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Research on Aging and Disability:
Determining Consensus Among Aging and Disability Researchers

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Abstract

Three of the most documented and generally accepted trends regarding the world's population are that, it is getting older, there are more disabled people, and acquired disability in older age should be expected. With Disability Studies and Gerontology as particularly suitable for exploring these issues, their respective limited research funding and policy priority, combined with the 'demographic shift' requires one to consider the breadth and depth of existing aging and disability research. Using a constructivist/social constructionism approach to an inductive research strategy, semi-structured interviews were conducted with four researchers in aging and disability, representing four specific areas of research. The participants generated data for five different questions, read both literally and interpretively, and processed into various tables for ease of analysis. The five questions posed were, how do researchers classify disabled older adults, what are examples of productive and unproductive aging and disability research, what issues have been neglected in past/current aging and disability research, what are examples of future directions for research on aging and disability, and who should be responsible for research on aging and disability in general. The purpose in asking these five questions relating to aging and disability research was to determine if there is consensus among researchers regarding each area. With increasing yet limited collaboration between Gerontology and Disability Studies, and limited research funding and policy priority for both, determining whether there is consensus among the foundations of all research, that is researchers themselves, was therefore the primary purpose of this study. While specific examples provided by participants rarely concurred, the general themes with which they were associated helped demonstrate when, where, and the frequency with which consensus was reached. Results of the frequency with which consensus was observed across the five questions varied from unanimous to none, and everything in between. Whether there was any degree of consensus or not however, the results, specific examples, and discussions throughout provide a useful starting point from which research/researchers can understand where aging and disability research/researchers 'are at'. For it is through this understanding that new knowledge and further collaboration regarding aging and disability can take place, so that ultimately increased research funding and policy priority can be obtained for issues involving both aging *and* disability, and the people these issues effect.

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CHAPTER ONE

Introduction

Three of the most documented and generally accepted trends regarding the world's population are that, it is getting older (Ebrahim, 1999; Knickman and Snell, 2002; PALS, 2001;), there are more disabled people (Human Resources Development Canada, 2003; Mayhew, 2003), and acquired disability in older age should be expected (Guralnik, 1996; Olshansky, Hayflick, & Carnes, 2002; Sheehan, 2003; Simmons, McCallum, Friedlander, & Simons, 2000). In response to these trends, everyone from politicians and policy makers, to advocates and academics have developed a direction, opinion, prediction, solution, caution, and conclusion regarding this "aging" and/or "disabling" of the population. While responsibility for understanding and preparing for this "demographic shift" is shared, the two most suitable candidates in terms of social research are the multi-disciplinary fields of Gerontology and Disability Studies. Studying issues primarily regarding aging and disability respectively, ideas of 'everyday experiences' and oppression comprise large segments of study for both. Unfortunately however, despite the fact that both are often closely related in considering similar issues and populations, there is very limited discussion and collaboration between the two (Kennedy & Minkler, 1998; NDA, n.d.; Putnam, 2002), thus creating potential redundancy or gaps in research, and inefficient use of both time and resources. In addition, sociological perspectives of both aging and disability tend to receive limited research funding and policy priority (Participant B, 2006; Participant C, 2006; Participant D, 2006; Binstock, 2003; Robert, 2003), thus increasing the need to consider the breadth and depth of research that currently exists. Perhaps it is because both aging and disability researchers are generally interested (and rightfully so) in the practical, 'real world' experiences of the populations they study, that a more theoretical or methodological study of research itself has not been done, one can not be sure. What one is fairly certain of however, is that the majority of aging and disability research/researchers seem to fail in training a critical eye in locating both their own research and that of their contemporaries *out* of the 'micro world' of individual studies, and *within* the 'macro world' of theoretical, methodological, and thematic realms of aging and disability research in general.

In an effort to develop and understand this necessary yet absent area, five questions were posed to four researchers involved in aging and disability research. The five questions were, what do researchers classify disabled older adults as, what are some examples of productive and unproductive aging and disability research, what issues have been neglected in past/current aging and disability research, what are some examples of future directions for

research on aging and disability, and who should be responsible for research on aging and disability in general. The purpose in asking these five questions relating to aging and disability research was to determine if there is consensus among researchers regarding each area. With increasing yet limited collaboration between Gerontology and Disability Studies, and limited research funding and policy priority for both, determining whether there is consensus among the foundations of all research, that is researchers themselves, was the purpose of this current study, as this knowledge can guide future research/researchers in a direction for understanding where aging and disability research/researchers 'are at', and the direction(s) to take from here in hopefully increasing collaboration, research funding, and policy priority.

The structure of the paper is divided into nine chapters following the Introduction, Background; Process, Purpose, and Rationale: Methods; Classifying Older Disabled Adults: Results and Discussion; Productive and Unproductive Aging and Disability Research; Results and Discussion; Issues Neglected in Research on Aging and Disability: Results and Discussion; Directions for Future Research on Aging and Disability: Results and Discussion; Responsibility for Aging and Disability Research: Results and Discussion; and finally the Conclusion. Chapter two, Background, details the initial literature review conducted, and how this general review uncovered inconsistency and repetitiveness within much of the aging and disability research being undertaken. Chapter three, Methods, describes the process, purpose, and rationale behind the four interview questions, the sample/participants, the interviews themselves, and finally the data coding and analysis. Chapter four, Classifying Disabled Older Adults, discusses the participants' classification of individuals presented in three vignettes, and how research in general classifies disabled older adults. Chapters six through eight discuss the results from the remaining five questions respectively, regarding when and where there is consensus among the researchers. The final chapter concludes the paper by providing a brief summary of each previous chapter and the subsections therein.

CHAPTER TWO

Background

What began as a general search for obtaining a specific topic related to aging and disability produced two unlikely reactions -frustration and confusion- and two separate observations; an abundance of research measuring, identifying, and classifying disability in old age and/or 'old age' itself, and inconsistent meanings and definitions of concepts related to 'aging/older people' and 'disability/disabled people'.

The first topic considered, and for which a literature search was conducted, was to understand the experiences and self-identification processes of older adults who acquire disability/disabilities as they age. Unfortunately the initial search results appeared somewhat limited or irrelevant, thus yielding few articles from which to proceed. In an attempt to maintain a focus of understanding some specific experiences of, or related to, disabled older adults, the search was expanded and altered several times to include a variety of different topics. These topics varied from formal education of health care personnel regarding disability and aging issues/individuals (James, 2004; McVey, David, & Cohen, 1989; North Illinois University, n.d.; Pacala, Boulton, & Hepburn, 2006; Robinson & Rosher, 2001), an important area considering the role and frequency they play in the lives of disabled older adults (Weksler & Goodwin, 1999); how policies and programs classify disabled older adults (Government of Canada, 2003; Government of Canada, 2006a; Government of Canada, 2006b; Hendricks, 2004; Morgan & David, 2002; Service Canada, 2006), an important area considering its definition, when compared with disabled older adults' self-classification, and various health/social service personnel's classification, may affect a policy/program's uptake and success; and 'disabled' identity (Beart, 2005; Deal, 2003; Reeve, 2002; Watson, 2002) 'older' identity (Bowling, See-Tai, Ebrahim, Gabriel, & Solanki, 2005; Bytheway, 2005; Cremin, 1992; Jones, 2006; Kaufman & Elder, 2002), and 'disabled and older' identities in general (Harrison & Kahn, 2004; Macfarlane, 1994), as the actual negotiation of the two in an individual's life appear infrequently within the literature. While these searches provided quantitatively more options, unfortunately there were hardly enough to clarify a specific dissertation title.

The actual process of using search words that returned applicable literature, and the literature which by title appeared relevant, but after further reading was far from, became increasingly problematic. In fact, more energy was spent reading with frustration and confusion than with interest and new learning. The abundance of research concerning

measurements, identification, and classification of ‘disability’ or ‘old’ age, and the inconsistency of terminology meanings and definitions regarding ‘aging’ and ‘disability’ were glaring. These two patterns emerged where they were neither actively sought nor expected to appear, and thus the combination of frustration, confusion, and an overt presence could no longer be ignored. As a result, the process of determining whether there is any consensus among researchers regarding classification of disabled older adults, productive and unproductive aging and disability research, issues neglected in aging and disability research, directions for future research, and who is responsible for all of the above began.

