet and to ask questions. I sometimes helped people with learning disabilities in reading the information sheet, as explained in Chapter 4. Contact details for the researcher were written on information sheets and on consent forms to allow people to ask more information on the study at any time.

All participants had the opportunity to refuse to take part in the research, and they knew they were entitled to refuse to answer any particular question. Every effort was made to facilitate the participation of each member of the identified participant group. Potential participants were advised to contact the researcher for assistance. The researcher provided the participants with a guarantee of anonymity and retained confidentiality, by storing information gathered during the interview safely and securely. Research participants were offered a report with a summary of the research findings at the end of the study. The report for people with learning disabilities will be designed to be understandable and accessible and distribute to the clients by the SEA.

3 Survey results

In this chapter the results of the web survey of SEAs are presented. The aims of the survey are, as in the first chapter, to:

1. Discover if SEA played a role in maintaining or promoting people's health;
2. Describe strategies to support health and/or prevent health risk behaviour;
3. Understand if employers have health promotion activities for their clients and what role job coaches may have in this respect.

The chapter starts with a description of Supported Employment Agencies (SEAs) characteristics, what they provide and the SEAs participation in the study by countries. This is followed by a description of health assessments operated by the SEAs to identify any relevant health issues among their clients, and that may be a way to establish if SEAs play a significant role in looking after the health of people with learning disabilities.

Further, this chapter focuses on the advice provided by SEAs in term of, easy to read leaflets and practical help related to health and any help in the face of traumatic events for their clients with learning disabilities'. Furthermore, the activity of linking with health professionals and planning with family or/and employers for a healthier lifestyle for the client, are analysed.

Obstacles perceived by SEAs' staff in dealing with the health of people with learning disabilities supported are also discussed. A wide range of reported health gains regarding people with learning disabilities lifestyles are also described. The knowledge of SEAs of the employers' health promotion initiatives is also described.

3.1 Description of SEA provision

Fifty agencies responded to the web survey. The majority of SEAs taking part in this study were from England. The distribution of the SEAs by countries is described in Table 3.1.

Countries	Frequency of SEAs responding to survey	Percentage
WALES	6	12
ENGLAND	38	76
SCOTLAND	2	4
NORTHERN IRELAND	2	4
Missing	2	4
Total	50	100

Table 3.1: Distribution by countries

The overall percentage response rate was difficult to determine and can only be estimated according to data reported by Associations and Unions directly contacting their SEA members. These numbers are based on the number of members each Organisation or Union have and, therefore on the approximate number of emails sent seeking participation (Table 3.2).

Supported Employment Organisations and Unions for each country		Number and percentage of agency for each country		Estimated number of member per Organisation or Union	
		n	%		
BASE	**England**	38	76%	160	24%
ASEA	**Wales**	6	12%	23	26%
SUSE	**Scotland**	2	4%	34	6%
NIUSE	**Northern Ireland**	2	4%	45	4%
Missing data		2	4%		
TOTAL		50	100%	262	19%

Table 3.2: SEA participation rates

We estimated 26% of SEAs member of ASEA and 24% of SEAs member of BASE took part in the survey. Lower response rates were received from SUSE SEAs' members (6%) and NIUSE SEAs' members (4%). However these percentages are only indicative rather than statistically representative, because definitive data was not available from the Associations and Unions on how many SEAs were contacted by each Associations or Unions. They are likely to be an under-estimate of response rate as the total memberships cited here include single person and non-SEA members who are interested in supported employment but who are not service delivery agencies. Further, some of the SEAs contacted may not support people with learning disabilities, and therefore excluded because they did not meet the sampling criteria of "supporting people with learning disabilities". It is difficult to estimate how many were excluded for this reason.

The SE agencies provided a wide range of employment related services (Table 3.3)

Activity	Frequency of SEAs	Percentage
Support for jobs in ordinary workplace	43	86%
Vocational training in ordinary workplace	24	48%
Jobs in your own enterprise	25	50%
Vocational training in their organisation	26	52%
Other activities	9	18%

Table 3.3: Agency provision

A great majority, (N=43) SEAs supported people who were employed in ordinary workplaces, while 25 SEAs also provided some jobs in their own organisation and 24 SEAs also provided vocational training for their employees in ordinary workplace (Table 3.3).

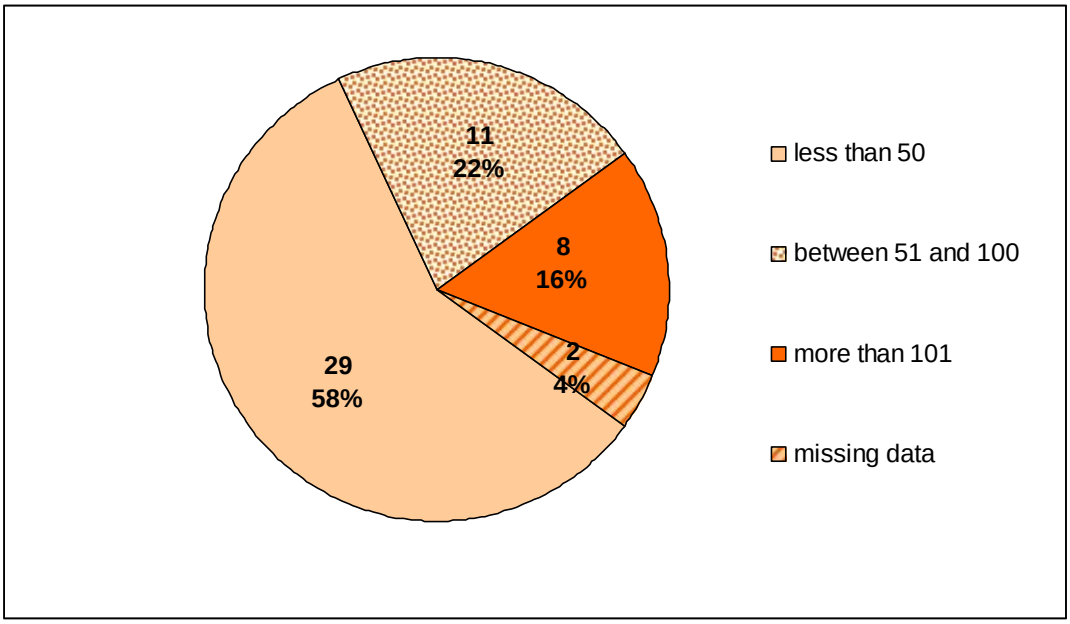

Figure 3.1: Frequency and percentage of people with learning disabilities supported

Over half of the sample (N=29) was composed of small agencies serving less than 50 clients (Figure 3.1). Eleven SEAs were of medium size, serving between 51 and 100 people and 8 were large SEAs serving more than 100 people. The last national survey of supported employment agencies also found size to be skewed towards small numbers of clients served (Beyer, Goodere and Kilsby, 1996) with 79% of SEAs working with 40 clients or less. Data from more recent large surveys in the UK suggest numbers have risen but that there remains a trend towards SEAs being smaller in size (Greig et al., 2014).

3.2 Health assessment

The majority of the SEAs in the survey (91%) carried out some form of assessment of new clients. Of those agencies, 94% reported that they considered health risk behaviours in their assessment.

The survey probed what questions SEAs asked about their client's health and health behaviour. The results showed that it is unusual for agencies to ask about client's lifestyle (e.g. diet, level of physical activity, smoking, alcohol use etc.). Fifty-six percent of the agencies did not routinely ask about clients' smoking behaviour, 52% did not enquire about clients' alcohol use, and 54% did not ask about clients' dietary choices (Figure 3.2). Figure 3.2 shows it is a little more common for agencies to ask about illegal drug use, with 28% asking and 26% sometimes asking questions on this topic. Agency enquiries about clients' impairment (78% of SEAs always asking) and about medical and psychological conditions (80% of SEAs always asking) were generally widespread.

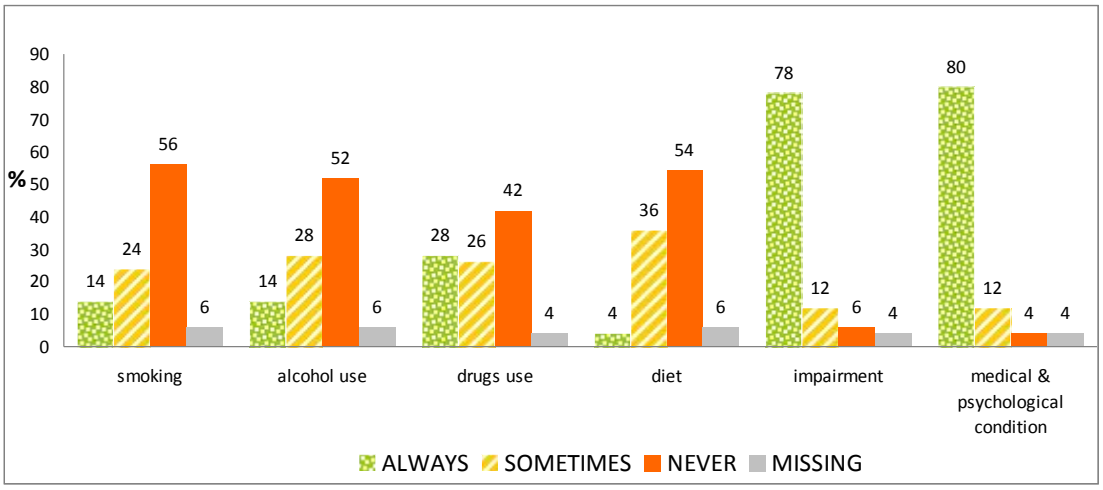

Figure 3.2: Aspects of health SEAs asked clients about

Almost the entire sample considered one or more health risk behaviours which need to be taken into account in their initial assessment (94%). While assessing their clients for employment, 60% of the sample considered aspects of the job that might promote the health of the client.

3.3 Advice on diet and weight

SEAs provided support advising their clients on diet if needed and requested by the client with learning disabilities, considering the whole sample of SEAs taking part in the study. It was more likely for agency staff to give verbal advice on healthy diet (68% always or sometimes do this) or verbal advice on physical activity (66% always or sometimes do) (Figure 3.3), than involving a clients in creating “a healthy eating plan” to address weight issues (Figure 3.4).

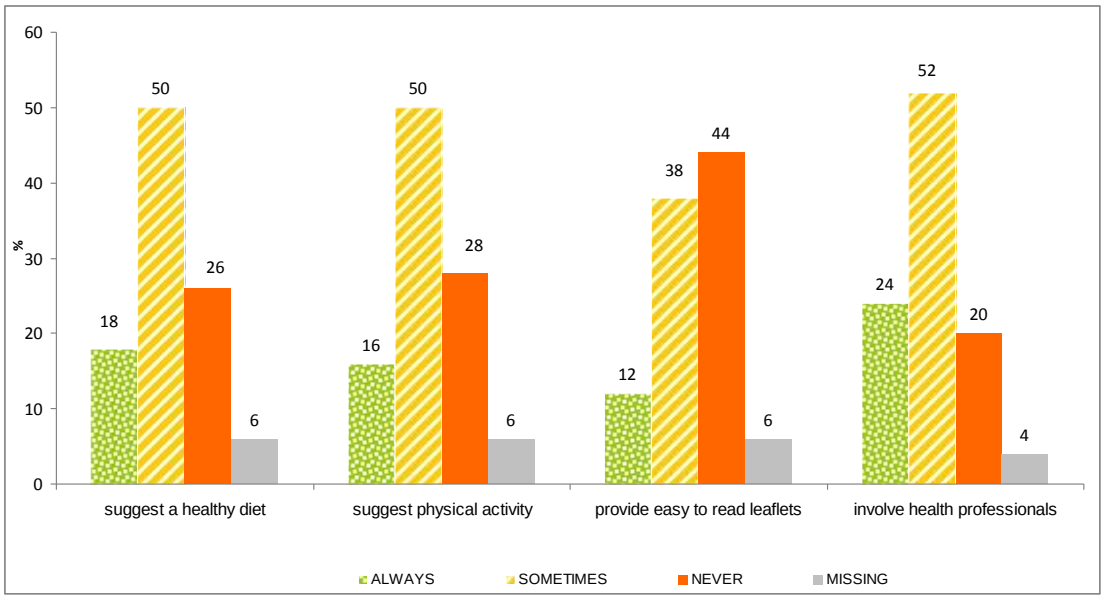

Figure 3.3: Actions to help clients with their diet or weight

SEAs provided easy to read leaflets relating to healthy eating (50% always or sometimes do this) and they contacted health professional if needed (76% always or sometimes do this) (Figure 3.4).

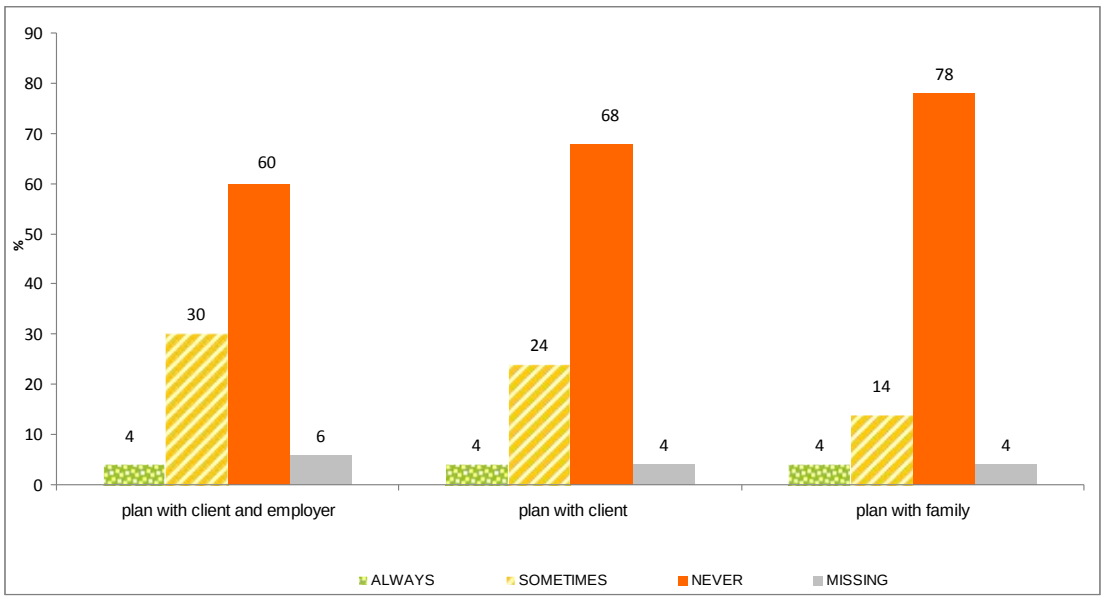

Figure 3.4: Plan with stakeholders to modify diet or weight

Figure 3.4 shows it was quite rare for SEAs to make plans to modify people's health behaviour that included employers (60% of SEAs do not involve employers) or families (78% SEAs do not involve families).

3.4 Advice on smoking

Sixteen percent of SEAs taking part to the survey routinely gave verbal advice or involved health professionals in advising on reduction of smoking, while 36% sometimes did both actions. Sixty percent of SEAs did not produce plans with employees with learning disabilities on issues related to smoking. In addition 68% did not make such plans with family members and 62% with employers (Figure 3.5).

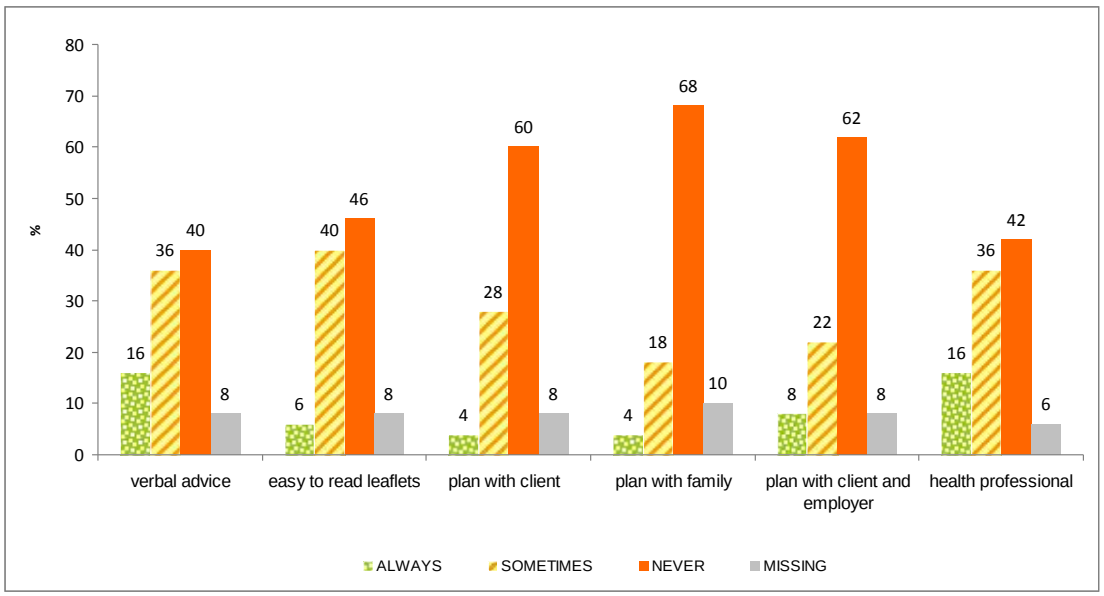

Figure 3.5: Actions taken by SEAs if client smoked

3.5 Advice on alcohol use

SEAs did not routinely make plans with client or family when client's use of alcohol was a source of concern. It was more likely for agency staff to give verbal advice, with 78% of SEAs always or sometimes providing verbal advice or 54% of SEAs always or sometimes providing easy to read leaflets to people on this issue. Intervention from health professionals was less common when people faced alcohol problems, with 58% of SEAs not contacting health professionals in this situation (Figure 3.6).

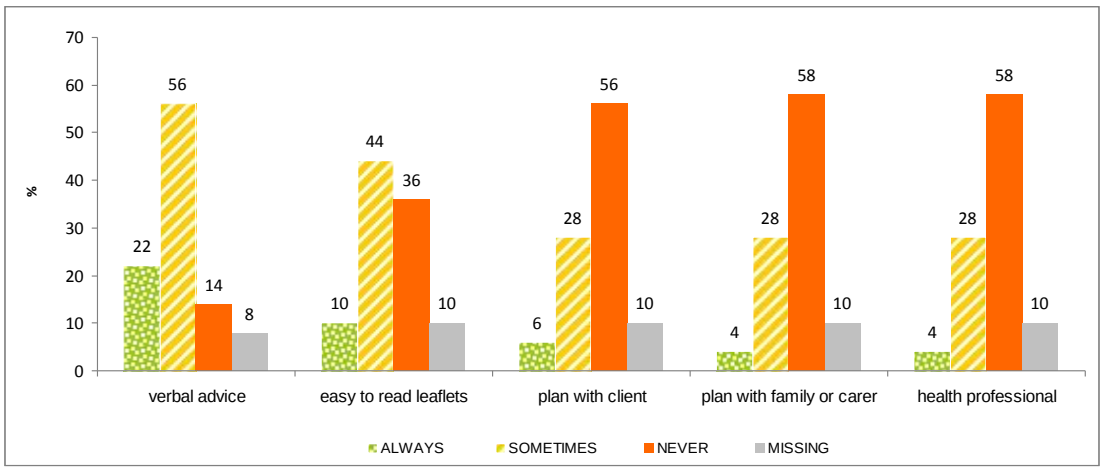

Figure 3.6: Actions taken by SEAs if clients used alcohol

3.6 Advice on drug use

Many SEAs said that they had no experience of this issue before. However they provided answers to the question saying they would not make plans with client or family when there are concerns about drug use.

Figure 3.7: Actions taken by SEAs if clients used drugs

About sixty percent of respondent said they would always or sometimes provide verbal advice to on this issue. About 30% of participant would not use easy to ready leaflets on the topic. The majority of the respondents (76%) would always or sometimes contact health professionals to deal with this issue (Figure 3.7).

3.7 Health promotion activities provided by employers

SEAs were generally unaware of employer led health promotion activities with 70% of SEAs not enquiring about these activities as a part of their employment placement process. One of my aims was to compare different size of SEAs to investigate their awareness on employers led activities for health. When considering the size of SEAs, and therefore comparing small, medium and large size SEAs, there was no significant difference on awareness of employers led activity for health promotion [χ^2 (df = 3, N=44) = 4.006, p = 0.26]. However I have to consider the small sample of SEAs we have available. This may represent a reduced opportunity to influence health as this also implies that SEAs did not work to support the access of clients to any employer led health promotion. However, this should be investigated further to better understand if employers have programmes to influence health, and also if job coaches play any role in helping to adapt these programmes for employees with learning disabilities.

3.8 Obstacles to health promotion

SEAs were asked what factors, in their experience, were obstacles to promoting the health of their clients (Figure 3.8). Factors relating to families and staff were reported more commonly than those relating to clients. Lack of support for healthy behaviour by family was reported as a barrier by 56% of SEAs, while examples of family members themselves

exhibiting poor health behaviour, and therefore acting as poor exemplars, were reported by 50% of SEAs. One of the most important obstacles was reported to be the lack of training for agency staff in relation to health and health promotion (52% of SEAs). Also, more than half of our sample of SEAs felt there was a lack of time for staff to consider health issues in employment as a part of their work.

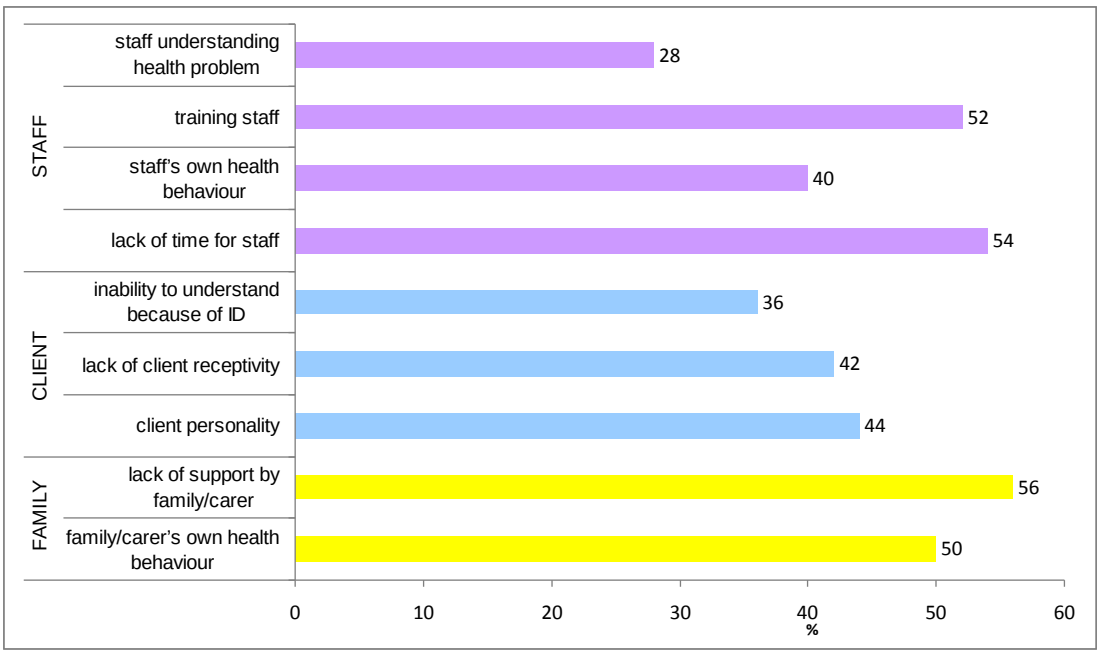

Figure 3.8: SEAs' staff perception of obstacles to health promotion

3.9 Practical help

In addition to providing input to clients and employers through advice and job design, SEAs also had a potential impact on people's health though signposting, and in some cases taking practical steps to help them access health care. Figure 3.8 shows that 80% of the SEAs helped their clients to attend a GP, 54% helped them to attend a dentist, 70% helped clients to get an eyesight test or to get glasses and 66% supported clients to get a hearing test or a hearing aid. In addition, 78% of SEAs helped their clients having regular meals at work and more than half of the sample helped

clients to attend sport or fitness sessions, all with the potential to impact positively on health (Figure 3.9).

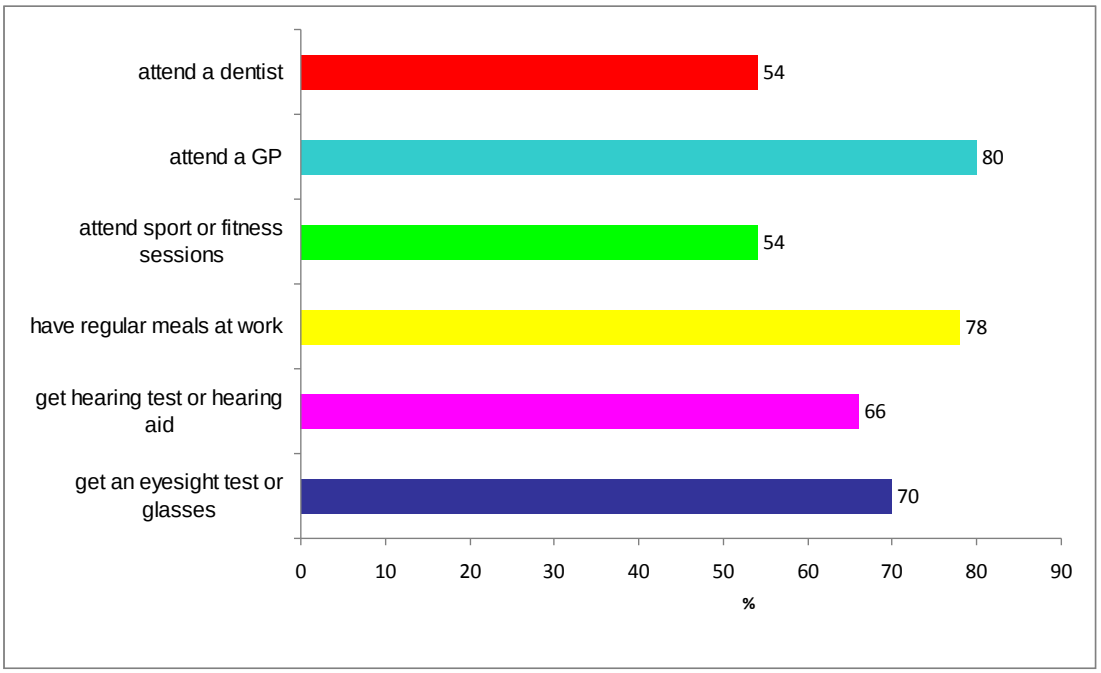

Figure 3.9: Agency staff practical help

3.10 Support for traumatic events by SEAs

Traumatic life events can represent a further threat to good health by increasing stress or having a direct impact on mental health. A majority of SEAs reported that they had helped clients in relation to traumatic events (Table 3.4). Interventions included helping in the case of problems with employers or colleagues, personal illness or injury, bereavement, relationship separation, problems with family, financial problems, or even with sexual problems. A small number of SEAs also provided assistance when clients had problems with the police. One agency supported a client by attending interviews with the police and during a court appearance. Some SEAs reported that they usually contacted agencies specializing in supporting these types of specific need experienced by their clients. Furthermore, SEAs also reported dealing with redundancy, with unexpected mental health breakdowns, depression and anxiety.

Agency helped person with	Frequency of SEAs	Percentage
Bereavement	43	86%
Illness or injury	44	88%
Separation, divorce, relationship break-up	44	88%
Problems with family members/others	43	86%
Problems with the police	23	46%
Problems with employer/work colleagues	48	96%
Financial problems	46	92%
Sexual problems	28	56%

Table 3.4: Support provided by SEAs for client traumatic life events

3.11 Reported health gains

Eighty percent of all SEAs reported some form of health gains for their clients after they had been employed and were in receipt of any help that the SEA provided. There were a number of themes among these reports, which relate to the key areas of activity mentioned by SEAs. The following quotes, recorded in opened questions, illustrate the types of health gains identified as having taken place by the SEAs' staff and these and are organised into primary themes.

3.11.1 Positive changes with weight problems

Work tasks can provide access to physical exercise with wages, co-worker opinion and management sanction providing a ready-made source of

motivation to do more physically. A number of SEA manager quotes reflected these themes:

Physical health improved where previously inactive. Healthy eating when staff canteen available.

More active and healthier eating patterns.

More regular meals; less junk food.

Losing weight, improved mental health.

Improved mental health. Improved diet and nutrition intake. Increased physical exercise.

For some people undertaking work which involves physical activity has improved their overall physical fitness and general co-ordination.

Weight loss due to increased physical activity.

Other benefits would be around physical activity in getting up and going to work.

3.11.2 Positive changes in smoking and alcohol use

Employees can be busier and less bored than when unemployed and may smoke only during breaks and in designated areas. These can be protective factors for smokers. Reduction in alcohol consumption was also observed, quotes from SEA managers including reflecting these changes:

30% fall in number of employees smoking.

Reduction in alcohol consumption. Reduction in smoking.

Requests for support to stop smoking.

Decreased smoking.

3.11.3 Improved lifestyle and well-being

Employment seemed to provide employees with the chance to have a role within society, to develop a sense of personal identity and to increase their own motivation to engage in life more generally. Quotes from SEAs again reflected the full range of impacts and their relevance to general health:

More positive attitude. Customers[1] *have a purpose to get up in the morning and go to work. Less time to sit at home.*

Motivation and with that comes general improvement in health.

An improvement in their sense of worth and therefore a lifting of depressive moods, […] Confidence, increased ability, better mental physical health, overall positive outlook. Improved general well-being. Improve rate of attendance in work. Improve self-confidence.

Giving them the discipline of work results in more self-esteem and social interaction with friends.

Confidence building, integration, self-esteem increase.

Improved behaviours sleep patterns, less episodes of poor mental health, more motivated, improved confidence.

[1] This SEA refers to the people with disabilities they serve as “customers.”

Increased independence and self-confidence leads to greater self-belief and feelings of well-being. Improvements both physically and psychologically.

An improvement in their sense of worth and therefore a lifting of depressive moods.

3.12 Secondary analysis

3.12.1 Analysis of differences for key variables

Analysis of variance has not been an acceptable option in my study because the distributions for the scores being compared were not normally distributed. The Shapiro Wilk test results are reported in the following table for each distribution tested (Table 3.5).

- The null hypothesis: The distribution is normally distributed
- The alternative hypothesis: The distribution is not normally distributed.

VARIABLE TESTED	Shapiro Wilk test value	df	Sig.	Skewness
Weight score	0.929	40	0.015	- 0.897
Smoking score	0.863	40	0.000	- 1.150
Alcohol score	0.935	40	0.024	- 0.496
Drug score	0.916	40	0.006	- 0.733

Table 3.5: Test of normality (1)

The level of significance used for p-values is < 0.05, therefore the null hypothesis is rejected in each case and the variables tested do not follow a normal distribution. All the distributions appear to be moderately negatively skewed.

The variables were then transformed with the aim to normalise their distribution. Because the distributions were all negatively skewed, the values have been reflected in order make them positively skewed. All the values have been subtracted from the maximum value of each distribution. A reflection and a LOG 10 transformation has been performed and the original transformation has then be reflected back afterwards. In SPSS a new variable has been created for each variable in Table 3.5

Compute LOG10 (name of variable) = LG 10 (max value – value)

The Shapiro Wilk tests were performed again for each transformed variable (Table 3.6).

VARIABLE TESTED	Shapiro Wilk test value	df	Sig.	Skewness
Computed Weight score	0.905	40	0.003	- 0.833
Computed Smoking score	0.902	40	0.002	- 0.079
Computed Alcohol score	0.920	40	0.008	- 0.644
Computed Drug score	0.935	40	0.023	- 0.459

Table 3.6: Test of normality (2)

Despite the transformation the Shapiro Wilk tests are < 0.05, therefore we reject the Null hypothesis that the distributions are now normally distributed. Looking at the associated histograms, it is clear that the distributions are closer to a normal distribution, but not enough to respect the assumption of normality. Looking at the skewedness score, three variables are still moderately skewed and only the computed smoking score variable is approximately normal. We can conclude that ANOVA cannot be used to compare this variable in relation to agency size.

3.12.1.1 Kruskall-Wallis test

The Kruskall-Wallis test has been applied instead of the ANOVA test to understand if there is a significant difference between different size SEAs. Testing differences in mean ranks can be used to compare agencies of different size. My data already met 3 of the 4 assumptions for this test (see chapter 2 p.75). The assumption not met is that the distribution of each group must have the same shape and therefore similar variances. To test this assumption I used the non-parametric test equivalent to the Levene test. I ranked my data, obtaining a rank value for all my scores. I then obtain the rank mean for each group and I calculated the absolute difference subtracting the mean rank from each individual rank score. I performed a non-parametric Levene test, using the analysis of variance where the dependent variable is the absolute difference calculated and the independent variable is the group variable I am comparing. Table 3.7 shows the results of the non-parametric Levene tests.

VARIABLE TESTED	Non-parametric Levene test value (F)	Sig.
Computed Weight score	0.340	0.796
Computed Smoking score	0.407	0.749
Computed Alcohol score	0.730	0.540
Computed Drug score	1.169	0.334

Table 3.7: Non-parametric Levene test statistics for equality of variance across test groups

For each variable p > 0.05, therefore we can reject the null hypothesis that the variances are different, meaning they have roughly the same shape of distribution for each group. The key assumption of the test is met, and therefore we can safely perform the Kruskall-Wallis test.

The Kruskall-Wallis test for weight problem variable showed a non-significant Chi square value (0.222, p=0.974) telling us that we can accept the null hypothesis that there is no significant differences between SEAs of difference sizes in the support they offer for weight problem variable.

Weight score variable: Groups compared	N	Mean Rank
Less than 20	14	22.96
21<x>50	13	21.73
51<x>100	10	21.70
More than 101	7	24.14

Table 3.8: Comparison of mean ranks for weight score by SEA size

Table 3.8 reports groups compared for the weight score variable, the number of response for each group and the mean rank.

Smoking score variable: Groups compared	N	Mean Rank
Less than 20	15	21.43
21<x>50	12	18.96
51<x>100	10	24.10
More than 101	6	26.00

Table 3.9: Comparison of mean ranks for smoking score by SEA size

Table 3.9 shows the groups compared for the smoking score variable. The Kruskall-Wallis test showed a non-significant Chi square value (1.673,

p=0.643) showing that we can accept the null hypothesis that there is no significant differences between SEAs of difference sizes in the support they offer for smoking problem variable.

Table 3.10 shows the groups compared for the alcohol score variable. The Kruskall-Wallis test showed a non-significant Chi square value (1.144, p=0.986), showing that we can accept the null hypothesis that there is no significant differences between SEAs of difference sizes in the support they offer for alcohol problem variable.

Alcohol score variable: Groups compared	N	Mean Rank
Less than 20	15	21.83
21<x>50	12	23.08
51<x>100	9	21.56
More than 101	7	21.07

Table 3.10: Comparison of mean ranks for alcohol score by SEA size

Finally, the assumption of equal variance has been checked for the drug score. Table 3.11 shows the groups compared for the drug use score variable.

Drug score variable: Groups compared	N	Mean Rank
Less than 20	15	19.97
21<x>50	12	23.96
51<x>100	9	22.00
More than 101	7	23.00

Table 3.11: Comparison of mean ranks for drug use score by SEA size

Also in this case we can assume the distributions have approximately the same shape and the Kruskall Wallis test can now be performed. The

Kruskall-Wallis test again showed a non-significant Chi square value (0.737, p=0.865) showing that we can accept the null hypothesis that there is no significant differences between SEAs of difference sizes in the support they offer for drug problem variable.

3.13 Implications of bias for the quantitative part of this study

In this study there are several implications of bias to be considered and discussed. Systematic bias could be in relation with the responsiveness rate, geographic representation and size of SEAs.

- **Selection bias:** in the attempt of reaching a consistent number of SEAs around the UK I used the Associations and Unions channel. However, as stated before, the response rate was estimated to be around 19%. Responsiveness of SEAs might be related with missing contribution from SEAs not engaged in health, or invitation sent to organisation not directly operating as SEAs but interested in SE, meaning our response rate may be underestimated. Our picture might be more positive than we would see from a more balanced sample.
- **Countries representativeness**: there may be a bias due to a lack of country representation. This could be due to differences in health and social care policies, which may impact on the role of SEAs. For instance the availability of advice from health professionals may influence how SEAs approach health issues and the way they deliver practical health, because the availability of the service may take up the load. The lack of representativeness hindered the chance to make useful comparison between countries.
- **Size of SEAs:** few of the SEAs taking part to this study are large agencies. Large agencies may have more resources and staff numbers, meaning they could have more chance to consider health in their practice. However, the lack of differences between SEAs of different sizes on the approaches to the key variables such as

smoking, weight etc., might suggest that bias are limited because large agencies do no differ from the others.

Overall the sample cannot be called representative, but a sample providing useful insight into the issues that are being faced by SEAs.

3.14 Conclusion

To conclude, SEAs carried out health assessment that was mainly focused on gathering information on impairment, medical and psychological conditions of the client with learning disabilities. Assessment was less focused on gathering information regarding individual lifestyle, such as smoking, usual diet and alcohol use. During the assessment, almost the totality of SEAs considered health risk behaviour, while only the 60% consider aspect of the job that may promote health for the perspective employees.

SEAs generally provided verbal advice on diet, physical activity, alcohol use and sometimes on smoking. They were rarely or never faced with drugs use/abuse in their activity, therefore this topic would not be directly investigated in the next research phase. SEAs reported that they had the opportunity to access a variety of easy to read leaflets on healthy diet and alcohol use to distribute to their client with learning disabilities. SEAs frequently referred to health professionals to help clients with their diet, weight and smoking. However, SEAs did not generally make plans with the client, employers or families on health related issues.

Nevertheless, being employed was linked by SEAs with positive changes in health. Major obstacles to health promotion were linked to a lack of support by families and carers of the client's health behaviour, together with a lack of time and training for SEA staff to tackle health issues in employment.

SEA provided practical help to access health care services, but most importantly helped their clients to have regular meals at work or to attend sport and fitness sessions. Furthermore, SEAs showed that they provided important support to people with learning disabilities who experienced a traumatic event in life, related with the work context or related with personal life. SEAs were generally unaware of any health promotion activities that employers may offer and therefore this represents a missed opportunity to engage clients in health promotion at work.

When comparing the agency size in relation of their support for weight issues, smoking, alcohol use and drug use, significant differences do not emerge among small, medium and large size agencies.

4 The researcher's experience of qualitative research

This chapter describes my experience with the Grounded Theory (GT) method. In this chapter I describe my approach to this study, how I recruited participants and the difficulties associated with being a foreign student in the field in the UK. This chapter reports how I became confident with the method of GT.

In the next paragraphs, I describe how SEAs were selected and how agencies were approached. I am discussing important points for the research such as the way I presented myself to SEAs and participants, and how I approached and got to work with. I am detailing the sampling strategies, implications for bias and I discuss auditability, validity and transferability for this study.

4.1 Which Supported Employment Agencies did I work with?

Using a mixed method of research, data from the quantitative survey helped when selecting SEAs. The criteria for this purposive sample were provided in Chapter 2, and they were founded mainly on the different levels of involvement of SEAs in health, and the location of the SEA (Table 4.1). Scores from the survey were summed in order to define SEAs that were very involved, moderately involved and not involved at all in the assessment and management of health. A full explanation of the construction of these scores is available at paragraph 2.1.2.7 (p.67) of this dissertation. The corresponding values for each SEA finally selected for inclusion are indicated in Table 4.1:

Health assessment: circled values indicate that SEAs frequently asked information about health; the plain values indicate sometimes that health aspects were assessed; the underlined values mean that SEAs did not assess the health of the client.

Diet and weight action: circled values indicate that SEAs frequently took action if their clients had problems with nutrition or had a weight problem. The plain values

mean that SEAs sometimes took actions; the underlined values mean that SEAs rarely or never offered intervention in this area.

Support to stop smoking: plain values indicate that SEAs sometimes supported the client to stop smoking. Underlined values mean that SEAs rarely or never supported the client to stop or reduce smoking.

Support to reduce alcohol use: plain values indicate that SEAs sometimes intervened in support of a client who wanted to reduce alcohol use; underlined values means that SEAs rarely or never offered intervention on this issue.

GEOGRAPHICAL CRITERIA		SCORES INDICATING INVOLVMENT IN HEALTH						COLLABORATION
SEAs	**AREA**	**HEALTH ASSESSMENT**	**DIET AND WEIGHT ACTION**	**SMOKING SUPPORT**	**SUPPORT REDUCING ALCOHOL USE**	**VERBAL ADVICE**	**OUTSOURCING**	
Agency A	England	**22**	14	12	12	10	8	6 months
Agency B	Wales	20	**17**	13	12	**13**	**12**	2 months
Agency C	England	**9**	14	12	n/a	n/a	n/a	5 months
Agency D	Wales	17	**7**	**6**	**6**	**5**	**4**	Refused
Agency E	England	17	**9**	n/a	**7**	9	**6**	Refused
Agency F	England	21	**11**	10	10	12	**11**	1 month
Agency G	Wales	**9**	**11**	**9**	**8**	10	**4**	1 week
Agency H	England	19	12	10	11	12	8	2 months

Table 4.1: Scores used for selection of SEAs for the qualitative part of the study

Verbal advice: circled values indicate SEAs frequently provided verbal advice around health, while plain values indicate verbal advice was sometimes provided. The underlined values indicate that the SEA did not provide verbal advice on health matters to their clients.

Outsourcing: circled values indicate SEAs contacted health professional where health issues were raised; plain values mean health professionals were sometimes contacted; underlined values mean that the SEA rarely or never contacted health professionals about health issues of clients

4.2 Approaching Supported Employment Agencies

With this sampling strategy I hoped to achieve a heterogeneous sample of SEAs that were very involved, moderately involved or not involved in the health of their clients with learning disabilities. Approaching Supported Employment Agencies

Approaching managers of SEAs was not an easy process. The first SEAs selected was the closest to the area where I worked in order to be able to pay more than one visit to the SEA, if needed. The general strategy was to send an email and a formal letter to the manager of the SEA explaining the purposes of the study (Appendix G). The letter was addressed to the manager and signed by my supervisor. In the letter it explained I was a research student carrying out this study and the researcher in charge of interviewing.

This formal contact was followed by a phone call after a week. The follow up call raised difficulties for me linked with self-presentation. Other PhD candidates highlighted how important it was to provide a good and appropriate presentation of themselves and their research to maximise participation (George 1989; Todd 1996). Many times the manager was reluctant to take part in the study, despite the letter and email. I decided to change strategy because of this. I felt the managers needed to hear about

the research and its purpose from an established person within the field to underline the importance of the work beyond a student study. I therefore asked my supervisor to do the follow up call for the first three SEAs. I thought that with his *savoi faire* and experience, he would have better chance to recruit the SEAs as participants.

After my supervisor made the follow up call, I called the manager back to provide more information about the study and eventually to agree the interview. After my supervisor's phone call, they generally had a positive attitude to the work. This change of strategy was useful in speeding up the process and recruiting as many SEAs as possible. Lastly, I had time to become more confident in presenting myself and my research and, by the end of the project, I was independent in making follow up calls, presenting myself, and my research. I believe that in general the first reaction of the manager was partially a direct consequence of my tangible anxiety and pessimistic attitude towards the possible refusal by the manager to take part in the study. We did not offer any reward for participation and so SEAs taking part in the study were really dedicating their time in organising interviews.