Measures, Indicators, and Identifying Disability in Old Age

The first pattern to emerge during the preliminary literature searches were the numerous articles providing measurements (Cutler, 2001; Guralnik, Fried, & Salive, 1996; Freedman, 2004; Jagger, Arthur, Spiers, & Clarke, 2001; Lamarca, et al., 2003; Litwin, 2002; Simonsick, et al., 2001), identification (Kaufman & Elder, 2002; Langlois, et al., 1996; Saliba, et al., 2001), or classification (Jagger, et al., 2001; Melzer, McWilliams, Brayne, Johnson, & Bond, 2001; Patja, Iivanainen, Vesala, Oksanen, Ruoppila, 2000) of disability in old age and/or ‘old’ age itself. Scales were developed (Prince, Harwood, Blizard, Thomas, & Mann, 1997; Sarkisian, Hays, Berry, and Mangione, 2002), questionnaires/surveys sent out (Bowling, et al., 2005; Kaufman & Elder, 2002; Lamarca, et al., 2003), and interviews conducted with everyone from disabled older adults themselves (Bowling, et al., 2005; Cremin, 1992; Jagger, et al., 2001; Kaufman & Elder, 2002; Lamarca, et al., 2003; Litwin, 2002; Sarkisian, et al., 2001) to practitioners (Cremin, 1992; Sarkisian, et al., 2001), and family (Cremin, 1992; Lamarca, et al., 2003). With a desire to know if one *really was* ‘disabled’ and/or to *what extent*, and to determine if relationships (Greenglass, Fiksenbaum, & Eaton, 2006) and associations (Litwin, 2002; Simmons, McCallum, Friedlander, & Simons, 2000) exist, the prevalence (Melzer, Izmirlian, Leveille, Guralnik, 2001), frequency/patterns (Jagger, et al., 2001; Sarkisian, et al., 2001), and profiles (Brayne, Matthews, McGee, & Jagger, 2001) of disability, impairment, diseases, illnesses, and conditions (most common of which were stroke, osteoarthritis, and depression) were determined, calculated, quantified, summarized, and discussed (see Moore, Rosenberg, and Fitzgibbon, 1999, for example). Ranging from small scale (Cremin, 1992) to large (Avlund, et al., 2004; Bowling, et al., 2005; Fried, Young, Rubin., & Bandeen-Roche, 2001; Jagger, et al., 2001; Lamarca, et al., 2002; Litwin, 2002; Sarkisian, et al., 2001), self-reported (Fried, et al., 2001; Hoeymans, Feskens,

Kromhout, & Van Den Bos, 1997; Jagger, et al., 2001; Langlois, et al., 1996) to scientifically/medically determined (Daltroy, Larson, Eaton, Phillips, Liang, 1999) data regarding activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (Jagger, et al., 2001; Moore, et al., 1999), and other measures and indicators (Avlund, Lund, Holstein, & Due, 2004) abounded. However, this is hardly representative of the experiences and wider implications of aging and disability. What about public policies regarding older disabled adults (Jongbloed, 2003; Kennedy & Minkler, 1998; Prince, 2003)? Health care, social security, retirement, and disability benefits? What about the transition of being 'non-disabled' for eighty years to 'disabled' for the first time (Pound, Gompertz, & Ebrahim, 1998)? The change in classification/identification (and lack of politicization) from being disabled at sixty-four, to being 'just old' at sixty-five (Macfarlane, 1994)? Surely these, and research considering aspects *other* than measuring, identifying, and classifying encompass the concepts of 'aging and disability', and yet these appeared either absent or incredibly limited.

While there were some measurement-type research which was innovative and original in either its methodology, scope, questions, or conclusions (see for example Freedman, 2004; Sanders, Donovan, & Dieppe, 2002; Strawbridge, Wallhagen, & Cohen, 2002), as they often looked at the *consequences* of disability as experienced by older people themselves, or placed their findings within *larger*, more theoretically/politically-based contexts, unfortunately these were few and far between. Although measurement-type research is required and important, as it provides quantitative base-line results for (hopefully) increased or improved policies, programs, and services, it should be equally represented in the literature, and equally important to go beyond the repetitive, (and therefore unproductiveness?) of this research, and ask 'so what?', or 'what next?'. Since it has been 'proven' that the majority of older people experience some kind of impairment, and knowledge regarding what to look for, how to measure and differentiate between 'mild', 'moderate', and 'severe' have been documented, what will be done? It is here that the majority of research on aging and disability ends, and it was an unfortunate yet common result, no matter which database, journal, or discipline was consulted.

Therefore, considering the sustained and unproductive focus of aging and disability research, and the limited quantity of other topics, what specific areas of aging and disability research are being neglected? What other examples are there of aging and disability research which is unproductive, and in contrast those which are productive? What should directions for future research examine? And finally, who should be responsible for these? It was with

these three specific questions in mind, as a result of limited research on aging and disability, which comprises the majority of this paper.

'Old' and 'Disabled': Inconsistent Definitions

After the initial frustration and confusion regarding the abundance of research measuring, identifying and classifying 'disability' and 'old' age, the same reaction was produced regarding the variability and inconsistency of meanings and definitions applied to concepts related to 'aged/aging' and 'disabled/disability'. Within single papers, and across various fields of study, the frequency with which the terms were either used interchangeably, or with a different meaning/definition was surprising. For example, while restricted mobility was defined as a 'normal sign of aging' in one paper (Pound, et al., 1998; Sanders, Donovan, & Dieppe, 2002), in another it was interpreted as an 'impairment' which 'disabled' (Moore, et al., 1999), often resulting in the (personal) acceptance and (general) acquirement of state-funded home adaptations (King's College London and the University of Reading, 2004; Lansley, et al., 2004). Despite the same presenting restriction, the different classification to which the impairment was ascribed can have several implications with respect to (for example), understanding and ascribing impairments in older age, health and social benefits, policy decisions, further research, and the list could go on. A second example is that despite a general consensus across nations and policies that age sixty-five and above is 'old age', within the aging *with* a disability community, the definition of 'old age' is often fifty-five, and even fifty years of age (Dagnan, Ruddick, & Jones, 1998; McCarron, Gill, McCallion, & Begley, 2005; Sano, Aisen, Dalton, Andrews, & Tsai, 2005), as this is when many begin to experience bio/physiological 'effects of aging'. Again, this difference can have huge social policy and political implications, as disabled people under the age of sixty-five and experiencing/presenting 'symptoms' of 'old age' are excluded from 'senior' services/programs/benefits, and disabled people over the age of sixty-five and experiencing/presenting the same impairments as pre-sixty-five are often excluded from 'disability' services/programs/benefits (Macfarlane, 1994).

While the majority of literature may adequately conceptualize 'disability' or 'old', and their meanings and definitions are clarified and understood, it is almost always in the context to that *specific research*, and not in relation to research, policy, or practice in a *wider* context. In other words, two papers who at first seem to be discussing the same population, disabled older adults, can at closer inspection be describing very different populations. The

consequences of this for research and practical outcomes in general can be profound, as numerous inconsistencies and differences among and between a study's terms can make it difficult, if not impossible, to adequately compare and apply aspects of one study to the next, and understand how to take results from various studies and create practical social and/or political outcomes and initiatives. Although some may argue that focussing on consistent meanings and definitions of concepts related to 'age' and 'disability' detract from 'real' progress and change for the population(s) in question, one could also argue that it is *because* of the inconsistency of definitions and terms that no 'real' progress and practical changes are being made in the first place. If research/researchers as a whole fail to consistently define who and/or what it is they are referring to, how should (for example) politicians and other policy makers act in return? How are researchers expected to adequately compare, contrast, analyze, or develop applicable conclusions when the very base, that is the population/people they are studying, is in question? As a result of these questions, and the inconsistency which prompted them in the first place that the final question, is there consensus among researchers regarding the classification of disabled older adults, was posed. It is this final question which rounds out the five areas of interest in this paper: issues neglected, productive and unproductive research, future research, responsibility for research, and classifying disabled older adults. Therefore, what began as a preliminary search for a dissertation topic regarding disabled older adults progressed to a paper attempting to determine if there is consensus among researchers regarding various areas related to research on aging and disability.

CHAPTER THREE

Process, Purpose and Rationale: Methods

Throughout the development and process of this paper there have been a number of positions and strategies grounding the research and methodology therein. However, constructivism/social construction and induction have been the dominant underpinnings, and ‘what’ type questions, forming the ontology of each particular question. While aspects of retroduction, interpretivism, and other strategies/stances were used, these were not dominant within the design. The overall purpose of this paper was to determine if there is consensus among researchers regarding five specific questions relating to research on aging and disability, by purposefully discussing and reviewing the “fundamental” and “authentic” educated accounts of four researchers themselves (Blaikie, 2003). Within constructivism and this research, ‘reality’ of the research initially reviewed, myself as an active participant in the process, and the data generated by the participants themselves are consistently regarded as constructs themselves, and existing multiply. Objectivity of all three (ie literature, researcher, participants) are considered relative, and ultimately not possible (Babbie, 2001; Maynard & Purvis, 2004; Stanley & Wise, 1993), as they are both contingent on a variety of factors and a dynamic process. Subjectivity of experience, knowledge, opinions, etc., therefore abounds throughout this research, however this is an important perspective and viewed as a valid source of data generation/processing, and therefore recorded, coded, analysed, and discussed in this manner.

There are several types of research questions (Babbie, 2001; Blaikie, 2005) or ‘intellectual puzzles’ (Mason, 2005), however for each of the five areas or questions considered in this paper (classifying disabled older adults, productive/unproductive research, issues neglected, directions for future research, and responsibility), while they do not specifically contain ‘what’ in their wording, at a basic level through interviews and data coding/analysis, each was designed to determine if consensus among participants regarding the five specific areas exists. Directed towards discovering and describing characteristics and patterns, ‘what’ questions require “descriptive answers” through the collection of “appropriate data” followed by the production of descriptions based on the data (Blaikie, 2005), all of which are highly subjective processes in themselves, and practised throughout this research.

Particularly useful for answering ‘what’ questions (Blaikie, 2005; Mason, 2005), three of the four primary characteristics of an inductive research strategy (the primary strategy used in this research) were employed. All of the data was recorded without selection or guesses as

to their relative importance. The data was analysed, compared and classified without using hypotheses, and from this analysis generalizations, or more specifically for this paper, *consensus* was inductively drawn as to relations between the data (Blaikie, 2005). The fourth characteristic of induction, that the “generalizations are subjected to further testing” (Blaikie, 2005:103), and the fact that it is recognized as “moving from the particular to the general” (Babbie, 2001; Mason, 2005) were not included. This research seeks to identify consensus among researchers, and thus the fourth characteristic is beyond the scope of the study, and counter to its ontology and epistemology to formulate and test “law-like propositions” (Blaikie, 2005), as from a constructivist point of view, these can never actually exist. While a deductive research strategy could have been applied to each of the questions (sequentially however, not simultaneously), and enough data was generated as a result of unsolicited explanations for choices by the participants, this was not the intention of the current paper, and therefore purposely albeit regrettably excluded. Where the explanations or ‘whys’ are used however is in the results and discussion chapters for each respective question. Producing generalizations or ‘conclusions’ for *this* data/research, and ‘further testing’ of their ‘law-like’ propositions should therefore be taken up in a subsequent study.

The Questions

Classification of Disabled Older Adults

The purpose of determining whether there is, or can be consensus regarding the classification of disabled older adults by researchers was spawned from the initial literature search conducted for this dissertation. During that process, it became evident that there was a lack of consistency and consensus with which meanings and definitions were applied to concepts such as ‘old’ or ‘disabled’, and the potential negative consequences this could have for both research itself and practical policy and program initiatives (see Chapter Two for more detail). By specifically asking individuals who are educated, studying, and working within the fields of aging and disability, a) how they would classify three specific individuals, and b) their opinion regarding how research in general classifies disabled older adults, the frequency with which there was consensus was the primary aspect being considered. The classifications available to the participants were developed from a previous research design (Cosentino, 2006), and used in this research.

A ‘spontaneous’ occurrence which took place during the first interview (and was included in each thereafter) was the posing of the question to the participants, ‘and why, or

what made you choose that?'. While this was not originally included in the initial question, as it is beyond an inductive approach, the generation and inclusion of their classification rationale seemed important to have recorded, and ultimately became welcomed sources of data during the respective analysis and discussion phases.

The Vignettes.

With regard to the 'three specific individuals' participants were asked to classify, this was inspired by Goodley's method of giving participants vignettes to inspire data generation (2000). Designed with the purpose of creating an equal base from which participants could classify, the 'vignette approach' offered a method determining that classifications given were drawn from the same source. While it is possible that the participants may have used personal examples in addition to the vignettes, the design of the question was done to guard against this. However, whether the vignettes were truly the sole source of inspiration for the classification data, this is not known, but neither is it productive to consider otherwise, as this would invalidate the data, and therefore the question as well.

Using articles gathered during the initial literature search, the original intention of the vignettes' design was to create 'original people' through a compilation of various sources to create 'ideal types'. This proved to be both time consuming and a methodological challenge however, and so a brief search of the literature on hand was used to locate 'preexisting people' who could represent a variety of common situations. In the end, three women named, 'Alice', 'Judith', and 'Mrs T.' (see Appendix #1 for the actual vignettes), were selected from Saxton (2005), Harrison & Kahn (2004), and a report from King's College London and the University of Reading (2004) respectively. Each was chosen for a particular purpose, as they 'typified' a particular classification it was hypothesized (from my subjective point of view) the majority of people would most likely choose. Therefore, *Alice* was used to represent people who present with general impairments unspecific to 'age', *Judith* to represent disabled people who enter chronological 'old age', and *Mrs T.* to represent people with typically age-associated conditions, although for each 'representative' their presenting impairments could be equally experienced by 'younger disabled' people as well. Each of these individuals were also *actual* disabled older adults. The excerpts used given to the participants to classify included both first person accounts and third person observations. This was designed purposely, as it was important that the voices and experiences of *real* disabled older people were used when the participants were asked to classify each accordingly. The only aspect

purposely omitted from each vignette was any specific reference to their chronological age. Had age been included in the vignettes it would have defeated the purpose of challenging and/or forcing participants to really think about how they would classify when no indicator of age exists. The selection of three *women* was also purposely chosen, as it is women who make up the majority of disabled older adults (Government of Canada, 2003), and it would be interesting to note if any participants questioned or highlighted the exclusion of men. Whether or not any of the participants recognized this is unknown however, as none of them verbalized any objection (which in itself could merit further consideration, although this is beyond the scope of the current research).

Contribution and Importance

The questions “How or where do you see your work contributing to the field of Aging and Disability?” and “Why do you think it is important?” were included in the interviews with participants, although excluded from any analysis or further discussion. Its original inclusion was designed as a means to compare what they “do” and its importance in general, to the data generated in the other four questions. While this appeared and remains a relevant method of analyzing the data, whether it was due to lack of attention or detail in the initial design, inappropriate use of time between the interviews taking place and actually analyzing/writing the data, or re-focussing and clarifying the purpose and intent of the paper that led to its omission, this remains unclear. In the end however, it is probably a combination of all three with which the decision was made to exclude the data from this question into any analysis or cross-comparison.

Productive and Unproductive Research

The purpose in asking for examples of productive and unproductive aging and disability research was to generate a list of examples which could be processed into themes, followed by analysis of whether there was consensus among the participants regarding each respective field of study. A highly subjective question which provided and asked for no definition of either ‘productive’ or ‘unproductive’, for the majority of the responses given, the participants went on to say (without being prompted or asked) why specific areas/examples were particularly productive/unproductive. While this provided very rich and interesting data, their rationale was excluded from analysis, as it was beyond the intention and scope of the question; it was only asking ‘what’. The rationale for including this question was due to the repetitive nature/abundance of research regarding measuring, identifying, and classifying

'disability' and/or 'old', and the thought that this must *not* be productive. In determining if there was consensus among researchers of productive and unproductive aging and disability research, it was hoped that a list of consensual themes would be developed, providing an idea of which research should and should not be continued, although not necessarily the reason 'why'.

Neglected Areas of Research

The purpose of asking participants to consider either past and/or present aging and disability research and any issues which have been/are neglected was again to develop a list of consensual issues which could inspire others to explore. Similar to the rationale for including the above question, this question also developed as a consequence to the abundance of measurement-type research; if the majority of research on aging and disability is concerned with one aspect, it follows that *other* areas must therefore be neglected as a result. It was for this reason that an attempt to determine what areas, if any, are being neglected in research on aging and disability was developed. Again, an explanation for why this might be the case was generally offered by the participants, however it remained beyond the scope of the question, and was thus excluded from further analysis. A second part to this questions asked participants to rank the issues according to importance. The rationale for asking this was that it would make subsequent data analysis simpler. However, each participant stated that they were unable to choose one over another, and so data 'ranking' and its importance was never generated, and thus excluded from further analysis.

Directions for Future Research

The *most important* directions for future research in aging and disability was posed to the participants, rather than simply *future directions*, because the qualification of which research was intended to force participants to narrow their choices to only a few, as opposed to extolling the full spectrum of areas which could be researched. With the previous questions asking for examples of productive/unproductive research and issues which have been neglected, it was important to determine where the participants saw directions for future research leading and for the purpose of this research, whether or not there was consensus. Similar to the 'neglected issues in research' question, this question had the same rationale in asking participants to rank the directions according to importance. All four declined once again however, stating that each area was equally important. Therefore no prioritization was

generated, and no further analysis conducted.

Responsibility for Research

The original purpose of this question was to determine who, for example which discipline, is responsible for issues being neglected in past and/or present aging and disability research. With the potential to generate numerous suggestions, criticisms, examples, and ideas, etc., it was important to determine if there was any consensus regarding *who* exactly should be taking and/or is responsible for this research. Although written as a sub-question to ‘issues of neglect’, the participants interpreted it (perhaps do to unclear wording) to mean who is responsible for research on aging and disability *in general*, and not necessarily with respect to issues being neglected. While not the intended data to be generated, their interpretation was adopted and subsequently used during data analysis and organization and writing of the paper.

The Interviews: Generating Data

Interviews have been called a “research conversation with a purpose” (Mason, 2005), with the ultimate purpose of obtaining knowledge one would not have if these ‘conversations’ never took place (Kvale, 1996:6). Kvale also states that, “an interview is literally an *inter-view*, an inter-change of views between two persons conversing about a theme of mutual interest.” (Kvale, 1996:14), of which this was particularly true for the population chosen. Although data for the questions could have been generated through a questionnaire, as they did not ask for descriptive answers, the semi-structured interview process allowed room for interesting ‘off-the-record’ conversation between established researchers and myself, a student researcher, and methodologically further clarification and explanation with regards to both the questions and their responses (Blaikie, 2005; Kvale, 1996).

Participants received the questions (see Appendix #3) prior to the interviews in an email confirming and outlining their participation, ethics, and consent (see below). Although this was not originally planned, all four either requested or suggested they review and consider the answers/their answers beforehand, with the rationale being that relevant and ‘better’ data from which to work with could be provided. The only section of the questions withheld however were the actual vignettes. This was done for the same reason the participants requested/suggested they receive the questions, so they could review and consider their answer. For purposes of analysis, the *initial* classification of each individual/vignette

was desired, not well thought out, and potentially more 'politically correct' answers. Following the participants' request, the questions were sent out Monday morning, with the first interview taking place Wednesday afternoon. The other three interviews took place that Thursday, and the actual vignettes emailed a half hour before each scheduled interview without their prior knowledge. Although this provided participants with thirty minutes to potentially read and review the vignettes, all of the participants were taking time from their work days to assist in this research, and was therefore chosen to save time sending/receiving during the actual interview time slots. All except one participant read the questions prior to the interview, and only one (a different participant from the previous) opened and read the vignettes prior to the interview. Participant D did not receive the vignettes to their correct email address, and so responded to question one via email later in the day. The duration of the interviews lasted from thirty minutes to over an hour, with the average length taking approximately forty-five minutes. Each interview was conducted over the telephone, at no cost to the participants, and all but one of the interviews were successfully recorded. While the reason for the first and also shortest interview (with Participant A) did not record is unknown, detailed notes were taken both during and immediately after the interview. Although the data generated from this interview was not as rich as the other three (due to the technical difficulties), for the questions being asked, it was more than adequate in providing the necessary data.