During the process of recruiting new SEAs, I decided to include an agreement slip (Appendix G) with the presentation letter. The purpose was again to speed up the process of recruitment. However, the agreement slip was rarely used by SEAs and the agreement to collaborate in the research was usually reached verbally over the telephone.

4.2.1 Presentation

Presentation is a vital step to positively access the research context. context of research and to guarantee the collaboration of participants (Shaffir 2005). I presented myself to participants as a student from the Welsh Centre for Learning Disabilities at Cardiff University.

I presented the research to managers and job coaches as related to the investigation of the role of Supported Employment (SE), and employment more generally, for the health of people with learning disabilities. I completed the description of myself saying that I was doing a doctorate. I was inspired by a PhD dissertation, an ethnographic study conducted in a special school. The head teacher understood that the ethnographer was a student, working towards a postgraduate qualification and motivated by personal ignorance, and the ignorance of other people, about special schools (Todd 1996). In other words the student defined his status as a researcher who wished to satisfy his thirst, and the thirst of other people, for knowledge about what went on in special schools.

In my study, participants understood that I was a student, working towards a doctorate and interested in health and SE. Indeed, some participants tested me, asking how much I did know about SE or how many people I had interviewed before. I simply told them the truth that I was there to discover their experience and disclose to others how they deal with health.

When presenting myself to people with learning disabilities, I described to participants that I was a student at Cardiff University interested in discovering what impact being in employment had on people's health. I kept the description of my work quite general because I did not want to influence the course of the interview, but I was always open to participant's questions about the study. I dedicated more time to presenting myself. I found this moment to be the most important one because it was able to influence the whole course of the interview.

4.3 Grounded Theory Method

The GT process started with the analysis of the research question that originated the interview questions for participants. After the Ethics Approval, the SEAs were contacted one by one and the collaboration was agreed. The transcription of interviews and analysis followed the

interviews; therefore the process took a year to be completed. The coding procedure and writing memos started immediately after each transcription, and they are detailed in the next sections, together with a description of the emerging themes and theory (Figure 4.1).

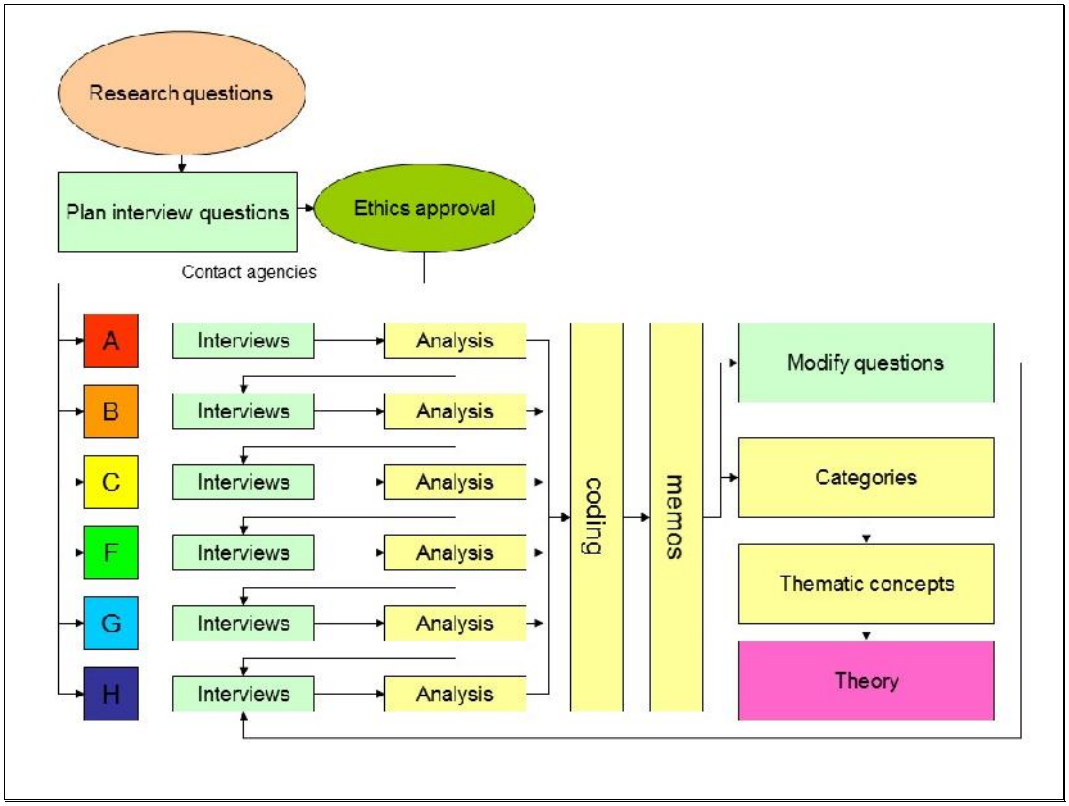

Figure 4.1: The process of Grounded Theory

The source of data in this research originates from the *looking, listening and asking* approach (Lofland and Lofland 1984), where the researcher mediates the world as investigator and analyst of data.

4.4 Sample

Interviews with 36 participants were held over a one year period. Table 4.2 shows how interviews were distributed across the interviewee types. Most of the managers I interviewed had been in that working position for a long period of time. Only one manager was recently appointed to cover the

manager position. Managers were generally busy people, and it took time to agree the interview timetable, as the research was not a priority on their agenda. However, when involved in the interview they all were visibly committed in this research, showing a great effort when replying to my questions.

	Number
Managers	7
Job coaches / employment consultant	9
Employees	20
TOTAL	36

Table 4.2: Participants in the qualitative aspects of the study

It was from job coaches and employment consultants that I learned about many stories of people with learning disabilities in employment. Job coaches were the closest people to employees with learning disabilities and were also the people who started the supported employment process.

The employees with learning disabilities that I interviewed had a range of different employment roles and had different levels of responsibilities. Their employment characteristics were varied, including jobs in open employment, jobs in a sheltered setting and mixed settings. Open employment can be defined as work in an ordinary workplace environment where the person with learning disabilities works surrounded by non-disabled people. A sheltered employment setting can be defined as an environment where the job was created around other people with disabilities. Thus, the person was working primarily with other people with disabilities. A mixed setting was defined as a setting where groups of

people with and without disabilities worked together in an ordinary workplace.

Despite the fact that SEAs set out to place employees in a "real job," participants were actually placed in a variety of work backgrounds that really showed how the reality of how employment can be. Seven people I interviewed were working as volunteers or in work experience, for less than 16 hours a week. Six people worked in a paid position for more than 16 hours per week, while 7 where in paid employment, but working less than 16 hours. Table 4.3 illustrates paid and unpaid situation in different employment settings.

	Working hours	Employment settings			TOTAL
		Open	Sheltered	Mixed	
Paid employment	>16 hours	1	3	2	13
	<16 hours	7	n/a	n/a	
Unpaid positions (work placements and volunteering)	<16 hours	2	1	4	7
TOTAL		10	4	6	

Table 4.3: Paid and unpaid positions and employment settings

4.4.1 Interviewing the employees with a learning disability: difficulties and new learning

Interviewing people with learning disabilities can be a real challenge for a researcher for many reasons. People with learning disabilities may have communication difficulties and may have difficulties understanding questions. They may answer questions thinking to what the interviewer wants to hear. People with learning disabilities may experience difficulties

in answering conceptual questions, rather than questions about their concrete life experience. They may experience difficulties speaking about the past, remembering times and dates (Nind 2008). While interviewing employees having learning disabilities, I encountered a variety of people with a range of communication abilities. It is therefore difficult to generalise on their difficulties. Indeed, every individual with learning disabilities is different and, there is no single formula for interviewing people with learning disabilities because they are a heterogeneous group (Goodley 1998; Nind 2008). For this reason this section is about the challenges I faced interviewing people with learning disabilities during the course of the research and how I coped with them.

The recruitment process was the most difficult for me because the SEA acted as the mediator between the employee and the researcher. It was generally agreed that the job coach, or someone within the SEA knowing the employee, presented the research information sheet to the employee before the interview. This was to help the employee to be more aware of the interview process and to avoid the employee being pressured indirectly to be interviewed. However, in two cases I had to read the information sheet with the participant before the interview. This was unexpected, but helped me to understand whether the document was comprehensible. Having informed choice before taking part in an interview was an important aspect of the ethics of the research. Flexibility was a key aspect of my research. At various times during data collection I had to reflect, re-think and take a different approach to my interviews to improve the quality of the data from people with learning disabilities.

4.4.1.1 Familiarisation with participants

Researchers have suggested the importance of dedicating a certain amount of time to familiarise themselves with, and to, participants, in order to build up a relationship, create trust and relieve anxiety (Simons et al.

1989; Forrester-Jones and Grant 1997; Forrester-Jones et al. 2004). I tried to recreate a conversational space before the interview, where we entered the room, we sometimes had a cup of tea together, and we got to know each other. The interview venue was the employee's choice, but generally took place within the SEA premises or at the employee's workplace. This was important to have a place that the participant felt comfortable in. I tried to create a "barrier free" interview setting as described in paragraph 2.1.3.4. (p.83). Creating a conversational space before the interview helped most of the participants to become familiar with me and the interview setting. I soon realised that the digital recorder was perceived as an obstacle by some participants. Therefore I specified that the recording of the interview was a practice that was useful for me, to help me to make best use of the information. I told participants that I was happy to switch the recorder off and take notes if the recorder bothered them.

4.4.1.2 Setting the scene for the interview

The best interviews I held were those run in the SEA's own premises. That is because I always had the chance to set up the scene for the interview. There was a room for the interviews for that day, with no interruptions, no telephone ringing and no strict time boundaries. Entering the room there was a feeling that the interview has been prepared (Burgess 2005). Instead, a room in the workplace is always a room in the workplace. The room was not prepared, I walked in with the participant and we had both to settle in to the new environment. There was not the dimension of welcoming that I was able to give when I had control of a room for the interview. Furthermore, people did on a few occasions walk in and interrupt the interview, and telephones did ring in the background for few interviews. The setting was absolutely important to create a good conversation.

Sociologists have written about the importance of physical context and spatial relationship in the educational context (Stebbins 1976; Webb and Webb 2005). Comparisons between studies have shown differences in the use of language in similar interviews held in different contexts. In one study interviews were held in the deputy head teacher's room (Scharff 1976; Shipman 1981; Burgess 2005) and in another study interview were conducted in a variety of rooms not linked with school staff (Willis 1977; Shipman 1981; Burgess 2005). In the study run in rooms not attributable to school staff, a variety of four-letter words were used by participants during the interview. Conversely, in the study conducted in the deputy head teacher's room, participant used good language, showing the context of the interview to have a certain influence on the interview itself.

My study confirms the importance of setting up the right context for the interview as it contributes to the success of the interview itself. However, in real world research, the researcher is at the mercy of others if they are to get the interview.

4.4.1.3 Third person supporting the participant

Interviews do not just take place in a physical context, but are also surrounded by a social context (Burgess 2005). I left the participant to choose if she/he wanted a third person as a support for the interview. Indeed half of participants with learning disabilities chose to have a person with them. I experienced interviews with job coaches, a carer and a parent in the room.

I always tried to place the supporter in the background of the participant's visual field. This was to reduce the focus on these other characters in the interview, and to keep the focus on the participant and myself. The presence of a third person certainly played a role. Sometimes their presence acted as a facilitator, as for example when the person omitted something I was not aware of, and this helped to complete the picture. In

some cases participants' speech was not so clear in the first instance, and a third person who already knew the participant well helped in gathering information from the participant or in helping to understand the point they were trying to make. In this case the third person may be an asset as underlined by Whitehurst, who reported the third person to be a mediator when there are communication issues or difficulties while interpreting answers (Whitehurst 2006; Nind 2008).

However, in some cases, the third person jumped into the conversation trying to explain the background of a statement the participant had just made. On one occasion the third person presence acted as an obstacle because the third person was attempting to answer on the individuals' behalf. In another interview, the influence of the third person was too strong, resulting in the failure of the interview. In this case the third person just replied on the person's behalf and could not be dissuaded from doing this. Here, I had to be flexible, and I was able to find time with the person alone after the interview, when spending time at their invitation visiting their workplace to see their job. I used this time to ask questions and I took field notes of the interview.

4.4.1.4 Guided Conversation

The structure of my interview was extremely flexible. I went to the interview with a sheet containing key questions and points in order to have a visual aid. However, when I became more confident this sheet became redundant.

I liked the expression used by Lofland and Lofland (1984) that the accurate name of the interview is "guided conversation". Indeed, this is what it was in my case. I gave a stimulus, the question, and the participant spoke freely about the experience. The challenge was to be flexible, start from one point and let the participant lead through his/her experience and beliefs. I found people to be really chatty and for them the "jigsaw puzzle"

of their experience built itself. With reserved people I usually followed the questions in order and used many sub-questions that I had planned in advance (Appendix I).

4.4.1.5 Silence

Interviews are composed by questions and answers, intercalate by moments of silence. Silence is as important as the conversation because it plays the same role as it does in music: without the correct pause melodies could not exist. The challenge for the researcher is to commit in listening to the narrative and interpreting the communication as well as the silence (Goodley 1998; Nind 2008).

During the interview silence has different meanings: "I am processing the question", or "I am thinking about it", or "I do not know how to answer to that." It may not matter what it means, but it is a vital part during the interview.

People are generally quite afraid of silence, and people try to fill all the spaces with useless words. I did it (even if I tried not to). Managers did it and job coaches did it, but not the people with learning disabilities. They used a period of silence, followed by effective words to answer the questions. I found them to be more straightforward than anyone else.

4.5 Deciding as you go

Grounded Theory generation was a process requiring constant comparison, searching for similarities and differences in my data. As already stated, data collection was immediately followed by analysis of data; therefore GT emerged step by step. In this framework, I progressively switched from a selective sample criteria to a theoretical sample criteria (Draucker et al. 2007). In other words criteria to select

participants defined at the beginning were re-thought along the course of the research according to the development of the study and as described below.

The purpose of the theoretical sample was to define and refine the categories when constituting the theory (Charmaz 2006). The reality is never how you design it; therefore I had to be flexible and adjust the recruitment criteria within the method agreed in my ethics application and in discussion with my supervisors. At the beginning of this research I asked for employees who:

- Were able to give informed consent to take part in an interview;
- Were able to communicate in a simple interview;
- Have been supported by a job coach;
- Have been trained in the workplace;
- Have been employed at least for 1 year.

In this study I did not have the chance to choose participants, as I only selected the SEAs and I let the SEA managers' choose participants on my behalf. To do so, I addressed the choice of participants with learning disabilities through the previously mentioned criteria. I asked for SEA managers to select people who were able to give consent and who were able to take part in an interview. This was extremely important to include people who were actually able to communicate, as this met my criteria in my ethical approval.

I also asked for participants with learning disabilities who had been supported by a job coach and trained in the workplace, with the aim of interviewing people with learning disabilities who used the SE service as intended in this research. I asked for people trained by a job coach because the interaction with job coaching provided an important context for understanding how this particular form of employment might have steps and processes that can assist in relation to health. I asked for people trained in the workplace because this training method and

contextualized learning was important to guarantee a successful employment experience.

Finally, I asked for employees with learning disabilities who were employed for one year, because I thought this was a reasonable time for a person to settle into a job and to start to enjoy any effects of employment on health. This included the development of friendships at work and the impact this might have in terms of positive health models.

However, despite further re-enforcement at each stage in the recruitment process, I really believe managers did not always closely adhere to the criteria for participants. I had to review the last criterion (person had been employed at least for 1 year) because managers contacted people who were in employment for less than one year. On occasions, I discovered this during the interview and therefore I decided with the research team to make a positive from this change in the selection criteria and to be more open to the variety of conditions and people in SE. Indeed, in the emerging categories, I found people employed for only a few months to be able to compare their life before and after employment, providing important inputs for this research. As a last step to this study, I had the opportunity to interview young employees with learning disabilities who have been in paid employment for few months. After a discussion with the supervisory team we decided to conduct the interviews, finding this to be likely to implement and form robust categories.

As the characteristics of participants became clearer, and the first categories started to emerge from the data, I realised, from memo-writing, that I was interviewing some people who were working only for a few hours a week. I wanted to also gather the experience of people working for a larger number of hours. Therefore I added the following criterion:

- We prefer to interview people working for a significant amount of hours per week (10+).

Indeed, working for a considerable amount of hours may influence the impact work has on personal health. It was at least likely that there would need to be a significant cumulative number of hours in work to have an effect on a person's health. The added criterion was introduced as a preference, rather than as an absolute, considering the initial difficulties in recruiting employees with learning disabilities in the study. The new optional criterion successfully led to more people working 10 or more hours per week being included in samples by managers of SEAs.

	Question emerged from participants	Questions emerged from data
Employees with learning disabilities	Do you have any worries at work? If yes, how do you cope with your worries? Do you go to a gym?	What were you doing with your time before employment? Do you have any health worries/concerns? What do you do when you are feeling unwell? Have you seen a doctor recently? What do you do in your spare time? What are your hobbies?
Managers	Do you have any example of ill-health after employment? How paid carers influence your clients' health?	Have you ever supported anyone to start self-employment? If yes, how may their health benefit in this process? Do you use any of your funding to promote health and well-being?
Job coaches	Do you have any example of ill-health after employment? How paid carers may influence your clients' health?	

Table 4.4: Emerging questions

I modified the interview guidelines in the light of my interview experiences. The interview questions were revised to gather more information on the emerging concept (Draucker et al. 2007). This was a key decision because new questions emerged from data and other questions were inspired by new concepts introduced by participants.

Table 4.4 summarizes the questions emerging during the course of the research. It happened that an employee spontaneously started to talk about something he was worried about at work. I asked how he coped with this situation. Therefore I added the question for the next interviews, finding this information to be relevant to the health of employees. Another client attending a gym invited me to ask other participants if they were attending a gym directly. I was really surprised with myself that I did not think of this question before.

From the early analysis of data I noticed some important information was missing from my questioning. I was not aware of what employees were doing with their time before employment. Therefore I asked this question directly during the interview. I also realised that I had not asked anything about their health worries, and what they did when they were not feeling well, and so I asked participants about this also. Early analysis led to ask questions on doctor visits and about who helped them to contact the doctor. I felt that this may open up some aspects of how job coaches helped people to tackle health issues.

Further questions on the activities that people did in their spare time, and any hobbies that they had, were useful to identify individuals' habits and interests, and to understand how employment might eventually modify their life habits, health and well-being. The same process was used with managers and job coaches. I asked if having a job helped to improve personal health, but I needed to add another direct question to detect any cases of ill-health being experienced following employment (Table 4.4).

I did not consider paid carers when I structured the first schedule of questions from the literature. A job coach highlighted there were differences between paid carers and family carers in relation to health that will be described in the result section. It was important to consider the difference by asking a direct question on paid carers. I asked, therefore, about the influence families and paid carers may have on the clients' health. Furthermore, self-employment appeared to be seen as an

employment option for some people with learning disabilities by some SEAs, and so I asked a question on this topic. I wanted to know if and how this employment option might be related to health if it was followed.

Finally, it was important understanding from a manager's perspective if they had used any of the funding they receive to support health promotion activities. This was relevant to understand how managers considered health in supported employment, and if they provided funded health activities.

4.6 Implications of bias for the qualitative part of this research

Despite the difficulties in getting on with SEAs at the beginning of this adventurous research, entering the research field was a satisfying experience. What I really enjoyed was meeting the characters I studied in the last two years: managers, job coaches, employment consultants, but most of all, employees with learning disabilities. I had an experience that I define as unique with each SEA.

Researcher has to be aware of potential selection bias in research. I was in charge of select SEAs within the 50 that took part in the quantitative phase of this research. However, I did not randomly select the sample for the qualitative phase because I wanted to have a wide range of SEAs offering a variety of support levels for health. This criterion might lead to several biases:

I need to be aware of the risk of **selection bias** however, meaning the sample is not truly representative of the SEAs. I opted for a purposive sample because I wished to gather data from a wide variety of SEA approaches to health. A "convenience sample" is one of the assumptions of GT sampling strategy because the aim is to maximise "variation of

meaning" in the GT research (Bryant et. al. 2007). Two agencies I selected refused to take part to the study without an explanation. Both SEAs scored low according to selection criteria, they may be not so involved in health management, and therefore discouraged in taking part in this research. However, my experience highlights how agencies scoring low had interesting management of health, but participants may not directly relate it to health.

The selection of SEAs may be subject of **information bias**, occurring when there is a form of misclassification in the scores. I considered some agencies particularly good with health matters, other less involved in health. This classification was based on scores from the questionnaire completed mainly by managers. Furthermore, the manager, may want to appear to lead a good service and have the tendency to answer questions to appear favourably under other people eyes. The questionnaire was not anonymous, but it was explained there was a chance the manager would be contacted for the next phase of research, therefore I believe this risk of a **social desirability bias** to be minimum.

I considered these biases in the GT research framework. One of GT assumption is to find excellent participants. In GT excellent participants are people experiencing the phenomenon under investigation (Bryant et al. 2007). Therefore none of these biases have implications for the results coming out from GT research. Instead what is relevant in GT is that participants must provide a rich contribution to the research. Another implication has been considered when managers were selecting employees with learning disabilities to take part in this research. There may be a risk of managers "cherry picking" participants. Managers may have selected employees who are

- More successful in work with fewer health problems;
- -more able to conceptualise health than others;

- More independent and able to act on health better than others;
- Fitter and more healthy than people with higher levels of disabilities who may suffer ill-health more than others.

Implications for this research are:

1. Employment is a naturally selecting context, where only the more able individual with learning disabilities are selecting;
2. Managers were generally selecting individuals available on the day or days I was going for the interview. Participants with learning disabilities belongs to a wide variety of people:
    a. Three participants have an autistic spectrum not really communicative;
    b. Four participants have severe communication problems. Two of them have been supported in their speech;
    c. Five of them were quite able but with relevant health issues;
    d. Three of them were quite able with no relevant health problems;
    e. Six of them needed help to deal with health because not independent.

Therefore it is likely managers where looking to involve employees available on the day, rather than "cherry picking" participants.

An implication is that people who had experience of ill-health or ill-health management have more to say than people who have not. Also more talkative people provide more contributions than quiet ones. This is a natural element of qualitative research.

4.7 Auditability, Validity and Transferability of this study

Lincoln and Guba (1985) defined the criteria to establish the trustworthiness of a qualitative research study (Lincoln and Guba 1985) to be:

- Auditability
- Credibility
- Transferability

In the light of these criteria I describe the quality of this study, examining these criteria and the techniques needed to pursue a good qualitative research study.

4.7.1 Auditability

The concept of auditability refers to the quality of the research process. A full description of how the research was designed was given in Chapter 2, but an audit trail, as intended by Morse and Field (1995), may be useful to summarize the process behind this qualitative research. Figure 4.2 reports a schematic summary of the research process. The quality of the study is determined by presenting the research for Ethical Approval to Cardiff University School of Medicine Research Ethics Committee. SEAs were selected and collaboration was negotiated, together with sampling criteria for the SEA manager to choose participants on my behalf. On the day of the interview, the setting was prepared with the aim to facilitate the flow of the interview. The research was then presented and I introduced myself to participants. The information sheet and consent form were further explained if needed, or read and completed together if it was not done before. The interview flowed differently from one participant to another.

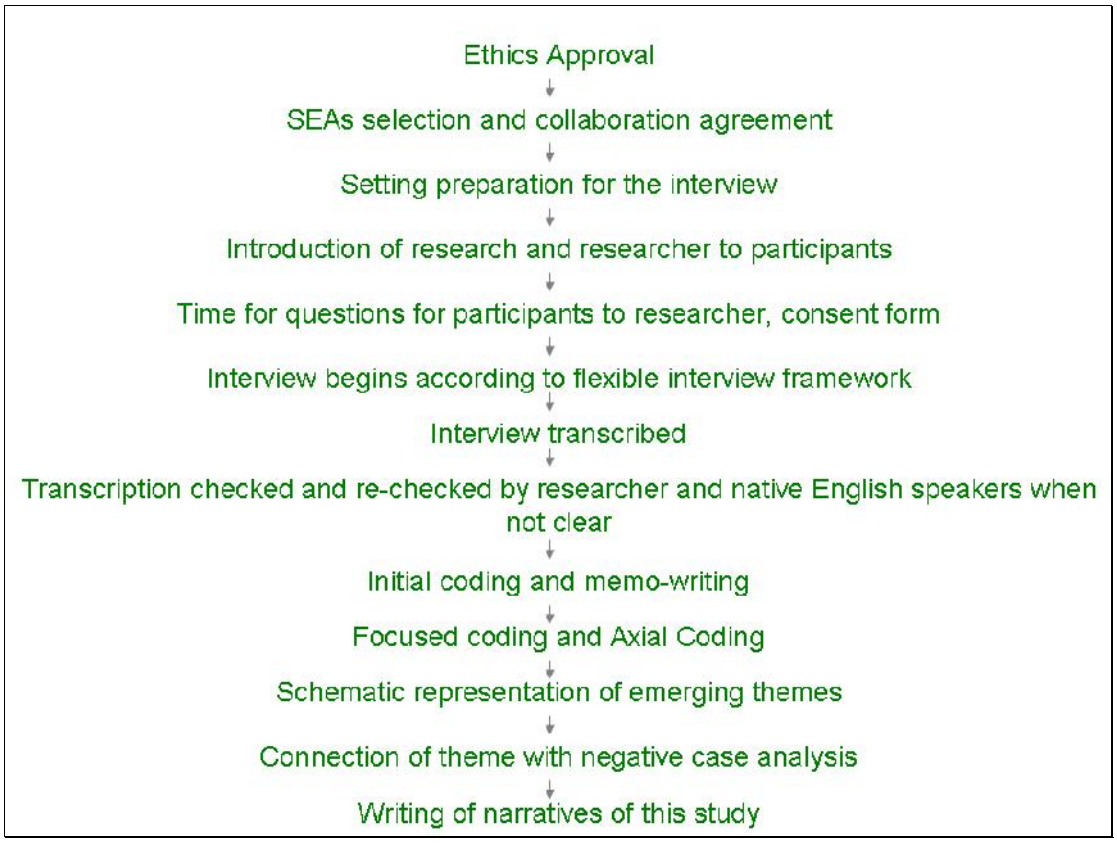

Figure 4.2: Audit trial

The interview was transcribed shortly after and re-checked for accuracy by myself and by a native English speaker if some expressions were too culturally grounded for me to understand. After transcription I started with the coding process which is detailed in the next chapter. I wrote memos to help in the process of analysis. I created more focused coding and started to link coding together comparing the emerging theory with the existing literature.

4.7.2 Validity

The validity of a study is, in other words, the authenticity and truth of data collected. Patton (1999) described credibility to be dependent on keeping to rigorous techniques and methods, with a high level of accuracy in data

analysis. Validity depends on researcher's training, experience and self-presentation. Finally, philosophical beliefs in qualitative methods and inductive analysis contributes to guarantee a credible study (Patton 1999). Several techniques were used to guarantee this study's validity:

1. Comparative method of data analysis;
2. Triangulation;
3. Negative or deviant case analysis;
4. Member checking.

In this research I constantly used a **comparative method of data analysis**. Following the split between Glaser and Strauss on GT in the 1990s, Glaser emphasized the importance of letting categories emerge from data, arguing against the coding paradigm introduced by Strauss (Glaser 1992). The coding paradigm introduced by Strauss is a structured way of coding that may be useful for a new researcher in the area. Indeed, it drives axial coding, inviting the researcher to find the conditions, interactions among actors, strategies and tactics, and the consequences of a phenomenon (Strauss 1987; Kelle 2005). I embraced the Glaser philosophy of letting the coding emerge from data, not considering pre-existing frames.

The second strategy to guarantee credibility of this study is the use of **triangulation**. In this study both methods triangulation and triangulation of sources were adopted. Methods triangulation, that is the use of both quantitative and qualitative methods, provided a complementary vision on data (Patton 1999). Indeed, the two methods lead to a form of comparative analysis of the same topic from data collected in different ways. Instead sources triangulation was possible because I interviewed three categories of people about the topic (managers, job coaches and employees with learning disabilities), looking at different theoretical positions on the same topic.

The third strategy was to adopt a **negative or deviant case analysis**, that is the strategy to detect and compare data that contradict the main idea emerging from data analysis (Lincoln and Guba 1985). These negative cases represented an asset to revise or confirm some ideas and think about possible links between data.

During my research I widely thought to use **member checking**, that is a quality control process based on checking the information provided by participants during the interview, with the aim to improve credibility and validity of this study (Lincoln and Guba 1985; Coffey and Atkinson 1996; Barbour 2001; Byrne 2001; Doyle 2007; Harper and Cole 2012). This is an important way of checking the quality of data collected, because the researcher is checking data from the source, giving the opportunity to participants to specify their thoughts, or to correct any wrong interpretation. Members checking may take place after the interview, when the researcher summarizes the findings for the participant and the researcher asks if the summary is accurate (Lincoln and Guba 1985; Harper and Cole 2012).

I found the summary of the interview with the participant after the interview to be too reductive if looking at the content of the interview. Indeed, I found myself as a researcher to be effectively elaborating the content of the interview only after 15-20 minutes following the end of the interview. Also, at this time, it is still hard to check about interpretations, as it takes time and commitment to provide accurate interpretations of data. According to Lincoln and Guba (1985) member checking may take place before the end of the research, where participants are provided with a report with the analysed data with the aim to check the contents (Lincoln and Guba 1985; Harper and Cole 2012). However, the idea of member checking is based on the assumption that the reality is fixed and it is not subject to changes over time. Furthermore, the participant may not agree on the interpretation given by the researcher or they may have changed their ideas on the topic (Morse 1994; Angen 2000). I found out that that the interview itself

changed the view of participants, because they had the chance to reflect on their own idea of health. In several occasion managers and job coaches reported they never openly thought about the impact of supported employment and employment on the health of their clients with learning disabilities, as reported in my field notes. For these reason I decided, with support from my supervisors, not to use member checking of the interview.

4.7.3 Transferability

Transferability is the possibility to transfer or relate findings to other settings. This is possible if the researcher provides a "thick description" of the setting, providing details and describing events taking place (Lincoln and Guba 1985; Morse and Field 1995). In order to get a thick description of the setting, the activity of keeping a diary was vital to record events or peculiarities of SEAs. A description of the setting and type of SEAs involved in this study was already available from the results of the web survey. This information contributed to the description of the settings that were the object of this study.

5 Grounded theory process for this study

This chapter describes the Grounded Theory process, starting from gathering rich data through interviews, followed by simultaneous data collection and data analysis. I will describe how data were used to construct analytic codes and categories, reporting several example of this procedure. I will then explain how memos helped in this process though the specification of properties, describing categories and identifying gaps. I will then explain how comparisons were made in each stage of the analysis, providing a description of how the theory emerged from my data collection and analysis. I will finally describe how the literature review was re-analysed with the aim to compare findings with the existing literature.

5.1 Gathering rich data

The process of gathering rich data is fundamental to conducting a significant analysis in grounded theory. This is because rich data provide a dense and detailed description of views, actions and contextual features (Geertz, 1973; Charmaz, 2006). The theory has been developed using narratives from the interview transcripts, diary notes, field notes and memos writing. In order to introduce the reader to the grounded theory I will begin with a brief presentation of employees with learning disabilities who participated in this study. The following descriptions provide an introduction for the reader to the analysis and form an important part of the analysis. Names used in the analysis are not participants real names but pseudonymous.

Table 5.1 reports the employment settings, the work role, the number of hours people worked per week and the time participants had been in employment. The employment role may be relevant for health in a number of ways. There are jobs that can be more physical than others and

potentially provide more exercise. Other jobs may have the potential to cause an individual to feel stressed which may impact on health. Some jobs may expose the person to environmental risks. Furthermore, the number of hours worked per week may be relevant to a person's health. The more time a person spends working in their specific workplace, the more they will feel the influence of that job and workplace on their health, either in a positive or negative way. The overall length of time the individual had been in employed may also have some influence on health.

Name	Employment characteristics	Role	Hours per week	Time in employment
Alan	Open employment (1 year fixed term)	Admin. assistant	8	2 months
Alison	Sheltered employment setting	Supervisor	37.5	19 years
Callum	Sheltered employment setting	Cleaner	22.5	4 years
Charlie	Open employment	Kitchen assistant	9	1 year
Daniel	Sheltered employment setting	Floating staff	24	9 years
Dean	Mixed setting	Kitchen assistant	24	10 years
Dem	Sheltered employment setting	Packing items	15	Unknown
Edmund	Open employment (1 year fixed term)	Office assistant	8	2 months
Eric	Open employment (1 year fixed term)	Office assistant	8	2 months
George	Mixed setting	Office assistant	Full-time	Unknown
Ian	Open employment	Gardener	16	2 years
Isaac	Mixed setting	Worker in an ordinary company	15	1 year
Lauren	Open employment	Office assistant	8	2 years
Leonard	Mixed setting	Worker in an ordinary company	15	4 months

Name	Employment characteristics	Role	Hours per week	Time in employment
Matt	Open employment	Shop assistant	3	Unknown
Paul	Mixed setting	Worker in an ordinary company	15	Unknown
Raphael	Mixed setting	Worker in an ordinary company	15	5 months
Roger	Open employment (1 year fixed term)	Supporting elderly people	5	2 months
Sonia	Open employment	Shop assistant	12	1 month
Susan	Open employment (1 year fixed term)	Supporting people with Disabilities	8	2 months

Table 5.1: Occupational characteristics of workers interviewed

I met and interviewed employees from a variety of contexts, working in a wide range of employment situations. They had different responsibilities and duties to be carried out.

5.1.1 Alan

Alan is a young employee who recently started his first employment experience supported by a supported employment agency. He has been employed as administrative assistant for two months. His main duties are answering the phone, making phone calls, booking meetings and typing documents on the computer. Alan reports that he enjoys the new employment experience even though he works for only 8 hours a week. He comments on being “not so smart” because of his learning disabilities, but he is confident he can work. Alan has a positive view of his employment experience, because he considers this fixed term placement

to be a good starting point for his career, but he wishes to work for more hours a day. Alan explains that he gets tired after work because he has plenty to do at work, but he enjoys it. Alan lives with his family, he wishes to move away and live independently, but he cannot afford it at the moment. Alan reported several health problems he had experienced in the last year, but despite these he is quite positive in relation to his health. Alan considers his job to have a positive influence because he has the opportunity to become more active in employment.

5.1.2 Alison

Alison is a full time supervisor of trainees within a sheltered employment setting. She started as a trainee herself and now she is a senior staff member who has the responsibilities for other trainees. Occasionally she covers other roles such as working in the canteen or performing cleaning duties. She has been working in this setting for the last 19 years, but she has done other jobs before this, such as working in a supermarket and in a laundry. Alison highlights how her job contributes positively to her life, as she is always busy, but she recognizes her job can be quite tiring. Alison lives on her own and, recently, she started to see a friend she met in the workplace. Alison reported that she suffers from depression and she has been treated for this for the last 15 years. She is experiencing back and knee problems, and now she is going through the menopause. Alison is aware of what she should eat to stay healthy, but she admits she does not like healthy food very much. Alison reported that she has been a smoker since her teenage years. She smokes about 20 cigarettes a day, also during break times, but she also reports it depends on how much stressed she is.

5.1.3 Callum

Callum is a young gentleman working as a paid cleaner for 22.5 hours a week in a sheltered employment setting. He has been doing this job for

the last 4 years. Before this he worked as a gardener for another company. Callum is aware that his job contributes to keeping him healthy and he has noticed that he has lost weight since he started work. Callum also reports his job to be positive as it keeps him motivated. Callum is also making choices about what he eats, and he prefers to cook from fresh ingredients rather than eat ready-made meals. He cooks fresh food and freezes these into small portions, in order to have it ready for future meals. Callum is an active person as he cycles and sometimes jogs. Before he injured himself he used to swim. Callum explained that he is a smoker, but the amount of cigarettes he smokes depends on his mood.

5.1.4 Charlie

Charlie is a kitchen assistant who has been working in a voluntary job for one year. He works 9 hours a week and his main duties are laying the tables, clearing the table, loading the dishwasher and filling the fridge up with bottles. Charlie was previously in a job at the local public library where he was working for the book returns service. He travelled independently to work, but he had to give up that job to take the job at the café. Charlie lives with his mother who also attended the interview to help. The interview was difficult as Charlie was not really keen to talk with a stranger. Therefore, following the input of the job coach, Charlie decided to take me around his workplace where he showed me his duties rather than explaining them to me. He seemed very enthusiastic about his job, and showed me his duties with a smile on his face. When we got back to the interview room he noticed a purse on a chair and, without thinking twice, he took it to the manager of the café. I observed that Charlie appeared to have good relationships with other workers and he moved with confidence within the workplace premises.

5.1.5 Daniel

Daniel is a middle age gentleman who is working as floating staff in a sheltered employment setting. He has been working for this company for 9 years and he is pleased with his job. He works 24 hours a week and he said his job is keeping him busy. Daniel lives independently and therefore he likes helping in the canteen because he is learning how to cook for himself at home. Daniel is concerned for his health as he has been diagnosed with high cholesterol and so he needs to be on a diet and take tablets.

5.1.6 Dean

Dean is a middle age gentleman who has been working for the last 10 years as a kitchen assistant in a mixed employment setting, working 24 hours a week. Dean's main duties are laying tables, serving, washing up and using the till. He is quite busy in his job but he wishes to learn more from his employment experience. Dean wanted to assist his supervisor while cooking in order to be able to use the new learning at home while cooking his own meals. Dean explained he started smoking because he was depressed, but he does not smoke during breaks at work. He smoked at home and before and after work, showing that employment was taking his mind off smoking. Dean gave up drinking following the loss of his brother for alcohol related reasons.

5.1.7 Dem

Dem is a young gentleman who is doing work experience in the sheltered employment setting. Dem works for 15 hours a week, his main duties are packing items and going out in a van for deliveries. Dem has been working in this position for a while, but he does not remember for how long. Dem is not paid for the work experience he is doing, but he believes his job contributes to him staying healthy as it helps him to stay active, eat the right amount of food and this motivates Dem to turn up to work. Dem lives

with his family and he claims he is living a healthy life even if he is not attending the gym anymore for problems linked with transportation.

5.1.8 Edmund

Edmund is a gentleman employed in a paid fixed term placement as an office assistant. He works 8 hours a week and he started this job 2 months ago. Edmund is happy in this placement, he explains he has to concentrate to perform his tasks well and listen to his supervisor. Edmund has been looking for a job over the last ten year, therefore he is grateful he had this opportunity. However he hopes for a full time job. Edmund believes his job contributes to staying healthy because he is moving around and he is keeping himself active. Edmund attends a gym and he is on a diet because he wants to keep himself healthy. He also linked health with being on diet, because it prevents illness and obesity.

5.1.9 Eric

Eric has been employed on a fixed term contract as office assistant for the last 2 months, working one day per week for 8 hours. This is Eric's first work experience because he recently ended his experience at college where he was attending introduction to business courses. Eric reported his job to be repetitive, showing few opportunities to have new contacts with people. Eric is a quite laid back person, answering the questions mostly with yes or no answers. He does not believe his job helped him to become healthier, but he did not explain the reason of this.

5.1.10 George

George is a middle age gentleman working full time as an office assistant with both employees with and without disabilities. He has been employed for a while in that position, but he does not remember for how long he has been doing his job. George was very welcoming and excited while taking

part in the interview with me and happily shared his experience. George is really active in the workplace, busy doing all sorts of tasks in the office. While travelling to work, George stops some bus stops before his workplace and he walks to work to exercise. Sometimes he does not even get the bus, walking all the way to work. George is working full time and this make a real difference in how he is spending his wages. He can afford to pay off his bills, take holidays, buy treats for his wife and to pay for travel to go and see his family.

5.1.11 Ian

Ian is a gentleman who has been working as gardener for the last 2 years. He works for 16 hours a day and his wages are very important to him. Ian is married with four kids already grown up. Ian described how earning money provides him with a sense of worth and pride, even if there was nothing left, after paying for bills. He was the only one in his family financially contributing with his wage. Ian is not able to read, therefore a job coach helped him to read the information sheet and consent form before the interview. The interview was quite difficult because Ian answered the questions mainly with yes or no answers. However he shared with me his worries about a lot of things in his life, but he stops worrying when at work because his job helps to keep his worries away.

5.1.12 Isaac

Isaac is a gentleman in his forties, employed as worker in a business environment. The setting he is working in is a mixed one, with mainstream workers and workers with disabilities. He has been in this position for the last year or so, and he works for 15 hours per week. Isaac has difficulties with his speech and he is quite laid back. In the interview he was not keen on talking about his health and his job. He is working in a business environment and he reported that his job did not really help him with his

health. He has bad legs and he takes painkillers for them. He did not specify what his duties are, even when I invited him to tell me more about his job.

5.1.13 Lauren

Lauren is an office assistant, working one day per week, for 8 hours, for the last two years. She was surprised I came a long way to listen to her. She was quite anxious about taking part in the interview. Indeed, she expressed her this feeling at the beginning of the interview. At the end of the interview she was relieved and happy that she had answered all the questions. She reported that she was pleased the questions were easy ones. At the end of the interview she went to see her co-worker and explained to her that the interview had been a good experience for her.

5.1.14 Leonard

Leonard is working 15 hours a week in a business environment with a voluntary job. Leonard's speech is sometimes difficult to understand because he speaks quite quickly and some of the answers were not always coherent. He is quite new in his current job being employed for about 4 months. Leonard's job was mainly packing briquettes and splitting wood kindle. Leonard highlighted the connection between a healthy body and a healthy mind, He did not have a hobby or take part in any sport. Leonard reported that his job helped him to be healthy mainly because it keeps his brain active.

5.1.15 Matt

Matt is a young gentleman who is working only 3 hours per week. Matt was really active doing his job as a pet shop assistant which involved catching animals, cleaning the animal's enclosures and generally looking after the animals. His health conditions were quite serious and he needed

to be looked after 24 hours a day. Matt came along with his personal assistant and she stayed for the interview. Matt took the opportunity to describe his job and his experience of what it is like to be in employment. He did answer all the questions; he expressed interesting concepts around employment and health. Matt broadened the concept of health out from food and diet and he related it to emotional concepts such as stress. Moreover, Matt associated health in this emotional sense, linking the concept of health with a stress free working environment. A significant contribution to a stress free working environment was the ability to listen to each other and to work as a team member. Matt explained his job was allowing him to save money and to use it when needed to treat his girlfriend.

5.1.16 Paul

Paul is a young man working for 15 hours per week in a business environment. He is in a voluntary job. Paul is covering a range of duties, but he underlined how the lifting of objects made him stronger. He reported he should exercise to stay fit and well. Indeed he plays football for a local team. He replied to my questions mainly with “yes” or “no” answers.

5.1.17 Raphael

Raphael is a young man working in a business environment, who suffered from diabetes. He therefore needed to check his glucose every day and to manage his insulin injections. Raphael was aware of his medical routine and he accepted it. Raphael did not smoke because he did not want to add another problem to his health.