The Participants

The population from which the sample were taken was researchers involved in the fields of aging and disability. Using non-probability sampling, which is representative in a theoretical rather than statistical manner (Blaikie, 2005; Mason, 2005), the specific techniques of purposive and convenience sampling were employed. Since purposive sampling requires researchers to think critically about the parameters of the population they are interested in and to choose carefully on this basis (Silverman, 2003), deliberate consideration was given to the general 'areas' of Aging and Disability/research to include, and the individual researchers therein. The four preferred 'areas' from which to select potential participants were a) a deliberate '*political*' position, b) deliberate '*theoretical*' work, c) work with a *specific* aging/disabled population, and d) work with the aging/disabled population in *general*. These four areas were purposely selected as together they could provide a wide spectrum of perspectives regarding research on aging and disability, and whether consensus could be

found between them.

Since there are literally thousands of individuals researching aging and disability, and hundreds working in the four areas specified in this research, the initial list of authors was subjectively chosen in that it consisted of individuals whose work and/or perspective I (subjectively) considered unique, focussed, interesting, and highly respected. Each also ultimately shared ontological, epistemological, thoughts, ideas, and views which were consistent with my own. While it may have been an interesting personal challenge, and provided more varied and rich data to interview those whose work I considered problematic, or in opposition to those stated above, they ultimately remained excluded for personal rather than methodological reasons.

Beginning with an initial list of fifteen individuals who were generated from a combination of authors located through years of researching/reading aging and disability, and suggestions of relevant researchers from a colleague in Canada. From these fifteen, each person's biography, bibliography, and selected writings were consulted, and the list narrowed to eight. The list from fifteen to eight was generated by determining who were the most applicable to the four general research areas. From this final list, all eight potential participants were emailed an introductory letter outlining the plans for the current dissertation, and the interview dates. From the eight sent out, one requested more information, and despite being given, declined to participate. Three of the authors suggested and known by the Canadian colleague, never responded. Interestingly, the four potential participants initially included and who comprised the original four of my 'top five' researcher participant 'wish list' all agreed to participate. While the fifth member of the 'top five' was the only participant to decline, the other four, Participant A, Participant C, Participant B, and Participant D, responded enthusiastically and with genuine interest in the topic, study, and outcomes. The four 'areas' each participant 'represented' were Participant A, deliberate political position, Participant B, work with a specific aging/disabled population, Participant C, deliberate theoretical work, and Participant D, work with the aging/disabled population in general. With each participants' work as a real motivation and inspiration for interest and research on aging and disability, and my own in particular, their acceptance to participate was exciting (encouraging!) and a little nerve racking as well. All four of the participants who agreed to participate were therefore chosen for very different, yet purposeful reasons. Although their specific areas of interest differed, all four were passionate about research, aging and disability, and their work, providing four unique perspectives to the same questions, resulting

in interesting data regarding consensus, or lack of, on research on aging and disability.

With regards to ethical considerations, since the sample were all familiar with ethics, confidentiality, etc., there was no need to go into any great detail. After the introductory letter was emailed, a second letter was sent outlining the plans for the data/dissertation, consent to take part, and consent to be recorded. With no intention to publish or present the material outside of the requirement for the MA (although three of the four felt this should be considered), three of the four agreed to have their names and any identifying institutions included (Participant A declined), and all four agreed to be recorded. Their consent was given by email, and again verbally before the interviews took place. A brief summary and additional information for each participant originally appeared in Appendix #2 of this dissertation (with any identifying names/institutions excluded for Participant A), however these have been omitted in all external/subsequent publications as per the request of two of the three remaining participants.

Data Coding and Analysis

Data generated for this research was obtained using interviews, a qualitative data generation technique for which open coding was used (Babbie, 2001; Blaikie, 2005) and thematic ‘codes’ developed (de Vaus, 1995). The data was read literally for the purposes of processing the data into various tables and coding them accordingly (Mason, 2005), analysed in a more quantitative manner, followed by interpretive reading for the purpose of ‘discussing’ the results. It was data regarding consensus for each of the five areas that was important, and the means to calculate this was through the frequency (ie number of times) a theme was given across the participants. Although transcription of the recorded interviews was initially ruled out as such detail would be an inefficient use of time and unnecessary for analyzing the data (as ‘rationale’ or answering ‘why’ was not required), it was evident very early in the coding stage that having the data physically on paper was necessary to process, organize, code, and later analyze the data.

The data for each question was organised, in general, according to the format below;

Table #1

| Question | | |
|-------------|--------|-----------|
| Participant | Answer | Rationale |

From these very data-rich/detailed tables, it was therefore much easier to organize and process the data for the relevant ‘what’ responses, and exclude the ‘whys’ (which were later used in

the 'results and discussion' chapters). Using data from the 'answer' column only, these were processed into a second table, so that only the data relevant for the ('what') question was visible. From these second series of tables, with no precoding allocated (except for the first part of question one), the data was analyzed again, and a set of general thematic codes developed as dictated by the data. To ensure consistency in coding each specific example to their respective themes, and for ease of analysis, that there were no multiply coded items, the process of coding each example was repeated twice over the course of one week using the same themes developed. While the majority of the responses were coded the same both times, when there was a discrepancy, the transcribed interviews were consulted. By reviewing these, it was possible to place the specific 'what' response in the larger context of what the participant was referring to/speaking about at the time, and thus from this 'larger context' the 'final' coded theme was given. Interestingly, the 'final code', based on the participants' responses, was generally the same theme it was coded as in the first of two data coding processes. After the data was processed into the second series of tables, it was at this point that the analysis of 'frequency' was conducted, and processed into a third series of tables. These final series of tables contained the frequency with which each theme(s) was given across the participants. Had the pure number of specific 'examples' been used for determining frequency, this would have been unrepresentative of the responses, and skewed the data as some participants gave multiple examples under one theme, and others gave only one. If the frequency of how many *examples* within a single theme were calculated, as opposed to the frequency with which the actual *themes* were given, this would have generated much different results, and not answered the five questions specifically, nor the primary purpose of the dissertation, to determine if there is consensus among researchers regarding five specific questions on research on aging and disability. It was data from these third series of tables that the 'results and discussion' chapters were predominantly written from.

Although the processing, coding, and analysis were similar for each of the five questions, the specific units of analysis varied slightly. Neither the responses from specific individuals nor the specific areas they 'represented' were the focus of this research, and therefore *not* the unit(s) of analysis. Although the data was initially organized into tables according to each participant, in the second and third series of tables each participant was 'removed' from their response, and assigned a letter. Since it was not relevant, for this study, to identify or connect 'who said what', and what *is* important is determining the *frequency* with which there was consensus across the four participants, the *frequency* with which themes were given by *individual* participants was the units of analysis. Therefore, the *themes* which

the data were coded into became the units of analysis, and it was the frequency with which they were given by participants that was analyzed.

CHAPTER FOUR

Classifying Disabled Older Adults: Results and Discussion

Results and Discussion: A General Note

Although only four interviews were conducted, the data generated from the participants was quite significant. Unfortunately however, due to length constraints it is impossible to discuss each response, suggestion, or idea in turn. Recognizing that the answers each participant gave are important pieces of data themselves however, all of the specific examples (rationales excluded) are included in Appendix #4. In this way, although they may not be discussed specifically, the reader remains able to learn, and hopefully use, what the participants said, while gaining a better understanding of the larger, macro issues within the data.

Classifying Disabled Older Adults

The first question of the interview with participants asked them to state how they saw the three individuals presented in the different vignettes (see Appendix #1 for actual vignettes). Originally stemming from confusion and inconsistency within the initial search of aging and disability literature, unfortunately responses from the participants provided no further clarification. In fact, their responses seem to concur with the literature in that perhaps there is no single method or term for classifying an individual who is both old (that is over the age of sixty-five) and disabled (according to a social model of disability (Oliver, 1990)). The only instances in which there was some, albeit quite minor, consensus was with 'Alice' and 'Judith'.

Alice

With regards to Alice, two participants classified her as 'older', while the other two classified her as 'older and disabled' and 'impaired' respectively. The rationale for classifying Alice as 'older' was primarily chosen because of her "sort of general impairments" and her "loss of capacity". Along similar lines, she was also considered 'older and disabled' because she "displayed conditions commonly associated with the aging process" while "clearly" having impairments, thus bringing her into a "definition of a disabled person covered by the Disability Discrimination Act". What was interesting about the classification of 'older' for Alice, and particularly the rationale for each respective choice, was that they appear to support and perhaps even reinforce the 'typical stereotype' of an older adult (Novak, 1997), a fact one participant quickly recognized in their answers after classifying all three women. Since it was difficult to identify exactly what was causing Alice's impairments, and

therefore an inability to produce a classification of disability/disabled, perhaps it was by ‘default’ that she was thus classified as ‘older’, as it is commonly assumed/expected (Cremin, 1992; Jones, 2006; Pound, et al., 1998; Sarkisian, et al., 2002), and science/social science demonstrate (Hayflick, 1994; Jagger, et al., 2001; Scudds & Ostbye, 2001), that as people age they experience biological and/or physiological senescence. Perhaps it was the fact that Alice was describing her list in terms of ‘general hates about aging’ (although the ‘aging’ reference was omitted), and awareness that as people age they generally experience such difficulties that she was classified as ‘older’ more frequently than any other classification, despite the fact that her ‘complaints’ could equally be attributed to impairment/disability.

Table #2

| Frequency with which Participants Classified Vignette #1: Alice | |
|--|-----------|
| Classification | Frequency |
| Older | 2 |
| Impaired | 1 |
| Combination of (older and disabled) | 1 |
| Does not matter; Disabled; None/Other | 0 |

Judith

All four participants found ‘Judith’s’ vignette both an interesting example and complex to classify. Purposely chosen for this reason, ‘Judith’ was meant to challenge, and stand in complete opposite to ‘Alice’, and her classifications demonstrated this exactly. In fact, one participant commented that, “You seem to want us to say disability”, which despite this observation (to which no comment was made), did little to deter her, or any others for that matter, from classifying Judith the way they did. Where Alice was generally seen as ‘older’, the general consensus for Judith was that she was ‘disabled’, albeit with a combination of ‘older and’ and ‘aging with’. The most common rationales for this classification were due to, a)the stated diagnosis of polio/post-polio syndrome, b)her participation in the disability movement, and c)her involvement with both the “outside world” and “external resources”. Again the classification, and more importantly the responses/rationales for choosing this particular classification appear to be based on connections and assumptions associated with disabled people (ie diagnosis of polio, politicization, and active involvement in ‘the world’), all of which are not generally associated with older people, but with disabled people instead (Abberley, 1996; Hummert, 1990; Novak, 1994; Shakespear, 1993). Despite the fact that aging was mentioned/referenced several times in Judith’s vignette, and although her age was purposely omitted, Judith is clearly aging, and yet only one participant classified her as both

‘older and disabled’. This is particularly interesting considering all four participants are involved in aging research, and yet only one participant clearly classified her as such.

Table #3

| Frequency with which Participants Classified Vignette #2: Judith | |
|---|-----------|
| Classification | Frequency |
| Disabled | 2 |
| Combination of (older and disabled) | 1 |
| None/Other (aging with a disability) | 1 |
| Does not matter; Impaired; Old(er) | 0 |

Mrs T.

Mrs. T was the vignette with the least consensus. She was classified as ‘disabled’, ‘impaired’, ‘older and disabled’, and finally one ‘undecided’. Although there was no consensus regarding her classification, two trends did appear within the rationales given for the responses; Mrs. T’s diagnosis of arthritis, and her use of public transportation and resources. The diagnosis of arthritis seemed to cause the most confusion and indecision for two of the four participants. For example, one participant commented that while, “normally you would say, ‘well, someone’s got arthritis, so they’re old’”, this is not necessarily the case, as “young people get arthritis too, so it’s difficult”. A second participant also made reference to the diagnosis of arthritis in saying that, “if it had only mentioned arthritis, I would have said ‘old’, but because of the others [ie impairments] I think she’s ‘disabled’”. It is interesting to note that perhaps it is arthritis’ common association with aging (Arthritis Society of Canada, 2006) that this factor became *the* identification over which the decision to classify Mrs T. as ‘older’ or ‘disabled’ was made. The use of public transportation/resources was the second commonality in the responses. In both instances however this “use” was associated with Mrs T’s level of impairment or disability, and therefore whether this ‘level’ indicated whether or not Mrs T was ‘disabled’ or ‘older’. For example, one participant stated that the use of public resources “could or could not be about disability”, while another commented that although Mrs T was “clearly impaired to an extent ... she seems able to use public transportation...”, and thus perhaps she was not disabled but merely ‘older’. In the end however, a classification could not be made, and so this participant chose to classify Mrs. T as ‘neither’, and was left undecided. It was interesting to note that the use of public transportation/resources, both of which are obviously used by both younger and older people, disabled and non-disabled, that was a key factor in deciding how to classify Mrs T.

Table #4

| Frequency with which Participants Classified Vignette #3: Mrs T. | |
|---|-----------|
| Classification | Frequency |
| Disabled | 1 |
| Impaired | 1 |
| Combination of (older and disabled) | 1 |
| None/Other (undecided) | 1 |
| Does not matter; Old(er) | 0 |

Research in General

The second part of question one asked the participants how they thought research in general classifies disabled older adults, using the same choices they were given for their own responses. Following what was found in both the initial literature search and the responses to the vignette classifications, although there was very little consistency among the participants regarding how research classifies, they were consistent in remarking that the classification used in research in general is often done inconsistently and interchangeably. For example, while one participant noted that research may “talk about disability or impairment with reference to older people”, one never “actually sees them being referred to as ‘having a disability’ or as being ‘disabled’”. Rather, they are “generally seen as old, aging, or aged”, or as two other participants stated, as using the terms “interchangeably”, and/or “with no real consistency”. Therefore, although none of the participants agreed on how research in general classifies disabled older adults, they did recognize and concur with the initial findings from the literature search and each other that, unfortunately, when it comes to researching and presenting disability and aging research, there is no consistency of terms with which to classify the population at hand. In an unsolicited response from Participant D, a possible explanation for this interchangeability/inconsistency was given in that there is actually “very little incentive” to make further distinctions in research’s terminology/classification because of the direction current policies and services are provided, in that policies/services are typically geared towards ‘younger disabled people’, and no distinct policies/services geared towards ‘older disabled people’. However, even if this is the case, this discrepancy harks back to the point made previously in that without any consistency or distinctions made, this can ultimately affect the very direction and population policies and services are attempting to assist.

Table #5

| <u>Frequency with which Classifications were given regarding How Research in General Classifies Disabled Older Adults</u> | |
|--|-----------|
| Classification | Frequency |
| Interchangeable (older and disabled) | 3 |
| Aging/Aged | 2 |
| Inconsistently (disabled ...ie definition of) (aging and disabled) | 2 1 |

Note: multiple answers were given

Summary

In terms of classifying disabled older adults, consensus was held among two participants for both 'Alice' and 'Judith', and no consensus regarding 'Mrs T'. Despite higher education and decades of work researching and working with disabled older adults, it was interesting to find participants classifying the respective vignettes according to common assumptions and stereotypes instead. With regard to research in general and how it classifies disabled older adults, while there was little consensus regarding the actual classification(s) used, it was acknowledged by all participants that the classification/terms which are used are often applied interchangeably/inconsistently. The results and implications for both of these findings are essential for the process and direction of future research on aging and disability, and thus require more detailed analysis in subsequent studies.

CHAPTER FIVE

Productive and Unproductive Aging and Disability Research: Results and Discussion

The question regarding productive and unproductive aging and disability research was asked in order to determine whether there is consensus among researchers regarding each respective disciplines' research. Inspired by the abundance of literature concerning measuring, identifying, and classifying disability and/or 'old' age, it was felt that this abundance must a) be unproductive, and b) that other, more productive research must exist. This four-part question was the only question to which there was both the most consensus (unproductive aging research) and the least (productive aging and productive disability research). An interesting occurrence in the data was recognizing conflicting responses given across productive and unproductive research, which will be discussed in the 'comparative' sections of productive and unproductive aging and productive and unproductive disability research respectively. A more detailed discussion of consensus/lack of consensus regarding productive and unproductive aging and disability research follow. However, an important side note worthy of mention is the following excerpt from one of the participants regarding the purpose and ability of research in general. Although this chapter highlights productive and unproductive research specifically, their comment is an important reminder for what research is meant to do; "all research, as long as it's well designed, and well thought through will always add something, always has the potential to add another dimension, or another perspective". From this observation then, even research one considers 'unproductive', may (for example) be 'productive' in that, while its purpose/rationale/conclusions may be questionable or problematic, its methodology may provide new techniques from which 'productive' research can benefit and use.

Productive and Unproductive Aging Research

Productive aging research was one of only two questions to which there was no consensus among any of the participants (see Table #6, and Appendix #4 for specific examples). With nine different themes generated from the specific examples given, not one theme was mentioned twice. Although it would be interesting to hypothesize different reasons for this lack of consensus, the methodology of this research does not permit. It is only data generated from the participants which is considered. However, using this data and comparing it with data from unproductive aging research, without hypotheses as to why, will be considered following a discussion of unproductive aging research specifically.

Within unproductive aging research there was unanimous consensus with the theme of

Health (see Table #7, and Appendix #4 for specific examples). The rationale given from all four was also unanimous; “we know... we don’t need to keep going at it”, “they’re only telling, or confirming things you could easily anticipate”. In essence, as one participant said, “it’s time to move on”. The consensus regarding this theme therefore echoes back to much of the research considered in Chapter Two, where health was *the topic* of concern, and measurements of ‘health’ (ie disability) paramount (which, interestingly enough, was the only other theme to which two of the four participants highlighted as unproductive aging research). The themes of both Health and Measuring/Identifying were also the two which received the most frequent consensus (nine and seven times respectively) across data from productive/unproductive research, issues neglected, and future directions (see Appendix #4), signifying that they are particularly important themes within aging and disability research.

Comparing Productive and Unproductive Aging Research Data.

With regards to the data generated by productive and unproductive aging research, comparing each questions’ results, although not outlined in the methodology of the paper, provides an interesting discussion and level of analysis. Between the two tables there was a total of twelve different themes, four of which, were cited as both ‘productive’ and ‘unproductive’. The four themes were Health, Measuring and Identifying, Perspectives Of, and Political Economy/Socio-Political. Although the themes of Health, Perspectives Of, and Political Economy/Socio-Political appeared in both productive and unproductive aging research data, they were essentially saying the same thing, albeit in a different way. Take Political Economy/Socio-Political, for example. While the theme appeared in the tables for both, and at first appearance looked as though they contrasted with one another, the participants were actually concurring that it is *productive* aging research. Noted outright as being productive research by one participant, the second participant used different phrasing, that aging research has been *unproductive* in “discussing social or political environments”, which in effect meant that they were echoing the same result. This ‘echoing’ through ‘different phrases’ was repeated for the themes of both Health and Perspectives Of (see Appendix #4 for specific examples), and highlighted that close analysis of data is necessary to ensure correct interpretation from which discussions and ‘conclusions’ may be drawn.