5.1.18 Roger

Roger is working on a one-year fixed term contract supporting elderly people in a day centre, serving dinners and spending time socialising with people attending the centre. Roger explained that he had not been healthy lately but he believes his job helped him to be healthy because he was eating heathy food at the canteen. His routine changed following employment as he was only busy helping his mother with housework, now that he is working in a part time position.

5.1.19 Sonia

Sonia was working in a part time work experience in a grocery shop, as a shop assistant. Sonia underlined the importance of the social side of her job because she gets to meet many people in her workplace. Before employment Sonia was sitting at home watching TV. Sonia suffers from asthma but she knows how to treat this herself. Sonia has been in this employment position only for one month since leaving education, therefore working is a new experience for her.

5.1.20 Susan

Susan is supporting people with sensory disabilities. She has communication difficulties and knows sign language. She uses this in her job, helping others. Susan was working 8 hours a week and she has been in this position for the last 2 months. Susan reported concerns related to her communication difficulties that might have affected her self-esteem. She also reported strategies to cope with it. During the interview we often stopped for a drink because Susan was s too anxious to carry on with the interview. Susan asked me to meet up again, and she was quite upset when I said to her this was not possible explaining the reasons.

5.2 The coding process

The process of coding transcripts and writing memos was on-going. I generated many codes, coding became progressively more focused on the topic and gradually more conceptual. Figure 5.1 shows diagrammatically the coding pathway from multiple codes through to categories and themes

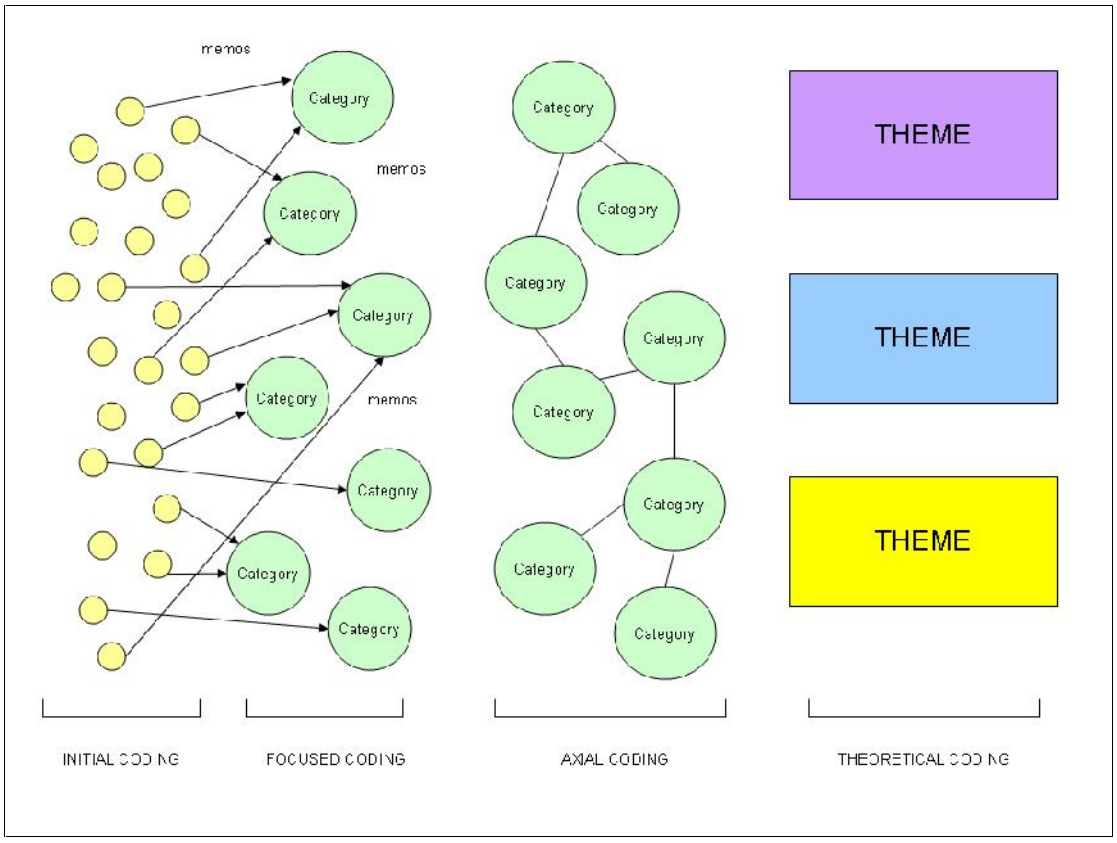

Figure 5.1: The coding process

The initial coding phase aimed to break data into discrete parts, remaining open to different possible theoretical directions (Charmaz 2006). The initial coding was tentative, provisional and needed to be reworded whilst the analysis progressed (Saldana 2009). In this research, incident-by-incident initial coding was adopted. In other words described events were compared with other described events. Here are several example of **initial coding** where I named segments of the data:

EXAMPLES

> *Paul (41): I tend to eat bananas, apples and that's about it. Carrots, lettuce, which is quite healthy. That's about it really.*

Initial coding: **Healthy eating**

> *Edmund (58): I work with my manager and supervisor. I am enjoying my time working with them.*

Initial coding: **relationships with colleague**

> *Leonard (10): We have a fork lift for heavy things. They made boxes as heavy, you know.*

Initial coding: **preserving health at work**

I created 3 hermeneutic units using Atlas.ti for each group of participants. For the first group, employees with learning disabilities, I created 102 codes, which were reduced to 83. Some of these were merged as they were repetition of other codes. These 83 codes were than compared and looked at also in relation with memos and field notes.

For the second group, managers, I created 172 codes that were reduced to 151. Some of these were merged, and some were not relevant to the topic object of study. These 151 codes were then compared and looked at in relation to memos and field notes.

For the third group, job coaches, I created 221 codes, which were reduced to 198. Some of these were merged, again some were not relevant to the topic. These 198 codes were then compared and looked at in relation to memos and field notes.

After this stage, the most meaningful data and grounded codes were highlighted. Grounded codes are those which have the most attached quotations. I decided which focused codes had the most analytic sense to help categorize the data.

I report here an example from interviews with people with learning disabilities. I selected the code "**work helps me to be healthy**" to identify all the opportunities being in employment gives to workers. I adopted the code "**diet at work**" to identify all the opportunities employment gives to people to become healthier. Several initial codes were merged into "**diet at work**" to better conceptualize this concept, such as "**lunch at work**", "**packed lunch**", **"buying food at work**".

I also selected the initial codes that made the most analytic sense for this study. For instance all the opportunities for individuals to keep active at work have been focused in one code which is "**physical activity at work**".

Focused coding allowed me to focus the analytic process and select the most meaningful set of data, which were then compared.

5.3 Memo writing

In this phase, the creation of memos was an important aid for the analysis as it helped in generating categories. Memos were sentences standing between data collection and the analysis, helping to increase the level of abstraction of data (Charmaz 2006). This is a fundamental step in GT analysis; memos needed to be spontaneous also during the analytic phase. Memos represented a first step of analysis, helping me to link data with the research questions, to write about code choices and definitions, to write about emergent themes and to reflect about the final report of the study (Saldana 2009). In this research, I produced memos with the aims of:

1. **Finding a gap in research:** memos were useful to highlight a gap in my research process. This is an example of a memo to underline that I was initially interviewing people working only a few hours a week.

> MEMO (12/01/12): Matt is working 3 hours a week. That's OK, but tries to interview people working for more hours a week (10+?). Consider changes.

2. **Reflecting about choices in coding:** memos were useful to underline an emerging concept, reflected in the process of focused coding. Here is an example of how a code changed over time, to underline how earning a wage allows the individual with learning disabilities to become more independent and experience freedom. The code "doing all sorts with wages" goes further than the initial code "spending wages" because underline a dimension of freedom and acquired independence.

> MEMO (MONEY ALLOWS TO DO ALL SORTS - 24/01/12): George is a really active person, passionate about photography and travelling. Having a job helps him to do new things. George recognizes also the importance of having a wage to pay bills and treat his wife. From George's narration it looks like he can do all sorts of things with this money. Without his wage he could not do all these. Therefore the code initial "spending wages" was changed with "doing all sorts" to give importance to this dimension of freedom and acquired independence that I perceived during the interview, and it was for participant priceless.

3. **Identify emerging categories and themes and create connections amongst data**: a memo can state an emerging theme or category and it helps in connecting a theme or a category to other themes and categories. Here is an example of how a job coach can be compared to a GP for the role in health he may cover.

> MEMO (JC as a GP - 15/03/12): Job coach could be as a GP. He/she flags things up! This is a central concept where the JC may detect health issues and report them to competent health professional in multidisciplinary meeting for instance. This concept may be connected with the need of health training for JC. Also it looks like JCs play some role in suggesting healthy pathways for their clients with learning disabilities.

4. **Connecting memos:** these memos are important to connect and compare the ideas of participants or analyse the ideas of the same individual in a different part of the interview. Here is an example reporting considerations around an emerging theme.

> MEMO (ME - ROLE OF SE 22/03/13): It is generally quite shared among participants in the study that health of their clients with learning disabilities is not at their competence. However, SEAs are responsible for health and safety of their clients with learning disabilities. This is in contrast with the activities for health several SEAs did. If it is not of your competence, why doing such activities, most of them not funded for? Because health is important in employment. This is at the centre of an emerging theme

The use of memos is positive because the first phase of the analysis is characterized by the generation of lots of coding. Memos are functional to focus the analysis and when new categories emerged and compared afterwards.

5.4 Comparison in data analysis

In my analysis I built an intensive network of relationships between codes, segments of data and memos. I kept the view of people with learning disabilities, managers and job coaches as separate, to best describe data emerging from each group. I constantly compared data within these three groups. In the next chapters I report on the working sheet that I used to compare data. I used several links such as:

- **Is associated with:** one concept is semantically associated with another concept. This does not mean there is a causal relation between the two codes but there is a link between concepts.
- **Is a part of:** a concept is a sub-category of another concept.
- **Is a cause of:** one concept is cause of another concept. There is a causal relationship between the two concepts.
- **Contradicts:** one concept contradicts another concept.

These links have an important role when comparing data, and they help in the drafting of a theoretical framework.

5.5 Searching the literature

At the end of the analysis, I searched the literature again in relation to the finding for each group of interviewees with the aim of comparing the emerging theory with the existing literature. This has been reported at the end of each findings chapter. In the conclusion chapter findings are then compared among groups of interviewees. Search terms (criteria) for systematic literature search at this stage were generated by findings. The purpose of searching the literature at this stage was to search if the literature reported previous studies that reported findings in the area. For this purpose the databases were searched with the following criteria.

1. Criteria 1: intel* disab* (topic) + employ* (topic) + active (topic) + health* (topic). Results: 10. 1 article relevant to the topic.
2. Criteria 2: learn* disab* (topic) + employ* (topic) + active (topic) + health* (topic). Results: 1 article not relevant to the topic.
3. Criteria 4: intel* disab* (title) + employ* (title) + type (topic). Results: 17 (English). 2 articles relevant to the topic.
4. Criteria 5: learn* disab* (title) + employ* (title) + type (topic). Results: 4 (English). 1 article relevant to the topic.
5. Criteria 6: intel* disab* (title) + unemploy* (title) Results: 3 (English). 1 article relevant to the topic.
6. Criteria 7: learn* disab* (title) + unemploy* (title) Results: 0 (English) article.
7. Criteria 8: learn* disab* (topic) + unemploy* (title) Results: 4 (English) articles not relevant to the topic.
8. Criteria 9: intel* disab* (topic), smok* (topic), empl* (topic). Results 12 but none relevant to the topic
9. Criteria 10: learn* disab (topic), smok* (topic), empl* (topic). 8 results (English) none relevant to the topic.

10. Criteria 11: intel* disab* (topic), alc* (topic), empl* (topic). Results: 15. 1 article relevant to the topic.
11. Criteria 12: learn* disab* (topic), alc* (topic), empl* (topic). Results: 22 (English) no articles relevant to the topic.

6 From coding to theory: the contribution of employees

The chapter describes the analysis process for the contribution of employees with learning disabilities. I will describe how data were compared to construct theoretical concepts, reporting the procedure and explaining the results. I will then explain how comparisons were made in each stage of the analysis, providing a description of how the theory emerged from my data collection and analysis. I will also explain how memos helped in this process though the specification of properties, describing categories and identifying gaps. I will finally describe how the literature review was re-analysed with the aim to compare the existing literature with results.

6.1 Job duties and health

The focused codes “duties at work” (17 quotations) and “work help me to be healthy” (12 quotations) were grounded in my data, therefore I took them as relevant codes to start developing a conceptual framework. A code is grounded when it is supported by many quotations. The following diagram reports how they are “grounded” and how they are connected in a network I named “Duties and Health Network”.

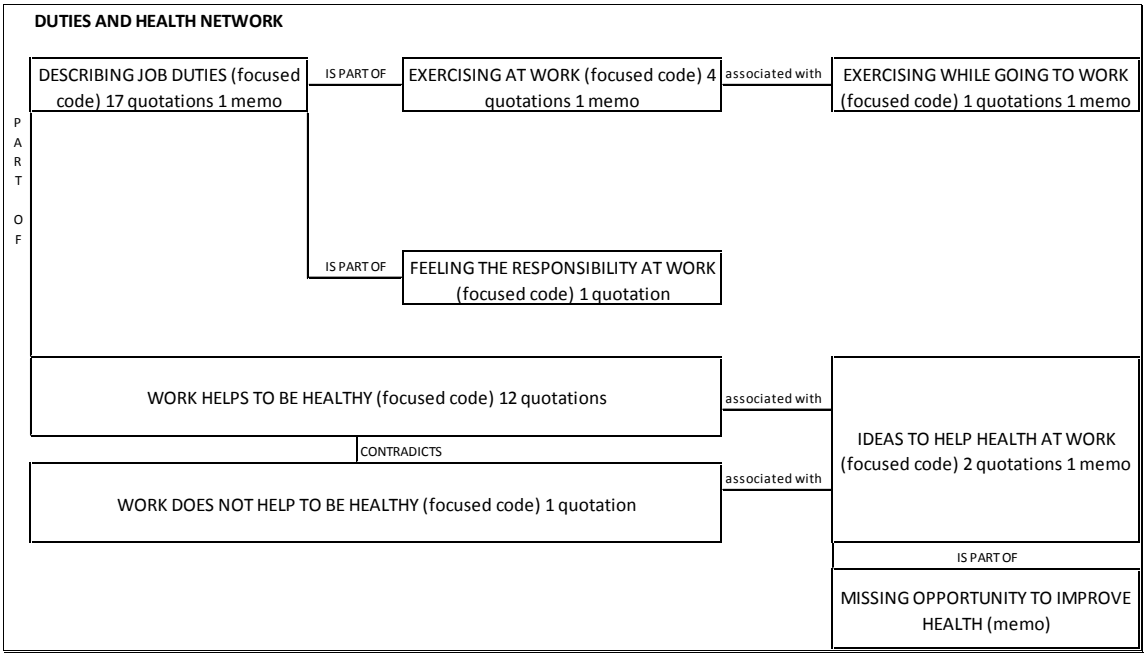

Figure 6.1: Duties and health network

Figure 6.1 shows how I connected codes, memos to develop the theory and it is supported by quotations. This network contributes to explain how employment may or may not influence health of employees with learning disabilities.

> MEMO PERSONAL STATUS IN EMPLOYMENT: Dean has been working as kitchen assistant for more than ten years. He is also a director of this company so he feels he is important within the company. His work status is relevant for his life and self-worth.

This memo was relevant to draft the narratives of the findings and to explain how employment may help with health.

> MEMO SOLUTIONS TO BECOME HEALTHIER: Dean offers solution to become healthier in the workplace.

This memo was relevant to highlight the contribution made by an employee about how a change in job duties may improve individual life.

The first element is the description of job duties which helped to explain how a job may influence the health of people with learning disabilities.

Dean and Charlie were generally quite active while carrying out their role as kitchen assistants.

> *Dean (employee): Serving, using the till, washing up. Helping the supervisor do all, work all around the kitchen, lay the tables.*

> *Charlie (employee): I work at (name of the bar). Mmmm. I lay forks, spoons, cutleries. Dishwasher. Lay the tables, food away, that's it. If the fridge is empty I filled it up again. I put the bottle in the front in the back.*

Leonard worked in a factory and also performed physical activities when in work. Leonard's job was quite physical, but he reports his job to be important because it helped him to keep his brain active.

> *Leonard (employee): I work in a factory; I am on a paper factory. I put rubbish in the bins. I do the wooden things, how are they called? Briquettes. I put it in the bags, in the big bags, plastic bags, you know. They come from (name of place), the briquettes. I split the kindle, I split the timber, and I split the wood. I split things apart as well, you know, I have done that as well. […] it (job) keeps your brain active.*

While Leonard was busy packing briquettes and splitting kindle, Dem was packing and tearing paper. He was also going out with the delivery van, an activity which was described to be "a change" in his usual daily routine.

> *Dem (employee): I work down, packing. I do (name of a place), just across the road here, I do that one day a week on a Tuesday. I do tearing paper and I am going out on the van delivery. That's what I do.*

Dem believes his work helped him to "build up a state". By which he meant that carrying out his job duties helped him to be active. Employment provides Dem with the commitment of turning up every day to go to work. Dem explained how being in employment helped him to stay healthy.

> *Dem: By keeping active, by eating the right amount of food. I feel that sort of build-up yourself a state, if you see what I mean. (Silence) Just trying to stay active, turning up to work every day. All days are great to come in.*

Callum works as a cleaner and he reported that he was active in employment because of all the cleaning duties he has to perform.

> *Callum (employee): We clean; we go out and clean flats, workplaces and toilets. I do the floors, toilets, walls, hand railings, windows, basically everything.*

Some participants worked as shop assistants. Matt was really active doing his job as a pet shop shopping assistant which involved catching animals, cleaning the animal's enclosures and generally looking after the animals.

> *Matt (employee): I take rabbits out of the enclosures, maybe 6 or 7 rabbits I have to catch. I take to another enclosure and then clean that out. And then, when it is clean up, I come back in and I am going in the other side with other rabbits.*

Matt explains how his job helped him to keep his mind active. The nature of the job duties he has to perform may help him to be healthy.

> *Matt (client): Yeah, it (the job) makes me use my mind.*

Furthermore Matt describes how his job helped him to improve his coordination. In the following quote Matt tries to explain this concept to me.

> *Matt (client): And also it makes me more aware of other things around me, mmm what they call it…. Do you know when you pick up stuff and you …? (Silence) coordination! That is the word!*

Shopping assistant, Sonia, underlined the importance of the social side of her job. A job had social implication for Sonia, who was sitting at home watching TV when unemployed.

> *Sonia (employee): Just staking shelves, that's it really. I get (to see) lots of people, yeah.*

The employment experience can help employees through developing the ability to be flexible in their duties, as they were required to cover different

duties in relation to what was needed in the company. Daniel described his job as “floating staff” meaning he had to work as a cleaner, sometimes helping in the kitchen and sometimes working in the warehouse looking after the trainees.

> *Daniel (employee): I am what it is named a floating staff. I do bits here and there. One day I may be put on cleaning, one day may be put on cooking in the canteen, one day I am put on a road to clean premises. Or I may be put in the warehouse to look after the trainees.*

George worked as office assistant and he was doing all sorts of office jobs, showing that he was quite active and flexible.

> *George (employee): (my job) is in the office. I do the boxes, I do the files, I do the scanning, I box things, paper, and I file things you know. All the sort of things I do, working here. Yeah. I do the kitchen sometimes, pans, hovering, sometimes. I do the cupboard next to us, sometimes. I scan paper.*

Alan and Eric worked as office assistants. Alan had a clear idea of his duties and he was interested in the new job. Alan had to make phone calls, booking meetings and generally having contact with people. This job positively stimulated Alan who learned about what problems drugs and alcohol can cause, as he started working for the Council drugs and alcohol department. Even if Alan did not think this job was complicated he was positively stimulated by it.

> *Alan (employee): My job is administrative assistant for the Council I live in. Basically I am doing spreadsheet, doing phone calls. The department I work in is the drugs and alcohol department. It is interesting. I only started last month, but I set out what drugs and alcohol can cause. My main job is answered the phone, booking meetings, making phone calls, typing up word documents, bits and pieces really. It is not rocket science, but it is interesting.*

Alan explained he gets tired because he has lots of work, not because he gets bored into work. This is according to Alan contribution was a good feeling because it was a good sort of tiredness.

> *Alan: I don't get tired because I don't know what I am doing; I get tired because I have lots of things to do. I prefer that, there is a difference between tired because you are bored, or bored because you have done a lot of work. It may just be me!*

Eric reported his job to be generally quite repetitive, showing few opportunities to have new contacts with people.

> *Eric (employee): I am working at the (name) Council. I do general things like scanning documents, working mails, photocopying, checking emails, data entry in spreadsheets.*

Employment can be enjoyable for employees who were responsible for other people. Having responsibilities for other people can be a new experience for an individual with learning disabilities, who may themselves have been viewed as dependent previously, and with positive effects on self-esteem and general well-being. At the same time, looking after other people can also represent a stressful situation and therefore a situation deserving attention. Roger was supporting elderly people in a day centre, serving dinners and spending time with elderly people attending the centre.

> *Roger (employee): I work with elderly people, I am there to serve their dinners, play games with them, and I do their breakfast for them, taking them company during the day. That's what I do from my job description.*

Susan was also looking after disabled people, using the skills she acquired at the SIGN course to help people who are deaf.

> *Susan (employee): My job is working in (name of place) and looking after disabled people, who are deaf or blind. I love my job, I love it! Last year, at the course sign, I am going help them; I am going to help people I love it.*

Alison had the responsibility of supervising trainees in a factory. She started as a trainee in the company herself, progressing to take on a team leader role.

> *Alison (employee): (I am a) Supervisor for trainees in the factory. I do a little bit of driving up to (name of the company), I clean for them as well, and sometimes I am going up when people are on holiday.*

Two employees describes how working help them to keep their minds busy. Ian describes that he sometimes had worries, but he did not have worries while working. Ian is a gardener and his job helped to keep these worries away.

> *Ian (employee) I do worry sometimes. I do not worry there (at work). I am happy.*

In conclusion, the employees reported several descriptions of work showing how they are physically active in employment and how they engage in many different activities. There were jobs with greater physical contributions, while others had challenges in terms of cognitive processes (such as counting, writing notes and spreadsheet, answering the phone) and social contents. There were some jobs that were quite repetitive, but that allowed the individual to meet and stay in contact with other people, while others did not offer the same social opportunities. Finally, there were jobs in which employees with learning disabilities were responsible for other workers. Employment contributes to build up a status that is relevant for individual life. These job features are relevant to the health of the individual because they may influence the health and well-being of employees with learning disabilities in employment.

6.1.1 Physical activity

This first network of data (Figure 6.1) opens up a new scenario of how employment may help people with learning disabilities with their health. The category which is more grounded into the data is that many individuals perform physical activity only because they are performing their duties. This represent the first part of theory emerging from data.

Furthermore, two employees explained how they decided to walk to get to the workplace. Alan lives not far from his workplace therefore he decided to walk to the workplace. Alan takes about 10 minutes to walk to work, walking 20 minutes during his working day.

> *Alan (client): I can walk in 10 minutes. It is not far at all. It is on my doorsteps.*

George instead lives far away from work, he travels by bus to work. When the weather is good, he stops 2 bus stops earlier, so he can walk to work from there. George decided to do this following the suggestion of a job coach, who invited him to walk to work in order to do some physical exercise.

Certainly employment is not the only context in which people may get active, but it is a constant one, as many individuals work for a certain number of day and for several hours a day. Therefore employment may be an important opportunity to get more active because it is “a constant” in the life of each individual.

There are other areas of life offering the chance for employees to be active. Employees reported some examples of how they get active outside work. Raphael walks a dog in his spare time, while Mark cycles during the weekend. Edmund attends a gym once a week and Lauren swims. Alan used to play football but he injured himself and he stopped following this accident. Mark was also swimming, but he broke his elbow and he never went back to swim. Alison was not doing physical activity because of a disability in her knees.

In conclusion, several factors may influence the level of physical activity of employees with learning disabilities. From job descriptions given by employees we understand how being in employment can help them to be more active. Employment is an important context to get active because is part of an individual routine. However, being in employment meant that some employees may not have time to do physical activities because they

are busy at work. One employee reported how he quit the gym because he was too busy working full time and with family commitments. However he walked to work, a good way to exercise without losing too much time.

From the analysis of the interview I discovered how several employees stopped doing physical activities because they have been injured, but they kept themselves active because they were performing their job duties.

6.1.2 New learning

One of the way employment may help the individual to be healthy is that employment may involve several new learnings. Dean highlighted a missing opportunity to improve health. He wanted to assist his supervisor while cooking in order to be able to use the new learning at home while cooking his own meals.

> *Dean (client): I would be able to eat all the right things at home and assist to cook at work it would help me a lot more. That is what I am trying to sort out at the moment. That would help a lot.*

Employment could be a learning context for Dean who can use the new learning at home. Daniel learnt how to cook fresh meals at work and transfer the new knowledge to be used for himself at home.

> *Daniel (employee): I eat partly, ready meal vegetarian food and fresh. Half and half. I am still learning upstairs (he is working in a canteen upstairs), cooking, so I can cook, I can cope; I know how to cook and when it is ready.*

The first network contributes to develop a theoretical framework about how employment may help to be healthy. Employment may help because the individual can increase the level of physical activity just performing job duties and on a daily basis. The individual may become more active while going to work. Employment may prevent the individual to do physical activity elsewhere because of a lack of time, even if many individuals reported to be quite active outside the workplace. Employment is not the

only context to get more active, but as employment is part of a routine, it is a constant one. Employees reported how employment helped with cognitive processes and provided social opportunities, but employment is also a source of new learnings, which may help leading healthy lives.

6.2 Healthy eating and weight loss in employment

The second network was about food intake at work. When looking at codes related with food intake at work, it emerged from data that the majority of employees had packed lunch, meaning this topic was mainly associated with diet at home. These codes are also associated with general understanding of healthy eating and also with the importance of having a social life at work (Figure 6.2).

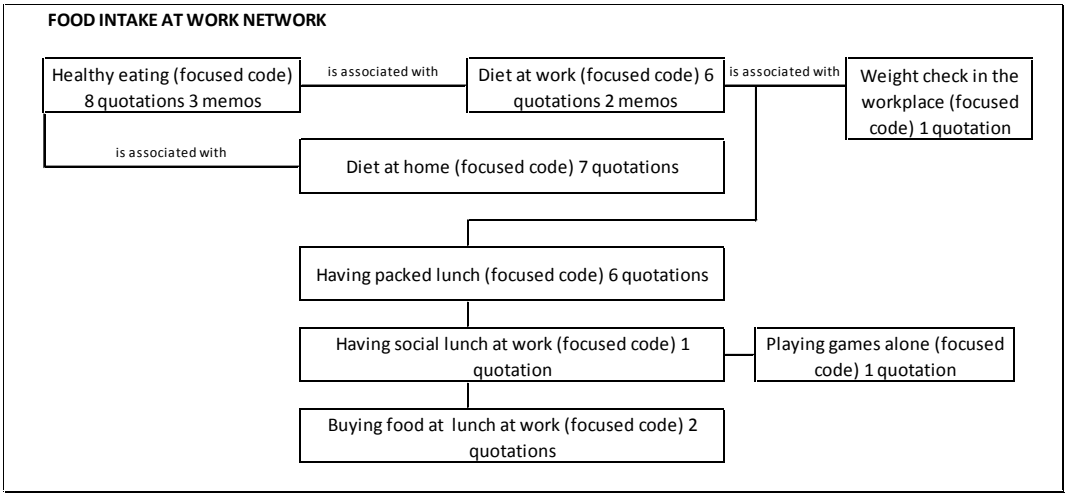

Figure 6.2: Food intake at work network

> MEMO OPPORTUNITY TO EAT COOKED FOOD: Dean has the chance to eat cooked food at work, while at home he is not eating much, but unhealthy ready to eat food rather than freshly cooked ones.

This memo was useful to focus the attention on the opportunity for an employee for his own health.

> MEMO GETTING 2 MEALS AT WORK: George works for a catering services and sometimes extra meals come back, so he gets another meal.

This memo was useful to understand that sometimes an employee may overeat in the workplace.

> MEMO OFFERING FAT FOOD WHEN MEDICAL CONDITION: During the interview with Daniel the agencies staff offered us homemade shortbread and minced pies. Daniel has been recently diagnosed with high cholesterol, therefore it may be indelicate to tempt him with these food. We put them in one side.

This memo was useful to remember one detail of what happened during that interview that may be related with the health of the employee.

Being employed means employees with learning disabilities have lunch in the workplace. The majority of the employees I interviewed ate their lunch at work. Some of them took packed lunches to work, prepared by themselves or by their families. The contents of these packed lunches reflected families' habits and personal preference in relation to food. The majority of employees ate sandwiches, crisps, some yogurt and fruit. I report five quotations about their packed lunch.

> *Dem (employee): I eat sandwiches, I have piece of fruit, and I have a bar of chocolate. I eat healthy things at work.*

> *Alison (employee): I may just get a pack of crisps or a chocolate bar or a cup of tea (at the canteen). I bring my own rolls, my sandwiches and my own stuff.*

> *Leonard (employee): Sandwiches. Meat sandwiches, cheese sandwiches.*

Raphael was not aware of what he had in his lunch box, because it was prepared by his mother. Raphael is diabetic, and having a packed lunch prepared by his mother helped him to eat the right food for his condition.

> *Raphael (employee) Mum makes me lunch box, because it helps with my diabetes. She always make it, I think I have sandwiches. I don't know what something black that must be pickle is in there, then. And I think it has got cheese in it.*

Other employees had lunch at the canteen. Daniel opted for vegetarian choices.

> *Daniel (employee) I am a vegetarian so they have got Chef vegetarian meals. So I get like sausages, meat likes, cottage pies and things like that, made out of Quorn.*

Being at work and in an unsupervised space offered opportunities for people with learning disabilities to over-eat. George worked in a canteen environment and therefore he sometimes had two lunches, if any meal was returned untouched to the catering service.

> *George (employee) Cooked meals. We catering meals, so sometimes the food comes back and I am having another meal.*

Dean had the only cooked meal, because at home he eats mostly crisps or sandwiches.

> *Dean (client): Well, it is all kind of cooked, very cooked meals that I do not usually do a lot for myself at home. I do not eat a lot [at home] to be honest. It is more for my medication it helps me to put on weight. I do not eat a lot towards. Maybe a sandwich, a pack of crisp or something when I am at home mostly I do not seem to eat a lot of cooked meals that I have been told I should eat more.*

Employees reported on what they usually eat at home. The nature of eating at home also had an influence on eating and food at work. Callum stopped eating ready meals at home, preferring to cook meals from scratch. He cooked fresh food and froze these into small portions, in order to have it ready for future meals.

> *Callum (employee): I do not eat so much fruit now for some reason, but I still do. Pasta, I have a cupboard full of pasta. You can make anything with pasta don't you? I do not eat a lot of cheese. I think there is quite fat in there, well, it depends what cheese you buy. […] I do veggies in the microwave, but generally all I do is on the top of the hob, all from scratch. It is cheaper, they do say, I do not do this because it's cheaper, you buy whatever you want. If you have got frozen veg in the freezer and you put in a microwave, but anything else I just cook. I used to do microwave food, but I do not do it*

> *anymore. […] And also starting here early and finishing late, the time I got home it is 6-7 o'clock. Do you want to cook? No, stick in the microwave. But now I don't. Someday I do enough food for about a week, so I cook it and then I freeze it. I do spaghetti bolognese, and I do it for something about a month. Massive.*

Some employees also chose ready meals options at home, with possible negative consequences on their health, because of the nature and usually low quality of ingredients used for the preparation of ready meals.

> *George (employee): Chicken. Chicken once. All sorts of things that you put in the oven. Ready meals that you can find in a shelf. Frozen.*
>
> *Alison (employee): What I fancy. May be pasta, sausages, fish and chips, microwave, you know, microwave lasagne, stuff like that. I get by.*

Several employees pointed out that being in employment helped them lose weight. Mark has lost weight and he considers his job to be quite good because it keeps him motivated and active.

> *Mark (client): Since I started this job I have lost a lot of weight, you know, going all the way around, up and downstairs. We are cleaning here as well, so going up and down. We are on the move and it is quite a nightmare. You basically, literally, non-stop. Lots of people have lost weight with this job, because you are constantly running around. It is quite a good job, it keeps you motivated, and it keeps you going.*

Instead George pointed out he learnt from the job coach what foods are healthy or unhealthy choices.

> *George (client): Healthy? You need healthy food. I have learned it from Justine! Cake, cut down, I get weight every Wednesday. I hate Wednesday.*

In summary, individuals' food intake styles in the workplace reflected their own eating habits or the family culture around food. Because the majority of individuals interviewed had packed lunches, there was not enough

evidence to establish whether eating at a workplace canteen can eventually help the individual to be healthier. However, for employees living independently, eating at the canteen was the only opportunity they had to eat a cooked meal, because they were not able to cook themselves. Certainly, the availability of extra food in the canteen may invite a hungry employee to have too much food. A healthy lifestyle at home was generally important for people living independently. This is mainly in the ingredients used during the preparation of ready meals. Preparing meals from fresh ingredients may help the individual conduction a healthy lifestyle. Some employees described how they lost weight after being in employment, meaning the change of lifestyle and duties performed at work helped them.

6.3 Social opportunities at work

The third network (Figure 6.3) is about social opportunities at work and the explanation of how and why these are related with the health of employees. The most grounded codes were “have good relationship at work” (10 quotations), “activities at break time” (6 quotations), and “going out with colleagues” (6 quotations). Most of the employees have good relationships with colleagues. This is supported by examples of activities during break time and some examples of social activities with colleagues outside the workplace.

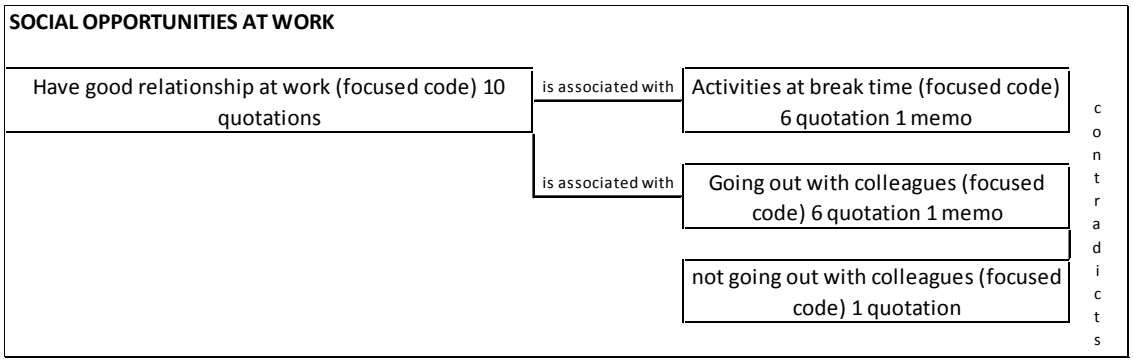

Figure 6.3: Social opportunities at work network

This memo highlights the importance of breaks to socialise with colleagues. This memo was functional to point at one relevant findings.

> MEMO SOCIALISE DURING BREAK TIME: Break is the time you can have a cup of tea and socialise with colleagues, chat and share problems or concerns. This is important for people living independently.

While looking at these focused codes it emerges how the work experience opened clients to new social opportunities. In employment individuals take the challenge to build up his/her own social network, with the support of the SEA. The social network the employee created within the workplace was even more important for people living independently. For these people break time represented an opportunity to socialize. Dean described these moments to be important to express worries and problems.

> *Dean (employee): (in my breaks I) Have a cup of coffee and a few biscuits and have a chat with my supervisor. If I had any problem with myself to, putting forward other (inaudible) worrying, bad things. […] Because I live independently and so I can say if something goes wrong.*

The supervisor can act as a sounding board listening to problems and providing sensible advice. Dean was living independently and therefore may experience a lack of staff who can talk about issues of concern. Alternatively, the confidence and positive relationship established with the supervisor during the working day may help Dean to talk about his worries. The supervisor may ensure Dean's worries do not escalate to a point where they become a health risk.

For most employees break time was a social opportunity to talk with colleagues.

> *Ian (employee): I get a treat, tea as well. I talk to my friends.*
>
> *Dem (employee): Usually just have drink, just chat. Just talking about what we were doing the week end.*

Edmund, recently employed as office assistant, believes break time was important to get to know colleagues, because during working hours people have to work, rather than getting to know each other.

> *Edmund (employee): I talk to people, think about this, pray. Generally if you sit down some people may come up to get to know you. Instead when you work, you have to work rather than get to know people.*

Few employees with learning disabilities shared a social life with colleagues outside the workplace. However, this was individual specific, based on personality and their likes and dislikes. Interviewees' attendance at social events with colleagues was limited to special occasions such as a Christmas meal, Christmas tour, birthday and anniversaries.

> *Callum (employee): We may get together at Christmas time, we are going out for a meal or just for a drink, but that's about it, it is the only time when we meeting up. We are together every day, so we don't need to see on Fridays. For Christmas, we plan, 4 or 5 of us to go for a meal or grab a drink.*
>
> *Matt (employee): I went to Christmas tours with them, I have got good working relationship with the manager and I have also got good relationship with the other employees.*
>
> *Ian (employee): No, I do not go at all. In special cases I am going to, like birthday, anniversaries, like that.*

This network of codes contributed to explain employment is an important source of social opportunities and new social learning. The employee with learning disabilities can build up his/her social network with people he/she

is working with. Employment gives the opportunities to open up a new social network with people not linked with the disability network. In other words, the individual with disabilities getting to know his/her co-workers because he/she was part of a working team. While the employee with learning disabilities was included in new social interaction he/she developed confidence, improving communication and social skills. In conclusion the relationships established in employment were generally seen as positive by employees, even if an employee reported his job to be repetitive and with few opportunities to socialise with colleagues.

6.4 Gaining an income

The third network is about one important outcome of employment: gaining an income. Employees reported how they spent their wages and how some of them saved incomes for the future. Some employees were not paid, because they were employed in a voluntary job or they were doing a work experence. These codes were important to develop a theory on how employment may help towards health (Figure 6.4).

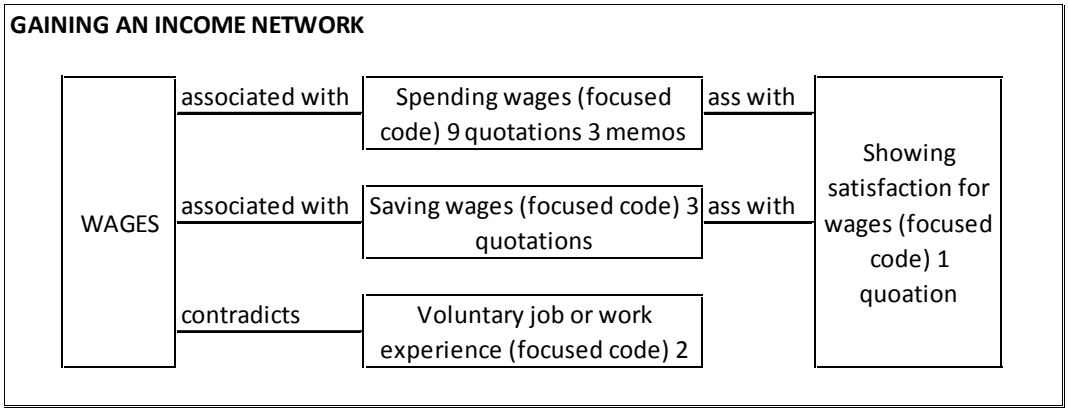

Figure 6.4: Gaining an income network

Indeed paid employment gave the chance to the individual with learning disabilities to become economically independent. This in turn gave them the chance to access goods and services that they had previously been unable to afford.

George, whose hobby was photography, was able to afford to pay for holidays to spend with his wife and his friend and to practice his photography. The ability to pay for holidays or travel helped the individual to be socially included in a network of friends and family.

> *George (employee): (with my salary) I do my bills, I do my holidays, I treat my wife, I go to my mum or she comes to see us, I do all sorts.*

Dean experienced the same advantage as he spent his money to travel and see his parents.

> *Dean (employee): It (salary) helps to go and see my parents. It helps me with all sorts of things when I am short. It helps quite a lot with the travel. It is few hundred miles away.*

Matt explained he was saving the money and use it when needed to treat his girlfriend.

> *Matt (employee): I save it (money). And if I need anything I take it out at the moment, and you know I buy it. I treat my girlfriend. I buy a meal; I buy dresses, once I bought a pair of shoes, jewellery. I bought all sorts.*

Ian described how earning money provided a sense of worth and pride, even if there was nothing left after paying for bills. He was the only one in his family financially contributing with his wage.

> *Ian (client): (with the wage) I sort out the house bills. I do not have any spare. We pay for our bills and then we get the food.*

In summary, becoming an active part of the productive society had a positive impact on individual self-esteem and helped in developing positive

feelings. Individuals with learning disabilities were able to afford to do what they liked helped them to feel like anybody else who has a job. I discovered people used their wages to pay for bills, food and leisure or saved some of their wages for the future. This was positive for their health because earning a wage gave them a positive and secure feeling for the future. People in voluntary jobs of doing work experience were not paid for the job they were doing, therefore they did not experience this feeling.

6.5 Smoking, alcohol use and employment

The fourth network is about smoking and alcohol use in relation to employment (Figure 6.5). This network describes employment may influence smoking and alcohol use behaviours.

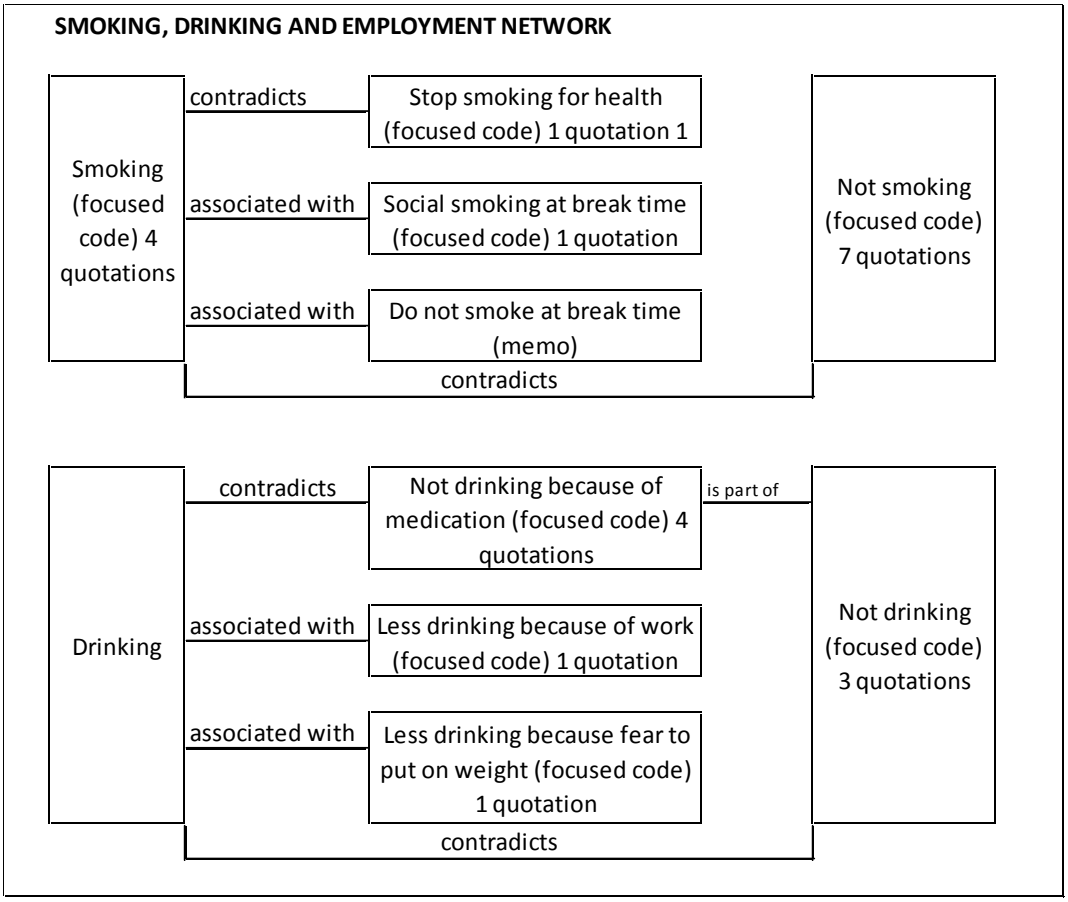

Figure 6.5: Smoking, drinking and employment network

6.5.1 Smoking

The majority of people I interviewed did not smoke. There were interesting differences in why people smoke and how they smoke at work. Some smoked to relieve stress or as a reaction to perceived stress. It is unclear if the workplace can act as a stressor that leads to increase in smoking. In a few examples it acted as a counter-balance, providing meaningful activity, and few breaks where a person can actually smoke.

MEMO SMOKING AND EMPLOYMENT Most of the people do not smoke. One individual reported to be a smoker and he smokes at break time. A way to socialise with his bosses? Another individual reported he does not smoke at break time at work, but before and after work and at home. Employment as protective factor? Cost of smoking may influence their choices now that they are working and therefore better understanding the value of money?

Dean started smoking because he was depressed, but he did not smoke during breaks at work. He smoked at home and before and after work, showing employment was taking his mind off smoking.

> *Dean (employee): Yes, I do (smoke). It is mostly for depression and things like that when I started smoking. I smoke one cigarette before work and when I get changed to go home. During the day I do not really smoke during the break time or anything like that.*

Mood and feelings are linked with the amount of cigarettes smoked. Alison has smoked 20 cigarettes a day since she was a teenager.

> *Alison (employee): Yes I do. I have been smoking since I was sixteen. It is a long time now. I don't smoke 40, 60 a day, I am not so bad, and I smoke about 20. It depends how stressed you are.*

Callum was going through phases, where sometimes he really needed to smoke for a week and then he had a break. He reduced smoking because he cannot afford it. Callum was a full time employee, living independently who had noticed the amount of money he could save by not smoking.

> *Callum: Oh, it is a while; I am going through like phases. I smoke for a week and then I have a week I do not smoke. I have a break. I do smoke, but I don't smoke as many as used to. It is so expensive now, I just can't afford it. It depends what mood is on me, I depend how I feel really. It's bad, I heard.*

Indeed, Callum explained he had a list of all the expenses and he calculated how much he can spend every day. It is certainly true that earning a wage incentivized people buying cigarettes, but it may also be true that an individual may better understand the value of the money spent when money was earned through hard work.

Co-workers' habits may influence people's health choices. Isaac smoked when finishing his meal as all his bosses do. Smoking may be seen as a social opportunity for Isaac to have an informal chat with his bosses.

> *Isaac (employee): I do (smoke). All my bosses smoke. I smoke, when I finish my meal.*

Smoking at break time may represent a chance to socialize with colleagues that an individual with learning disabilities may undertake with the excuse of smoking a cigarette.

Several employees never considered smoking as an option. Raphael did not smoke because he did not want to add another problem to his health and also because members of his family are smokers. Raphael was annoyed about his family members smoking; therefore he spent much of the time in his bedroom to get away from the smoking. Being in employment can be a good opportunity for Raphael to avoid this situation that sounds uncomfortable to him.

> *Raphael (employee): I have health problems and that one (smoking) as well? My family does, too much. I am used to it, I had enough. I am in there constantly, in my bedroom, because they have just decorated it.*

Edmund and Susan were aware of the consequences of smoking, therefore they never started smoking.

> *Edmund (employee): I have never smoked. Even in school I have never smoked. When I was in school I've heard smoking causes cancer, ever since, I have never smoked myself. My mind is always somewhere else, dedication mostly.*

> *Susan (employee): No, me I have never smoked. I don't like it. Why do you want to hurt yourself? Why some people do?*

An employee gave up smoking to stay healthy.

> *George (employee): I stopped when I was 24 and I started again when I was 38, now I am 50, 12 years ago. My last cigarette when I was 42. I stopped to stay healthy.*

In summary, fifteen employees out of twenty did not smoke. However employment may act as protective factor, keeping the individual's minds

busy preventing the individual to smoke during break time. In another case smoking at break time was used as a way to socialise in the workplace. Earning a wage may increase the chance for an individual with learning disabilities to buy cigarettes and smoke. Though an independent adult may recognise that he/she can save money by not smoking and stay healthier without it. Finally, the employment situation may help the individual to stay away from an uncomfortable situation at home where all the family members smoke.

6.5.2 Alcohol use

Most of the employees I interviewed were not allowed to drink because of medication.

> MEMO ALCOHOL USE AND EMPLOYMENT Most of the people I interviewed did not drink because of medication. Some stopped for several reasons. One individual reduces alcohol intake during the week thanks to employment. Another reduced not to increase his weight. He learn drinking may help to gain weight. New learning at work.

This was generally grounded into data. Matt, who suffered from epilepsy, cannot drink alcoholic drinks.

> *Matt (employee): No! I am not allowed to drink at all. Because I am on (name of his therapy medicine). If I touch any alcohol with this medicine it can kill me.*

Alison was having therapy for depression, therefore she cannot drink alcoholic drinks.

> *Alison (employee): No, I can't drink because of medication. I haven't touched any alcohol about 15 years now. Only soft drinks, tea and coffee.*

Roger drank low alcohol content drinks because of the epilepsy medication he uses.

Roger (employee): (only) Shandy, because of my epilepsy.

Other employees did drink alcohol occasionally when going out with friends. George avoided drinking too much because he did not want to gain weight as he was checking his weight at work.

George (employee): I drink sometimes; I do not drink too much because I put on weight.

Callum chose to slow down drinking during the week, because he was in employment. Employment acted as a protective factor for alcohol use in Callum's life.

Callum (employee): It depends. During the week I may just have the one, and it is about it. During the weekend I generally go a bit crazy. During the week when you are working you do not want to feel groggy don't you?

Alan needed to reduce his alcohol intake because of health problems, but he still liked to drink "to let his hair down", but he reported he has never been sick because of drinking alcohol.

Alan (employee): I still go out and enjoy. I just have limits to the amount that I drink and I don't smoke, if I smoked I would not probably be talking to you. I do drink, to let my hair down. Few drinks, nothing to mad, I don't get sick for alcohol, never been. Just enjoy. When I go out I drink vodka, single, probably 4 vodka and cokes, 5 in occasion or something and few ciders, 3 ciders, I don't drink over. Or I don't drink, only soft drink. I have never been sick as most people do. I enjoy myself but not ending up in the hospital.

Dean gave up drinking following the loss of his brother for alcohol related reasons.

Dean (client): I stopped drinking when my brother, one of my brothers, has died for it. I used to be a heavy drinker which did not agree with my (inaudible). I stopped drinking because of that reason.

In conclusion, most of the employees I interviewed were not allowed to drink at all. Some decided to have drinks with a low level of alcohol. Employment acted as protective factor in two situations. An employee did not drink too much because he did not want to gain weight because this was checked at work. Another employee stopped drinking during the week because he was in employment and he did not want to feel unwell because he has been drinking. It is still unclear how employment may facilitate or hinder drinking alcohol in this research because we had few examples of how employment may act as protective factor. Furthermore, it is unclear what role work colleagues may have because only four employees go out with their colleagues after work, and this happen only in special occasion such as birthdays and Christmas.

6.6 Comparison within data and the literature

The 5 networks were linked together to build up a “Super network” explaining the ways employment may influence the health of employees (Figure 6.6).

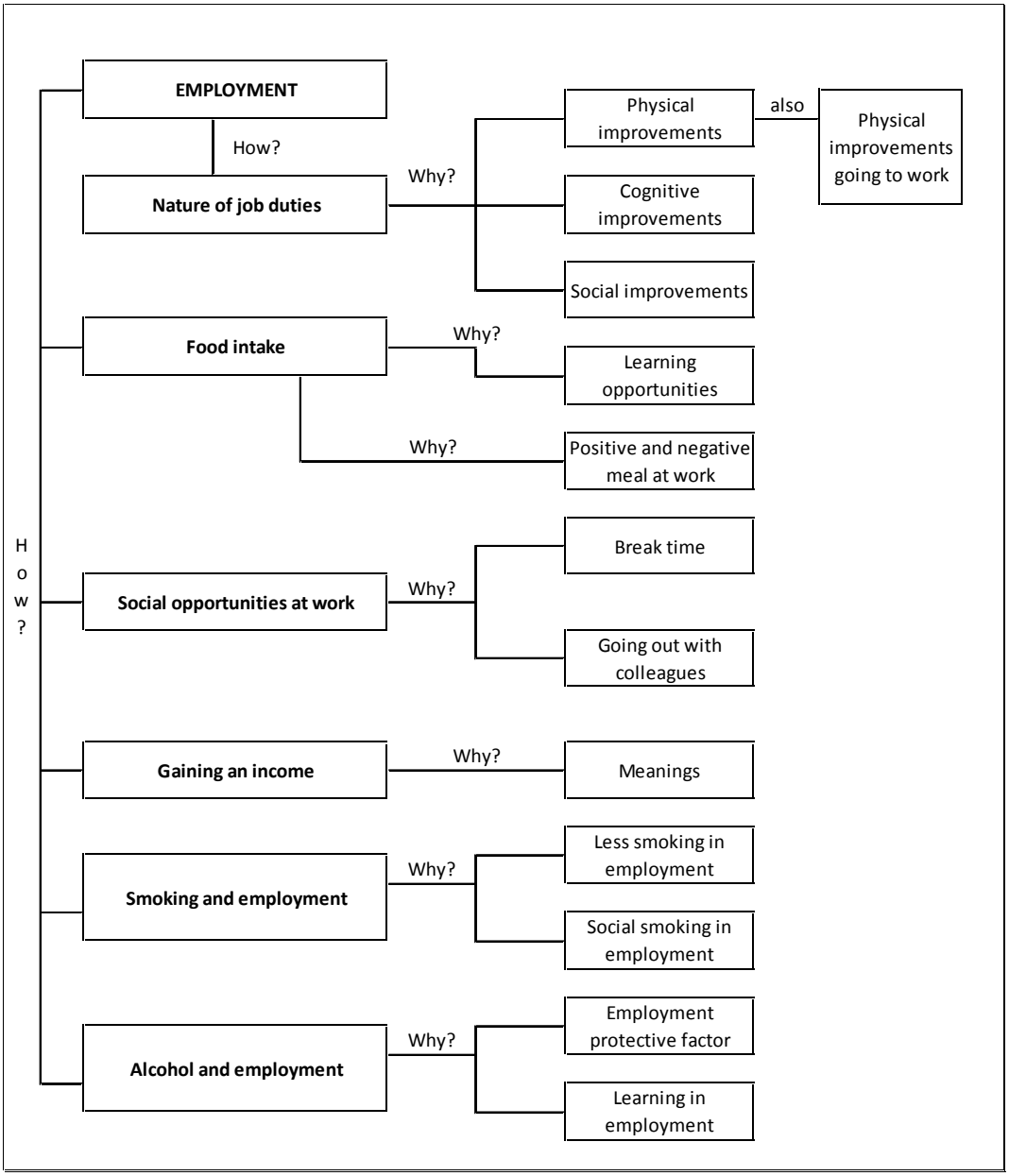

Figure 6.6: Super network (1)

Employment offers many opportunities to conduct healthy lives for people with learning disabilities. This is supported by employees' contributions as they claim to live physically active lives in employment. Most of them reported to be physically active performing their duties, and many of them reported they were doing a wide range of job duties. Temple (2009) highlighted employment to be a source of physical activity for individuals with learning disabilities. Temple's study was a small qualitative study (13

participants) involving only people with learning disabilities considered “active people” according to pedometer measurements, therefore this study has some limits due to the size and sample selection. Despite this, it showed how employment and going to work were important potential sources of physical exercise.

In my study many employees claimed their jobs to be flexible and variable. Indeed, they did not always perform the same duties, they were quite variable, especially from people in sheltered employment settings, because they were able to work at different roles within the same company. However, other jobs in open employment were reported to be more repetitive, but with the advantage of providing social opportunities such as meeting a wide range of people. Kober (2005) showed that employees in open employment experienced a better quality of life if compared with employees in sheltered employment, but there are no differences when comparing individuals working at high and low ability levels. According to contributions from people with learning disabilities in my study the sheltered employment setting offered the chance to change role within the same organisation and also the possibility to progress in employees careers. This was positive for people’s health because employees had the chance to access new learning through employment, such as cooking healthy food. However, in sheltered employment settings there were fewer chances to socialise with people outside from the disability environment. A longitudinal study examined adaptive skills (such as adaptive behaviours, social skills, cognitive abilities), in two consecutive points of time, showing employees moving from a less integrative employment to a more integrative employment to have higher scores in adaptive behaviours, while people staying in the same employment type showed no changes (Stephens 2005).

An employee reported how employment helped in improving employees’ co-ordination. Employment may lead employees to feel tired because they have been working, but not bored as they were before employment. This has been already found in a study considering both individuals with and

without intellectual disabilities; in this study employees were less bored when in employment than unemployed (Jiranek et al.1990).

Furthermore from the contribution of employees with learning disabilities in my study I discovered how employment helped employees leading mentally active lives and increase their motivation in turning up to go to work every day. Employees reported not just improvements in getting more physically active, but also mentally. It means employment helped them to keep their mind busy. As a results, they may be less worried and less bored than before employment as reported by some of them. Few employees reported their job to be repetitive and with few social opportunities.

Performing job duties is not the only way to take advantage of health opportunities from the employment experience. Some employees were walking to work, taking the advantage of doing physical activity while going to work. If overall employment is an important context to get more active, as a downside it may happen that an individual working full time may not have the time to do physical activity outside work as reported by an employee. However, few employees were working full time, with the majority working few hours a day for few days a week.

It was not possible from this study to understand if eating in the employment setting may have effects on health. This was mainly because employees had packed lunch prepared by themselves or by other members of their families. For people eating at the canteen and living independently, this may be the only opportunity to have a cooked meal per day. However, the availability of extra food at the canteen can lead employees to over eat. Indeed, employees may not know how to cook for themselves at home, preferring to eat sandwiches or ready to eat food. However, being employed in a kitchen may help employees to learn how to cook food from fresh ingredients and use this new learning at home for themselves. This may contribute to leading healthier lives.

In one case it emerged an employee recognised he has lost weight because he was moving around in the workplace. Another important consequence is that employees may learn what food is healthy and what is not from people they interact with in the workplace. Employment can therefore be a source of new knowledge to live healthy lives.

Earning money from employment increased self-esteem and confidence through a range of factors: paying for bills, travel, treating loved ones and make saving for the future.

Social opportunities were recognised to be important especially for people living independently. Chatting at break time is an opportunity to talk about problems, worries and get advice from a colleague. This may be one of the few opportunities people living independently have. Also people with learning disabilities can get together with people not coming from the disability environment.

Employees do not usually get together after work, apart from special occasions such as Christmas meals or birthdays. A literature review on social inclusion for people with learning disabilities in employment, reported how some studies highlighted trust and reciprocity established among employees with learning disabilities and co-workers to be one of the inclusion aspects of employment (Lysaght 2012). A qualitative study involving co-workers and managers participating in a co-workers training course, highlighted how the support of a co-worker is fundamental for the individual with learning disabilities and how the trust and friendship coming from the relationship can help the employee with learning disability to be socially included (Farris 2001). Interactions with co-workers in the workplace are certainly important, because co-workers may garner employees' thoughts and at the same time employees practice their social skills with people outside from the disability setting.

Employees may also socialise when smoking a cigarette with bosses or co-workers during break times. Unhealthy behaviours from co-workers may encourage the employee with learning disabilities to smoke.

However, it emerges that employment is mostly acting as a protective factors for several reasons. The first reason is that employees smoked less or not at all when at work. Furthermore, employees find it to be expensive, as earning themselves the money, they may better understand the value of it and the efforts necessary to earn it. Employment may also take the individual with learning disabilities away from an uncomfortable situation at home, where all family members are smoking in the house.

Most of the employees do not drink alcohol because of medications or because of personal choice. For those who drink, employment can act as a protective factor. This is because the individual may decide not to drink during the week not to feel unwell when working. Also an individual limited his drinks because he did not want to put on weight that was regularly checked in the workplace. In the existing literature a qualitative study involving 10 individuals with learning disabilities with alcohol related problems, showed how they would prefer to report their problems on a one to one basis or to friends rather than in group. Some of them also mentioned the importance of provision of services for employment, but this study does not specify how services for employment may help with alcohol related problems (Taggart 2007).

6.7 The theory: Opportunities and new learnings for a healthy life in employment

The emerging theory in this study explains how and why employment is an opportunity and a source of learnings for employees with learning disabilities. Employment is an opportunity because it contributes to increase individual physical activity while working and/or while going to work. Employment is an opportunity to exercise cognitive abilities and to socialise with people, learning and consolidating social abilities. Employment allows the employee to feel more independent thanks to the income earned while working. Employment can act as a protective factor on smoking behaviour and alcohol use, while is not clear how it may

influence eating habits. Employees with learning disabilities may learn new healthy habits in employment, and the individual can transfer these new learnings in other contexts. Employment may hinder healthy habits, as the workplace may be a place to overeat or employment may take the individual away from sports or physical activities, but overall employment represents an opportunity to become more active and learn healthy habits.

7 From coding to theory: the contribution of managers

The chapter explains how the theory emerged from the contribution of SEAs' managers. I will describe how concepts emerged from data, reporting the whole procedure through the most meaningful worksheets. In the following paragraphs the emerging categories are described and explained and findings are compared with the existing literature and the emerging theory is stated.

7.1 Data analysis and comparison within managers' contributions

Data analysis has been carried on in the same way as for the contributions of employees. The most grounded codes have been highlighted and they represented a lead to explore data. They are: "signposting to other projects for health", "family influence", "assessing", "coordinating a care package". Starting from these codes contributions have been compared within this group of participants.

7.1.1 Employment and health

The codes "signposting to other projects for health" (6 quotations) and "coordinating a care package" (4 quotations) guided the first draft of the analysis. They provide some clues to how managers consider health in their practice. Figure 7.1 reports the final draft of the first conceptual network.

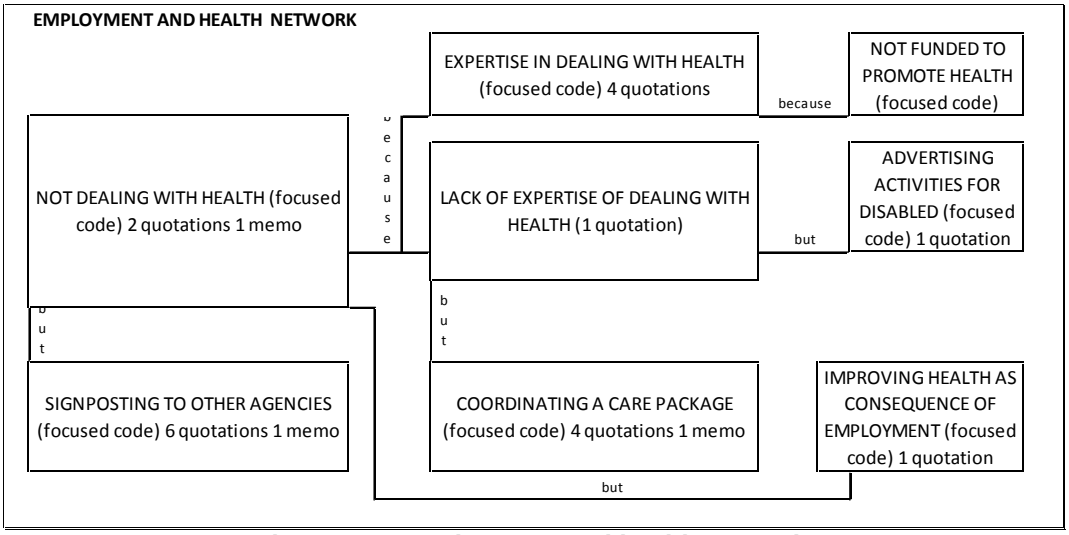

Figure 7.1: Employment and health network

In this study managers identified that they had a responsibility to deliver good employment opportunities. The following memo highlights this point and helps with the analysis.

> MEMO: Health is part of the SE process but is not a commitment in the SEAs' agenda.

Managers often considered health, but only to the extent that good health was needed to maintain a job or, if poor health acted as a barrier to getting a job, the health issues needed to be accommodated for any job match. This position was exemplified by manager Alex. Alex believes that understanding individual disability or personal health issues is central to the employment experience, but only in respect of identifying a barrier to the SEA's principle concern of obtaining the job.

> *Alex (manager): Within our (SEA) role, predominantly it is about trying to secure employment for our guys. But along with developing of that we would need to know about the individual disability, about their health.*

Manager Oliver also took this position, suggesting that SEAs were not health agencies and their staff were not health experts. Oliver stated that SEAs' staff had learned over the years to act cautiously with health, because health was not their competence.

> *Oliver (manager): [...] we are not a health agency, we are not health experts […] and anything outside of employment we have learnt over the years to be a little cautious about trying to get too involved with.*

However, manager Alfie recognised that improving health was an effect of employment because health may improve following the implementation of the supported employment process, even if health gain was not a planned outcome. Analysis of manager Alfie's responses showed that his clients with learning disabilities had a positive employment experience and he believed that if SEAs focused on promoting employment, then positive impacts on mood and on health may occur, even if this was not the primary aim.

> *Alfie (manager): They (clients with learning disabilities) are having a good time (in employment), they are having a good laugh and if by doing that they are going to get healthier, brilliant, but it's not the drive.*

In this case the manager felt no ownership of any health outcomes; they either came or did not come as a secondary effect of the job and one which they seemed to have no influence over.

Managers reported that dealing with health was not one of their SEA commitments towards their clients with learning disabilities. The main reason was that SEAs were not funded to promote health for their clients; therefore they did not have a clear obligation to support health. Manager Alfie described that SEAs were funded to carry out particular activities. SEAs did not receive funding for health therefore there was not a clear commitment for SEAs on health. This was in contrast to the idea health was important get and maintain employment.

> *Alfie (manager): So, it's difficult sometimes because the way we are funded, sometimes directs the way that we work. There is not a really clear obligation for us to support the health of our clients through, but it is common sense that if our client is fit and healthy, either it's going help us when we train clients.*

However, even if SEAs did not receive funding for health, they promoted and protected health through informal activities. These activities were in place thanks to the involvement of volunteers around health as reported by manager Antonina. Antonina did not agree with the fact they need volunteers to run a wellness group, but it was the only way for her service to address health activities.

> *Antonina (manager): No (we are not funded). I wish, but we are so lucky to have people volunteering. I do not think it is the way it should be, but I am delighted there are people who have got real passion out for the community, and if you find them, you can do things (run wellness group), even if you do not have the money.*

Manager Alfie shared his belief that health was important in getting employment, but he confirmed that they did not receive any funding.

> *Alfie (manager): So we think that if people are in good health, there are some advantages in people getting employment, but we do not receive any funding streaming to do that.*

SEAs' actions were generally influenced by the fact they did not receive funds to promote the health of their client.

The second reason was that SEA were not health experts, therefore they may not have the knowledge to intervene. In a professional sense, competency in the area of health was a dividing feature between managers. Some managers saw health as an area of technical expertise, the realm of other professionals, a professional competence that they did not have. This seemed to consider health outcomes that anyone could identify or aspire to, to be off-limits to their SEA.

Fear of being regarded as incompetent, or treading into what were seen as other professionals area of concern, was also part of this reluctance to see health improvement as a part of what SEAs could achieve. Manager Alex highlighted the limits of SEA's competence, feeling that SEA staff needed to be extremely cautious when dealing with health, by recognizing

that their priority was to support employment and that there were other agencies better placed to address the health needs than SEAs.

> *Alex (manager): We have to draw a line where our support starts and stops, so we have to be quite mindful over there, because we are aware that may be other agencies, which have better contacts, to be able to deal with health issues or things like that.*

Providing supported employment was seen as part of a "care package", providing holistic support to the client. Manager Becky described that there were different sort of activities that could promote health such as: walking groups, social inclusion activities, healthy eating at the local café and supported living processes within the organisation the SEA is working for. In this service supported employment was part of this wider network of concern looking at the person holistically.

> *Becky (manager): So we are kind of coordinator of a care package if you like, we can't physically do it ourselves, but fortunately we have got the resources within (name of the trust) where we can place people for a few weeks elsewhere just to see how things improve really. And that is kind of our holistic approach really, […] we have our local café project that offers healthy eating, menus, healthy eating plans or cookery tester sessions, so if it has highlighted to us that someone really need it, supporting those life skills, maybe signpost to one of those projects for a little while, to get their skills of feeling healthier themselves. Another project is (name of project) which is a walking group that do sailing and horse riding and physical activities, also encourage social inclusion to help people that maybe are experiencing mental health, social excluding, maybe depressed we would signpost to the walking group to help with those issues. We monitor it and check with them now and again to see if everything is going OK. […] Yeah. We do spend a lot of time with other multi-agencies working as much as we can about the difficulties coz it could be we are setting out somebody up to fail or having accident in work, you know, there is a lot of responsibility for us to try and get as right as we can. Yeah.*

This service delivery structure and care package arrangements for particular individuals may be organised such that it may help SEA to tackle health problems, signposting the problem to partner agencies.

SEAs are not formally committed to promote health because they are not funded to get this outcome. However health is considered an important factor for successful employment and health improvements can be positive outcomes of employment. However, health is not a primary driver of supported employment. It emerges how SEA must be mindful about health and safety measures because it is their commitment and it is part of the service they offer. However, some SEAs provided a wide range of support for the individual and therefore opportunities to improve health for employees with learning disabilities.

7.1.2 How SEA's process may be connected with health

Initial information emerged from the analytic process for managers showing how the SE process was connected with health. A network about how and why SEA's process may be connected with health emerged from data (Figure 7.2). The first node of the network is about assessment and specifically the descriptions of how and why the SEA staff assessed clients accessing the services to find a job. The second node is about the role covered by job coaches and their influence on employees' health. The third node is about the connection with health professionals and the reason why they are contacted by SEAs. The fourth node is about informal opportunities offered by the SEA itself for health. Finally the fifth node is about the relationship between employer actions and the health of their workers.

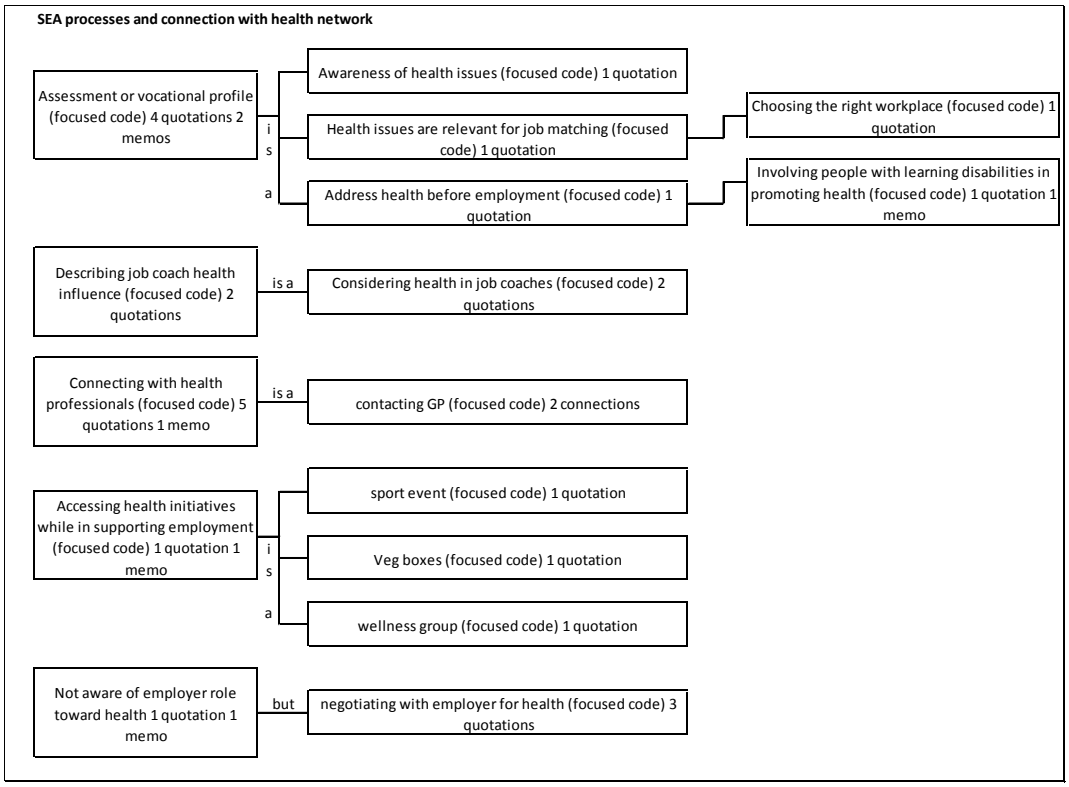

Figure 7.2: SEA processes and connections with health data network

7.1.2.1 Node 1: Assessment, the way to match the right employment

As a part to the SE process, every SEA asked questions about the health of their clients with learning disabilities who were referred to them for services. According to their managers, a wide range of reasons why assessment was important for the health of the individuals with learning disabilities are possible. Manager Becky believed assessment allowed the disclosure of health issues that should be taken into account by the service in finding them jobs. More importantly, health problems were named and described using the clients' own words. This was relevant because SEAs had the chance to better understand the disability and health problems, and because SEAs had ways to communicate this information to employers (with the clients' permission). This is an important source of knowledge on the health of clients with learning disabilities, because it allowed the SEAs to set up reasonable adjustments with the employer in the workplace to accommodate clients' health needs,

but at the same time this can be a problem if the agency does not understand health issues.

> *Becky (manager): We have a vocational profile document and it is looking at a person holistically […] There are specific areas of health and health issues for our clients to disclose to us. But more importantly for them to be able to put in their own words what their difficulties are, so that when we are approaching employers we are using the words of the individuals, how they would describe how their difficulties or their disabilities are. […] It goes in a bit more details also looking at their physical health requirements and their mental health and whether they see they need any reasonable adjustments in the workplace to accommodate those health issues.*

Manager Alex reported that the assessment process was important in understanding what sort of health problem a person experienced and to plan the required support and getting ready for work. In the early stages of an individual's supported employment assessment several questions are routinely asked by some SEAs about medications, health conditions and special dietary requirements. SEA staff also enquired if the client had had a health check with their GP recently or if they had left employment in the past due to health reasons. SEA's staff also enquired if the client would need further health support while preparing for work.

> *Alex (manager): We have been asked lots of questions from the early stages about their health, if they are on any medication, when it is the last time they saw their GP for a check-up and things like that. On our application form we do ask about health, if they have any health condition do we need to know about, details of their health condition and how it is managed. If they do have to take medication for this, if they are in special dietary requirements, if they do need any support while they are out preparing for work and if they have left employment due to ill-health, mental and physical.*

While sometimes health assessment was quite detailed, in other situations the assessment procedure was limited. Oliver reported SEA staff asked only about health issues that were possibly relevant to employment. SEA concerns were around the person being safe in employment and appropriately matched to a job. Oliver stressed the importance of not

asking about medical conditions, because it may result in overstepping the limit their SEA had in relation to health roles. However, while this limit may be clear to SEA staff, it may not be so clear for a client with learning disabilities. Indeed, individuals with learning disabilities may not be aware that a specific medical condition may cause problems in employment. As a results there is a possibility that health issues may be discovered later on, when they are already in employment.

> *Oliver (manager): We kind of put the ball into the persons' court to say: is there stuff that you think we need to know about, relevant to your health? And (which are relevant) to help you to get a job? But we have to be really careful not to overstep the mark asking about someone's medical conditions or health. […] We have to make sure the person is safe and OK as an agency helping to make sure the person is safe. […] if there are information we need to know about, we try to get them to tell us, and sometimes we discover things as we go […] We want to know if there is an issue that we need to know about, that has been dealt with or by the person or the person health practitioner. Especially because the employer needs to know and for us to be effective as a job matching kind of agency.*

Manager Antonina disliked the word "assessment", because she felt it was not the right one to identify how issues are best disclosed. Antonina wished to understand from the first steps what the cognitive abilities of her clients with learning disabilities were or if they had mental health issues etc.

> *Antonina (manager): I am not assessing it (health), I am just wishing to know. If they cannot read there is no point in sending a letter to them, it is a waste of time! Let's talk with them. By medical I do see this broader than their mental health and all their cognitive abilities.*

The assessment is important to understand specific needs and in order to best orientate the individual towards one job or another.

> *Declan (manager): It is an assessment, I do not like the term, but ultimately it is an assessment of needs that determines what need to happen next and from that they put on one or another road.*

The assessment is functional if we want to select the most appropriate job in relation to any health issues. Becky reported the importance of knowing, for example, if a person is overweight with stamina issues.

> *Becky (manager): You know if we are in front of someone who really wanted to do a physical job, maybe a little overweight, and maybe having stamina issue not to be able to stand all day.*

Manager Becky described how clients may not be able to tolerate bright workplaces because of epilepsy; they may prefer warm offices or cold workplaces. This was translated in the need to accurately choose the right workplace for a specific individual that lowed for their problem.

> *Becky (manager): A person (client with learning disabilities) that couldn't cope with bright lighting, warm offices, cold offices, all of that has got a part to play […] You know if we are in front of someone really wanted a physical job with maybe a little overweight and maybe didn't have the stamina issue to be able to stand all day.*

Manager Alex described how some jobs may be excluded from the range of opportunities because of pre-existing health conditions revealed through the SEA's assessment within the vocational profile. This was translated in practice into the choice not to place a client who had back pain in a physical job like gardening.

> *Alex (manager): When we see our customers for the first time, we do vocational profile. That is to look at all the areas of work they want to go into, but being mindful of any sort of health conditions they may have. So if (a client has) bad back we wouldn't put them into a garden environment where there is lot of physical work.*

In summary, the assessment procedure or vocational profile was the first stage where the health of clients with learning disabilities was taken into account. The assessment procedure allowed the identification of health issues and personal difficulties. This allowed SEA staff to describe the disability and health issues to employers and take measures to face it. The assessment procedure was sometimes facilitated by the presence of care

plans or reports from social workers or GPs. However, the assessment procedure may not be a one off process, because the nature of the disability and the nature of some health issues ensured that the SEAs needed to continuously monitor the health issues of an individual.

Overall, the assessment procedure varied from quite structured and detailed in order to detect health issues in some SEAs, to the process being much less structured in others. In the latter case, the reason was to avoid entering into an area that was not seen as a part of SEA competence; questioning clients with learning disabilities on health conditions. However, an individual may not know what information about their health might be relevant for employment, and health issues may need to be disclosed afterwards, when the person is already in employment.

The idea of health being a pre-condition to employment was more powerfully embedded in the minds of SEA managers than improved health being an outcome of employment. Manager Oliver thought that if a person is healthy, he/she had more chance of being successful at work and to stay in employment. Health became an issue to deal with if the individual with learning disabilities perceived it as a source of difficulty.

> *Oliver (manager): A healthy person is more likely to be successful, securing and keeping a paid job. If there are issues of health being a difficulty for a person that is an issue that will need to be addressed.*

Manager Alfie reported how not being fit and well can limit the job opportunities that an individual has, and therefore the SEA's ability to find them a job.

> *Alfie (manager): If you aren't fit that can limit your job opportunities.*

However, a person may not be so healthy or not have sufficient endurance at the time she/he applied for a job. Consequently, SEAs assessed clients'

personal health and needs as part of the actions they take in order to understand if the client was ready to work. Manager Declan described his agency activity primarily as an “assessment of needs”. SEA staff set out formally to understand what personal needs were and addressed them before the beginning of the employment experience. What was really important for Declan was that an individual may not be immediately ready to work, but that he/she can prepare to work with the help of the SEA.

> *Declan (manager): [...] the understanding that not everybody we are going support will have the stamina on day one to hold down a job. I think there is a process to build up that stamina quite quickly, but they may be things in there that would need addressing before someone starts. […] (Name of the agency) is an assessment, I do not like the term, but ultimately it is an assessment of needs that determines what need to happen next and from that they put on another road.*

Health was not SEAs’ core business, but health was core to employment. Managers saw the main role of SEAs as supporting individuals with learning disabilities to get and maintain a job. Therefore SEAs needed to consider the health of their clients. This was relevant to the SEAs because a healthy individual was more likely to have a greater range of jobs to choose from. Secondly, a healthy individual was more likely to get and stay in employment. However, not everybody presented the perfect conditions to start a new job. It was the SEA’s duty to avoid moving someone who they believed was not ready in health terms for employment into employment. Managers did believe that they could influence health but mainly to achieve a certain level to make the job placement successful. Health issues that may results in a problem for the individual into employment need to be tackled and addressed by SEAs.

One option to tackle health problems that may become an issue in employment was to involve health professionals before starting the placement process. Manager Declan explained how he involved health trainers with learning disabilities to advise and support SEA clients with learning disabilities on health issues. That was felt to be a good idea to

promote a wide range of healthy activities, but for lack of funding this initiative was stopped.

> *Declan (manager): In (name of the city) we have got some health trainers which was people having learning disabilities who were trying to provide advice and support. […] our original idea was to work with them and (name of the agency) so when someone signed up for employment they would immediately be signposted as well to a job coach and also to a health trainer and also again that will be some assessment of needs and the sort of things we were looking then as well as the dietary stuff, we were looking at walking clubs, we were looking for people to access the local authority gyms and swimming pools, […] And again some of that Saturdays clubs idea. It is a fabulous idea, but the difficulty is proving the business case and having it funded separately to employment funding.*

According to managers health was an important pre-condition to employment and therefore it was important to address health issues early in the SE process.

7.1.2.2 Node 2: Job coaching and health

The second node of the emerging network reports how the job coach was, the person in charge of checking that everything was in place for the client.

Manager Rachel described several tasks of job coaches: the first task was to ensure clients were safe at work, had the right food and built up positive relationships with colleagues. This care process was itself able to nurture the desire to establish a friendship with the JC, which may be of importance to the client's on-going health and well-being.

> *Rachel (manager): They (job coaches) are out there with that individual, to make sure everything goes right for them. Make sure the individual has the right food, the correct moving in their handling, making sure that they build relationships and build a friendship has a huge impact. If you haven't got a friend you feel quite lonely, having a friend, somebody who cares about you has a huge effect.*

Manager Alex suggested job coaches can motivate healthy behaviours, by suggesting eating healthy food instead of unhealthy food.

> *Alex (manager): Someone sat down maybe having a lot of bags of crisps, lots of sweets, and all these sort of things. And maybe (JC) just sitting down and say: "Have you thought about a piece of fruit?" Just little things like that, might make a little bit of difference.*

In summary, the job coach acted as a supporter for the employment experience, but also for clients' health. This was possible because of the important relationship the job coach established with the clients. The job coach was able to motivate clients to choose healthy behaviours and motivate them for healthier lifestyle, thanks to the element of trust and confidence established in their relationship. It is clearly important how the job coach conceives their role, and how they think about their own health, if there is to be a more consistent approach to harnessing job coaches in this low level health promotion role.

Also, the job coach was in the right position to notice poor health or health behaviour in the workplace. Manager Declan compared the job coach to a GP, because he/she may detect health issues, but may not take direct actions to sort the health issue out.

> *Declan (manager): The job coach like a GP may flag this (health) stuff up, but won't necessarily do much about this stuff themselves.*

Manager Oliver described how the job coach can identify a health issue and pass it on to health professionals or to other relevant stakeholders.

> *Oliver (manager): Job coaches are more likely to identify if there is a health issue in the first place and therefore are more likely to be able to help to do something about it. That is just talking about the issue with the person and perhaps helping the person to engage with support elsewhere, with family members, doctors or health practitioners.*

Manager Alex reported that the JCs were in general not committed to health, but that they were in the right position to spot risks to people's health and provide suggestions to pursue a healthier life. However, these informal suggestions were not generally on the job coaches' agenda.

In summary, job coaches acted to protect health in different directions. They need to be multi-tasking in the way they approach their roles as they occupy a role of motivators, they are able to notice health issues emerging in the workplace and they may be in a position to alert and contact relevant health professionals.

7.1.2.3 Node 3: Connecting with health professionals

Figure 7.2 reports how employees with learning disabilities may access health initiatives by attending the SEA for training or other activities promoted by the SEAs. This is the third node of the emerging network of codes. Indeed, the SEA passed information on to their clients about health promotion activities in the area. Manager Oliver explained how clients attending meetings or training at the SEA premises often accessed the nearby gym.

> *Oliver (manger): Just around the corner, there is a gym and some people access that while they are with us. But that's not set up by supported employment. We have genuine supported employment, training activities not paid to evolve people from day services. It tends to be people from those services that access to the gym. Some people in employment are accessing the gym on the days they are not working and it helps promoting their health, which is actually relevant in getting a job.*

Manager Alex explained how a client with learning disabilities accessed the local gym while attending a training unit of SEAs.

> *Alex (manager): So we would make some sort of recommendations towards that (health concern). We have got a new centre, just opened; we have got activities advertised for people with*

> *disabilities. We passed on to our guys in case they are interested in that, making them aware of that. We have seen results from our guys in the training unit accessing in gym here, just feeling better about themselves, more confident, and coming out of theirs shelves a little bit more. It is a long road, but for some people has been quite important to do. I can certainly see the benefits of it.*

Manager Alex reported health conditions, such as obesity, were observed in the training unit and SEA staff gave advice on possible barriers obesity may raise into employment. As shown in the next memo, this is a relevant but difficult issues for managers of SEAs. Indeed, employees are vulnerable adults, therefore it is hard to define the boundaries of interventions on the health case as reported in the following memo.

> MEMO: Obesity may be a barrier for several employment positions. Managers are dealing with adults. They are vulnerable adults therefore it is hard to define the "ideal" level of interventions on this matters by SEAs. Maybe just making sure they are correctly informed about obesity and health risks? Do they know what to do to fight obesity?

SEA staff passed information on physical activities, on a local gym, to incentivise the client attending and maybe losing some weight to be able to access a wide range of employment positions.