Table #6

| Frequency with which Themes were given regarding Productive Aging Research | |
|---|-----------|
| Theme | Frequency |
| Choice and Control | 1 |
| Health | 1 |
| Housing | 1 |
| Life Course Supports | 1 |
| Measuring and Identifying | 1 |
| Methodology | 1 |
| Perspectives Of | 1 |
| Political Economy/Socio-Political | 1 |

Table #7

| Frequency with which Themes were given regarding Unproductive Aging Research | |
|---|-----------|
| Theme | Frequency |
| Health | 4 |
| Measuring and Identifying | 2 |
| Employment/Poverty | 1 |
| Perspectives Of | 1 |
| Political Economy/Socio-Political | 1 |
| Methodology | 1 |
| Specific (sub)Population | 1 |
| Theory/Concepts | 1 |

Productive and Unproductive Disability Research

Productive disability research had the same results as productive aging research in that there was no consensus among participants regarding any of the six themes (see Table #8, and Appendix #4 for specific examples). Again, although it would be interesting to hypothesize why this lack of consensus exists, as it is only data generated from the participants which is considered, the section following the next paragraph will compare and discuss the data from productive disability research with data from unproductive aging research, without hypothesizing why.

While there was no consensus within productive disability research, three of the four participants concurred that Measuring and Identifying was an area of unproductive disability research, and two of the four that Health was unproductive disability research (see Table #9, and Appendix #4 for specific examples). Due to paper length restrictions, and in order to devote discussion to as many themes a possible, the discussion for this question concerns Measuring and Identifying only, as it was the theme with the most consensus, and the theme

of Health has already been discussed. Citing similar rationale given in unproductive aging research regarding Health (“time to move on”), the participants spoke of Measuring and Identifying in a similar way, although they expanded on these thoughts as well. For example, measuring and identifying was seen as an “obsession” within research of “just trying to come up with other, more sophisticated ways of classifying impairments”. Of having these “sophisticated classification systems” (for example Jagger, et al., 2001; Melzer, McWilliams, Brayne, Johnson, & Bond, 2001; Patja, Iivanainen, Vesala, Oksanen, Ruoppila, 2000) and “accurate demographic information” (for example Melzer, Izmirlian, Leveille, Guralnik, 2001; and Brayne, et al., 2001), and yet being “very, very far away from having useful information”. Succinctly summarizing what all four participants repeated several times throughout the interviews, and a sentiment first presented in Chapter Two with regards to the abundance of such research, one participant stated that, while these measurement/classification-type studies are “necessary”, they are also “not productive”. While acknowledged that it holds some merit by all four participants, measuring and identifying, the ‘necessary evil’ of disability research, was ultimately found to be unproductive among the majority of participants.

Comparing Productive and Unproductive Disability Research Data.

When comparing data across productive and unproductive disability research, there were two predominant themes generated in both; Health and Theory/Concepts. Rather than discuss the theme of Health again, the theme of Theory/Concepts will be discussed instead, as it is a theme that has yet to be presented. This theme is also particularly interesting as its appearance within both tables was generated by the same participant. Although this current discussion involves one individual, and is therefore counter to the purpose of the paper (ie to discuss consensus among researchers), it highlights that ‘consensus’ may not necessarily be found within one individual either, and that this lack of personal consensus can itself be productive as it provides critical reflection. While Participant C stated that disability research was *productive* in “developing theory/theories” and having “discussions about issues, topics, and meanings”, they also stated that disability research was *unproductive* in “transferring” these discussions into “some empirical evidence about what we would need to do to change something”. Disability research was *unproductive* in “moving conceptualizations into more concrete items around research that one can make actual policy decisions around”. Therefore, although this *lack* of consensus may appear to contradict itself, closer analysis of the data demonstrates that it does not, and in contrast, it actually provides an interesting critique of the

same issue. While no literature could be located confirming this criticism as it tends to consider the impairment/disability debate (see Barnes and Mercer, 1996, Patterson & Hughes, 1999, for example), this was a criticism noted by one other participant (although not in reference to this question in particular), and one shared by a number of Disability Studies MA students as well (personal communication, 2006).

Table #8

| <u>Frequency with which Themes were given regarding Productive Disability Research</u> | |
|---|-----------|
| Theme | Frequency |
| Health | 1 |
| Life Course Perspective | 1 |
| Methodology | 1 |
| Political Economy/Socio-Political | 1 |
| Program/Service Development | 1 |
| Theory/Concepts | 1 |

Table #9

| <u>Frequency with which Themes were given regarding Unproductive Disability Research</u> | |
|---|-----------|
| Theme | Frequency |
| Measuring and Identifying | 3 |
| Health | 2 |
| Theory/Concepts | 1 |

Summary

Productive and unproductive aging and disability research was the only question for which there was both the most consensus, unproductive aging research, and the least, productive aging and productive disability research. Nine different themes were generated for productive aging research (see Table #6), and eight for unproductive aging research (see Table #7), resulting in twelve different themes in total. From those twelve, four themes, Health, Measuring and Identifying, Perspectives Of, and Political Economy/Socio-Political, appeared in both tables. Health was unanimously cited by all four participants as unproductive disability research, with the most common criticism being that it was “time to move on”. With regards to the four themes appearing in both data tables, closer analysis of the data revealed that while they first appeared to contradict each other, it was actually a difference in phrasing which prompted the initial observation, thus highlighting the

importance of correctly reading and analysing data. Within productive disability research, six different themes were generated (see Table #8), for which there was no consensus. Three themes were generated for unproductive research (see Table #9), thus producing seven different themes in total, of which two, Health and Theory/Concepts, overlapped. In terms of unproductive research, consensus was held with Measuring and Identifying (three participants) and Health (two participants). The most common rationale for Measuring and Identifying was similar to that cited in unproductive aging research, and unique in that it was criticized as a necessary but unproductive “obsession”. Both Health and Theory/Concepts appeared within the productive and unproductive disability research data, and an analysis of the doubly mentioned Theory/Concepts highlighted that a lack of consensus within one individual’s responses can provide a deeper level of analysis and critiquing regarding one theme in particular.

CHAPTER SIX

Issues Neglected in Aging and Disability Research/Research on Aging and Disability: Results and Discussion

The purpose in asking participants to provide examples of either past and/or present aging and disability issues neglected in research was to determine if there is consensus among researchers regarding what the issues are. This question also developed as a consequence to the abundance of measurement, identification, and classification type studies, as it followed that *other* areas must therefore be neglected as a result. There were seven themes generated for issues neglected in aging and disability research: Methodology, Life Course Supports, Perspectives Of, Political Economy, Specific Aspects of Aging, Health, and Specific (sub)Populations (see Table #10, and for specific examples see Appendix #4). Life Course Supports, Perspectives Of, Political Economy, and Specific Aspects of Aging were each mentioned by two different participants, and Health and Specific (sub)Populations once. Methodology received the most consensus with three participants giving three different specific examples.

Methodology

One participant stated that more *qualitative* research was necessary in aging and disability research, as there is an “excessive amount of quantitative” being produced. An example of this can be found in the number of ‘measurement-type’ studies which abound in aging and disability research (see Chapter Two), and the fact that the majority of these are concerned with the ‘pure numbers’ of how many older people are disabled (Melzer, et al., 2001; Jagger, et al., 2001), where they are disabled, both physically and geographically (Brayne, et al., 2001; Langois, 1996), how disabled they are (Avlund, Lund, Hostein, & Due, 2004; Moore, et al., 1999), etc. Very few consider more qualitative factors such as what these experiences and numbers actually mean for individuals/society, how they respond, etc..., although Freedman (2004), Pound, et al. (1998), Sanders, et al. (2002), and Strawbridge, et al. (2002) offer some good examples.

A second participant stated that disability research in particular neglects the issue of *individuals* as it generally focuses “almost exclusively on society”. They went on to say that,

perhaps as a reaction to the medical [model of disability], the individual is pushed all the way into the ‘societal’ or ‘political’, but people with disabilities *do* have health problems, they *do* have individual issues related to their own lives, and in abandoning that, it doesn’t really help... (Participant B)

The issue of ‘individual versus society’, or ‘impairment versus disability’ is a common criticism and source of division within Disability Studies itself (see Barnes and Mercers’ *Exploring the Divide: Illness and Disability* (1996) for example), and within the data generated by participants in this study as well. The fact that at least one participant¹ stated that this was a clear issue *neglected* in the research, and there was much discussion generated around disability researches’ ‘focus’ signifies that this issue will likely continue to be debated, and hopefully both ‘focuses’ will be developed so that both ‘individual’ and ‘societal’ perspectives will eventually be presented, discussed, and better understood.

Longitudinal studies ‘tracking people’s psychological and social experiences’ (for example) was an issue for a third participant as being both highly neglected and an “obvious area crying out for this type of approach”. They stated that while there are numerous studies regarding longitudinal *medical* research involving older people, and studies ‘tracking’ disabled *children’s* experiences over a number of years, there were none, or at least very few to their knowledge, ‘tracking’ non-medical experiences of disabled older adults. While there are some excellent aging and disability longitudinal studies in the United States and Canada (see for example ‘The Baltimore Longitudinal Study of Aging’, 2005; ‘Aging in Manitoba’, n.d.; and ‘The Nun Study’, 2006), this participant stated that in general “people tend to be quite short term and pragmatic about their research”, which is perhaps why any longitudinal studies resulting from the literature searches for this paper revealed an abundance of ‘measurement’ or ‘medical-type’ tracking studies (Avlund, et al., 2004; Hoeymans, et al., 1997; Jagger et al., 2001; Scudds, et al., 2001; Simons, et al., 2000), and very few others (Dagnan, et al., 1998).

Table #10

| Frequency with which Themes were given regarding Issues Neglected in Aging and Disability Research | |
|---|-----------|
| Themes | Frequency |
| Methodology | 3 |
| Life Course Supports | 2 |
| Perspectives Of | 2 |
| Political Economy/Socio-Political | 2 |
| Specific Aspects of Aging | 2 |
| Health | 1 |
| Specific (sub)Populations | 1 |

¹ Two of the remaining three spoke of similar criticisms within the interviews, however they did not actually state that it was an issue neglected in research specifically, and thus excluded from the data.