> *Alex (manager): (Health improvements are) Turning up on time, being dressed appropriately, these sorts of things. But also looking at someone overweight, maybe targeting a development plan targeting it and so "how do you feel about that? Are you comfortable with this?" This could have a detrimental effect on your employment chances for doing a job, for example. It does become recognized and so we make arrangements, we have a gym on site, some of the guys may use, they have a programme, to feel far better themselves and confident, saying "I have lost so much weight!" or "I have achieved that "or "I have met new people". Through carers and parents they may be able to say; actually we have seen a bit of a change in the individual.*

Manager Alfie described it as "risky" for the SEA staff to deliver health related activities because they were not trained in health issues. However, this lack of training did not prevent SEAs providing sport activities that were intended as an attempt to keep the clients active, rather than as a

project to promote clients' health as report in the quote and in the following memo.

> *Alfie (manager): There are difficulties and risks attached delivering sport activities and health and fitness and giving advice when you are not a doctor or a clinician. We try not to focus on the fact we are not experts, and just focus on the fact we are trying to get people more active.*

MEMO: SEAs' managers may claim sport activities are not just related with health but also with social and learning opportunities and therefore link sport activities with the core of SEAs' business. Important point of the theory.

Manager Rachel explained that health professionals were contacted when needed and it was very condition specific.

> *Rachel (manager): We are more involved with the health professional if there is a specific condition, if they have got their problems or if they have diabetes, yes, we are more involved then. If there isn't anything majorly specific for the individual, the only time is when health reviews are called, when the care manager calls the review. So yeah, but it is very condition specific.*

Alternatively, if a health problem was identified, some agencies preferred linking with carers and families first, to be the first point of contact. Manager Oliver explained SEA staff did not deal with health professionals in every case, but it was case specific because some clients with learning disabilities may have a closer relationship with health professionals.

> *Oliver (manager): Carers will be the first we are addressing the health issue if we are spotting something at work, because it is much more appropriate to be done from the agency that supports the person at home.[..] We do not deal with health professionals in every case and with every person that we work with, but some people may have a very close relationship with health practitioners. There may be a community nurse that helps support the person application and in the workplace, maybe occupational therapy and GPs that are working with the person on a particular issue.*

Manager Alex simply thought it was a good practice to record the name of the GP in case health problems arose.

> *Alex (manager): For the benefits of the client we may suggest linking with the parents and go to see your local GP and things like that. We sort of write GPs names down for sort of reference for the future that maybe useful if linking with them if we have health concerns or something that can come up as we work with the individual.*

In summary SEAs linked with health professional if there were health issues to be tackled. SEAs adopted a soft touch approach, providing employees with leaflets of a local gym or discussing a health issue that my hinder employment opportunities. SEAs may offer solutions to tackle a health problem, or offer sport activities which also offer social and learning opportunities. SEA staff contacting health professionals is condition specific, and some SEAs preferred to contact families first. SEAs also kept GP records in case of health issues occurring whilst in employment.

7.1.2.4 Node 4: SEA informal health initiatives

I will now present node 4 (Figure 7.2), describing how SEAs planned and delivered health initiatives aimed at improving personal health. This was an innovative and unexpected part of the agency provision.

> MEMO: Good point: SEAs offer health activities or programme because they feel they need to. Would individuals with learning disabilities benefit from these initiatives?

The first initiative was run some time ago and it was designed for people living independently, but it was no longer available at the time of interview because of lack of funding. It included the provision of boxes with vegetables and all the ingredients to cook an easy, but healthy meal. The box included an easy to read recipe for people with learning disabilities, enabling the individual to cook and share with friends this experience.

> *Declan (manager): There is a programme I ran 2 or 3 years ago that was noticing that people that are now living independently, no one gave the skills to actually cook. They were able to shop, but*

> *they were buying pies or microwave stuff. So what we did is a programme working with the local coop and we had a scheme where we had 2 or 4 people with learning disabilities who ran the programme with the support worker and what they did every week they would provide kind of like an organic veg box, but within that box you had everything you needed to make two meals. We went to the coop and they provided fresh veg for us like peppers, parsley, whatever you might need. There was all vegetarian, however there were some of the option where you can add meat if you wanted to and there where many recipe cards accessible, to show how to chop an onion and fry. […] The idea was to not only to cook for yourself, but then introduce some social; you might invite someone else and cook for them as well. […]. It didn't quite worked as I invented it, but never of the thing I ever set up never quite work in the way I invented it. But the idea of providing healthy food was a way of kind of influencing in that family thing.*

The SEA delivered the training and prepared the clients to run an Olympic Games sport event. It was challenging, but people learned how to be more active and how to motivate other people.

> *Alfie (manager): We decided to have like a two weeks training course first where we taught the individual how to deliver and learn the sport, get involved in sport and become the athlete's motivator that they can do not just in the sport day, but in the day service they are in. We had an introduction day and it was a six days programme.*

Manager Antonina described the wellness group run in the SEA, where a teacher offered a well-being session where clients with learning disabilities learn how to relax themselves.

> *Antonina (manager): We definitely made a change, as we speak now, there is a new group going next door, a wellness group. They meet once a week. A volunteer teacher, a school teacher comes in between her school lessons schedule; she gives a well-being session to staff, supported adults coming to us each day. They all come out relaxed. That (course) has been running 3, 4 weeks now.*

In summary, some SEAs provided health related activities that they were not receiving funding for. Indeed, the veggies boxes initiative was no longer available. The Olympic Games was a great success and it will be

followed in the future by a football tournament for people with disabilities. Other initiatives like for example the wellness group continue because of the work of volunteers and are not yet a fully implemented part of the service or model.

7.1.2.5 Node 5: Lack of awareness on employers' role for health

Figure 7.2 last node is about the lack of awareness of managers about health initiatives organised by employers. Managers attempted to describe the role of the employer in the health of their employees, but the majority were unsure about the role played by employers. Manager Alfie hypothesized that large employers may have the resources to promote health. However, it was a difficult area, as it was not clear if health was the employer's responsibility or the individual's responsibility. Alfie hypothesized that employer's indirectly promoted healthy lifestyles at work through offering food choices in the working premises.

> *Alfie (manager): I don't think really. I do not know, maybe large employers, maybe they have resources to do that. I am not sure; you have to put a line between what has to be the responsibility of the employer and the responsibility of the individual. […] What they can possibly do is make it hard to have an unhealthy kind of life, not having a chocolate machine and fizzy drink machine at the end of the office. There are things you can do indirectly.*

Collaboration between SEA's manager and employers was about the individual personal situation. Manager Becky reported some employers to be concerned about employees' behavioural changes at work. A signal such as clothes not being washed may raise the alarm bell for SEA staff to go and see the individual.

> *Becky (manager): They (employers) may ring and say I don't know what is going on today but, she is not being right or they might mention her clothes haven't been washed or that maybe help to raise the alarm being more aware that we need to be going in and looking at what is going on, some are less understanding.*

SEA staff constantly nurtured the relationship with the employer in order to negotiate changes at work when ill-health occurred. Manager Becky explained how she negotiated hour changes to suit a person who experienced a health condition.

> *Becky (manager): We can have people who while are in employment have episodes of ill-health and it is about nurturing the relationship with the employer, that the person can have time out of employment until they are recovered. […] For specifics bad health at work we have a couple of people in care, so we are going into negotiations with employers, saying that person is struggling a bit at the moment, have some flexibility with their hours, you know, if they are starting early, can we make it a little bit later.*

> MEMO: EMPLOYERS AND ILL-HEALTH: Employer referring if ill-health or something is wrong. Employer train employees with learning disabilities Is it useful for them? How are they involved? Gap!

This memo was useful to start and think about at some points and new questions. However, managers are not so aware of activities organised by employers, therefore there are some gaps that should be considered in future researches.

In conclusion, the communication between SEA staff and employer was fundamental for the health of employees with learning disabilities, but it was mainly case specific. Employers were able to detect health problems and employees' behavioural changes in the workplace. These were then reported to SEA staff in charge to address these issues, contacting the relevant support network. Communication with the employer was vital to negotiate reasonable adjustment to accommodate an employee who developed ill-health. However, SEAs' managers were not aware of health activities organised by employers. This may represent a missed opportunity to promote health through employment.

7.2 Relationship network

Managers highlighted how the relationship with the job coach can be important and may have an influence on employees' health. In employment the individual established relationship with colleagues which may influence his/her health. Besides, managers reported that we should not underestimate the family and carer influence. The following network is about other relationships which may influence the individual's health (Figure 7.3).

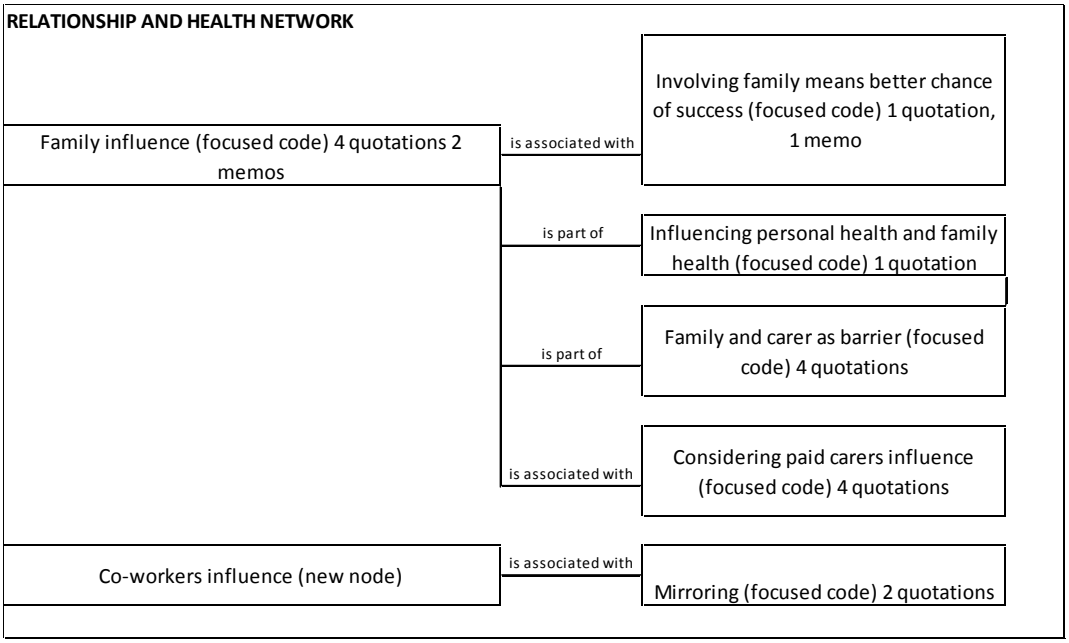

Figure 7.3: Relationship and health network

7.2.1 Mirroring co-workers

In employment people with learning disabilities may imitate their co-workers they spend time with (Figure 7.3). This practice was positive as it helped the employee to think about healthy habits. Manager Rachel reported how healthy eating may be learnt observing other co-workers eating healthy food or avoiding sugar in their drinks.

> *Rachel (manager): I think that people mirror people. They (clients with learning disabilities) do not want to eat chocolate or a packet of crisp if*

the co-worker is eating yogurt and an apple. They are not putting three spoons of sugar in their tea. I had physically seen it. The lady she had coffee, three sugar and she built up a fantastic relationship with a key-worker. She used to drink black tea, no milk, no sugar and at the end the lady working there wanted the same.

This is a fundamental point in the analysis because mirroring could be used to improve the lifestyle of individuals with learning disabilities within the workplace.

7.2.2 The family and carer influence

The influence of family and carers on the health of people with learning disabilities was significant in this study. Family is the context where both healthy and unhealthy habits are most likely to be primarily learned. The influence of family on people's health was described positively and negatively by participants.

MEMO: FAMILY ROLE: Some managers explain how the family play an important role in the supported employment process by facilitating or hindering it. It is worth to consider family role for health in relation with employment.

Manager Oliver described how caring parents helped their children with basic hygiene and in identifying health issues, while other parents negatively influenced their children's behaviour, being potentially part of the problem.

Oliver (manager): Family members can be really important in either helping or hindering the health of that individual to be as good as can be. So, on a positive side, Mum and Dad can be there to remind something basic as cleaning their teeth or bathing or if you have got a pain and you have to see a doctor. They may spot something unusual about the person on physical appearance or health or mental health and therefore to be able to help prompt the person to do something about it, seeing a doctor or going to hospital. In the negative side not every family is as active, not every Mum and Dad is active as that and they can be actually part of the problem.

Some people with learning disabilities lived their lives following the same health behaviours as their parents, with a similar effect on their health. Manager Alex reported involving parents was a variable contributing to success in getting a job, but SEA staff needed to be extremely careful not to highlight a health problem that was not perceived as such from parents.

> *Alex (manager): We can have people choose to leave their life as the same fashion of parents, it can have a knock on effect to their children and how they want to leave their lives and that can be really difficult to break if it was a negative aspect of that […] and sometimes you have families and carers who are really proactive, but there are people at the other end of the spectrum. It is a bit of a balance out there, really. If you involve families lot more you can have greater success in getting that person a paid position. If there is a health issue we have to be really respectful, we have to do things really carefully because it could be that if you are talking about someone's weight, they may be thinking it is not much of an issue. You have to be really mindful and respectful. They may not see a problem. […] By involving the parents, involving the families, you are going to have great success in changing some of the health issues. If you have someone on board and show that's where we are and that's where we are going achieve doing these steps. If they agree it is much more likely it is going to work because they are going to work with us, and pass that influence at home as well.*

Manager Declan explained how SEA staff dealt with a background of poverty and unemployment in the family of person with learning disabilities they were supporting. Poverty and unemployment hindered healthy lifestyles.

> *Declan (manager): The problem we have is that the people with learning disabilities are in three or four generations of unemployment, so people we are supporting come from families that never had job as well. So that is another barrier for us, so the implication there. So we are not dealing with disability, but it is about poverty. Once you are dealing with poverty then food and nutrition and exercising is a huge problem and that is where your obesity comes in and where the junk food culture and the bad sweets and I think in that sense we are just dealing with families.*

Involving the family in the process of support was for many SEAs good practice. Manager Becky described the family being the people who knew

the client with learning disabilities the best. Negative family habits around food may be carried on by the person with learning disabilities, particularly when parents had disabilities themselves. A way forward was an alliance with social workers, who tried to help with a healthy eating plans and being more active.

> *Becky (manager): Parents and carers obviously know the one they love best, so we do liaise with parents and carers. Sometimes it's becoming a conflict because we want somebody moving out of a conflict zone and parents and carers wanted to stay there. "He has always eaten this or that, he won't eat anything else or…." […] And some of our parents and carers have disabilities themselves so that can be difficult as well, you know, so yes, it is a difficult one, because you may be trying with what we are doing and maybe lining with social worker and maybe the house, they are all trying with a healthy eating plan, get somebody exercise a bit more to increase the stamina so that they can stand for longer, you know.*

Manager Rachel reported that some parents felt their son or daughter's disability was an excuse for their children to avoid physical exercise. This may compromise job negotiation as parents thought their children were not able to tolerate a physical job.

> *Rachel (manager): We are all the same, being a parent, it is your child, and you want the best for your child, don't you? But sometimes parents could think their children do not need to exercise, he is disabled, leave him alone. […] I can see where they are coming from. "My daughter working in the cold, in the rain? No, she is quite happy to stay in a corner of the day centre". […] Yes I understand, but are you giving the right choices? As parents or carers we can give the opposite of what we really want, or do the opposite of what it is good for them.*

In conclusion, in the view of SEA managers families had a mixed influence on individual health. It was generally agreed it was important for SEAs to involve families in the process of SE, because they were generally people who knew the individual with learning disabilities best. However, involving families was a challenge when health problems were not perceived as a problem by the family. Several families were supporting the health of their

relatives, while other families did not appear to address unhealthy behaviour. Employees with learning disabilities may come from a background of environments associated with poverty which may exacerbate unhealthy eating and lack of exercise.

Paid carers also played an important role in promoting the health of the clients as described by manager Oliver.

> *Oliver (manager): I suppose the other thing in term of paid carers, […] (is they) have a role to play helping to promote individuals own health as well.*

Manager Rachel explained how paid carers actions were often limited by constraints around having to keep to the care plan and consider health and safety measures. They did not want to take responsibilities if their actions were not in compliance with the person's care plan. This attitude may prevent the individual with learning disabilities experiencing new life opportunities.

> *Rachel (manager): There are so many policies and procedures and constraints. I think carers are scared to do a lot of things. Going out with the individual doing snowballs, there is nothing wrong, but if somebody broke his finger? Normal things like go for a run or going in the park, shopping, staff is really scared to do unless is down in their care plans. We have gone health and safety mad and it stops a lot of things. […] I think health and safety sort of stopped all that for people, but I think if it is written down in the care plan they are quite prepared to do that. They are not doing it if it's not written down. It is sad. The experiences a manager had with a paid carer were absolutely negative for the client. In one case the SEA was able to keep the person in employment, in the other case a lady quitted the job and so far she has not come back to work, needing more care to help her to socialize.*

Manager Antonina reported having had negative experiences with paid carers. A paid carer unsuccessfully encouraged a client to leave the company he was working for, because his job was made part-time due to the economic downturn. Antonina fought to keep this gentleman in a part-

time position, when the carer wanted to take him out of employment completely.

> *Antonina (manager): This year I had to complain about a paid carer because she was encouraging one of my employees to leave, because I have not got enough hours for him, because of the cut backs. Rather than make him redundant, we were keep him and making him part-time, because it seemed to be the best thing for him. His paid carer was encouraging him in front of me and in front of (employment organisation) to give it up, the work he has here and go into unemployment. Encouraging this to somebody who has a mild learning disability and ongoing mental health options. I know it is not ideal that it's to be part time, when I have additional hours, we always try to give to him, but I think it is better to have that than sitting at home, it would be an absolutely disaster. It was a national paid carer that was recommending that as a responsible route.*

Antonina reported a story where another paid carer successfully encouraged a client to leave the job because of a temporary health condition, with negative consequences on the client's life. Indeed, the client was still unemployed at the time of the interview, and the client needed more support because she had become socially isolated.

> *Antonina (manager) Her (client's) carer recommended that probably it was a little bit too much, back pain, headaches, symptoms causing her too much distress, probably she would be better off, not being in employment. She was encouraged, against all of our advice to give up a full time job with a local farm company. She was on a production line. That's was a couple of years ago and she hasn't worked since. And all that was wrong with her is that her body was going through a natural change […] there was a not big underling problem. […] We have nothing to deal with her anymore, but one of our colleagues, she keeps in contact with her and as far as I know she is not doing anything now. My cynical view is that she is a burden on taxpayers, because now she needs even more careers, because she has to be able to socialize, to go out and shop. I don't have a very good opinion (of paid carers) and it is based on experience.*

In conclusion the role of paid carers was controversial. Paid carers needed to respect the care plan made with the person that sometimes limited their actions in relation to the cared individual. SEA staff also reported arguable

choices carers took in relation to employment and health, leading some people to lose a job and to become more isolated.

7.3 Comparison within data and analysis of the literature.

The data reveal that SEAs were not generally committed to promoting health as part of their agenda but SEAs did offer many opportunities to become healthier in the workplace. However, it does appear that potential opportunities have been missed by SEAs. Figure 7.4 reports a super network summarising the findings emerging from the analysis of the contribution of managers. It shows a number of important factors such as:

1. **Lack of formal involvement in health:** from the manager's contributions, SEAs did not see themselves as health related agencies and were not experts in health or promoting health. Therefore, SEAs generally do not consider health as a priority and SEA's tried not to become too involved with health issues. This was generally explained by the opinion that SEAs were not funded to support health and furthermore and SEAs did not have the right knowledge to support clients with health.

2. **SEAs were not funded to deal with health and they felt their staff not to be competent enough to deal with health matters**, therefore they used multidisciplinary approaches and linked with appropriate agencies and health professionals. One manager of a SEA reported the service to be part of a wider organisation offering also health support. This agency was able to count on a wider network which helped with the employees' health.

3. **Good health is a pre-condition to accessing employment:** SEAs helped the individual to get, and stay safe in employment. SEAs performed a structured assessment including relevant health questions, they ensured the client was working safely and they

influenced clients' health throughout job coaching. Indeed, several jobs were excluded because of a pre-existing and known health issue, or reasonable adjustments were adopted to limit the risk for employees' health.

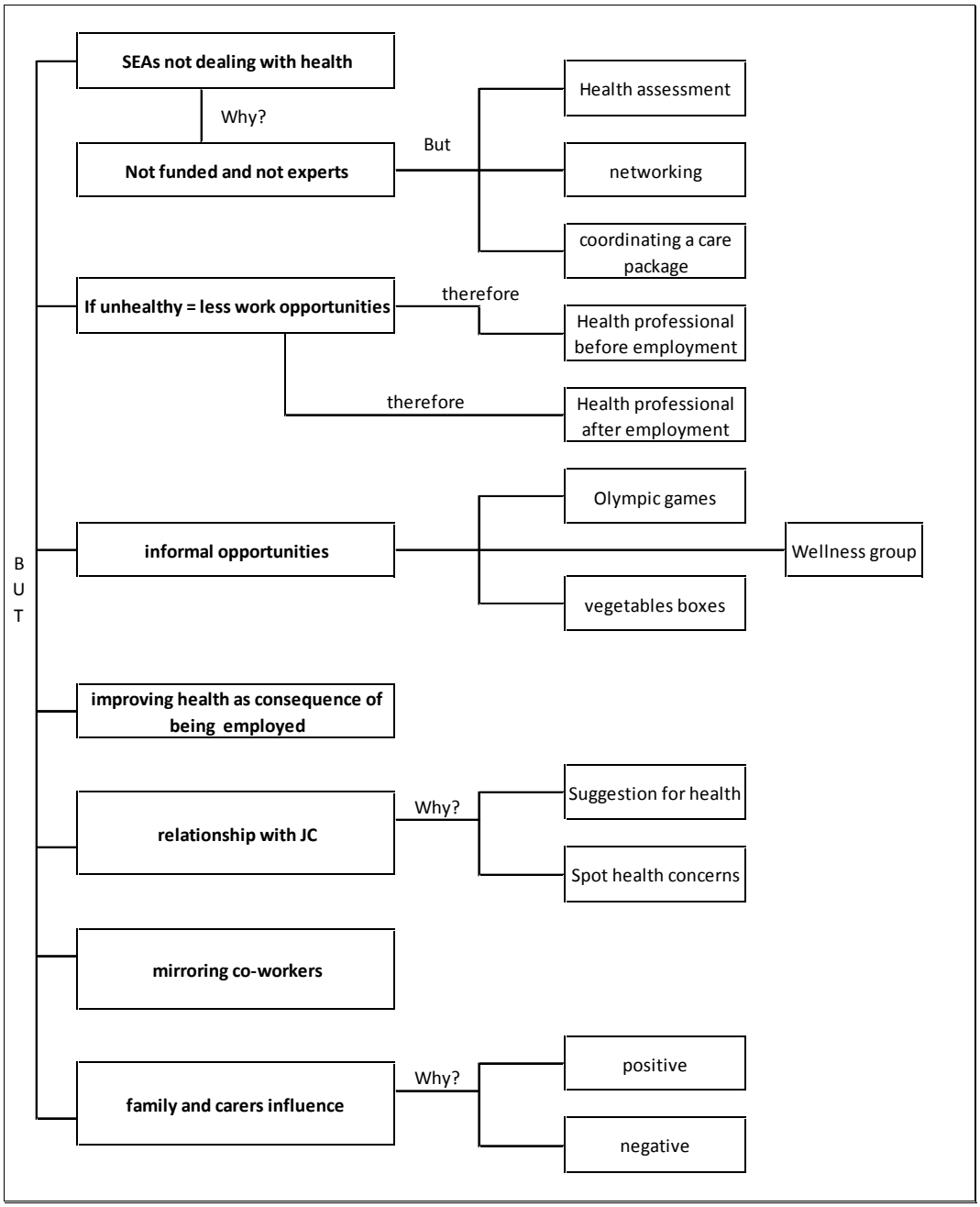

Figure 7.4: Super network (2)

4. **Job analysis, job negotiation and job coach monitoring activities were fundamental steps to protect clients' health and to match a job to a client's health need.** However, SEAs did not

explore using the right job match to improve people's health. This could have been done by choosing a job with episodic standing when if there is a need to build up stamina. This represented a missed opportunity for SE to improve the health of individuals with learning disabilities in employment.

5. **The job coach was seen to be in the right position to spot if the person had any health problems and to assist in finding help** if the person needed it to address the problem. The job coach was often able to establish a relationship of trust with the client with learning disabilities and this had some health benefits in terms of motivation, advice giving and signposting to other health related services. This has been already highlighted in previous research (Beyer and Kilsby 1998; Beyer et al. 1996).

6. **Collaboration with employers on health promotion was not well developed**; particularly SEAs did not generally know what the employer was offering their employees in this respect. However, the communication with employers on health issues was important for the employees' health, through helping to identify problems, and solving these, early on.

7. **SEAs ran several health initiatives on an informal basis**, with the aim of improving the health and well-being of clients with learning disabilities. These initiatives are promoted because there is a general feeling that employees with learning disabilities would benefit from this activities. SEAs claim these health initiatives have an impact not just on health but primarily on social and relationship side of employees' lives.

8. **Employees with learning disabilities started to exhibit more healthy behaviours after mirroring their co-workers who had more healthy lifestyles.** This may be seen as an important future

opportunity, with co-workers potentially helping clients to lead healthier lifestyles.

9. **The role of families on health was dependents on the family lifestyle and how the client was influenced by it**. Managers considered the involvement of families paramount to a successful SE process. This is because families facilitated the process of supported employment.

10. **The carer role on health was controversial on health.** Carers must respect the care plan and sometimes this may hindered health opportunities and lead to arguable choices.

7.4 The theory: no health commitments but opportunities for healthy lives

The emerging theory describes how and why SEAs were not committed to support employees' health, but looking after employees' health was a consistent part of their duties performed during assessment and job coaching.

Health is a pre-condition to employment because employment can be negatively affected by ill-health; health is therefore a relevant factor to be known and protected in SE. Several opportunities to support employees to achieve more positive health appear to have been missed out because employees' health issues hindered work opportunity, rather than work duties being considered as a way to became healthier. In other words few SEAs acted to help improving health in employment.

However, several informal activities were set up by some SEAs in the attempt to improve the health of employees. These activities were promoted by SEAs' staff, who claimed these activities to be organised not

just to improve employees' health but also to improve social skills and offer new learnings. Only a portion of SEAs considered SEAs' staff lack of health competence to be an issue. The role of SEAs' staff is to protect health through job coaching and the SE process and to promote health through job coaching and informal health initiatives. It emerged how job coaches and co-workers had a central role because employees with learning disabilities mirrored their positive health behaviour. Indeed, the relationships between the job coach and co-workers may impact on the employee's health and this aspect should be furtherly investigated in future studies. The influence of family and carers', together with their "health culture", had an impact on employees' health that has to be considered.

8 From coding to theory: the contribution of job coaches

The chapter describes how the analysis process was developed from coding to the emerging theory for data from job coach interviews. Job coaches supported their statements with practical examples of how health is considered in SE. Several codes were generally grounded in the data. The emerging themes were “assessing health” (12 quotations), “improving health” (12 quotations), job coaching (6 quotations) and “job analysis considering health” (5 quotations).

8.1 Health benefits of being in employment

Several health benefits of being in employment were reported by job coaches. In the conceptual analysis health benefits are linked with good mental health and cognitive improvements for the person of being employed and by the fact people with learning disabilities are learning new skills (Figure 8.1).

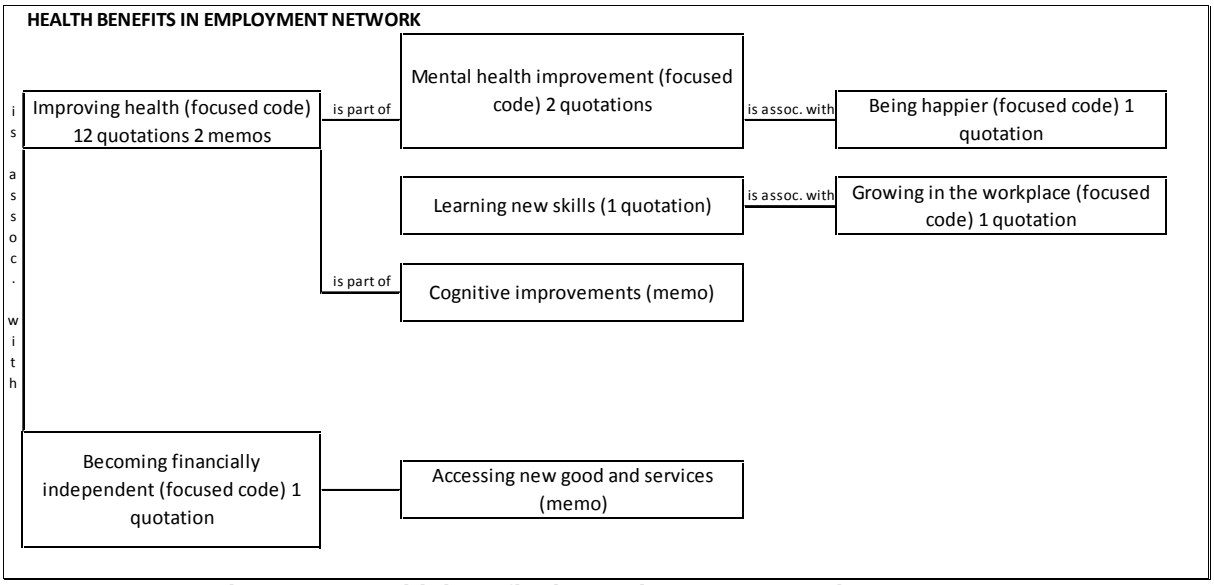

Figure 8.1: Health benefits in employment network

Job coach Chloe reported how she noticed health improvements in employment. Employment may not be an option for every person with a learning disability because she reports for some people employment may not be the right option. But for others employment helped employees to build confidence, self-motivation and improve their quality of life. These improvements took place if the work environment was appropriate for the individual. An assessment was carried out to check out if the work environment was appropriate.

> *Chloe (JC): Me personally, I see customers spread wings and fly. Some people see them because they have illnesses or health issues as they can't do anything, you know? Put some sort of fluffy stuff around them and protect them, is this necessarily a good thing? For some people yes, I would say yes, definitely, they do need to be protected and for them is not a realistic option to go to work, but in the other side I would say definitely. I see people improve health wise from being at work and as long as the environment is appropriate, of course. […] They do improve, I have seen people who had asthma, quite severe, but because they concentrate on something else, it is taking away the anxiety. It is quite interesting to see how sometimes it works*

Job coach Justine explains how employment had a positive impact on employees' lives, while giving sense of direction, achievement and a purpose in life.

> *Justine (JC): I feel employment gives them a purpose, a sense of direction, a sense of achievement.*

Job coach Ava described how she has been doing intensive job coach support to help an employee with customer service and other interactions. Teaching a new skill through job coaching makes the individual happier and more confident than before, therefore this new feeling may help with general health.

> *Ava (JC): So she is working with customers now and I am going in and doing some intensive job coach support with her, mainly based around customer service and social interactions with others, because she interacts, you know, it is teaching a new skill and she is lot happier and she is a lot more confident and I think in turn it would help with her general health and well-being, you know with her mental health.*

When the employee was working more than 16 hours per week, the process of coming off welfare benefits started. Job coach Anthony described that this was usually perceived to be a stressful process, both for the client and the family because of the loss of a secure source of money. However, becoming financially independent allowed clients to cultivate their passions, such as going to a football match.

> *Anthony (JC) Going into employment is all about getting off from benefits, they are going be financially able to maintain the job, being financially secure, because a lot of them are coming off of benefits long term, so that's always really stressful, not just for the customer, but for the family and key workers involved and things like that. [...] One person I know can afford to go to see Liverpool games now. The social aspect for him, he used to go to the pub and see on Sky. He can go with his key worker and see it. It is a great deal for them to be in work.*

Being able to pay for a football match or to buy a present for a loved one had a huge impact in developing sense of self-worth and inclusion in wider society. The employee with learning disabilities was actually able to do what he liked and what generally other people can afford to do. Job coach Justine highlighted how Gregory started to afford to pay for extras such as holidays when he started to work full-time.

> *Justine (JC) […] so lots of things he never ever experienced, and the fact that he can buy his wife presents, you know, the financial, have another holiday. It is things we take for granted, but it is things Gregory has never been opened to have it until he came to work, until he actually came to work five days a week.*

Work experience had different meanings for people with learning disabilities. Job coach Chloe described how an employee developed a positive feeling and sense of gratitude towards the State. He received welfare benefits related to his disability and now the employee was giving something back to the community throughout employment.

> *Chloe (JC) One of my customers said: "I get money paid by the State; I want to give something back". As a result they feel good about themselves because they are actually giving something back. From a health perspective it seems to help them to cope, maybe even improve.*

In summary, employment may help with health in different ways. The main way is that employment contributes by increasing personal confidence and gives a sense of direction and a purpose in life. It increases self-motivation and sense of achievement and it contributes to increasing quality of life. Earning a wage in employment means that a person can access goods and services that are inaccessible to them when they are not in employment. Employment and SE helped the individual to learn new social skills which contributed to make the individual happier and able to face a wider range of social situations.

It emerged from the data and analysis that health improvements in employment are linked with the assessment of needs and health issues in SE.

8.2 Assessing health to match to the right employment

The assessment, together with personal care plans, were used by job coaches to monitor the health of clients with learning disabilities in

employment. The following network is about the assessment of health in SE (Figure 8.2).

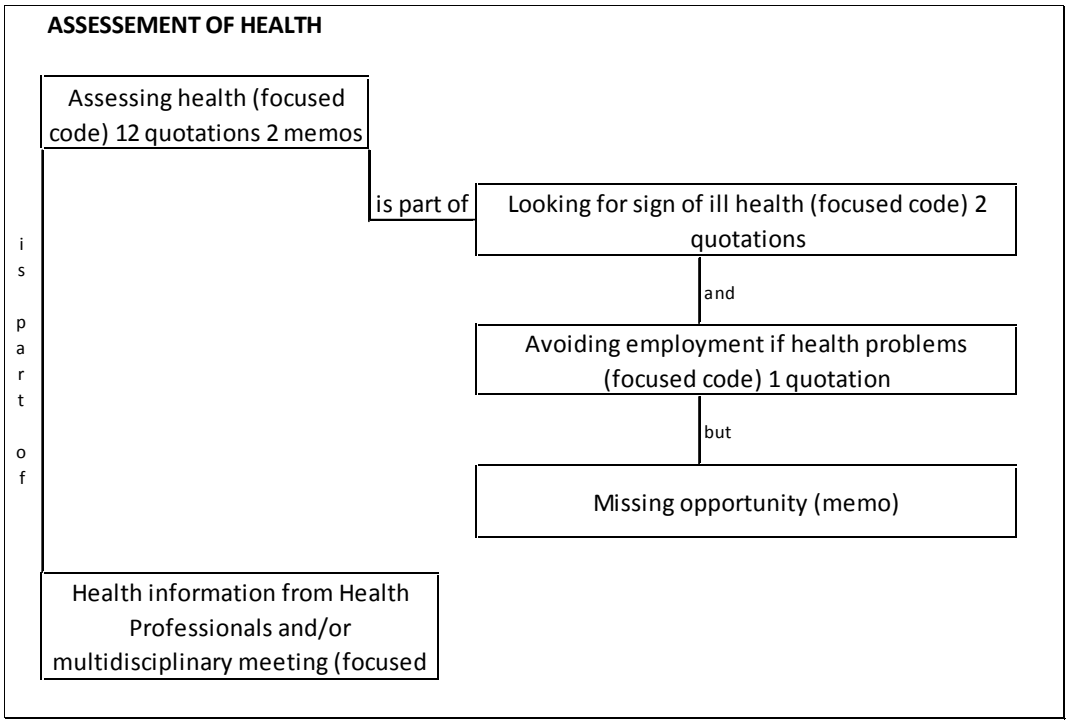

Figure 8.2: Assessment of health network

Job coach Bethany relied on the care plan and on multidisciplinary team meetings to help with monitoring the client with learning disabilities. This is an important point which underlined how the assessment was not just a one off process, but it needed constantly to be monitored, recorded and discussed in multidisciplinary team meetings.

> *Bethany (JC): If they have got a physical disability, we go through their care plan, we work alongside the multidisciplinary team. You can have an individual who can be up and down with the disability, so you have to work closely with them, because some days and some weeks they could be feeling worse than others, so it is a constant monitoring process which we have to record.*

SEAs looked at the abilities and at health issues in the assessment process. Job coach Chloe highlighted that they already have information on client's health from reports from social services or GPs. The assessment phase was also important for understanding what the person can do, what is the most appropriate time of the day that they can work

and to make arrangement for the right training or placement, which may be helpful to preserve or improve a clients' health.

> *Chloe (JC): When we first meet with the customer we established at that point what health issues they may have. We do have a report coming from social services sometimes or GP reports, depending on the level of their physical issues. We would assess the customer; check realistically what they can do. For example if they need to have injection during the day, or they need to have a rest or maybe they are better in the morning and not in the afternoon, I would make sure that the placement and the training area was appropriate for them and also inform the relevant person who are there of the restrictions or things that we need to look at.*

"Vocational profiling" was another term used by job coaches to indicate the collection of information around candidates' aspirations, knowledge and health. Job coach Ava explained SEAs were provided with a care plan for each client, which was important in their understanding specific needs and to agree the right level of support in employment.

> *Ava (JC): We have a referral form which indicates certain areas of health concerns, conditions, or medication, to get quite a good idea early on. Also we are provided with a care plan which would also give us the individual specific needs that would be required to their level of support. So it is quite tailored to an individual need. Each individual would be different. In Jack's case we knew early on that he took a number of different types of medications and that he suffered with epilepsy. Therefore we needed to put a number of things in place during the course […] before considering his work readiness to go into employment. And also we would look to support the individual with job coaching and looking for signs if he wasn't well.*

The assessment as described by job coaches was not a one off process, but involved a constant monitoring of activity by job coaches. At the start of the assessment process the SEA would look at existing care plans and then focus on the assessment procedure or "vocational profiling with the client". They also called multidisciplinary meetings to address health issues and health concerns; both pre-existing and those that developed

during employment. The ongoing assessment procedure was key to match the right job with the right employee.

8.3 The core steps of SE to understand health

The next network is an initial conceptualisation of how SE stages may influence health and how the choice of employment is influenced by health.

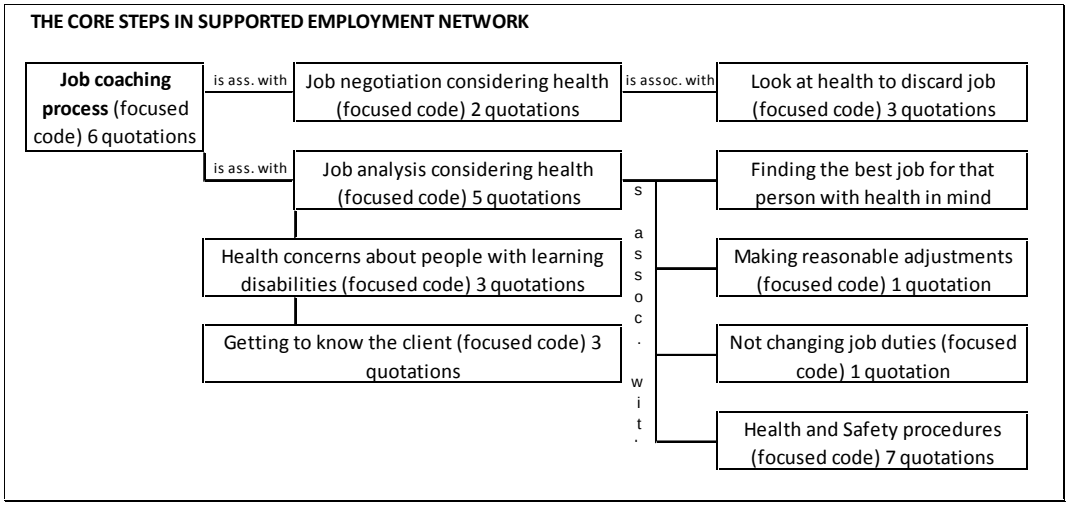

Figure 8.3: The core steps in supported employment network

The job coaching process is described with particular attention to job negotiation with the client in order to exclude jobs which may not be appropriate for the person. Job analysis is reported to be an important step to find the best job for that person. To get to this point the job coach has to get to know the person and making reasonable adjustments in the workplace.

8.3.1 The value of health in job negotiation

Job negotiation was reported to be a fundamental phase in supported employment and in relation to health. This could be deduced from the

general attitude of job coaches, who from one perspective let clients with learning disabilities select a number of desirable jobs, but from another, job coaches addressed personal aspiration and desires when considering health issues. Job coach Ava helped a client who wanted to start a job that was potentially detrimental for her health to re-think about it, and choose another career.

> *Ava (JC): I have got an individual that suffered with Scoliosis and she recently wanted to go into childcare and we looked at what that would it means for her in terms of lifting and standing and you know all those parts that she… we had a large discussion around whether does it actually suit her.*

From Ava's interview it was clear that the discussion was quite important and probably difficult to lead, because it may sound from the participant point of view as though the job coach was ignoring their dreams and aspirations. However, other factors in job selection played a fundamental role. One of these was choosing the right job and the right workplace for an individual. Indeed, the job and the workplace were generally selected with consideration of personal health issues and health problems that may occur when a person is in employment. Medical conditions such as epilepsy or being overweight, but also personal preferences, directed the choice of the job and of the workplace.

Physical conditions such as being overweight may cause an individual to have insufficient stamina to stand up all day. This variable itself excluded a range of jobs for individuals who could not stand. Also, it was felt that people who may be nervous would not cope with a loud job environment.

> *Ava (JC): Perhaps if somebody was very overweight maybe standing for long period of time as well may be not appropriate. Maybe somebody who use to be very nervous and doesn't cope with loud noise.*

It was a common feeling among job coaches that it was important to find the right workplace to prevent accidents and to preserve personal well-

being. Job coach Sarah explained the importance of looking at the health and well-being of every individual in the perspective workplace, to avoid health threats.

> *Sarah (JC): you have to look at the health and well-being of every individual into the workplace, just to make sure that whether workplace they are going in that's not going to have an adverse effect on their health and well-being.*

Job coach Ava stressed the importance of avoiding several workplaces such as kitchens or busy workplaces for someone who suffers from epilepsy. The main reason of this choice was to avoid unwanted accidents in the workplace.

> *Ava (JC): Somebody, perhaps, with known epilepsy, we would try to steer away from certain types of employment, things that maybe triggers to somebody's conditions. And often working in very hot kitchen, very busy places would perhaps not be the best idea. [...]*

The role of the job coach went further than that: the workplace layout was wisely looked at to see if it was suitable for that individual. Job coach Sandra described how the job choice was important, but also the layout of the workplace, to find out if it was suitable for a specific client.

> *Sandra (JC): When we support people in employment, we set up the placement, we talk about health issues, we look at that placement to see if it is suitable for the participant, picking up their needs regarding the type of work they are interesting in […] Also we do our health and safety, to ensure everything is there, and you know, the building […] Somebody comes saying I would like to work in a shop, you take into consideration the layout of the shop, if there are stairs, if they have to go upstairs a lot […] You say if that shop is going be suitable. So it is not just the job, it's the layout of the building.*

Job coach Ava reported she was mindful of a client's health conditions and carefully thought about the right placement and the right venue for a meeting. This was done not to trigger a well-known health condition. In front of an individual who wanted to change working sector, she set up a

training place, avoiding busy workplaces, not to trigger ill-health for this client. Ava also carefully planned her meetings with the client according to their client health needs, preferring quiet venues rather than busy ones.

> *Ava (JC): This chap […] wants to change direction, from working in retail, […] he wants to go into catering. So what has been set up at the moment is for him to go along into a training café and he has actually a condition with his hands. When he is anxious he suffers with a skin condition, so we made them aware of that by the social worker who is putting a care plan together for us, to pick up the points we need to be aware of. In certain situations he gets very anxious so we want to avoid those. It could be that when we are meeting in a café, we need to make sure it is a quiet café or it is in a very quiet area, he doesn't like noise and we soon establish his likes and dislikes, his triggers.*

In summary, job coaches were consistently mindful about how to select the right job for the right individual, because this was the main commitment in their agenda. Job searches were tailored to the individual; work tasters and placement helped to understand if the job fitted the person's needs. Job negotiation with the client was a valuable step in supported employment in relation to health because the features of the desired job were taken into consideration and discussed about thinking at the client. This was not described as an easy process, but it was certainly important to ground individual's dreams and desires when health was an issue. Health conditions may result in discarding several job options, but also several environments not suitable for an individual. This was fundamental to preserve individuals' health and to avoid accidents in the workplace.

However, there seems to be a loss of opportunities. There seemed to be no consideration of how a job match could assist in improving health rather than accommodating for poor health. In some circumstances physical elements of a job may improve stamina and fitness and allow people to have further career options. This remains a largely unexplored possibility within SEAs and job coaches.

8.3.2 Job analysis and negotiation of reasonable adjustments with employers

After addressing clients' choices in considering the job characteristics and the workplace, the job coach was in charge of analysing the job and teaching it to the client with learning disabilities. Job analysis is an important preparation phase that builds up the foundation for the job coaching stage. It was in this stage that reasonable adjustments were discussed to suit individual health needs. Job coach Ava explained how peculiar situations, such as the need to drink a glass of water, had to be written down in job analysis, and for the employer to know.

> *Ava (JC) There is a lot of preparation before we even get that job coaching stage and again I have somebody that worked in (big chain of clothes shop) and he worked for 4 hours and he often need to have a glass of water that was written in his job analysis he can go often and have a glass of water without specific breaks.*

It was often stated that before job analysis it was good practice to get to know the person first in the assessment and through job experiences and job tasters. It helped to identify health conditions, other problems and it aims to prevent failure due to physical or mental health issues. Job coach Bethany explained she learned the job as if it was for her, but paying attention to the disability or health condition of the individual to be placed. According to Bethany it was vital to have several meetings with the client, to get to know them well. The job analysis was discussed with the employer, the client and eventually with the manager of SEAs to be "bomb proof" for the client who was starting employment.

> *Bethany (JC): I learn the job as it is for myself, but when you know a health condition with somebody, I try again to be that person. If you have a limitation in the use of your arm, then I'll try it, how it would do it, so you have to work out what is the easiest way for that person to set into the job. But you have got to know the person first. I would like to have quite a lot of meeting with the person first, to really know exactly what they want to do. [...] Task analysis raises*

> *question on risk assessment and what it is needed to be put in the workplace. You have to consider it all. It is all down to communication. I go through with the job analysis with the employer, the individual, if I am not sure I go to my manager, because I like to be bomb proof, because I find that important in the job setting, you know?*

Job coach Ava described how health issues acted as key barriers to employment and reasonable adjustments were needed to particular job tasks or equipment to support the client in employment. This was possible for instance when providing shaded glasses for a gentleman suffering from epilepsy, to minimize the risk of seizure.

> *Ava (job coach): The gentleman I am referring to works in a very large store, with fluorescent lighting, so we would insure he is wearing his shaded glasses to protect his eyes, which will minimize any possible seizures in the workplace and also inform the employers and we provide them with information like an epilepsy profile. Again in the event of seizure how an individual has to be supported and signs to look out for.*

The issue of health continues following commencement of employment. Job coach Chloe fought with an employer to negotiate time in employment to protect an individual's personal health. A lady's health condition was compromised and work was worsening her health condition. The only solution was a reduction of working hours, to avoid the worst scenario of this lady resigning for health problems. The job coach had to negotiate hard with the employer to achieve the reduction of working hours to allow this lady keeping her job while preserving her health.

> *Chloe (JC) I had a case not in this SEA, where a lady was quite ill and health would be affected by doing the hours the lady was expected to do by the employer. I was very concerned about that and I expressed my concerns in a loud sort of way about the issue, and we negotiated with the employer to bring the hours down. They didn't. So I gave the lady an ultimatum if I have to be honest with you. I said to the lady, it's your health or it is the job? She was like: "I want still to work". I went and I had a lot of meetings with the employer, a lot of meetings and eventually he agreed she would not do more than 12 hours per week.*

Though job coach Chloe successfully negotiated a reduction of the working hours, job coach Justine described how job duties were difficult to change. She believed the nature of the job was physical at its core and that job duties cannot be changed to accommodate health issues. Little adaptation was made to help with the job duties such as using a trolley to lift heavy items.

> *Justine (JC): No, I do not think, modify job duties; job is as physical as it is going to be, you know, so. Unless you looked at the other way somebody has difficulties. Probably some little adaption if things are heavy. If I see Gregory getting something heavy I say "Gregory gets a trolley, use a trolley to pick up, push it through". Advice on making the job easier.*

In summary, job analysis was characterized by the job coach having a good knowledge of all aspects of the client with learning disability. This knowledge was useful in selecting the best job for that person and to best support in employment. Job analysis was shared with the client and with the employer, and reasonable adjustments were negotiated to safely accommodate the job for that specific client if reasonable adjustments in employment were an option. Participants reported however that a change of job duties in open employment was not always possible due to the nature of the job itself.

While job coaches analysed the job and negotiate reasonable adjustment with the employers, they must also consider the key health concerns seen in people with learning disabilities.

8.3.3 Health concerns around people with learning disabilities

The job coaches' role in supporting clients with learning disabilities, allowed them to be aware of health problems commonly experienced by clients with learning disabilities. As an example, job coach Ava reported epilepsy to be a common health issue among people with learning

disabilities independent of whether or not it is influenced by the nature of the job. In this way job coaches represent an important early warning system for detecting physical or mental health changes and they can assist in bringing help into play.

However, participants shared the idea that every individual is different. Job coaches felt that they needed to be extremely careful when interacting with clients with learning disabilities. Job coach Bethany described she often experienced situations where people with learning disabilities acquiescence. They tried to please the job coach or other people, choosing the option which best pleased them. This “pleasing” attitude was worth mentioning because the attitude to please was sometimes seen as detrimental for the health of clients with learning disabilities. Indeed, people with learning disabilities may start a job they did not want to do or that did not fit their interests or needs, to please others. Bethany offered a solution that was getting to know the client very well, with the aim of creating a positive relationship that could support their taking positive actions in relation to the clients’ health.

> *Bethany (JC): I would like to have quite a lot of meetings with the person first, to really know exactly what they want to do, because if you work with somebody and if you are not understanding what they want to do and you put them into the job perhaps they do not want to do, but it is just to say ‘yes’ to you, because they want to please you, that can have a detrimental effect on the mental health as well as the physical.*

Overall, job coaches were aware of common health problems experienced by their clients with learning disabilities. Job coaches considered the importance of the time spent in getting to know the individual, to avoid inappropriate employment choices and detrimental effect on individual health.

8.3.3.1 Health and safety procedures

Job coaches were formally committed to consider and check that health and safety procedures were in place all the time. Job coach Sandra explained how she checked the facilities of the building and the workplace environment to see if the job and its setting suited the health of the client with learning disabilities.

> *Sandra (JC): We do our health and safety to ensure everything is there, and you know, the building, if there are facilities, rest rooms, toilet facilities, places where they can eat if there is not. Places with lots of fumes and dust, but that is on our sheets so we check every aspect of it because it can affect health.*

Job coach Sarah described it was important to determine if the workplace itself may have an adverse effect on health and well-being.

> *Sarah (JC): In our vocational profile, […] you have to look at the health and well-being of every individual into the workplace, just to make sure that whether workplace they are going in that's not going have an adverse effect on their health and well-being.*

Therefore the working environment was analysed to understand any impact on health. Anthony detailed the list of tasks a job coach must do to guarantee there would not be an adverse impact of the workplace on the health of clients with learning disabilities. These included task analysis, looking at the environment the individual was going to work in, and therefore advising on adjustments in the workplace. The job coach checked if the health and safety and first aid procedure were in place.

> *Anthony (JC): We do risk assessment, we do task analysis, we do adjustment advice as well, and we are going into the workplace. We make sure we have the regular health and safety, first aid and things like that. We look at the environment they are going in, we look at the task.*

Job coach Ava considered how the workplace may influence somebody's health, such as working in a busy workplace or wearing special glasses.

> *Ava (JC): (the work) environment as well is considered, if it is a very busy place, if somebody needs eye goggle protection, all these.*

Job coach Justine described how the SEA approached any possible hazards to health arising from actions that clients performed in their job duties. Manual handling and health and safety courses were widely offered to clients by the SEA. These courses were relevant for clients and employers because the client was trained to avoid hazards and the employer knew general health and safety procedures had been covered.

> *Justine (JC): If there is a lot of lifting maybe involved in some of the jobs, they would go in a manual handling course, they will be thought how lifting properly and posture.*

Anthony stated that manual handling course are available together with food hygiene courses to support clients and consequently employers, who knew that the training took place within the SEA.

> *Anthony (JC): We do manual handling courses, if there is a kitchen is food hygiene courses, so the employer knows he has been supported as well.*

When the right health and safety measures were not in place, the job coach needed to take certain actions. Job coach Chloe reported that if these key actions were not taken by the people in charge, the job coach had the formal duty to stop the placement in order to preserve the health of the employee. Chloe described how she had to stop a placement because the correct immunisation was not up to date.

> *Chloe (JC): He didn't have the right protection because he was working with metal and you need to have the right protection. […] Because it was a risk, maybe a really small risk and I know he wasn't covered, no he wasn't. So I wasn't going continuing that placement and that placement actually stopped at Christmas because I said to the family that if the inoculations are not up to date, he can't work there.*

The job coach had the duty to check on the health and safety of the client before and after employment and for the duration of the support process. This is a formal duty for SE; however considering health as a wider concept is not a formal duty for SE. This introduces the next network which explain the reason why health is not a formal part of SEA plan.

8.4 The reason why health is not a formal part of SEA plan

The next network reports the reasons why health is not a formal part of SEA work according to the view of job coaches (Figure 8.4).

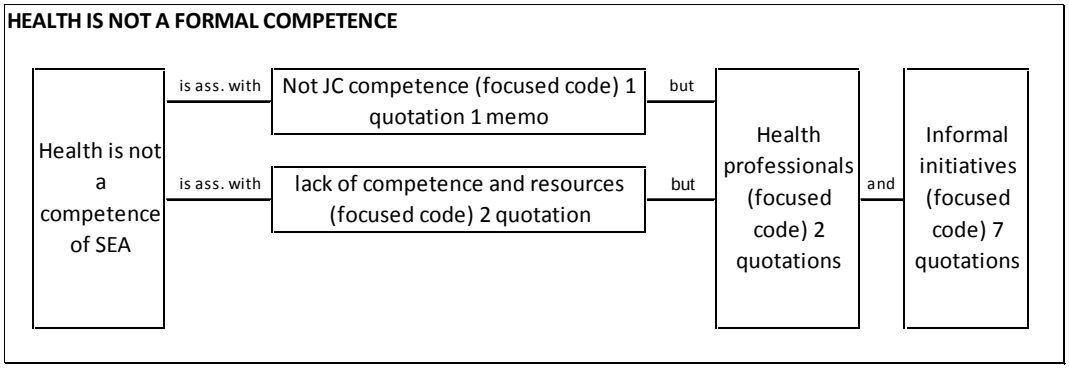

Figure 8.4: Health is not a formal competence network

Job coach Ava explained that SEAs considered health but then referred to key figures in the health and social care areas such as the social workers, carers or parents. The first reason is that health was seen as more of a social worker, family or carer competence.

> *Ava (JC): Although we do consider that (health) a lot, we also refer to social worker or carers or parents, because health is more their area, you know.*

This view of health being professionalised appeared to be a barrier to SEAs considering, and planning, for positive health outcomes from jobs.

Job coach Chloe described a situation where a client was required to have an inoculation in order to be able to stay in a specific placement. In this case it was the carer's duty to arrange an appointment with the GP, following the job coach advice. In this situation the inoculation did not happen and this resulted in the loss of a client's placement. Indeed the only action the job coach Chloe was entitled to perform was giving advice and acting as a point of contact, making sure everything was in place to preserve clients' health.

> *Chloe (JC): I cannot take him (employee who needed the inoculation) to the surgery and let him have the injection because it is not for me to say. He has a registered carer through the social services and I cannot do anymore than that.*

Justine did not feel job coaches were competent enough in what was necessary to promote health, and they should be trained for this.

> *Justine (JC): The job coaches would need to be educated in promoting health. I mean they would need some training themselves in promoting health and well-being with people with learning difficulties.*

Sarah carried on, telling the story of a job coach spotting a possible allergic reaction to a material. The client with learning disabilities would probably not be able to make the association between the use of latex gloves and the symptoms, which has been identified by a job coach.

> *Sarah (JC): People working with latex gloves, they were not realizing they were allergic to that, so obviously having the job coach there with them, the job coach realized it. The person with the learning disability would not make that connection. They may not be major health issues, but if the JC hadn't being working with that person that may not be identified as quickly.*

Occasionally there were worrying changes in clients' behaviour. In these situations job coaches decided to take actions to try to understand the underlying reason. Chloe reported her strategy of improvising unplanned visits to the workplace in order to check on the individual's health and well-

being. If something was wrong in the workplace the job coach called meetings with the manager, the client and the family before taking actions.

> *Chloe (JC): With customers, I would go out myself meeting with the customer, if they are coming into (name of the agency) I will go and find them and have a chat with them. They do not probably realize what I am doing, but I am just assessing the situation, just checking to make sure that everything is OK. If I see any change of habit, if I see any change of personality, if I see any issue that make me a little bit suspicion then I call meetings. We get together and we have a chat with care managers, parents and the customer, because if there is something wrong and they have a health issue which could affect where they are in placement.*

The main resource highlighted by job coaches was the availability of health specialists to be contacted when there are issues with health. The next sub-category describes when and how job coaches contacted health specialists.

8.4.1 Job coaches contacting health professional in employment

Job coaches may have an intermediate role as explained by Joseph. He felt he had a “motivator” role; because he is in a position to identify the health aspects that needed to be improved. Afterwards, the job coach referred to the right support network to address the health need.

> *Joseph (JC): Because you act as motivator, you try to find the areas where they need to improve on their health, on their work, on their daily life. You are there to find the support network around the gaps you identify and that they need to improve.*

The job coach acted as a facilitator in contacting relevant professional figures who were able to help with health issues. Job coach Sarah reported the importance of job coaches identifying any adverse effects of work and directing the client to consult a GP to sort the problem out.

> *Sarah (JC) If they have the right support in place obviously they have not the stresses and also if they have an underlying health condition, we are also there on the spot to be able to identify if that person has an adverse effect in the workplace or if that person should be consulting a GP, we are there to facilitate that's happening.*

Job coach Ava reported her collaboration with health professionals to be positive, because they provided a competent support for job coaches while they were facing clients' health issues.

> *Ava (JC): In the past we have worked alongside with mental health nurses, you know, professionals, it has not been really much my field, others maybe more experienced with mental health. It is interesting when health professionals approaching, because obviously we are only employment support advisors, we are dealing with that side of things which is separate from health.*

Job coach Anthony highlighted they had a wide range of services available, from the Council to NHS options to help people cope with bereavement, stress, anxiety, dyslexia, hearing problems and other health problems.

> *Anthony (JC) We use Access to Work to fund health needs. We have access to Council, we have NHS options and they do confidential courses, they do bereavement courses, stress and anxiety courses. […] We use dyslexia assessment and they will tell us what to do to keep them into employment. […] We can attend hospital appointment if needed, if they have a hearing problem. If we can't we know somebody who can.*

Several SEAs worked closely with a multidisciplinary team. Job coach Ava explained that the collaboration with health professionals was considered important in addressing the lack of competence of job coaches on health issues.

> *Ava (JC): I worked with the epilepsy nurse with Jack and insured that I had up to date information because they do not always remember that I need that information myself to forward to employers.*

Health professionals, such as psychologists, were contacted to address the loss of confidence of an employee. Job coach Ava was successfully supported by a psychologist to help a client with low self-esteem, who needed to increase their confidence to be successful in employment.

> *Ava (JC) And I worked quite closely with a gentlemen in (name of a large chain of clothes shop) at the moment that has some issues, working with the psychologist at the moment to… because this chap has a confidence issue really, he is often saying "I am a rubbish worker", saying this, saying that, "I am not doing this". I am working quite closely with him to put together a task analysis for him and initially I couldn't see the point of it, because I thought this person was very able and understood each of his roles, but it was more of the benefit others and of that person and also for him to see that he is doing each of these roles and he would tick to say: " I did it", "I am really good", you know, and then if anyone else says to him "you haven't done whatever", it is on black and white because has been checked by supervisor that he has done it. The psychologist said it is merely for his interest, you know, and how somebody thinks.*

The availability of a network of health professionals represented a resource for job coaches when dealing with employees' poor health as explained by job coaches. Job coaches appeared to be comfortable when interacting within their network of health experts.

8.4.2 Job coaches health initiatives

Some of the clients with learning disabilities expressed a wish to become healthier through their job. Job coach Justine reported that learning to cook and setting up a healthy menu could help clients in leading healthy lives.

> *Justine (JC): Jason came to me and he said he'd like to lose some weight. Is rather a large man so what I have set together, because I am also doing a diploma in diet and nutrition, I put him together a 4 weeks menu cycle of suitable food for him, I printed it out explained what he had to buy at the shop, I gave him a list of food. I also*

> *compiled a weighting sheet for him with "started weight", "loss of weight" and "up to date weight". It was all printed for him and he kept it in a folder, quite important that he had all his paperwork and every Wednesday we would weigh him and we would see if he had lost or gain. For the first 6 months to a year he had done very well, he had lost nearly 3 stones, really, really it was working well, after a while, initially when he had lost a large amount of the weight his enthusiasm incurved a little bit I think, so we tried other ways to encourage him to say how are you doing?*

Justine also offered leaflets to motivate the client in healthy behaviours.

> *Justine (JC) I also got him some leaflets on some swimming clubs that he joined and he also joined a gym and that was for people with learning difficulties, just a couple of brochures that I picked up from a doctor's surgery once. So I kind encouraged to do it as well, which he did undertake for a while, but he is not doing as much as he was. But he did say now it is the New Year so he would like to get back into it again.*

Job coach Ava addressed unhealthy eating habits in the workplace. One of her clients was drinking too much Coke; therefore Ava encouraged her to drink healthy drinks instead, writing this onto a referral form.

> *Ava (JC): If somebody perhaps has a very poor diet, I've got an example really of somebody who loves her Coke and obviously when she goes to placement we have trying to discourage her in drinking too much coke, so it has been put onto the referral form and staff at (name of the placement workplace) and to be sure she is trying to drink healthy drinks during her time at placement.*

An initiative was set up as a sports day for clients of SEA and people from the day centre, with the main aim to increase physical activity. Job coach Joseph was extremely passionate about this initiative, not just because the level of physical activities of people with learning disabilities increased, but also because this experience taught people with learning disabilities leadership skills and made them responsible for demonstrating a new sport to a group. The initiative was run to celebrate the Olympics and it included 5 Olympic disciplines taught by people with learning disabilities to other people with disabilities.

> *Joseph (JC): The project is about the will to create a sports day, with the Olympics, focused on giving the skills to young people, the leadership, being able to present information their selves, able to manage a group. We had 10 people with learning disabilities from a day service attending this course, we paired the individuals and they had to deliver like a sport each. […] We learnt how to motivate mates, we learnt a sport, we had a pentathlon event about two weeks after. It was all based around the 5 continents rings and we had a sport for each continent. On that day they had to be the official and demonstrator. One person had to do all the scores, all the markings type of things. They had to design all the marking sheets, decide how they are going to score it, different things they had to measure and do different things as well.*

People with learning disabilities who engaged in this project acquired a wide range of abilities: from using electronic devices, to explaining how to perform a specific sport as explained by job coach Joseph.

> *Joseph (JC): In the sport day we had about 150 people. We had a practice first. The most difficult was the relay, because it was not a big relay. We had electronic devices that you wear on your fingers and they had to learn how to use these devices. It was challenging.*

Thanks to this event, it was discovered that an individual with learning disabilities was a very talented runner, possibly a candidate for the next Special Olympics.

> *Joseph (JC): One of the guys was ridiculously quick, and if trained, he would do 100 meters less than 11 seconds. He has got so much energy. We are trying to put him up for the Special Olympics next year. We are trying to put him with a real coach.*

Some individuals may not be ready to work for a number of reasons, such as, having difficulties interacting with others, a lack of confidence or health issues. Job coach Ava linked with other agencies that were able to support people who were having difficulties starting up in employment.

> *Ava (JC): Well, perhaps some people are not quite ready for employment and we can provide alternatives. I had individuals, they were very socially isolated. We have a number of different organisations we can refer to, to help people to gain independence*

> *and confidence and mix, you know, make friends. […] we have individuals we are currently working with, that we have assessed in placements situations that they were not really ready for works were able to talk to other organisations.*

It was only a minority of job coaches who sometimes used their close connection to the client to give them advice on healthy lifestyle and other health related issues. The bond that developed between the job coach and the client appears to be important in determining whether proactive health improvement steps are taken (over and above any naturally occurring health improvements arising from the work itself). This in turn appeared to be dependent on the extent to which job coaches were aware of the health of the client and the extent to which they felt empowered to promote health.

8.5 Employers' role in health and their cooperation with job coaches

Job coaches reported how they interact with employers to make reasonable adjustments in the workplace. SEAs were in a key position to help people understanding and accessing any existing employer health promotion initiatives as a part of helping employees settle into their workplaces in general. However, I found that SEAs were surprisingly unaware of what was being offered by employers in this regard. Understanding what was available is clearly an essential part of a strategy to help people with learning disabilities be a part of it. The next figure represent the network of relationship of codes related to this topic (Figure 8.5).

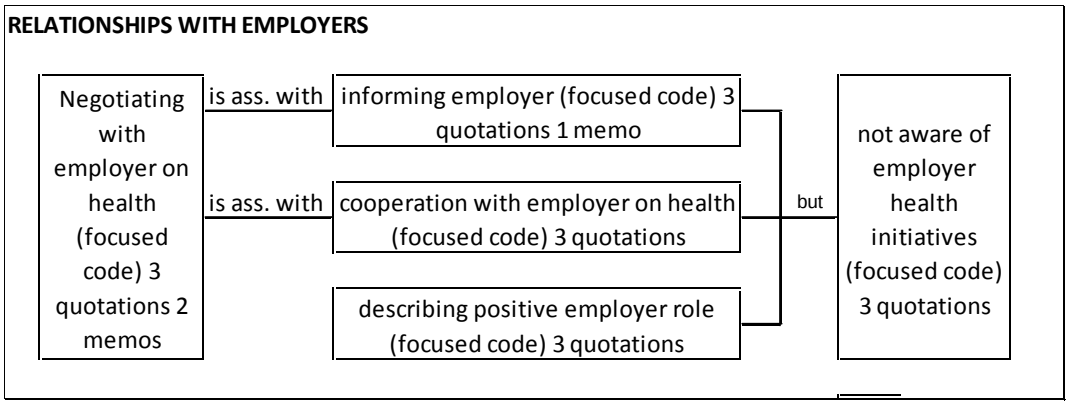

Figure 8.5: Relationships with employers network

Job coach Ava reported that some employers promoted healthy eating and healthy food choices at work.

> *Ava (JC): Although I have people like going into training placement and they worked in organisations where healthy eating is promoted, you know, and healthy choices.*

Overall, employers organised all sorts of events but none seemed to be related to health as reported by job coach Ava.

> *Ava (JC) They know that they have regular events […] Usually they work toward raising money for a specific charity, dressing up, not so much towards health I think it is about raising money, you know. I cannot think at any health related (silence).*

Interviews with job coaches confirmed that SEAs were not generally aware of health initiatives promoted by employers. However, job coach Antony reported several examples of activities promoted to nurture social links within the employees such as a barbeque with employees. Other activities were directed to promote new leaning, such as a new language. Finally, an employer funded an employee to do the blue mile, giving time off for this individual to be trained.

> *Anthony (JC): The employers say to come for a barbeque this weekend, because it is really nice to see, when a person excels in the job at the point he is going back to the social activity. There is an employer who has somebody offering foreign languages,*

> *because a lot of employees go abroad, one year is French, our customers are all open to that. We have a customer who is trained to do the blue mile swim and the employer is funding all that, giving time off to do extra swimming to build his stamina up. Our employers are really sympathetic and they want to get our customer to the best they can be.*

In conclusion, the knowledge of employer's activities in promoting health was not widespread in SEAs staff. Some employers do not promote activities to improve the health and well-being of their employees. Others facilitated healthy choices such as offering healthy food. Employers generally organised social activities rather than health activities. However, there were positive examples, such as an employer funding an employee to do the "blue mile" and giving time off to be trained. The blue mile is a competition where the competitor has to swim for a mile. This was an important example of how employers may act to promote the health of their employees.

Overall the flow of communication between SEAs and employers helped to support their clients' good health. This aspect was identified by job coach Ava who reported how a supportive employer addressed a health problem of an employee, who preferred to smoke at meal times instead of having her lunch. This issue was addressed and the lady was able to have her meals.

> *Ava (JC): The majority of employers do not have café as they did years ago and tend to be more vending machines on premises […] Also guys working part-time are not entitled to breaks, although I have a lady working in (large chain of cafés) she would go long hours of working and not eating preferring to smoke. We have addressed that and now she has a break and she has a sandwich. The employers themselves are very supportive with this young lady they do notice perhaps if she is not eating or smoking a lot.*

Job coach Chloe reported an example where an employer employing a person with epilepsy, wanted to understand and learn what to do in case of a seizure, and passed the new learning to co-workers.

> *Chloe (JC): We do get employers who are very understanding. I have got the most amazing person (employer) who is a manager and I wanted a placement for somebody with serious epilepsy, and you know the issues coming with that. […] This employer is so incredible. He said to me: "if it happens what do I do?" I said to the medical team to explain exactly what to do. […]. The employer made the staff aware on what to do if that person does show any sign, what to do, which is awesome.*

Many employers were reported to care about the health of their employees with learning disabilities and overall the communication with job coaches on health related matters was positive.

8.6 Co-workers' role for health

Co-workers are people working with the employees with learning disabilities. Analysis of the interviews showed that they played an important role on the health and well-being of clients with learning disabilities. The following figure reports the network emerging from data (Figure 8.6).

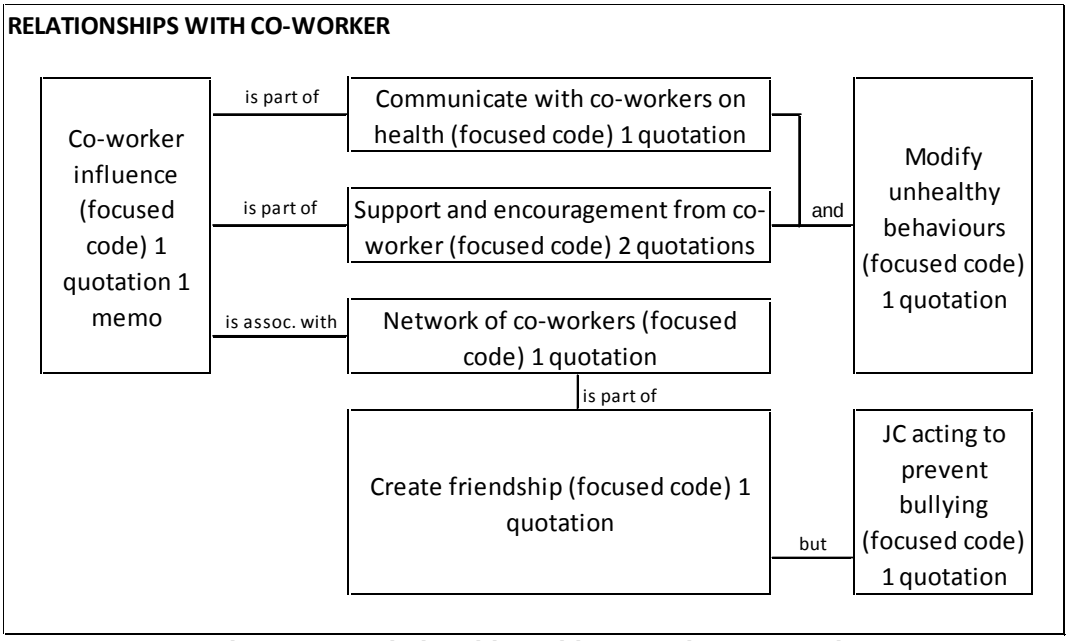

Figure 8.6: Relationships with co-workers network

Job coach Sarah reported that co-workers needed to be supportive with employees with learning disabilities to help them to be successful in employment.

> *Sarah (JC): They need to be opened, they need to be supportive, and they need to be inclusive. If they weren't they have an adverse effect on people with learning disabilities and make feel the person with learning disability as they are doing something wrong, they may feel as people do not like them.*

The role of co-workers went further, as they encouraged and supported healthy behaviours, helping employees with learning disabilities becoming more aware and passing new learning to their families. Job coach Justine

reported office assistant Gregory had lots of encouragement if he was walking to work. Gregory, who was seeking to lose some weight, reported his achievements to co-workers. The relationships with co-workers helped Gregory to be more aware of food labelling, to refer to it, and healthy eating.

> *Justine (JC): Gregory gets a lot of encouragement about what they are doing. Gregory is coming to work saying "I walked, I left two bus stops, I walked". He gets a lot of encouragement from co-workers. He always says people when he has lost weight, but he never tells people when he put on weight. There is a lot of encouragement about that. And also they ask "what are you having today for lunch Gregory?" He is becoming more aware now of labels and shops of the healthy eating, the calories, he is starting to understand things like that. Before he never ever had a look or read that or thought about.*

Evidence was gathered by job coach Ava who observed how being part of a working team may help change behaviours, such as reducing smoking, and to improve the individuals' quality of life.

> *Ava (JC): I had a person that suffered with depression. Actually she is gone into paid employment, who smoked very very heavily as well. And she works 16 hours a week now; she is socially interacting with people, colleagues she works with. She builds up a friendship, she goes to the cinema, they have nights out as a team and she is happier and healthier. You know, she built on a confidence.*

Some large employers structured a supportive network within their staff, promoting support among their employees. This was reported by job coach Chloe.

> *Chloe (JC) Managers at the (name of supermarket) are normally known to be good and they have a massive role to play as they promote teams, colleagues support. (Name of another supermarket) does the same, even if they have a JC from (name of SEA); they have an infrastructure that works with a customer until they are up to a speed. They are doing very well with our customer. They are very supportive and feedback every issue.*

Job coach Bethany highlighted how spending time with co-workers was also a social matter linked with the feeling of creating a friendship.

> *Bethany (JC): It is making friendships it's including them, isn't it? It is a social thing. You have to work hard to get to know the person. Sometimes it would be good to educate them sometimes; they can be quite scared themselves.*

Job coach Anthony described how co-workers represented an asset to the person in employment. However, he sounds a note of caution, noting that sometimes job coaches must act carefully to prevent bullying.

> *Anthony (JC): A lot of them nurture when they know that there is somebody working there with the disability and the medical condition and a lot of the time they would help as much as they can, a lot of the time they would be the natural support. […] if there have been issues like bullying or name calling, we have had that in the past, some people have had not a lot of awareness, and colleagues who have come with that and addressed that.*

Overall, co-workers played a positive role for employees with learning disabilities. Co-workers' support helped employees with learning disabilities to be successful in employment, and also in promoting the employees' health. In some cases, co-workers helped the employees with learning disabilities increase their awareness of healthy eating and acted as individuals to talk to about health achievements. Co-workers played an important role as the workplace environment can be a good place to develop friendships. However, there may be a risk of bullying, that may be prevented or addressed by SEA staff.

8.7 The family and carer influence

Job coaches reported how families and carers may influence the employee's health both positively and negatively as emerging from the next network of codes (Figure 8.7).

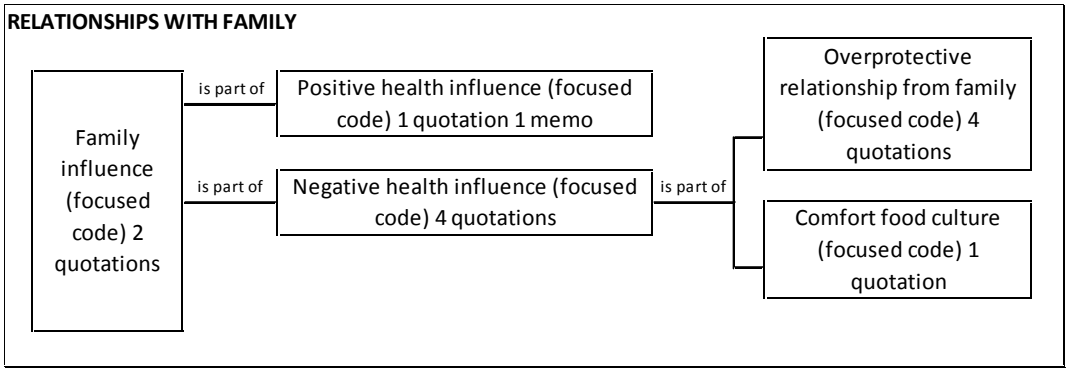

Figure 8.7: Relationships with families network

Job coach Ava reported that one parent had a positive impact on her daughter's life when she was looking for a job. She was engaged in sport activities, therefore her mother asked for a job which would not take her daughter away from sport.

> *Ava (JC): I had a lady in her 40s with (diagnosis), mum is very keen to promote her health through exercise and that has to be mindful, when looking for work as well for her we did not take away from the activity she already has. She plays tennis and she would like this activity to continue.*

Another parent had a possibly negative effect on her daughter. Here the mother used to buy her daughter cigarettes, re-enforcing this behaviour to continue.

> *Ava (JC): Some are more aware than others, there is a greater awareness. I have one mum that will say cut down on the smoking and she goes abroad and she bought cigarettes, you know. The house is trying to work very hard to make sure she is cutting out and something like that would happen. Unfortunately parents come across that way, you know.*

Job coach Justine reported that negative influences coming from the family were not intentional, but originated from a “comfort food” culture. Comfort food culture was still popular; therefore, when a person with learning disabilities was down, junk food represented a comfort to fight feeling blue. Justine reported the culture will change in years to come, but at the moment they need to cope with it.

> *Justine (JC): Mmmm. I think there are very big influences, not necessarily good influences. That is my experience. With all the best willing of the world you can set up a menu plan, some exercise, but when they go home their parents or carers things can be very different. It is the old fashion things, oh, it is a little bit down, lets him have a bag of crisps or a packet of sweets. Not let’s have a nice walk or exercises; it is more like comfort food. They are not great influences. With generations it is going to change, but I think that at the moment we have got a lot of people…. […] is that generation that is not as well educated as yours. I think in time that would change, but on the whole I don’t they are great influences on that side of things, but not intentionally bad, but just not educated enough to know better.*

Thus, excessive protection coming from parents may be counterproductive, resulting in this being an obstacle for the independence of an individual with learning disabilities. Job coach Sarah described how some parents appear to be over protective, preventing their children with learning disabilities to become independent.

> *Sarah (JC): Not always in such a positive manner, may be not intentionally, but I think parents and carers are very protective of people and very reluctant sometimes for allowing that person to move forward, gather their independence. I think sometimes parents and carers can add additional pressure or barriers and obviously the job is to support the individual to move through those barriers.*

Parents had an understandably strong desire to protect their children, and they had often doubts that their children were able to do the job they were employed for. This may influence they self-esteem and act as an obstacle towards the independence of individuals with learning disabilities, but also

have an impact on individual's health choices. Job coach Chloe reported a story of a mother who was doubtful about her daughter's ability to do the job she was employed for. Chloe suggested this lady's mother go to see her daughter at work, for her to understand the value of her daughter in employment.

> *Chloe (JC): Some parents, carers of my customers protect far too much, to me I feel like a derogatory effect on some of my customers, at the point they have more capabilities, they can do more things than their parents and carers believe they are able to do. A lady who works in one of the biggest hotel in (name of the city), her mother, when we had the annual review, said that she can't do anything. I know that she cleans the foyer, the main front hallway, she does all the wood work, and the glass work in this huge hotel, and she goes there for two hours Mon to Fri. Actually I have mentioned to her mum, maybe she need to come down and actually see her daughter in action, because maybe it is going open her eyes a little bit more on what her daughter is capable of.*

In summary, job coaches' contribution highlighted both a positive and a negative impact on health. Whilst on one hand families may assist their children to stay active, on the other hand families may re-inforce negative health behaviours. Families may also be overly protective and hinder opportunities for their children to exercise, or some families pursue a culture of "comfort food". Job coaches found some families to be doubtful about their children abilities in employment, an attitude that may hinder an individual's sense of pride and motivation.

8.8 Comparison within data and analysis of the literature.

In conclusion, the SE process as seen by job coaches, offered several opportunities to improve the health of employees with learning disabilities.

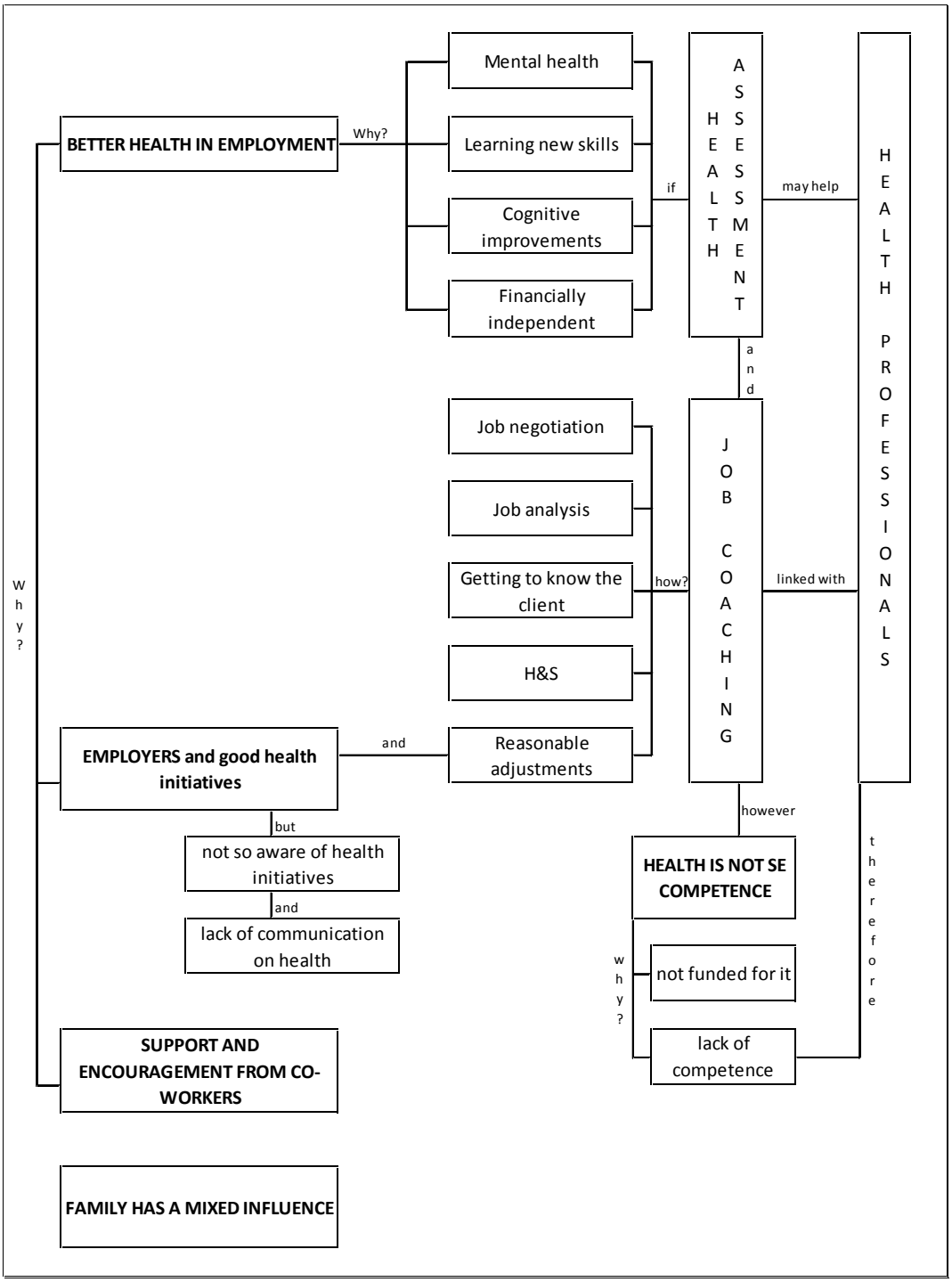

Figure 8.8: Super network (3)

Figure 8.8 highlights the main points of the emerging theory.

It is grounded into job coaches contributions that employment helped in achieving health benefits for employees with learning disability. This is also clearly expressed in many research studies for the general population (Black 2008, Jahoda 1982, Nordenmark 1999, Dodu 2005, Waddell and Burton 2006).

Job coaches reported how an appropriate environment was needed to help employees improve: their confidence, self-motivation and quality of life. Indeed, previous literature highlighted that the most important factor to succeed in employment was personal motivation (Beyer and Kilsby 1997). In my study job coaches helped employees in learning new skills, such as different ways to communicate with colleagues. Health was improving as a consequence of the confidence coming out from the application of these new skills.

Furthermore, employment provided economic resources and individuals started to access goods and services that were inaccessible before employment. This helped to develop a sense of self-worth and inclusion. A previous study has shown how monetary gains were an important source of motivation for people with learning disabilities in employment (Andrews and Rose 2010)

The assessment was a useful process to get to know the employee, including issues around their health. Job coaches approached the supported employment process considering health as a key issue. However, their consideration of health issues was related primarily to job readiness, negotiating the most appropriate job with the employee and accommodating existing health issues in the jobs found throughout reasonable adjustments. Indeed reasonable adjustments have already been reported as crucial across health care delivery for people with learning disabilities (Mencap 2004).

Job coaches were generally aware of the health problems experienced by employees and job coaches were formally committed to check if all the necessary health and safety measures were in place in the workplace.

Therefore health was considered throughout the SE process because health was a relevant part of individuals' lives, but health was not a formal part of the SE plan. This was because health was generally regarded as a family or a social worker matter. Furthermore job coaches were not competent in health; and managing health issues was seen as going beyond job coaches' roles. However, health was widely considered by job coaches who, for example, planned unexpected visits to monitor the situation and check on the employee with learning disability.