Summary

Although the specific examples of issues neglected in aging and disability research, and within the theme of 'Methodology' in particular, were quite different (qualitative, longitudinal/'tracking' (aging research specifically), and focus on the individual (disability research specifically), they each concurred with methodological areas highlighted in the majority of literature reviewed for the 'background' to this study (see Chapter Two), and within Disability Studies literature, and longitudinal studies literature as well. When considering issues neglected in aging and disability research, there appears to be consensus in that different methodological approaches need to be applied to studies of both aging and disability.

CHAPTER SEVEN

Directions for Future Research on Aging and Disability: Results and Discussion

The purpose in asking researchers to provide examples of directions for future research on aging and disability was to determine if there was consensus between them regarding which ‘directions’ should be taken up. In total, there were nine different directions for the future research on aging and disability generated by the four participants: Choice and Control, Employment/Poverty, Independence, Life Course Perspective, Measuring and Identifying, Perspectives Of, Political Economy/ Socio-Political, Policy, and Support Networks (see Table #11 for results, and Appendix #4 for specific examples). The only theme with which there was consensus regarded future research from a Life Course Perspective, and was given by two of the participants. For the remaining seven themes, only one participant provided examples within each, thus resulting in no other consensus regarding future directions for research on aging and disability.

Life Course Perspective

With regards to a life course perspective, between the two participants who cited this as a direction for future research, they gave a total of four different examples, of which one was shared by both; “looking at people from much more of a life course perspective”. The first participant stated that “maintaining, recording, and releasing the life histories of older people with intellectual disabilities” was a particularly important direction for future research, as this current generation have generally lived the majority of their lives in institutions; “they just don’t... *nobody* knows their history. Nobody can help them reflect on what’s happened in their lives”. Rather than working with, studying, and seeing these people and their cumulative life experiences from a life course perspective, both research/researchers and various practitioners/service workers either ‘forget’ to consider this aspect, or really do not know. Developing methods to “maintain, record, and release” these histories from a life course perspective therefore seems an important way to begin this process. A process to which there does not appear to be any published literature. While a life course perspective has been applied to aging with an intellectual disability in other, albeit limited, areas (see for example Evenhuis, et al., 2001; Thomson, Glasson, Bittles, 2006; and Seltzer & Krauss, 2001), the majority of these life course perspective studies consider families/caregiving, and particularly caring for a child with an intellectual disability (Emerson, Grant, Nolan, Keady, 2003; Grant & Whitwell, 2000; Lefley, 1997). There is little to no research regarding older

adults with an intellectual disability.

The second participant was more general with their population, and simply referenced research regarding ‘people’ in general as requiring a life course perspective applied to it in future studies. No further elaboration or rationale was provided however, and while this should have been recognized during the actual interview, unfortunately it was not, and by the time the data analyzed and written up, it was too late to contact for further clarification (due to time constraints). Without this data however, it is difficult, and counter to the methodology of this paper, to establish a possible explanation, and unfortunately no discussion regarding their example can take place.

Table # 11

| <u>Frequency with which Themes were given regarding Future Directions of Aging and Disability Research</u> | |
|--|---|
| Life Course Perspective | 2 |
| Perspectives Of | 1 |
| Choice and Control | 1 |
| Employment/Poverty | 1 |
| Independence | 1 |
| Measuring and Identifying | 1 |
| Political Economy/Socio-Political | 1 |
| Policy | 1 |
| Support Networks | 1 |

Summary

Although nine different themes were generated from the examples given, only one of these formed a general agreement among two of the four; directions for future research on aging and disability from a life course perspective. While the majority of research looking at aging and/or disability from a life course perspective has been published since roughly the mid-1990s², thus signalling an important and growing trend in research, these same results showed that a life course perspective as applied to *disabled older adults*, and older adults with an intellectual disability in particular, are absolutely in need of future research by the fields of both aging and disability.

² Obtained by entering the search terms ‘life course perspective aging disability’ into various data base and search engines available through the University of Leeds.

CHAPTER EIGHT

Responsibility for Aging and Disability Research: Results and Discussion

The question, who is responsible for aging and disability research, was designed to determine if there is consensus regarding *who* exactly should be responsible for taking research forward. Six different themes were generated, and consensus shared among Disability and Gerontology (three each), and Health and Medicine and Other (two each), (see Table #12, and Appendix #4 for specific examples). Maintaining consistency with the previous chapters, only the more frequent themes will be discussed here, which were Disability and Gerontology.

Disability and Gerontology

Disability and Gerontology were both cited by two participants as being responsible for aging and disability research for the same reasons, a)they are both multi-disciplinary fields of study which provide a “collective perspective” required in looking at the variety of issues regarding this population, and b)because both need to “broaden the scope of their current analysis”. The third participant, while concurring with the other three that Disability and Gerontology should be responsible provided different rationale. They stated that Disability should be responsible because of its “sounder theoretical base”, and Gerontology because of its tendency to focus on medicine, an aspect often neglected in Disability research, both of which were highlighted in data generated in earlier questions (see Chapter Five). All three participants felt that Disability and Gerontology were equally responsible for this research, as each had a particular vested interest and specialized knowledge base for ‘one half’ of the population/area which makes up aging and disability. What was interesting to note however was that while yes, both Disability and Gerontology were equally responsible for this research, it was not necessarily the case that they should be doing this *together*. This ‘omission’ is interesting as there is a small, but increasing trend in the literature to look at aging and disability *simultaneously*, and to consider their *shared* areas of commonality (Kennedy, 2002; Kennedy & Minkler, 1998; NDA, n.d.; Priestley, 2002; Priestley & Rabiee, 2002; Putnam, 2002), and the fact that each area of study was also recognized by the four participants as having different ‘productive’ and ‘unproductive’ research previously (see Chapter Five), and yet neither were not noted as taking *together* and completing research on aging and disability *together*.

Summary

Six different themes were generated regarding who should be responsible for research on aging and disability. Health and Medicine, and Other were stated across two participants, and Disability and Gerontology across three. Citing similar rationale for why Disability and Gerontology should be equally responsible (both are multi-disciplinary, both need to “widen their scope”), did not equate however with participants stating that aging and disability research should be doing this *together*, a trend slowly but increasingly evident within literature, and a method to incorporating and using the productive and unproductive aspects of aging and disability research respectively which was highlighted by all four participants earlier.

Table #12

| <u>Frequency with which Themes were given regarding Responsibility for Research on Aging and Disability</u> | |
|--|-----------|
| Theme | Frequency |
| Disability | 3 |
| Gerontology | 3 |
| Health and Medicine | 2 |
| Other | 2 |
| Governing Bodies | 1 |
| Public Policy | 1 |

CHAPTER NINE

Conclusion

The world's population is getting older (Ebrahim, 1999; Knickman and Snell, 2002; PALS, 2001;), becoming more disabled (Human Resources Development Canada, 2003; Mayhew, 2003), and should expect to acquire disability in old age (Guralnik, 1996; Olshansky, Hayflick, & Carnes, 2002; Sheehan, 2003; Simmons, McCallum, Friedlander, & Simons, 2000). The result of this "aging" and/or "disabling of the population" has been a variety of directions, opinions, predictions, solutions, cautions, and conclusions from everyone from politicians and policy makers to advocates and academics. With Disability Studies and Gerontology as particularly suitable for exploring these issues, their respective limited research funding and policy priority (Participant B, 2006; Binstock, 2003; Participant C, 2006; Robert, 2003; Participant D, 2006), combined with the 'demographic shift' and variety of possible areas resulting from this requires one to consider the breadth and depth of aging and disability research that currently exists. Unable to locate literature which has critically looked at research on aging and disability itself, and frustrations appeared inconsistent and there was an abundance of measuring, identifying, and classifying disability and/or 'old' age studies (see Chapter Two)), five questions were posed in semi-structured interviews to four researchers involved in aging and disability research. The five questions asked, a)what researchers classify disabled older adults as, b)what are some examples of productive and unproductive aging and disability research, c)what issues have been neglected in past/current aging and disability research, d)what are some examples of future directions for research on aging and disability, and e)who should be responsible for research on aging and disability in general.

Using a constructivist/social constructionism approach to an inductive research strategy, semi-structured interviews were conducted with four researchers in aging and disability, Participant A, Participant B, Participant C, and Participant D. Representing four specific 'areas' of research, the participants generated data which was read literally and interpretively, and processed into series of tables. Analyzed by 'theme' rather than 'individual participant', consensus regarding each question ranged from unanimous (once) to none whatsoever (twice). In terms of classifying disabled older adults, consensus was found for the first two 'individuals', (two of the four participants), and no consensus for the third. With regard to how research in general classifies disabled older adults, while there was no consensus regarding the actual classification, all four acknowledged that the

classification/terms used are often applied interchangeable and inconsistently. Considering the lack of consensus regarding the very base of who researchers are studying, the population itself, and the importance of having some sort of shared meaning/definition signifies that more detailed analysis is required from subsequent studies. Productive and unproductive research was the only question which produced both unanimous consensus and none whatsoever. This chapter also highlighted the importance of reading and analyzing data correctly, as data that first appeared in opposition, after closer inspection, was actually producing the same result albeit through different phrasing. The consequences of misreading data could have had a negative and incorrect interpretation from which the discussion, and summaries would have been based on, and potentially future discussions and research as well. Seven different themes were produced from the issues neglected in aging and disability research data, of which four were generated from two participants, and one, Methodology, generated by three. With regards to the theme of Methodology in particular, there was consensus among all three participants that methodological approaches different than those currently being used need to be applied to both aging and disability research. Although nine different themes were generated from the future direction of aging and disability research data, only one of these, Life Course Perspectives, shared consensus among two of the four participants. This perspective was also noticeably lacking in current literature, however on a positive note, it is also an area which has been, and continues to be increasingly developed. Responsibility for aging and disability research, the final question posed to the participants, generated six different themes, with two citing Health and Medicine, and Other, and three citing Disability and Gerontology respectively. Although the three participants stated that Disability and Gerontology were equally responsible, it was interesting to note that, counter to findings within current literature, they did not identify the two as needing to work collaboratively and/or simultaneously.