Job coaches often referred to health professionals to address a health issue. In this respect job coaches acted as mediator between the client and the health experts. Some of them worked in multidisciplinary teams to report emerging health issues. Job coaches also worked as motivators to change a certain behaviour.

The job coaches' influence was as a resource for employees with learning disabilities health, but there were some gaps in their practice. Indeed, few of them were aware of health activities promoted by employers. The interactions between job coaches and employers were only case specific and addressed to accommodate a person in a specific job position. This interaction was certainly important, but the actions of job coaches could be expanded. Indeed, several job coaches were proactive when employees wished to live healthy lives.

Job coaches also reported how co-workers helped the employee with learning disability to lead healthier lives. Co-workers were supportive and helped employees in developing friendships. There were episodes of bullying and name calling that job coaches had to address, but generally co-workers had a positive relationship with employees with learning disability. Health wise, co-workers encouraged healthy behaviours such as

encouraging an employee who was walking to work or teaching a person how to recognize healthy and unhealthy food by reading food labels. A job coach also reported an employee reducing smoking following employment and their relationship with co-workers.

Families had both a positive and a negative influence on the health of employees with learning disabilities. This finding is important because the influence of families has been reported by job coaches to be a strong one.

8.9 The theory: not just health and safety but opportunities to lead healthy lives

Job coaches reported that they influenced the health of their clients with learning disabilities at each stage of supported employment, but job coaches were not formally committed towards health, only guaranteeing that health and safety measures were in place. The main reason for this seems to be that SEAs are not funded to promote health, but to preserve it. Job coaches interacted with employers to exchange information on a specific case and to negotiate reasonable adjustments, but they were not aware of activities to promote health organised by the employer. According to the job coaches, co-workers played an important role for the health of employees with learning disabilities because they can provide support and encourage the employee to choose healthy lifestyles. Overall, employment is important to improving an individual's health because employment is a source of learning, positive mental health and physical ability improvement as well as a source of independence stemming from raised income.

9 Discussion and conclusion

This study was designed to identity the role of Supported Employment agencies (SEAs) in promoting the health of people with learning disabilities in employment, using a national survey and a grounded theory study. In this chapter the findings of this mixed method study are discussed. The chapter starts with the theory coming out from the triangulation of contributions from each group of participants. A discussion about findings from the whole study related with the literature is reported, followed by a discussion of the strengths and limitations of this study. Finally, suggestions for potential interventions and future researches are made.

9.1 The theory: Formal and informal opportunism for health in employment and supported employment

The following theoretical framework emerged from the triangulation of participant's contributions. The emerging theory explains how employees with learning disabilities have several opportunities, both formal and informal, to improve their health while in SE. Employees' health benefited from their:

1. Status of employee;
2. Status of client of a SEA;
3. Status of user of informal opportunities promoted by SEA such as wellness groups, sport activities, vegetable boxes within the SEA.

SEAs did not have a clear commitment to promote the health of their clients' with learning disabilities and they were not funded to promote health. The main formal commitment for SEAs was limited to promote health and safety in the workplace. However the employment and

supported employment experiences provided a wide range of opportunities:

1. Increasing employees' physical activity level while in work;
2. Increasing employees' physical activity level while going to work;
3. Reducing unhealthy behaviours such as smoking and alcohol drinking because in employment;
4. Learning about healthy habits in employment and in supported employment, (e.g. learning to read food labels, learning how to cook);
5. Learning and consolidating social skills while in employment (e.g. learn how to interact with colleague or users of the service they are working in);
6. Mirroring co-workers in their healthy behaviours;
7. Earning an income and becoming more independent.

Nevertheless health was a central element in each phase of supported employment:

1. <u>During the assessment procedure:</u> health was looked at to avoid employment failure due to ill-health, but employment was not considered a way to improve health.
2. <u>While job coaching:</u> the job coach played a central supportive role for health during the SE process, but they did not have enough knowledge on health related matters.
3. <u>While linking with employers:</u> job coaches linked with employers about emerging or existing health issues, but they were not aware of health activities organized by employers.
4. <u>While contacting health professionals:</u> multidisciplinary meetings were called because SEAs' staff was not competent enough to deal with health.

Overall, the only formal commitment for SEAs was to guarantee a safe working environment and a successful employment experience. However, this research disclosed how employees benefited from a wide range of health opportunities, both formal and informal, coming out from their position in employment and in supported employment. Employees were indeed the ones who benefited from the opportunity of health in employment and supported employment.

9.2 The study in relation to research in the field

This study is, to my knowledge, the first study that considers the health aspect of supported employment for employees with learning disabilities. Findings from this study constitute new knowledge that I will interpret and link with previous literature.

9.2.1 The job coach role in relation to health

This study set out the central role of job coaches and employment consultants for health alongside the process of supported employment. Previous literature clearly describes how job coaches play a central role for clients with learning disabilities (Kilsby and Beyer 1996; Beyer and Kilsby 1998; Chadsey-Rusch et al. 1999; Townsley et al. 2009). This study emphasises the role of job coaches for health, alongside the main phases of supported employment, starting from the assessment, job search, job analysis, job training and ongoing support. From this study the trusted relationship with the job coach helped in improving the clients' general health. However, the lack of time to deal with health problems and the lack of training were highlighted to be major obstacles to health promotion. This study highlighted that job coaches knew referral routes for health professionals and were in a position to advocate for positive health behaviour.

9.2.2 The role of assessment for health

Assessment is the first step into the supported employment process, and it is vital to consider the level of support a person will need to find, get, learn and maintain a job (Beyer and Robinson 2009). Health was also fundamental for a client who wanted to get, and successfully maintain, a job. For this reason clients' health was assessed by SEAs staff to understand any potentials obstacles for the client. It allowed employees to identify and describe not just their individual skills and interest (DH 2009, 2010a), but also their own disabilities and their own health problems. In this study, the assessment of health was important to determine if the client was ready for employment or if the client needed further access to other services before they entered employment. The Department of Health states among the principles of SE the right to work safely, guaranteed by a good risk assessment, taking into account the workplace and personal characteristics (DH 2010a). Despite this recommendation, a small number of SEAs did not consider health behavioural risks in their assessments.

In this study I identified that the SEA's initial assessment focused primarily on known medical and psychological conditions, probably because they appear to be more relevant to getting and keeping a job. This is because considering and identifying such medical and psychological conditions, might prevent health and safety issues in employment for the employees. Indeed, other unhealthy behaviours such as smoking, inappropriate diet and use of alcohol, were generally considered as "personal choice behaviours", and not relevant to employment. However, in this study there were a few cases where these behaviours influenced the employment condition and well-being of employees. These behaviours were addressed in a formal manner, such as writing these behaviours into a referral form for the employer to know about, or in informal ways such as verbal advice given by SEAs staff to employees.

9.2.3 The job search activity

A previous study (Di Terlizzi 1997) and Government paper (DH 2010a) highlighted the importance of involving people with learning disabilities in the SE process to provide them the opportunity to choose in a supportive environment. Findings in this study highlighted health to be a central aspect during the activities of searching for a job. SEA staff negotiated the search with clients, addressing personal aspiration but alongside any restricting health issues. In this phase, SEA staff predicted if a specific work experience was likely to be a positive experience, or identified the number of hours the client with learning disabilities should work, considering also relevant aspects of health. The workplace environment was analysed and selected to be the most appropriate one to suit the person, in keeping with the health issues the client experienced as suggested in the literature (DH 2010a). The current study highlights job matching to be an important process usually driven by the desire to accommodate health needs. Ideally job matching should consider how a job can improve health for the person and not just to accommodate health problem. This study also highlighted evidences of individuals improving their stamina, their physical and mental health because they were in employment.

9.2.4 The job analysis and job training activities

The job coach had the important role of analysing the job and identifying the most appropriate way to train the employee for that particular set of job tasks. Job analysis is a fundamental step in SE to guarantee that the individual with learning disability will set well into employment (Beyer and Robinson 2009; DH 2009, 2010a). This study set out the importance of employees' health related to a specific employment position. A correct analysis prevented the client from failing because of any existing physical and mental issues.

Job analysis was followed by training, usually carried out by a job coach. As seen in several studies, the job coach is a central figure in vocationally

profiling and training the client with learning disabilities (Beyer et al. 1996; Beyer and Kilsby 1998; Beyer and Robinson 2009). Indeed, in this study the job coach was ideally situated to address the integration of health and well-being measures within the workplace. Job coaches were in charge of negotiating reasonable adjustments, sometimes considered crucial in previous report for an individual to stay safely in employment (MENCAP 2004). The job coach was a resource to check if health and safety was adequate for employees with learning disabilities (Beyer and Robinson 2009). In the current study health and safety was a duty for SEAs, of primary importance for SEAs, and almost all their staff were trained to deliver it.

This study identified how fundamental the job coach role was in identifying poor health and poor health behaviour. Previous studies highlighted the importance of the quality of support and interpersonal dynamics in SE (Johnson et al. 2009). The current study confirmed the importance of this support role, showing how risk assessment, task training, the observation of an employee at work and unexpected visits to the workplace were strong tools for job coaches to spot health problems emerging in the workplace.

9.2.5 Ongoing support of health

The importance of ongoing support is well described in SE, where the job coach and the SEA provide direct support that fades over time with the decreasing demands of employees (DH 2010a). From the survey results SEAs staff supported positive health by providing verbal advice on healthy diet and alcohol. Advice on healthy diet and advice on activities to increase physical exercise were also reported by SEA staff during interviews, while none commented on providing advice on alcohol use. SEAs were less proactive when advising on smoking, probably due to this being regarded as an “adult” behaviour that would not influence the employment experience. As an exception informal advice and interventions were taken if the smoking behaviour was influencing vital

work related activities such as having lunch in the workplace for an employee who was underweight. SEAs were reported to access easy to read leaflets to prevent negative health behaviours, but few references to the use of this material was made during interviews with SE job coaches.

Few SEAs referred on to health professionals for smoking or alcohol advice, possibly because these behaviours did not directly threaten the employment condition.

It seems that SEAs and the job coaches they employ occupy a potentially central role in helping people to be employed and to gain the health benefits of being employed. Job coaches may be in a position to help individuals socializing without using smoking as a social opportunity, as happened with one of participants. Job coach may help the individual to reflect on financial savings they can make by giving up smoking. There is a range of opportunities job coaches have to help individuals with learning disabilities reflect on their health to help them and make positive health changes in their lives.

9.2.6 The workplace culture and the promotion of health

According to this study results, the workplace was a place in which changes in clients' health could be identified. Perceived health gains were generally reported by participants in the study, the most significant coming directly from the clients' voices. Health improvements originated from belonging to a specific workplace culture as identified previously in the literature (Fillary and Pernice 2006). The workplace culture offered social opportunities with colleagues and other people such as customers of the company where the employee was employed, as reported by other researches (Rogan et al. 1993; Forrester-Jones et al. 2004; Jahoda et al. 2008). In this study the employment experience for an individual with learning disabilities resulted in being included in an ordinary job position, where he/she can access learning opportunities and benefit from the economic and psychological aspects of earning a wage. Indeed, only a

few examples of health risks in the workplace were reported, and they were linked with social difficulties or the job not perfectly suiting the person. These difficulties were generally addressed by job coaches, in collaboration with other stakeholders, who found the right solutions.

9.2.7 The role of employers and co-workers for health

Co-workers and employers of people with learning disabilities noticed behaviour changes, or the onset of a health problem within the workplace. The connection between the workplace and the job coach was on-going; therefore health issues were reported to the job coach. In this respect, the activity of mirroring co-workers for health related behaviour was highlighted in this research. Job coaches and managers observed people improving their health though observing and copying co-workers.

It was reported that employers were investing in their employees' health, and we know that obtaining a healthier workforce has financial advantages (DWP 2009). In both the survey and interviews within this study SEAs were generally unaware of any health initiatives organized by employers for their employees as reported. Therefore the study did not provide information on the involvement of employees with a learning disability in health initiatives organized by employers, but the absence of such involvement is a concern.

9.2.8 The impact of families on health

Support to employment from family is important because represents a real asset for the SE process. It is grounded in the literature that empowering the individual and the family is a significant issue for the employment experience (DH 2009, 2010a). The importance of family support was confirmed in this study. SEAs considered families to be important partners in employment for people with learning disabilities. SEAs staff cited lack of support by families to provide good role models in respect of health as a barrier to good health among workers. However, on the other hand, SEAs did not generally invite families and carers to make plans around health

issues. The influence of families was mixed, with some families positively influencing the health of their relatives with learning disabilities, while other families influenced their relatives' habits with less healthy lifestyles.

However they might represent an obstacle when SEAs staff acted to reduce unhealthy habits. SEAs pointed out ambivalent experiences they had with paid carers. Paid carers generally had to follow an agreed care plan. This approach from one side protects the person from possible hazards; on the other hand it might hinder people with learning disabilities in taking important life opportunities. Indeed, some paid carers influenced the choices an individual with a learning disability made on the employment experience, with important consequences for their lives. In this study some carers discouraged their relative from carry on with employment, with reported consequences such loss of confidence, some sense of failure and increased social isolation. The job coach acted to prevent this, calling meetings with the carer and trying to support the importance of employment.

9.2.9 SEA health initiatives

There were no previous studies examining SEAs health initiatives for their clients with learning disabilities.

Some SEAs approached health using a holistic approach. These SEAs belong to a wider organization providing services for a range of life aspects such as employment, leisure activity and health. These SEAs were unexpected areas of intervention and may warrant further studies.

Overall, SEAs contacted a health professional or referred to multidisciplinary meetings if a health condition arose or when the SEA was faced with a health problem in the workplace.

Most importantly, some SEAs planned activities to improve the health of their clients with learning disabilities. A SEA planned an Olympic day initiative run by people with disabilities for people with disabilities that

aimed to improve physical exercise, stamina, personal confidence and leading abilities. Another SEA ran a wellness group to incentivise a healthy approach to work, while another SEA facilitated healthy eating with vegetable boxes delivered to the doors of people with learning disabilities. Job coaches helped individuals to pursue their “healthy goals” like losing some weight or learning how to cook to conduct a healthier lifestyle.

The introduction of these initiatives underlined how some SEAs staff felt the urgency of making a change toward better health for their clients with learning disabilities.

9.2.10 Health and employment as viewed by employees with learning disabilities

Previous studies have highlighted how job satisfaction was negatively correlated with loneliness (Petrovski and Gleeson 1997). In this study employees with learning disabilities were generally satisfied with their employment experience. Some of them highlighted they would like to work for more hours a day. Indeed, this study gives an image of the reality as described by previous studies highlighting many people with learning disabilities worked part-time, paying low tax and retaining benefits (Beyer et al. 1996; Beyer and Kilsby 1998; Melling et al. 2011). In the current study it emerged that part-time positions were preferred as they did not affect the welfare benefit flow for the person.

Employees with learning disabilities reported mild, moderate or quite severe health problems, widely affecting their lives. However, the employment conditions generally helped people with learning disabilities in improving their previous life experiences, of being unemployed or employed in unsatisfactory positions.

Furthermore, being paid for the job they were doing represented an important factor, supporting the previous literature (DH 2010a). The current study highlighted the chance for people with learning disabilities to

afford to buy products or access services they had never had the chance to access before.

Many participants with learning disabilities highlighted the social side of employment. They interacted with co-workers on general issues, but also about health related matters. Several studies have highlighted a fundamental effect of employment on social inclusion in an ordinary working setting (Kilsby and Beyer 1996; Forrester-Jones et al. 2002; Forrester-Jones et al. 2004) and the positive effect of becoming a member of a specific “working culture” (Fillary and Pernice 2006), but other highlighted detrimental effects such as misunderstanding and exclusion in the workplace (Di Terlizzi 1997).

In the current study a relevant aspect for health was discovered in the activity of mirroring other people in the workplace. In some cases people with learning disabilities working in a specific working culture, modified their behaviour toward positive health behaviours to imitate a co-worker or a job coach. Thus, the work context became a learning one where an employee was able to learn healthy habits through observation and practical experience.

Employment gave tangible evidence of people with learning disabilities experiencing positive health outcomes. Employees with learning disabilities became more active in employment and sometimes while going to work. People with severe learning disabilities were reported to have improved their physical skills by performing work tasks.

Previous research has highlighted that few people with learning disabilities have a balanced diet (Emerson and Baines 2010). In the current study people with learning disabilities were generally quite aware of healthy eating. However, when they referred to their day to day life, they claimed to follow a healthy diet. Among people living independently the culture of ready meals was quite popular, with some exceptions where individuals preferred to cook food from fresh ingredients.

9.3 Potential for supported employment and health

Previous studies reported improved well-being in SE (Beyer et al. 2010), good quality of life (Griffin et al. 1996; Eggleton et al. 1999; Kober and Eggleton 2005; Verdugo et al. 2006; DH 2010a) and cognitive improvements (Garcia-Villamisar and Hughes 2007). The current study highlighted that SEAs had the potential to make positive changes to the health of the employee with learning disabilities, even if this was not the main focus of the service. As we have seen, the job coach figure was extremely important and helpful to address, directly or indirectly, health issues.

There are two central mechanisms through which the role of supported employment supports health. The first is that health improves when the SE procedure is delivered correctly (formal pathway). The second is that many SEAs plan extra activities for their client to support and promote their client's health (informal pathway). It seems that, for the first issue, SE staff are well placed to deliver outcomes, while for the second considerable changes are needed as I highlight below.

The first position is dependent on all the processes highlighted in this research working to promote health. SE contributes to health through a good assessment involving health aspects, followed by caring about health and safety aspects of any job found. Health is a central part in the phase of job negotiation, job analysis and negotiation of reasonable adjustments for that individual in the workplace, not just in catering for existing health conditions but also planning to improve health.

The second position instead sees the SEA as active planners of activities for health, highlighting that there may be a need to health individuals with learning disabilities in employment to become more active or in general healthier through specific health interventions. We have seen that SEA staff are not usually trained to promote health and that they may not have

the knowledge and the competences to do it. This was an important point highlighted by several managers, who felt they needed to be extremely careful with their competences limits in relation to health.

Careful consideration is needed of the balance between cost and benefits if there was to be investment in SEAs as a service that can promote health benefits in employment.

It could be recommended that these study findings, should inspire the activity of the Health and Well-being Boards and Clinical Commissioning Groups (CCGs) in England. CCGs and Local Authorities have the duty to prepare strategies to improve the health and well-being of their local community and to reduce health inequalities (DH 2013). CCGs and Local Authorities might help in further developing SEAs competence towards promoting health outcomes. Indeed, these research findings showed health support can be integrated with employment and skills programmes, such as supported employment. The SE service is tailored to the individual (EUSE 2009),is looking at the person holistically and therefore health is a valuable individual dimension that needs to be taken into account.

Indeed, when considering the results of this study in relation to Public Health Policy, it is clear how employment and supported employment may help to deliver important public health goals. In this research an individual reduced drinking during the week because of work commitments, showing that this behaviour can be reduced thanks to being in employment. This study carries evidences of people with learning disabilities losing weight in employment, choosing healthier diets and being more active. Results showed people reducing smoking while at work, while other used smoking as the way to be socially involved with their managers. These results meet some elements of the Public Health agenda, but further studies are needed to gather more evidence in this respect.

It would be important also to analyse the mirroring behaviour of people with learning disabilities, in other words the tendency of people with

learning disabilities to imitate healthy (or unhealthy) behaviours of co-workers and job coaches. This may result to be a powerful way to promote health in supported employment and employment.

9.4 Strengths, limitations and reflections on this study

This paragraph aims to explain the strengths and limitation of this study in relation to the methods adopted.

This mixed method study offered an in depth analysis of the role of SEAs in promoting the health of people with learning disabilities. This was a strength of the study as the first quantitative phase, represented a vital lead in to the second qualitative phase. This is because the topic had not been previously investigated; therefore the web-survey was a real asset to get an understanding of the role of SE for health. The quantitative element was also of value for sample selection and planning of the second qualitative phase.

The first limitation was the moderate size of the sample (50 SEAs) for the quantitative phase of this study. This is a common issue in surveys and leads to concerns over the representativeness of the sample. I was unable to track how many SEAs were contacted and, of those, how many supported people with learning disabilities, therefore meeting the criteria for taking part to the survey. On the positive side there is no reason to suspect systematic bias and the responses showed range of inputs to health.

A further limitation is that the quantitative phase of this study considered only the views of staff in SEAs, usually managers or job coaches. This limitation was addressed in the qualitative phase, where employees with learning disabilities were involved. Furthermore, the web-survey provided a snap shot of the role of SE on health, but it provides few data on how SE

influenced health. This limitation was also addressed in the qualitative phase.

For the qualitative phase of my study Grounded Theory (GT) was chosen as the best theoretical method to answer the research questions and meet the research aims. GT has the strength of being a qualitative and well-structured approach (Pidgeon and Henwood 2009). Grounded theory allows for the gathering of rich data. Such data can inspire clear and original insights into people's experience identify future projects and practical suggestions. However GT can be time consuming because of the ongoing process of gathering and analysing data. Also it might be difficult to determine when the saturation criteria for the sample are reached. The concept of saturation, that is the point where no new information was observed in the data (Guest et al. 2006), represented a difficult decision to make. In the literature several studies report different threshold of saturation: Bertaux (1981) report that a qualitative study needs the contribution of at least 15 individuals, while Creswell (1998) report that a GT study should have 20-30 participants and Guest et al. (2006) reported that saturation occurred after 12 interviews, while meta-themes were already present after 6 interviews (Bertaux 1981; Creswell 1998; Guest et al. 2006).

I had to consider what the most appropriate saturation point in my research was. For interviews with managers and job coaches saturation was reached after about 8 interviews. While considering interviews with people with learning disabilities, saturation was reached later, and the study benefited from more contributions. Overall, researchers cannot be sure whether they have reached saturation for all the themes because even if the same theme appears several times with the same meaning, a new interview may carry innovative experience related with that theme.

A further issue in representativeness of my data is that the selection of individual with learning disabilities was through self selection by the SEAs. There may have been a tendency to select the most successful

employment experience from SEAs staff points of view, but the selection of participants was more linked with their availability on the day I was attending the SEA than individual abilities as explained previously.

When considering the quality of the interview, several factors played a role. The best setting for the interview was the SEA, where I was able to organize the interview setting before the interview. This setting certainly played a positive role in the interview. This was probably due to the creation of a welcoming prepared environment. Preparation did not take place when the interview was held in the workplace. This might represent an element of disturbance in the interview. Furthermore, the presence of a third person during the interview played an ambivalent role. Sometimes it facilitated the interview as the third person provided background information that was important to understand the individual answer. In other cases the third person played as an obstacle, when she/he answered to the question on the interviewee behalf. My role was important to avoid this influence to compromise the positive flow of the interview.

9.5 Future development of this study

The study findings open up many directions for future research, with the aim of increasing knowledge and delivering better services to people with learning disabilities and their families. Potential future directions include:

- An intervention study, comparing SEAs staff trained in promoting health outcomes for their clients with learning disabilities and a paired control group of SEAs staff not receiving it. This idea originated from the study results on “mirroring” healthy behaviours, and from a study on the process of empowering people with intellectual disabilities by Direct Support Professionals (Flatt-Fultz and Phillips 2012). The study aim would be to evaluate the efficacy of training in promoting health, and the potential of mirroring healthy behaviours. The research would be designed to understand if

training in promoting health outcomes would be beneficial to people with learning disabilities entering employment and to understand the balance among costs and benefits of the approach.

- An intervention study empowering the health of employees with learning disabilities and those of their family. A programme of empowerment around healthy lifestyles and strategies that aim for better health in the employment situation would be delivered in collaboration with SEAs. A comparison between health attitudes before and after the programme would provide ideas on empowerment interventions that might impact on families and on the individual life. Views of families and people with learning disabilities would need to be captured. Similar studies have already been carried out with families of people with learning disabilities to examine how families and carers facilitate inclusion, choice and control for family members with learning disabilities (Jingree and Finlay 2012).

- A longitudinal study to better understand the relation between health and employment for people with learning disabilities. This study would investigate health changes following employment, through the evaluation of lifestyles and the health of people with learning disabilities at different time of the employment experience. Lifestyle and health indicators would be considered together with personal experience linked to employment.

9.6 Concluding statement

This study provides new knowledge on the role of SEAs in promoting positive health behaviour of employees with learning disabilities. This new knowledge has the potential to improve the SE service toward health and to direct future choices for SE in relation with health. This study is

contextualized in a society which recommends the promotion of health and well-being of the community members through the novel activity of Health and Well-Being Boards and Clinical Commissioning Group. This study might set up new considerations in the field, where development of SEAs competence towards health may be promoted. Results from this thesis acknowledge health support can be integrated with employment and supported employment programme.

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APPENDIX A

Sheltered, Supported and Customized Employment: the history so far

In the past assisting people with learning disabilities at work has been a source of worry for years, primarily because people with a learning disability were considered to be less productive than the general population. Therefore, since 1944 the UK created a *Disabled Person's Employment Act*, defining a *Quota Scheme* equivalent to a minimum of 3% of disabled people for every employer (Barnes 1991; Berthoud et al. 1993; Hyde 1996, 1998). The application of the scheme was weak and almost all employers were under quota, also because there were not enough administrators to check the employment condition. Furthermore, most of the disabled people were placed in special employment programmes such as **sheltered employment** and not in ordinary jobs. Indeed, sheltered employment offered a protective environment where people had a chance to be engaged in activities and be paid for it, but they were at the same time segregated in a protected reality (Hyde 1998). An amendment of *Disabled Persons (Employment) Act* was developed in 1958, where the way to fund sheltered employment was revisited and achievable through competition (LabourResearch 1995; Hyde 1996, 1998). Workshop managers were encouraged in restructuring the labour process, helping SE to progressively emerge and replace sheltered model (Hyde 1998).

However, over the years changes in the welfare system drove the priority from the needs of people with learning disabilities to employers needs. In the following years, after 1990, the New Labour programme "*Welfare to Work*" introduced compulsory vocational training to improve productivity and introduced deregulation. The *Quota Scheme* was replaced in 1996 by the employment provision of the *Disability Discrimination Act* (DDA) that protected primarily the individual with disabilities, rather than the group of people with disabilities. In 1987 a group of British professionals, inspired by the SE in the USA learned how to apply their method, in particular staff training methods to promote training of people with learning disabilities in the workplace. In the US a law had been passed in 1986 that defined SE

and provided a national system to fundi and deliver it. However, there is not a specific law in the UK related to SE. The main document inspiring Supported Employment service is the DDA, which acts as framework for a change in attitude towards discrimination. Within this framework, discrimination at work is illegal as far as any aspect of employment is concerned.

The new model of SE provides a chance for people with learning disabilities to learn employment tasks and enter an open job. An open job is defined as a typical occupation that everyone could do, paid at the going rate for the job. This definition excludes all the work that has been created for people with learning disabilities and points out that real employment is are different from vocational training, work experience and work preparation. Indeed, a real job is in a setting where the proportion of people with learning disabilities is comparable as the proportion of people who we normally find in the general population, about 6%. The worker needs to be supported as long they require it, and as long as the person is performing satisfactory at work. This support usually begins with job finding, progresses with on-site task and social training, job supervision and ongoing monitoring (Beyer et al. 1996).

In order to regulate and protect **supported employment**, agencies joined together in early 1990's in national organizations representing this type of service. National Associations of Supported Employment were created and unified in 2006 as *British Association for Supported Employment* (www.base-uk.org).

Recently the DDA has been replaced by the Equality Act in 2010, enforced by the Equality and Human Rights Commission. The Equality Act places a responsibility on public bodies to actively remove barriers to equality in a range of life areas, including employment. Scholars in the field of SE highlighted that in recent years, policies have undergone a number of changes (Melling et al. 2011). Policy documents such as *Valuing People Now*, followed by *Valuing Employment Now* in England, *Fulfilling the*

Promises in Wales, and *The Same as You* in Scotland, have led to significant progress in highlighting SE as the support mechanism of choice for people with intellectual disabilities. At the same time, since 2010 the *Work choice Programme* has been the main framework for developing the SE of people with disabilities.

In the US a new version of employment support, called **Customized Employment,** has been developed (NCWD 2005; O'Bryan 2008; Beyer and Robinson 2009). It presents many similarities with the classical SE approach, with the difference in emphasizing the importance of ensuring the applicant fits well with the employer needs, through an individualized support approach (Parent 2004). It describes individualized techniques of promoting employment and it is characterized by a personalized approach of the relationship between the job seeker and the employer, meeting both needs (DOL 2011). This approach focuses more on personal characteristics and needs and spends more time on the process of gathering information about the person and the employer to provide a better fit between them. The approach has been used to allow people with more complex disabilities to access employment and may therefore bring employment to people with a significant need for low level, positive health intervention.

APPENDIX B

Weight disorders, smoking and alcohol use

Weight disorder:

Obesity and overweight represent ever-growing problems across developed and developing countries, due to new food cultures and general lifestyle habits. Obesity is defined by the WHO as abnormal or excessive fat accumulation able to impair health (www.who.int). Obesity increases the likelihood of developing various diseases, in particular hearth diseases, type 2 diabetes, certain types of cancer such as breast and colon cancer (www.nhs.uk), breathing difficulties, and osteoarthritis (renoveldiscoveris.com).

The World Health Organization (WHO) classifies overweight, underweight and obesity considering the body mass index (BMI). It is calculated considering the person's weight, expressed in kilos, and divided by the square of the person's height. The National Institute for Health and Clinical Excellence (NICE) defines a classification considering the BMI (Table B1).

CLASSIFICATION	BMI
Underweight	Less than 18.5
Normal weight	18.5 – 24.9
Overweight	25.0 – 29.9
Obese	30.0 or over

Table B1: BMI classification Source NICE, 2006 (Crawley 2007)

While obesity is a medical condition, overweight represents interval state between normal weight and obesity and it is the area where the person has the chance to take previsions in order to avoid health complication.

In the fifties, Vague already noticed a higher risk in developing health issues, predominantly cardio-vascular diseases, in individuals with "android shape" than individuals with "gynoid shape" (Vague 1999; Ashwell 2009). Later, Margaret Ashwell suggested a way to check health

status from the measurement of waist circumference, based on Vague and other scholars' studies. She associated the individuals' waist circumference with their height and reporting them on the following chart (Figure B1).

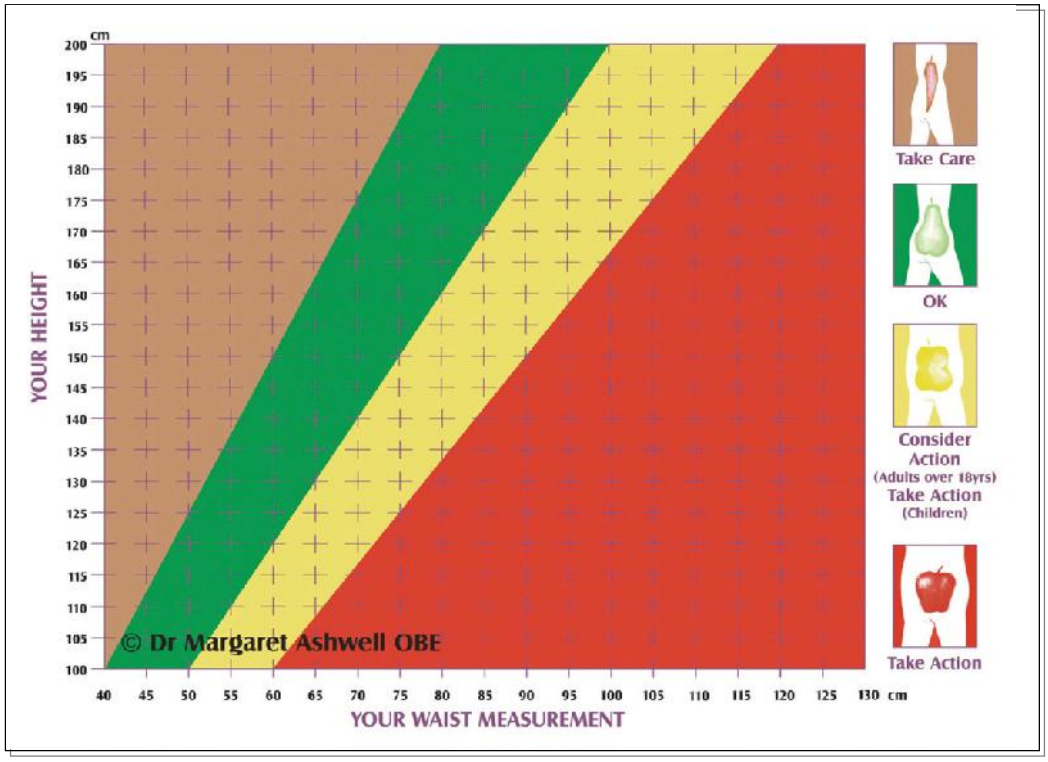


Figure B1: Ashwell Shape chart (Ashwell 2009)

In this way it is possible to understand personal risk. The brown area is called the *take care area*, meaning the person is underweight and needs to gain some weight. The green area means the person has a healthy "pear shape" where the fat is usually stored under the skin, around the bottom, hips and thighs, and therefore less harmful. The yellow are instead identify the area where certain action need to be considered in adults and need to be taken in children. Finally the red area is the action area, where people definitively need to take actions, because the fat has been accumulated internally, meaning the individual is more at risk to develop health conditions.

According to a National Diet and Nutrition survey, waist measurement allows to spot 35% of men and 14% of woman having a normal BMI, but at risk to develop health conditions because of central fat distribution (Ashwell 2009; Ashwell and Gibson 2009).

Smoking

The smoking issue is of great interest for the UK government which adopted measures to reduce this behaviour within the population. Smoking is a risk factor which leads to the development of health issues such as heart disease, cancer and respiratory problems. Since the 1st July 2007 smoking is forbidden in public places. New laws and policies to disincentive smoking are taking place to face with the problem. Despite the policies and the falling in the number of people smoking, the problem still represent the leading risk factor in 2010 (Murray et al. 2013). The NHS is offering support for people who want to quit smoking throughout the "Smoke free" programme, advising people on how to stop to smoke and highlighting downsides of smoking for personal health, financial aspects and social aspects. However, the efficacy of this type of campaign for people with learning disabilities is unknown.

Alcohol use

Alcohol use is considered to be the cause of 34,000 deaths in the UK each year within the general population, as one in five men and one in seven women regular exceed the Department of Health guidelines (Marsden 2011). The last campaign against alcohol abuse "Change4Life" aim to raise awareness on health risks associated with drinking. Indeed, a new TV advert shows how alcohol "sneak up on you", encouraging people to check their drinking habits, emphasizing how many calories are contained into their drinks and estimating a cost of drinking (www.gov.uk).

Government guidelines suggest men do not exceed 3-4 units of alcohol a day, and women do not exceed 2-3 units (Figure B2).

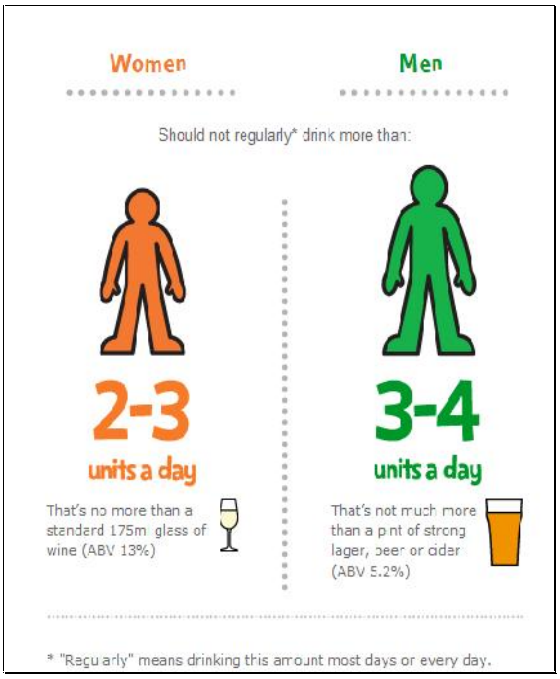
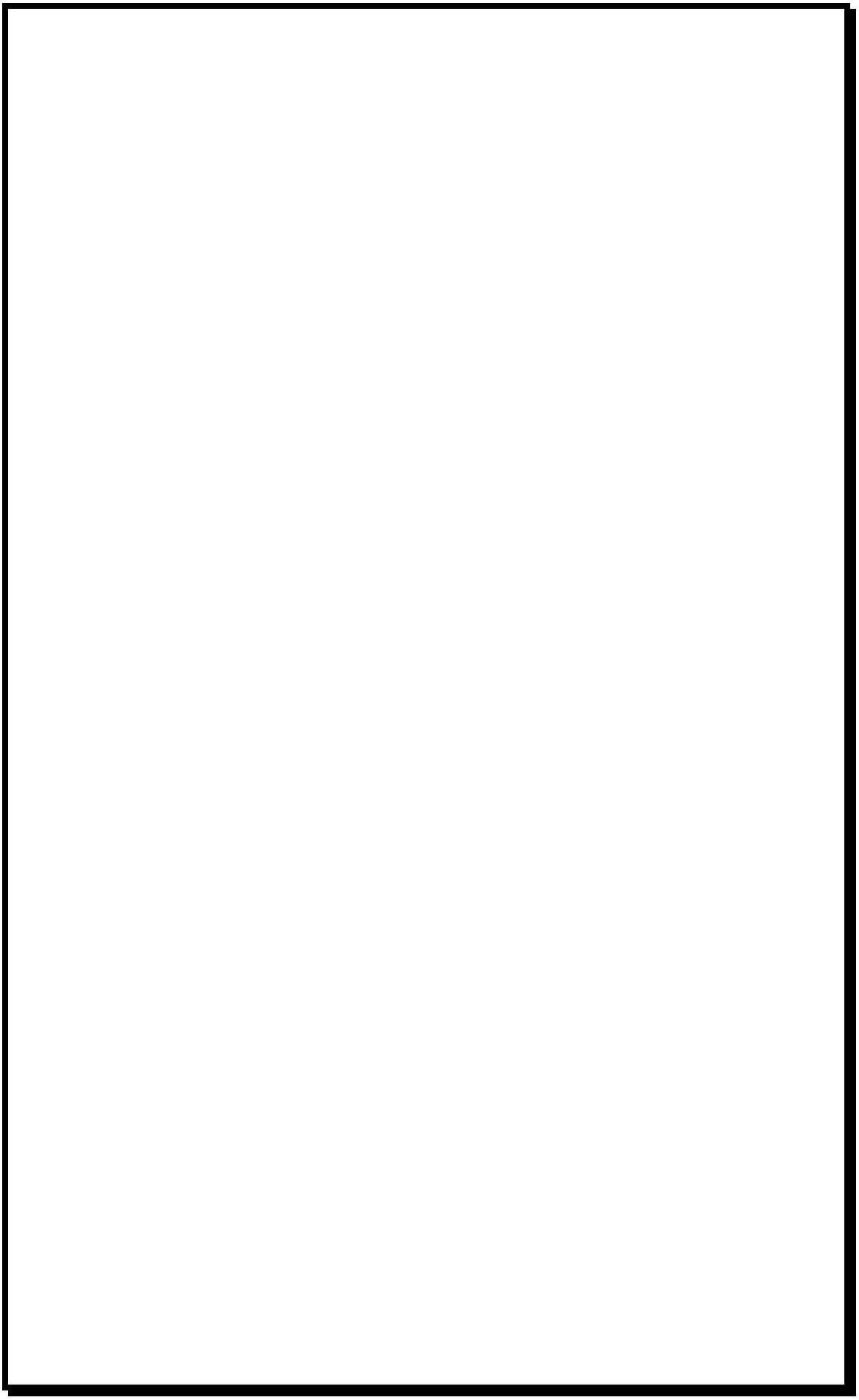


Figure B2: Government guidelines (from www.nhs.uk)

However, the effectiveness of this campaign for people with learning disabilities is unknown.



APPENDIX C

Learning disability diagnostic classification

Diagnostic classification of learning disabilities

Clinical definitions are generally fundamental to reach agreement among professionals in the sector and to get an understanding of the evolution of the disorder over the time. Therefore a short reference to the diagnostic methods currently used is summarized below.

The World Health Organization reported the Classification of Mental and Behavioural Disorders (ICD-10) listed in different categories. The manual refers to mental retardation rather than learning disabilities. Furthermore, the manual reports disorder of psychological development linked with scholastic skills, disorder of speech and language, mixed specific developmental disorders (including the previous two categories, but where not a predominant category of disorder may be highlighted), pervasive developmental disorder, such as autism, Rett Syndromes, Asperger's syndrome and other disorders of psychological development (WHO 1992).

The American Association on Mental Retardation [1] describes learning disabilities referring to limitations in present functioning, manifested before the age of 18. The limitations generally affected communication, self-care, home living, social skills, community use, self direction, health and safety, functional academics, leisure and work (AAMR 1997; Gates 2007).

The Diagnostic and Statistical Manual of Mental Disorders (DSM IV) is a widely shared multi-axial assessment of mental disorders, useful to create diagnostic consensus among specialists. It includes the assessment of:

a. Axis I: clinical disorders;

b. Axis II: personality disorders, mental retardation;

c. Axis III: general medical conditions;

[1] The association was renamed American Association on Intellectual and Developmental Disabilities.

d. Axis IV: psychological and environmental conditions;

e. Axis V: global assessment functioning.

Learning disabilities disorders are usually first diagnosed in infancy, childhood or adolescence (APA 2000).

None of the previous diagnostic manuals specifically refers to people with learning disabilities. Therefore a group of learning disability psychiatrists in the UK and Republic of Ireland wished to improve the diagnostic classification for learning disabilities for those people, creating the DC-LD classification, to be used as a complementary diagnostic instrument to the ICD-10. The choice of a complementary classification is supported by the differences of some psychiatric disorders in people with learning disabilities compared with the general population. DC-LD is based on a hierarchical representation of 3 axes:

- Axis I: severity of the disabilities;
- Axis II: cause of learning disabilities;
- Axis III: psychiatric disorder divided in different levels (developmental disorders, psychiatric illness, personality disorders, problem behaviours and other disorders).

The assessment of personal intellectual functioning is generally based on psychometric tests. The most popular test now in use is the WAIS IV (Wechsler 2008) which is standardized specifically for an individual's cultural background. However, it is relevant to assess the adaptive and social functioning; professionals have to look at daily life and how the person adapts to it. This is about the ability to self-care, being able for instance to satisfy primary needs such as feeding, cleaning need and getting dressed. It involves also the ability to communicate, get engaged in a social context such as work and leisure. In order to be defined as a

learning disability the onset of the condition has to appear before adulthood (18 years of age).

Causes of learning disabilities

According to the Royal College of Psychiatrist (RCP 2001), learning disability may be caused by: congenital malformation and deformities (encephalocele, microcephaly, congenital hydrocephalus, congenital malformation of corpus callosum, Arnold-Chiari syndrome);

- chromosomal abnormalities (Down Syndrome, Prader Willi Syndrome, Fragile X Syndrome, Turner Syndrome, Cri du Chat Syndrome etc);
- conditions originating in the prenatal period (maternal complication of pregnancy, functional abnormalities of placenta, condition of umbilical cord, complication of labour or delivery, extremely low weight, congenital rubella or toxoplasmosis, neonatal listeriosis);
- infectious diseases (meningitis);
- endocrine, nutritional and metabolic diseases: (phenylketonuria, etc.).

APPENDIX D

School of Medicine Ethics Approval for Quantitative and Qualitative study

Tuesday 26 January 2010

Elisa Vigna
Welsh Centre for Learning Disabilities
2nd floor, Neaudd Meirionnydd
Cardiff University
Heath Park

Dear Ms Vigna

Re: The role of supported employment in promoting positive health behaviour of people with learning disabilities at work

SMREC Reference Number: 10/03

This application was considered by the School of Medicine Research Ethics Committee [SMREC] on Wednesday 20 January 2010.

Ethical Opinion

On review, the Committee decided that approval could be granted, provided that the following amendments were made:

1. That in the Health Promotion section on page 1 of the information sheet, that the word agencies is corrected.
2. That in the Taking part and consent section on page 2 of the information sheet, that the word choose is corrected in the first paragraph.
3. That in the second paragraph of the Taking part and consent section, that the second sentence is amended to say "This is because you may be contacted at a later date."
4. That question 7 on the Web questionnaire is corrected to say activities as opposed to activity.
5. That question 19, answer choice h, is amended to say "carry out basic personal hygiene."

To progress this application, the Committee requires clarification of the above points by Monday 1 February.

Documents Considered

Document Type:	Version	Date Considered
Application Form	V1 11/01/10	20/01/10
Explanation of Answers – Attachment 1	V1 11/01/10	20/01/10

Document Type:	Version	Date Considered
Details in support of School of Medicine Ethical Approval Form – Attachment 2	V1 11/01/10	20/01/10
Participant Information Sheet	V1 11/01/10	20/01/10
Web questionnaire	V1 11/01/10	20/01/10

If you have any queries, relating to the points raised, I would be happy to discuss these with you.

Yours sincerely

Dr Andrew Freedman
Chair, School of Medicine Research Ethics Committee

Monday 26 September 2011

Elisa Vigna
WCLD
Department of Psychological Medicine
2nd Floor, Neuadd Meirionnydd
Cardiff University
Heath Park

Dear Elisa,

Re: The role of supported employment agencies in promoting positive health behaviour of people with learning disabilities at work

SMREC Reference Number: 11/36

This application was reviewed by the School of Medicine Research Ethics Committee on Wednesday 14th September 2011.

Ethical Opinion

On review, the Committee granted ethical approval for this project. The Committee have asked that any documents that will be distributed to the participants are proofread and checked for typos.

Conditions of Approval

The Committee must be notified of any proposed amendments to the methodology and protocols outlined in your submission. Also, any serious or unexpected adverse reactions that may arise during the course of the study must be reported to the Committee.

Documents Considered

Document Type:	Version:	Date Considered:
Application Form	V1 01/09/2011	14/09/2011
Supporting Document	V1 01/09/2011	14/09/2011
Email to Agencies	V1 01/09/2011	14/09/2011
Participant Information Sheet, Consent Form, Interview Schedule (Managers)	V1 01/09/2011	14/09/2011
Participant Information Sheet, Consent Form, Interview Schedule (Job coaches)	V1 01/09/2011	14/09/2011
Participant Information Sheet, Consent Form, Interview Schedule (People with Learning Disabilities)	V1 01/09/2011	14/09/2011

With best wishes for the success of your study.

Yours sincerely,

Dr Andrew Freedman
Chair, School of Medicine Research Ethics Committee

APPENDIX E

Employment and Health web survey

Welcome

The role of supported employment in promoting positive health behaviour of people with learning disabilities at work

Dear colleague,

You are being invited to take part in a research study as a representative of your Employment Agency. Before you agree it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information (Our contact details are given below). Take time to decide whether or not you wish to take part.

Thank you for reading this.

Purpose of the study

Health promotion in the workplace is increasing in importance and in government attention. Government recognise the importance of employment in maintaining people's health and well-being. Increasingly, employers are concerned to promote the health of their workplaces through formal health promotion activities at work. This is becoming an important aspect of workplace culture in some companies. People with learning disabilities face barriers in getting, learning and keeping a job. They will also face barriers in engaging with work-based health promotion activities.

Supported employment agencies play a central role in finding, teaching and maintaining a job for people with learning disabilities. We have little information on how supported employment agencies help people with learning disabilities to engage positively with employer-led health promotion or more generally help them to be healthy at work. The study aim is to provide information about this aspect of the work of supported employment agencies with their clients who have learning disabilities.

Health promotion

In particular this study focuses on the health and well-being promotion activities of supported employment agencies for people with learning disabilities. We consider health and well-being promotion as the process of enabling people to increase control over their health conditions and, consequently, improving health and well-being (WHO, 2005). There are many ways in which health and well-being can be supported through giving people correct information, training people to improve the quality of working conditions, involving experts to advise if the person has a specific problem and organising health promotion events, among others.

The study

This study is a project sponsored by the Welsh Centre for Learning Disabilities at the School of Medicine, Cardiff University. The work will form a part of a PhD carried out by Elisa Vigna and also contribute to the research programme of the Welsh Centre for Learning Disabilities on Supported Employment.

This online survey will be distributed to Supported Employment agencies across the UK. It represents the first stage of a PhD study that will last for 3 years. The study has the support of the UK industry representative bodies: British Association of Supported Employment; Scottish Union of Supported Employment; Association of Supported Employment Agencies (Wales); and the Northern Ireland Union of Supported Employment.

Taking part and consent

It is up to you whether or not you take part on behalf of your agency. The study concentrates on agencies working with people with learning disabilities, either solely or as one client group. You will be free to withdraw at any time and without giving a reason. You may not answer particular questions if you choose. By finally submitting your response you will be consenting to the use of the data you provide in the particular ways we specify here.

You will be asked to provide your contact details (your name, position in the organisation, telephone and email contacts). This is because you may be contacted at a later date. Should you be selected, the contact details you provide will enable the researcher, Elisa Vigna, to invite your organisation to take part in a later stage of the study. By completing this survey you do not commit your organisation to any further work.

Definition of people with learning disabilities

We consider people with learning disabilities to be those who have a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) and with a reduced ability to cope independently (impaired social functioning) which started before adulthood and which has a lasting effect on development. The definition includes adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average or even above average intelligence – such as some people with Asperger's Syndrome (DH, 2001).

Security and use of the data

The data you provide will be kept on a secure server for the duration of the project, after which it will be destroyed. Data from organisations will be anonymised by substituting any contact details with a code number. Only the researcher and the research supervisors will have access to the responses you provide and only they will know which agencies have responded. Reports and presentations on this stage of the study will not name any agency and data will be reported together so that no agency will be identified.

To access the survey, please click continue

The web survey consists of 22 main questions in 6 sections. We estimate that it will take around 20 minutes to complete. You can save your responses and come back to the survey question any number of times before you submit. The survey tool allows you to save your results part way through and come back to it a number of times to complete it if you wish.

If you require further information on this survey, or the wider study, please do not hesitate to contact Elisa Vigna at the Welsh Centre for Learning Disabilities:

email: vignae@cf.ac.uk

Office: 029 20687204

Address: Welsh Centre for Learning Disabilities
Cardiff University
Neuadd Meirionnydd
Heath Park,
Cardiff, CF14 4YS

Thank you for your support.

Section 1: Your details

This section asks you about your role and the agency.

Your name:	
Your position in the organisation:	
Name of your Agency:	
Address of your agency:	
Contact telephone number:	
Email:	

Section 2: General information about your agency

1. Which of the following **employment services** do you provide (tick any that apply)?

- o Support for jobs in ordinary workplaces
- o Vocational training in ordinary workplaces
- o Jobs in your own enterprise
- o Vocational training in your organisation
- o Other (please specify):

2. How would you describe your agency and the work it does in relation to employment?

3. Do you support **people with learning disabilities**?

- o YES
- o NO

3a. (*If YES)* How many clients with learning disabilities do you support in employment **at the moment**?

- o less than 20
- o between 21 and 50
- o between 51 and 100
- o between 101 and 150
- o more than 150

3b. *(If NO)* Thank you very much for your time and collaboration. You need complete no further questions. Please submit your questionnaire.

4. Do you provide **training in the workplace** for people with learning disabilities?

- o YES
- o NO

4a. (*If YES)* what models of training do you use?

- o individual training (one-to-one)
- o small group training
- o other (please specify)

Section 3: The processes you use to pursue employment

5. Do you have an **assessment programme** to outline the needs of the person with a learning disability?

- o YES
- o NO

5a. *(If YES)* Which aspects do you consider in your assessment programme?

	YES	NO
a. personal attitudes	☐	☐
b. abilities	☐	☐
c. physical barriers	☐	☐
d. cognitive barriers	☐	☐
e. dreams/aspirations	☐	☐
f. health risks behaviours that have to be taken into account	☐	☐
g. aspects of jobs that might promote health for the person	☐	☐
h. other (please specify)_____	☐	☐

6. What **client characteristics** are **predictive of success** for people getting employment?

	Always important	Sometimes important	Not relevant
a. basic skills knowledge (reading, writing, spelling)	☐	☐	☐
b. physical impairment	☐	☐	☐
c. gender	☐	☐	☐
d. client personality	☐	☐	☐
e. social background	☐	☐	☐
f. amount of welfare benefits received	☐	☐	☐
g. family or carers support	☐	☐	☐
h. other (please specify)_____	☐	☐	☐

7. What **activities** do you provide in **support of your client**?

	YES, we always provide	YES, if requested	NO, we do not provide
a. how to fill in an application form	☐	☐	☐
b. how to write a CV	☐	☐	☐
c. how to dress appropriately for an interview	☐	☐	☐
d. how to behaviour appropriately during an interview	☐	☐	☐
e. attending the interview with the client	☐	☐	☐
f. other (please specify)_____	☐	☐	☐

8. Do you provide **"health and safety"** advice during your training?

- o YES
- o NO

8a. *(if YES)* Could you tell us what advice do you provide? (Please, tick any that apply)

- o risk assessment for a person in the workplace
- o general advice on how to act safely in the workplace
- o specific advice on how to act safely in the workplace (use of equipments etc.)
- o practical demonstration of how to be safe in the workplace (right behaviour on how to avoid incidents)
- o advice on routine at work (when it is allowed to have lunch, breaks etc.)
- o distribution of easy to read leaflet explaining health and safety
- o advice on how to take in safety transport to the workplace
- o other (please specify)

8b. *(if YES)* How long does the training last?

9. Does your agency ask if an **employer provides health promotion activities** (e.g., workplace anti-smoking, healthy eating, positive mental health or anti-stress campaigns, information, group sessions, or incentives)?

o YES
o NO

9a. *(if YES)* Do you ask for information about these activities from employers?

o YES
o NO

9b. *(if YES)* If you know, could you give us an estimate of the proportion of your employers have activities to promote health and well-being?

9c. *(if YES)* These activities are more frequent in (tick the appropriate):

o Large employers (more than 30 employees)
o Small employers (less than 30 employees)

10. Does your agency give **advice and support to employers** on how to involve a person with learning disabilities in their health promotion activities?

o YES
o NO

10a. *(if YES)* What advice and support do you give?

11. Do you provide **monitoring/on-going support** of workers after they are placed?

- **o** YES
- **o** NO

11a. *(if YES)* What do you provide during monitoring/continuous support? (Please, thick the appropriates)

- o periodical monitoring visit of staff to the client workplace
- o worker can contact us if there are concerns or problems
- o employer can contact us if there are concerns or problems
- o other (please specify)

11b. *(if YES)* Do you check on the workers involvement in health promotion activities at the company?

- YES
- NO

11c. *(if YES)* What aspects of the workers health do you check on, if any?

Section 3: Health problems

12. Does your agency collect any information on any of the following information about a **client's health behaviour**?

	Always	Sometimes	Never
a. a client smokes	☐	☐	☐
b. a client's alcohol intake is higher than government policy limits	☐	☐	☐
c. a client use of drugs	☐	☐	☐
d. a client usual diet	☐	☐	☐
e. a client level of physical activity	☐	☐	☐
f. a client height and weight	☐	☐	☐
g. a client impairment(s)	☐	☐	☐
h. a client medical condition	☐	☐	☐
i. a client psychological condition (depression, phobias, anxiety etc)	☐	☐	☐

13. If the client with learning disabilities is **overweight/obese** or **underweight**, would your agency:

	Always	Sometimes	Never
a. suggest an healthy diet	☐	☐	☐
b. suggest more physical activities	☐	☐	☐
c. provide easy to read leaflets relating to healthy eating	☐	☐	☐
d. build a plan with the client and employer to make positive changes to diet in the workplace	☐	☐	☐
d. make a healthy eating plan with the client	☐	☐	☐
e. make a healthy eating plan with family or carer	☐	☐	☐
f. Involve appropriate health professionals in treatment and any plan	☐	☐	☐
g. other (please specify)_____	☐	☐	☐

14. If the **client smokes**, would your agency:

	Always	Sometimes	Never
a. give verbal advice	☐	☐	☐
b. provide easy to read leaflets relating to reducing or quitting smoking	☐	☐	☐
c. build a plan with the client and employer to make positive changes to reduce smoking in the workplace	☐	☐	☐
d. we plan actions with client	☐	☐	☐
e. we plan actions with family or carer	☐	☐	☐
f. Involve appropriate health professionals in treatment and any plan	☐	☐	☐
g. other (please specify) _____	☐	☐	☐

15. If the client **abuses alcohol**, would your agency:

	Always	Sometimes	Never
a. give verbal advice	☐	☐	☐
b. provide easy to read leaflets relating to reducing or quitting alcohol	☐	☐	☐
c. build a plan with the client and employer to make positive changes to alcohol consumption	☐	☐	☐
d. make a plan with the client to reduce or quit alcohol	☐	☐	☐
e. make a plan with family or carer to reduce or quit alcohol	☐	☐	☐
f. involve appropriate health professionals in treatment and any plan	☐	☐	☐
g. other (please specify) _____	☐	☐	☐

16. If the client **abuses drugs**, would your agency:

	Always	Sometimes	Never
a. give verbal advice	☐	☐	☐
b. provide easy to read leaflets relating to reducing or quitting drug taking	☐	☐	☐
c. build a plan with the client and employer to make positive changes to drug consumption	☐	☐	☐
d. make a plan to quit or reduce drug taking with client	☐	☐	☐
e. make a plan actions with family or carer to reduce or quit drug taking	☐	☐	☐
f. Involve appropriate health professionals in treatment and any plan	☐	☐	☐
g. other (please specify) _____	☐	☐	☐

17. Which factors could be obstacles to promoting the health of your clients? (Please, tick any that are appropriate)

- **o** lack of understanding about health problems by your staff
- **o** lack of training on health promotion for your staff
- **o** inability of clients to understand because of learning disability
- **o** lack of client receptivity
- **o** client personality
- **o** staff's own health behaviour (e.g., if staff smoke themselves etc.)
- **o** family or carer's own health behaviour (e.g., if staff smoke themselves etc.)
- **o** lack of support for change by family or carers
- **o** lack of time for staff to intervene during training/monitoring
- **o** other (please specify)

18. Have you noticed health gains in people with learning disabilities after being employed?

- o YES
- o NO

18a. *(If YES)* What kind of health gains has your agency noticed?

19. Have members of your staff members helped people with learning disabilities to:

	YES	NO
a. get an eyesight test and/or to get glasses	☐	☐
b. get a hearing test and/or to get a hearing aid	☐	☐
c. have regular meals at work	☐	☐
d. attend sport or fitness sessions	☐	☐
e. attend a GP	☐	☐
f. attend a dentist	☐	☐
g. helping the client with basic activities (reading, writing etc)	☐	☐
h. carry out basic personal hygiene	☐	☐
i. what to do if the person feels unwell at work	☐	☐
j. other (please specify)_____ _____	☐	☐

Section 4: Training of agency staff in relation to health and health promotion

20. Do members of your **staff** (**job coaches, employment specialists, job trainers etc.**) receive training in any of the following (tick any that apply):

	YES	NO
a. health and safety at work (in relation to client placement)	☐	☐
b. risk assessment for clients health promotion	☐	☐
c. health problems people with learning disabilities commonly experience	☐	☐
d. common medications and their effects	☐	☐
e. common mental health problems	☐	☐
f. other (please specify) _____-	☐	☐

Section 5: Social aspects of employment

21. What aspects of **social skills development** do you provide? (tick all that apply)

- **o** appropriate behaviour to keep in general on the workplace
- **o** appropriate behaviour to keep during lunchtime
- **o** how to communicate effectively with the employer
- **o** how to communicate effectively with colleagues
- **o** how to communicate effectively with clients
- **o** how to make new friendships
- **o** other (please specify) _____

22. Have you supported any client with learning disabilities to cope with one or more of these traumatic life events?

	YES	NO
a. bereavement	☐	☐
b. illness or injury	☐	☐
c. trouble with housing/moving house	☐	☐
d. break up of a steady relationship	☐	☐
e. separation or divorce	☐	☐
f. problem with family members	☐	☐
g. problem with a close friend	☐	☐
h. conflict with a work colleague	☐	☐
i. problem with the employer	☐	☐
j. problem with a flatmate	☐	☐
k. problem with the police	☐	☐
l. financial problems	☐	☐
m. sexual problems	☐	☐
n. other (please specify)_____ _____	☐	☐

APPENDIX F

Internal reliability of scores and descriptive statistics

Descriptive Statistics								
SCORE	**Items**	**N**	**Cronbach's Alpha**	**Minimum**	**Maximum**	**Mean**	**Std. Deviation**	**Variance**
Health assessment	9	44	0.847	11	27	18.0909	3.86889	14.968
Diet and weight action	7	46	0.857	7	21	16.5217	3.2778	10.744
Support to stop smoking	6	45	0.886	6	18	14.8444	3.14032	9.862
Support to reduce alcohol use	6	45	0.861	6	18	13.8222	3.05472	9.331
Verbal advice	5	42	0.882	5	15	10.3571	2.9452	8.674
Outsourcing	4	45	0.865	4	12	7.9778	2.46327	6.068

APPENDIX G

Invitation letter for managers of supported employment agencies

"Dear (*name*),

Many thanks for completing the "Employment and Health Promotion survey". We hope you had the chance to look at the brief report with the results that *BASE (or ASEA or SUSE or NIUSE)* distributed to all its members.

Your agency has been selected to take part to the second stage of the research. We are asking your participation as manager of your agency to take part in an interview with Elisa Vigna, the researcher for this study. This study is to understand the strategies that supported employment agencies use to promote the health and well-being of their clients with learning disabilities. The aim of the interview is to know more about your provision in term of health promotion for your clients with learning disabilities.

This study is a project that has ethical approval from the Research Committee of the School of Medicine, Cardiff University. The work will form a part of a PhD carried out by Elisa Vigna and also contribute to the research programme of the Welsh Centre for Learning Disabilities on Supported Employment.

Moreover, if you agree to take part, we would like to ask your collaboration in contacting a small number of clients with learning disabilities currently employed in real job to take part to an interview.

The objective of the interview will be to obtain their point of view on the supported employment process and their perception of healthy lifestyle in the workplace.

Recruitment criteria for employees with learning disabilities are that:

- They are able to give informed consent taking part in interview;
- Their verbal abilities are such that they can communicate in a simple interview;
- They were supported by a job coach;
- They were trained in the workplace;
- They have been employed at least for 1 year;

We prefer to interview people who work for a significant number of hours per week (10+).

In order to get a complete picture of the topic from different point of view, we will also ask for a permission to interview a small number of job coaches or job trainers working in your agency.

If you decide to take part to the study, letter of invitation explaining the study will be sent to you by post and by email that can be given to every participant in the study and institutions to obtain consent.

A timetable can be negotiated to meet with your commitments and requirements.

If you have any query, please, do not hesitate to contact us.

We look forward to hear from you and to start a constructive collaboration.

Yours sincerely,

Stephen Beyer

WCLD – School of Medicine
Cardiff University
2nd floor - Neuadd Meirionnydd
Heath Park
Cardiff
CF14 4YS

Phone: 029 206 87204

Fax: 029 206 87100

Emails: beyer@cf.ac.uk
vignae@cf.ac.uk

Health and Employment Study

Please, send this sheet back using the enclosed prepaid and addressed envelope to inform the researchers of your choice.

☐ I wish *Agency A* to take part to the "Health and Employment Study".

☐ *Agency A* will not be able to take part in the "Health and Employment Study".

PRINTED NAME: _____

SIGNATURE: _____

S. Beyer – E. Vigna

WCLD – Cardiff University
2nd floor Neuadd Meirionnydd
Heath Park
Cardiff
CF14 4YS

Phone: 029 206 87204

Fax: 029 206 87100

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vignae@cf.ac.uk

APPENDIX H

Interviews:

Consent Forms

and

Information Sheets

Welsh Centre for Learning Disabilities, School of Medicine, Cardiff University

Manager information sheet

The role of supported employment in promoting positive health behaviour of people with learning disabilities at work.

You are being invited to take part in a research study as manager of a Supported Employment Agency. Before you agreeing it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with the researcher if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Purpose of the study:
Supported employment agencies have a central role in helping people with learning disabilities to find and maintain a job, but at the moment little is know about their role in promoting peoples' health and well-being. The study's aim is to understand the strategies that supported employment agencies use to promote the health and well-being of their clients with learning disabilities.

It is up to you to decide whether or not to take part. If you do decide to take part you will be interviewed on the topic of health, how supported employment helps to promote it, and what barriers might exist to it promoting health. Interviews will be held in a place that is convenient to you. Interview will last approximately 45 minutes and we will ask you if we can record the interview. We may need to interview you more than once as new issues arise within subsequent interviews with other agencies.

We may use quotes from interviews in our reports or articles. All personal details (names, agencies etc) will be made anonymous by the researcher, as a guarantee of confidentiality.

All the information provided will be kept secret and safe, stored on password protected hard drives and not be accessible to other people. The information gathered will be used for research purposes only. No one other then the research team will see what you say.

This study is a project that has ethical approval from the Research Ethics Committee of the School of Medicine, Cardiff University. The work will form a part of a PhD carried out by Elisa Vigna and also contribute to the research programme of the Welsh Centre for Learning Disabilities on Supported Employment. The work is supervised by Dr. Stephen Beyer.

For further information please do not hesitate to contact Elisa Vigna:

CONTACT DETAILS:

Researchers:
Elisa Vigna
Dr. Stephen Beyer

Address:
Welsh Centre for Learning Disability
Institute of Psychological Medicine and Clinical Neurosciences
School of Medicine
Cardiff University
2nd floor Neuadd Meirionnydd
Heath Park
Cardiff – CF14 4YS

Emails: vignae@cf.ac.uk; beyer@cf.ac.uk

Telephone numbers: 029 206 87216
029 206 87204

Fax: 029 206 87100

Welsh Centre for Learning Disabilities, School of Medicine, Cardiff University

CONSENT FORM FOR MANAGER

The role of supported employment in promoting positive health behaviour of people with learning disabilities at work.

Researchers:
Elisa Vigna (PhD student), Dr Stephen Beyer, Prof. Michael Kerr, Dr. Stuart Todd (supervisors)

Please write your initial in every box to agree and take part to this research

	INITIALS
1. I confirm that I have read and understand the *information sheet* dated 1st September 2011 (version 1) for the above study.	
2. I have had the opportunity to ask questions.	
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	
4. I agree to take part in the above study	

Name of participant:_____

Date:_____

Signature:_____

CONTACT DETAILS:
Address:
Welsh Centre for Learning Disabilities
Institute of Psychological Medicine and Clinical Neurosciences
School of Medicine
Cardiff University
2nd floor Neuadd Meirionnydd
Heath Park
Cardiff – CF14 4YS

Emails: vignae@cf.ac.uk; beyer@cf.ac.uk
Telephone: 029 206 87216 or 029 206 87204
Fax: 029 206 87100

Welsh Centre for Learning Disabilities, School of Medicine, Cardiff University

Job coach information sheet
The role of supported employment in promoting positive health behaviour of people with learning disabilities at work.

You are being invited to take part in a research study as job coach of a Supported Employment Agency. Before you agreeing it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with the researcher if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Purpose of the study:
Supported employment agencies have a central role in helping people with learning disabilities to find and maintain a job, but at the moment little is know about their role in promoting peoples' health and well-being. The study aim is to understand the strategies that supported employment agencies use to promote the health and well-being of their clients with learning disabilities.

It is up to you to decide whether or not to take part. If you do decide to take part you will be interviewed on the topic of health, how supported employment helps to promote it, and what barriers might exist to it promoting health. Interviews will be held in a place that is convenient to you. Interview will last approximately 45 minutes and we will ask you if we can record the interview. We may need to interview you more than once as new issues arise within subsequent interviews with other agencies.

We may use quotes from interviews in our reports or articles. All personal details (names, agencies etc) will be made anonymous by the researcher, as a guarantee of confidentiality.

All the information provided will be kept secret and safe, stored on password protected hard drives and not be accessible to other people. The information gathered will be used for research purposes only. No one other then the research team will see what you say.

This study is a project that has ethical approval from the Research Ethics Committee of the School of Medicine, Cardiff University. The work will form a part of a PhD carried out by Elisa Vigna and also contribute to the research programme of the Welsh Centre for Learning Disabilities on Supported Employment. The work is supervised by Dr. Stephen Beyer.

For further information please do not hesitate to contact Elisa Vigna:

CONTACT DETAILS:

Researchers:
Elisa Vigna
Dr. Stephen Beyer

Address:
Welsh Centre for Learning Disabilities
Institute of Psychological Medicine and Clinical Neurosciences
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Telephone numbers: 029 206 87216
029 206 87204

Fax: 029 206 87100

Welsh Centre for Learning Disabilities, School of Medicine, Cardiff University

CONSENT FORM FOR JOB COACH

The role of supported employment in promoting positive health behaviour of people with learning disabilities at work.

Researchers:
Elisa Vigna (PhD student), Dr Stephen Beyer, Prof. Michael Kerr, Dr. Stuart Todd (supervisors)

Please write your initial in every box to agree and take part to this research

	INITIALS
1. I confirm that I have read and understand the *information sheet* dated 1st September 2011 (version 1) for the above study.	
2. I have had the opportunity to ask questions.	
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	
4. I agree to take part in the above study	

Name of participant:_____

Date:_____

Signature:_____

CONTACT DETAILS:
Address:
Welsh Centre for Learning Disabilities
Institute of Psychological Medicine and Clinical Neurosciences
School of Medicine
Cardiff University
2nd floor Neuadd Meirionnydd
Heath Park
Cardiff – CF14 4YS

Emails: vignae@cf.ac.uk; beyer@cf.ac.uk
Telephone: 029 206 87216 or 029 206 87204
Fax: 029 206 87100

Welsh Centre for Learning Disabilities, School of Medicine, Cardiff University

Employee information sheet

The role of supported employment in promoting positive health behaviour of people with learning disabilities at work.

Hello,

I would like to know more about supported employment and health.

Why am I doing this project?
I want to understand what it is like for employees' health to be supported to get a job.
In this interview I will listen to you and I will record what you are saying. I may need to see you more than once to know your point of view on new issues coming out.

Would you be happy to have a chat with Elisa, the researcher in charge for this research?
You can ask her more information if you wish. You can take time to decide if you want to take part to the study.

This is Elisa

How long will it take?

The chat should take about 30 minutes.

It will take place somewhere comfortable for you, in a room in your workplace site or in another place. This is up to you.

You can ask to end the interview at any time. You can have someone else there as well if you want to.

Do I have to take part?

We hope you will say yes. We want to know what you think. You can say no, it will not affect your job or services you get.

What will happen to the information?

What you tell me I will not tell anyone else. The information you give will be recorded and written down. We will write about what is important to you.
Your name and personal information will not be used. No one will be able to recognize you from what we write.

This study is run by the Welsh Centre for Learning Disabilities, School of Medicine, Cardiff University.

If you want more information contact Elisa Vigna:

CONTACT DETAILS:

Researchers' names:
Elisa Vigna
Steve Beyer

Our address:
WCLD
Institute of Psychological Medicine and Clinical Neurosciences
School of Medicine
Cardiff University
2nd floor Neuadd Meirionnydd
Heath Park
Cardiff – CF14 4YS

Our emails: vignae@cf.ac.uk; beyer@cf.ac.uk

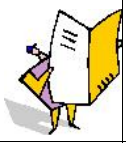
Our telephone numbers: 029 206 87216
029 206 87204

Fax: 029 206 87100

Welsh Centre for Learning Disabilities, School of Medicine, Cardiff University

CONSENT FORM FOR EMPLOYEE

Please write your initials in boxes below

WHAT?		INITIALS
	I have read the information about the research.	
	I agree to talk to Elisa about the topic “work and health”.	
	I know I can stop at any time and without giving reasons.	
	I agree Elisa will record what I will say.	
	I agree Elisa will write down what I said.	
	I understand Elisa may contact me more than once to hear my idea on the topic again.	
	I know that what I said may be written about in reports or articles, but that I will not be identified.	

YOUR NAME:_____ **Thank you very much!**

SIGNATURE: _____

DATE:_____

CONTACT DETAILS:

Researchers' names:
Elisa Vigna
Steve Beyer

Our address:
WCLD
Institute of Psychological Medicine and Clinical Neurosciences
School of Medicine
Cardiff University
2nd floor Neuadd Meirionnydd
Heath Park
Cardiff – CF14 4YS

Our emails: vignae@cf.ac.uk; beyer@cf.ac.uk

Our telephone numbers: 029 206 87216
029 206 87204

Fax: 029 206 87100

APPENDIX I

Interviews

Interview with managers

INTRODUCTION

In this interview we want to understand your agency's provision in term of health promotion for people with learning disabilities.

When answering the questions please think of your day practice and provide practical examples when you can.

All personal details and names will not appear in any reports. Quotes may be used, but will be anonymous.

The interview will be digital recorded and transcribed in order to best use the information you will provide.

A report will be given at the end of the study as a feedback of our collaboration.

I hope you had time to read the information sheet. If you have any questions I am happy to take them. Are you happy to sign the consent form?

1. How do you **deal with health** in your supported employment process?
    a. What do you ask about health in your **assessment/vocational profile?**
    b. How are the **person's health issues addressed in job search**?
    c. Do **job negotiation and job analysis** take health into account?
    d. How do you take health into account in **your ongoing support?**

2. In your experience does **having a job improve the health and well-being** of people with learning disabilities? *By well-being I mean a satisfactory condition of happiness, prosperity and welfare which allows a person to realise his potential.*
    a. Do you have any example of **ill-health** after employment?

3. How important is supported employment in improving health of these **people compared to other influences** (e.g. family, health services, education….)?

4. **Should** supported employment **be concerned more with improving peoples' health**?

5. **Can you use any of your supported employment process stages** to promote health?

6. How important **is job coaching in promoting the health and well-being** of people with learning disabilities?
    a. How important is the job coach's **personality**?
    b. How important is the **relationship between the job coach and their client**?
    c. How important is **task training**?

d. How important is a **job coach's health awareness**?
e. How important is a **job coach education and confidence**?

7. Do **employers** promote the health and well-being?
    a. How?
    b. Are people with learning disabilities involved?
    c. How?
    d. Do you help?
    e. How?

8. How do **families or carers** influence the health and well-being of people with learning disabilities?
    a. How paid carers influence your clients' health?

9. Do you involve **third parties (such as health professionals**) in your support around health at work?
    a. What do you think of **involving health professional** before employment?

10. Do you use any of your **funding** to promote heath and well-being?

11. Have you ever supported anyone to start self-employment?
    a. If yes, how their health may change in this process?

A short report will be provided to all participants at the end of the research as feedback.

Interview with job coaches

INTRODUCTION

Thank you for taking part to this study. In this interview **we want to understand your agency provision in term of health** promotion for people with learning disabilities.

When answering the questions please think of your **day practice** and provide **practical examples** when you can.

All personal details and names will not appear in any reports. Quotes may be used but will be anonymous.

A report will be given at the end of the study as a feedback for you.

The interview will be digital recorded and transcribed in order to best use the information you will provide.

I hope you had time to read the information sheet. If you have any questions I am happy to take them. Are you happy to sign the consent form?

1. How do you deal with the **health of people with learning disabilities** in your **process of support**?
    b. What do you ask about health in your **assessment/vocational profile**?
    c. How are the **person's health issues** addressed in job search?
    d. Do **job negotiation and job analysis** take health into account?
    e. How do you take health into account in **your mentoring**?

2. In your experience **does having a job improve the health and well-being of people with learning disabilities**? By well-being I mean a satisfactory condition of happiness, prosperity and welfare which allows a person to realise his potential.
    f. Do you have any example of ill-health after employment?

3. How important is **supported employment** in improving the health of these people **compared to other influences** (e.g. family, health services, education…)?

4. **Should** supported employment be concerned with improving peoples' health?

5. **How important is the health** of people with learning disabilities in **whether you can get them a job**?

6. **Can you** use any of your **supported employment process stages to promote further health?**
    g. **How**?
    h. If you do that, could you please **give an example**?
    i. How do you manage **issues of disclosure** of health impairment?
    j. Have **you ever modified job duties to influence** health?

k. Have **you ever negotiated with employer** around health issues?

7. How important is **job coaching** in promoting the health and well-being of people with learning disabilities?
    l. Do you think your **personality** may influence your client's health behaviour?
    m. How important is **the relationship** between you and the client for their health?
    n. How important is your **task training** for health?
    o. Do you think **your health awareness and training** may influence your client's health?

8. Do **employers** promote the health and well-being of their staff?
    p. How?
    q. Are people with learning disabilities involved?
    r. How?
    s. Do you help?
    t. How?

9. How do **families or carers** influence the health and well-being of people with learning disabilities?
    a. How paid carers influence your clients' health?

10. How do **co-workers** influence the health and well-being of people with learning disabilities?
    u. How do they impact **on health at work**?
    v. How do they impact on **efforts to improve health**?
    w. Do they impact **thorough any work place health promotion activity**?

11. Do you involve **third parties (such as health professionals**) in your support around health at work?
    x. What do you think of involving health professional before employment?

A short report will be provided to all participants at the end of the research as feedback.

Interview with employees

INTRODUCTION

My name is Elisa and I work for the Welsh Centre for Learning Disabilities at Cardiff University. Your supported employment agency (name) is helping me with my project.

We are running a research study on supported employment. We want to know if it helps make workers healthier. We want to understand your point of view on health at work.

The interview will be tape-recorded and then written down so we can understand what you said. No personal information or names will be used.

A report with the results of the whole study will be ready for you as a feedback in one year time.

If you have any questions on this study, tell me at anytime. I will answer your questions. You can stop the interview at any time. If you want a break, feel free to take it.

Before starting the interview we will go thought the information sheet again, if you want.

1. What is your job?

2. How **many hours** do you work?

3. **What do you have to do**?

   a. *Do you have to lift things at work?*

   b. *Do you lift things at home?*

   c. *Do you have to walk about at work?*

   d. *Do you have to walk about at home?*

   e. *Do you have to keep going at work?*

   f. *Do you have to keep going at home?*

   g. What **do you have to do at home**?

   h. How **long have you been working for**?

   i. What were you **doing with your time before employment**? (If it is not a long time ago!)

   j. Do you have any worries at work?

   k. If yes, how do you cope with your worries?

4. Do you travel far to work?

   a. How do you travel to work?

b. Did you get any help to travel to work?

5. What does **being healthy means to you**?

a. What do you have to do to be healthy?

b. What should you not do to be healthy?

c. Is there anything you should eat to be healthy?

d. Is there anything you should not eat to be healthy?

e. Do you have **any health worries**?

f. When you worry about your health, **what do you worry about**?

g. What do you do when you are feeling **unwell**?

6. Does **your job help you to be healthy**?

a. How?

b. How not?

7. Do you get paid at this job?

a. What do you do with your wages?

8. Who do you work with?

a. Do you have **good friends** at work?

9. What do you do at **breaks and lunch**?

10. What **do you eat for lunch at work?**

*a. Do you bring your **lunch from home**?*

*b. Do you **eat out**?*

*c. Do you use **the canteen at work**?*

d. Are meals subsidized at work?

e. What do you **eat at home**?

11. Do you go out with people from work after work?

12. What do you do with them?

a. Do you have drinks?

b. What do they drink?

c. What do you drink with them?

13. Do people smoke at work?

a. Do you smoke at work?

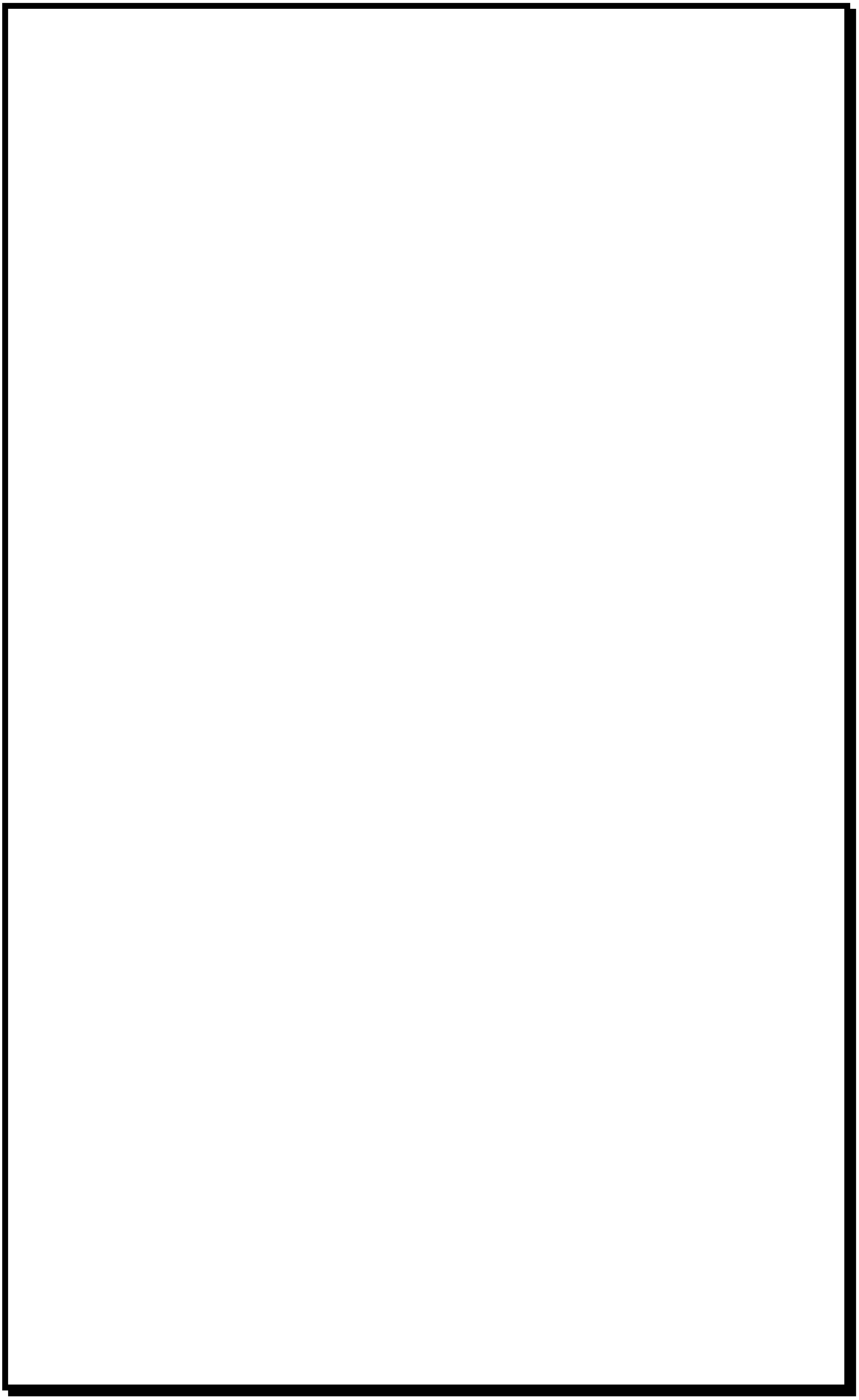
b. Do you smoke at home?

14. Have you seen a **doctor** recently?

15. Do you go to a gym?

16. What do you do in your spare time?

17. What are your hobbies?



Glossary

British Association for Supported Employment (BASE): it is the English national trade association representing agencies involved in securing employment for people with disabilities (base-uk.org).

Coding Paradigm (Strauss): it is a paradigm that can be used to structure data and to identify relationship between codes. It is helpful during the phase of axial coding and it is structured in four items stating:

- conditions;
- interactions;
- strategies;
- consequences (Strauss, 1987; Kelle, 2005).

Employment consultant: people providing support for people with learning disabilities in achieving a job career. It is always used as synonym of job coach or job trainer.

Empowerment: “an iterative process in which a person who lacks power sets a personally meaningful goal orientated toward increasing power, takes action toward a goal, and observes and reflects on the impact of this action” (Cattaneo and Chapman, 2010 p. 647; Flatt-Fultz and Phillips, 2012)

European Union of Supported Employment (EUSE): it was established to develop supported employment in Europe. It provides guidelines and training material for professionals and service providers operating in the field of supported employment for disabled and disadvantaged people (www.unie-pz.cz).

Health: the health concept is a broad concept having one negative and one positive meaning. The negative one is translated in the absence of disease or illnesses, and the positive one is a state of physical, mental and social well-being (WHO, 1946; Naidoo and Wills, 2000).

Health fields: the health field concept (Lalonde, 1981) is the result of the combination of different elements:

1. human biology (genetics, ageing and complex internal system of the body);
2. environment (external health matters, not controllable by the individual);
3. lifestyle (individual habits and personal decision linked with lifestyle);
4. health care organization (how the health care system is organized: quantity, quality, nature, arrangements and resources).

Health promotion: it is a recent idiom, introduced the first time by Lalonde in the seventies (Lalonde, 1981). Health outcomes depend on the combinations of elements such as human biology, environment, lifestyle and health care organization. Therefore, more attention have to be paid on research to basic human biology, on how to improve the natural environment in conjugation with the diffusion of a new understanding of "self imposed risk" due to negative lifestyles (MacDougall, 2007).

Job coach or Job trainer: it is a person providing individual support and training for a person with learning disabilities in getting, learning and maintaining a job.

Northern Ireland Union of Supported Employment (NIUSE): it was established in 1994 as association of individuals and organizations providing paid work opportunities for people with disabilities in Northern Ireland (www.niuse.org.uk).

Scottish Union for Supported Employment (SUSE): it was established in 1995 as umbrella organization for public, private and voluntary bodies operating in supported employment in Scotland (www.susescotland.co.uk).

Supported Employment (SE): "is evidence-based and personalized approach to support people with significant disabilities into real jobs, where they can fulfil their employment aspirations and achieve social and economic inclusion" (DH, 2010, p.2).

Sheltered Employment or Sheltered workshop: job or workshop recreating a protected work environment where basic skills could be learned and behavioural intervention may be in place. This employment condition was designed to be a stepping stone toward job and skill development, but sometimes it does not happen in practice (Rusch, 1986; Siporin and Lysack, 2004)**.**

Wales Association of Supported Employment Agencies (Wales ASEA): it is the Welsh association for supported employment delivering a service for people with learning disabilities. It was set up in the early 1990s and it is now working closely with the British Association for Supported Employment (BASE) (www.learningdisabilitywales.org.uk).

Well-being: there are several definitions of the concept of well-being. Within these definitions there is a general agreement that well-being is experienced when an individual experience a prevalence of positive feelings, absence of negative feelings such as depression, satisfaction in life and fulfilment (www.cdc.gov).