The purpose in asking the five questions relating to aging and disability research, and ultimately the purpose of this entire paper was to determine if there is consensus between researchers, the 'foundations' of research itself. Whether there was consensus or not however, it is hoped that the results, specific examples, and discussions throughout provide a useful starting point from which research/researchers can understand where aging and disability research/researchers 'are at'. For it is through this understanding that they can continue where others have left, and add new knowledge and increased collaboration regarding aging and disability, so that ultimately, increased research funding and policy

priority can be obtained for issues involving both aging *and* disability, and the very population these issues effect.

Bibliography

Abberley, P. (1996) Work, Utopia and Impairment. In L. Barton (ed.), *Disability and Society: Emerging Issues and Insights*, London: Longman

Aging in Manitoba. (n.d.) The University of Manitoba, Canada, <http://www.aginginmanitoba.ca/>, (Accessed August 20, 2006)

Arthritis Society of Canada. (2006) *Introduction to Arthritis*, <http://www.arthritis.ca/types%20of%20arthritis/default.asp?s=1>, (Accessed August 20, 2006)

Avlund, K., Lund, R., Holstein, B., and Due, P. (2004) Social Relations as Determinant of Onset of Disability in Aging, *Archives of Gerontology and Geriatrics*, Vol. 38, No. 1, pp. 85-99

Babbie, E. (2001) *The Practice of Social Research*, USA: Wadsworth/Thomson Learning

Barnes, C. and Mercer, G. (eds.) (1996) *Exploring the Divide: Illness and Disability*, Leeds: The Disability Press

Beart, S. (2005) 'I won't think of myself as a learning disability. But I have': Social Identity and Self_Advocacy, *British Journal of Learning Disabilities*, Vol. 33, No. 3, pp. 128_131

Binstock, R. (2003) The War on "Anti-Aging Medicine", *The Gerontologist*, No. 43, pp. 4-14

Blaikie, N. (2005) *Designing Social Research*, Cambridge: Polity Press

Blaikie, N. (2003) *Approaches to Social Enquiry*, Cambridge: Polity Press

Bowling, A., See-tai, S., Ebrahim, S., Gabriel, Z., and Solanki, P. (2005) Attributes of Age-Identify, *Ageing & Society*, Vol. 25, pp. 479-500

Brayne, C., Matthews, F., McGee, M., and Jagger, C. (2001) Health and Ill-Health in the Older Population in England and Wales: The Medical Research Cognitive Function and Ageing Study (MRC CFAS), *Age and Ageing*, Vol. 30, pp.53-62

Bytheway, B. (2005) Age-Identities and the Celebration of Birthdays, *Ageing & Society*, Vol. 25, pp. 463-477

Cosentino, A. (2006) MA Course Paper for *Research, Strategy, and Design*, University of Leeds

Cremin, M. (1992) Feeling Old Versus Being Old: Views of Troubled Aging, *Social Science and Medicine*, Vol. 34, No. 12, pp. 1305-1315

Cutler, D. (2001) Declining Disability Among the Elderly, *Health Affairs*, Vol. 20, No. 6, pp.11-27

Dagnan, D., Ruddick, L., and Jones, J. (1998) A Longitudinal Study of the Quality of Life of Older People with Intellectual Disability after Leaving Hospital, *Journal of Intellectual Disability Research*, Vol. 42, No. 2, pp.112-121

Daltroy, L., Larson, M., Eaton, H., Phillips, C., Liang, M. (1999) Discrepancies Between Self-Reported and Observed Physical Function in the Elderly: The Influence of Response Shift and Other Factors, *Social Science and Medicine*, Vol. 48, No. 11, pp .1549-1561

Deal, M. (2003) Disabled People's Attitudes Toward Other Impairment Groups: A Hierarchy of Impairments, *Disability & Society*, Vol. 18, No. 7, pp. 897-910

de Vaus, D. (1995) *Surveys in Social Research 4th Edition*, Australia: Allen & Unwin

Ebrahim, S. (1999) Demographic Shifts and Medical Training, *BMJ (British Medical Journal)*, Vol. 319, pp. 1358-1360

Emmerson, E. (2003) Mothers of Children and Adolescents with Intellectual Disability: Social and Economic Situation, Mental Health Status, and the Self-assessed Social and Psychological Impact of the Child's Difficulties, *Journal of Intellectual Disability Research*, Vol. 47, No. 4., pp.385

Evenhuis, H., Henderson, C., Beange, H., Lennos, N., and Chicoine, B. (2001) Healthy Ageing – Adults with Intellectual Disabilities: Physical Health Issues, *Journal of Applied Research in Intellectual Disabilities*, Vol. 14, No.3, pp.175

Freedman, V. (2004) Resolving Inconsistencies in Trends in Old-Age Disability: Report From a Technical Working Group, *Demography*, Vol. 41, No. 3, pp.417-441

Fried, L., Young, Y., Rubin, G., and Bandeen-Roche, K. (2001) Self-Reported Preclinical Disability Identifies Older Women with Early Declines in Performance and Early Disease, *Journal of Clinical Epidemiology*, Vol. 54, No. 9, pp. 889-901

Goodley, D. (2000) Researching Self-Advocacy, in Goodley, D. *Researching Self Advocacy in the Lives of People with Learning Difficulties*, Buckingham: Open University Press

Government of Canada. (2003) *Defining Disability: A Complex Issue*, <http://www.sdc.gc.ca/en/hip/odi/documents/Definitions/Definitions.pdf>, (Accessed May 19, 2006)

Government of Canada. (2006a) Services for People with Disabilities. (2006) http://www.pwd_online.ca/pdf/Disability_Guide_ENG.pdf, (Accessed May 22, 2006)

Government of Canada. (2006b) Services for Seniors. (2006) http://www.communication.gc.ca/guides/seniors_aines/pdf/services_for_seniors.pdf, (Accessed May 22, 2006)

Grant, G., Nolan, M., Keady, T. (2003) Supporting Families Over the Life Course: Mapping

- Temporality, *Journal of Intellectual Disability Research*, Vol. 47, No. 4-5, pp. 342-351
- Grant, G., and Whitwell, B. (2001) Differentiated Coping Strategies in Families with Children or Adults with Intellectual Disabilities: the Relevance of Gender, Family Composition and the Life Span, *Journal of Applied Research in Intellectual Disabilities*, Vol. 13, No. 4, pp.256
- Greenglass, E., Fiksenbaum, L., and Eaton, J. (2006) The Relationship Between Coping, Social Support, Functional Disability and Depression in the Elderly, *Anxiety, Stress, and Coping*, Vol. 19, No. 1, pp. 15-31
- Guralnik, J. (1996) Assessing the Impact of Comorbidity in the Older Population, *Annals of Epidemiology*, Vol. 6, No. 5, pp. 376-380
- Guralnik, J., Fried, J., and Salive, M. (1996) Disability as a Public Health Outcome in the Aging Population, *Annual Review of Public Health*, Vol. 17, pp.25-46
- Harrison, T., and Kahn, D. (2004) Perceived Age, Social Integration, and Disability: A Case Study of Aging Women, *Journal of Loss and Trauma*, Vol. 9, pp. 113-129
- Hayflick, L. (1994) *How and Why we Age*, New York: Ballantine Books
- Hendricks, J. (2004) Public Policies and Old Age Identity, *Journal of Aging Studies*, Vol. 18, pp. 245-260
- Hoeymans, N., Feskens, E., Kromhout, D., Van Den Bos, G. (1997) Ageing and the Relationship Between Functional Status and Self-Rated Health in Elderly Men, *Social Science and Medicine*, Vol. 45, No. 10, pp. 1527-1536
- Human Resources Development Canada. (2003) *Disability in Canada: A 2001 Profile*, <http://www.sdc.gc.ca/en/hip/odi/documents/PALS/PALS.pdf>, (Accessed May 19, 2006)
- Hummert M. (1990) Multiple Stereotypes of Elderly and Young Adults: A Comparison of Structure and Evaluations, *Psychology of Aging*, Vol. 5, No. 2., pp. 182-193
- Jagger, C., Arthur, A., Spiers, N., Clarke, M. (2001) Patterns of Onset of Disability in Activities of Daily Living with Age, *Journal of the American Geriatrics Society*, Vol. 49, No. 4, pp. 404-409
- James, OFW. (2004) Training in Geriatrics and Gerontology, *Geriatrics and Gerontology International*, Vol. 4, pp. S2
- Jones, R. (2006) 'Older People' Talking as if They Are Not Older People: Positioning Theory as an Explanation, *Journal of Aging Studies*, Vol. 20, pp. 79-91
- Jongbloed, L. (2003) Disability Policy in Canada: An Overview, *Journal of Disability Policy Studies*, Vol. 13, No.4, pp. 203-209
- Kaufmann, G., and Elder, G. (2002) Revisiting Age Identify: A Research Note, *Journal of*

Aging Studies, Vol. 16, pp. 169-176

Kennedy, J., and Minkler, M. (1998) Disability Theory and Public Policy: Implications for Critical Gerontology, *International Journal of Health Services*, Vol. 28, No. 4, pp. 757-776

King's College London and the University of Reading (2004) *Introducing Assistive Technology into the Existing Homes of Older People: Feasibility, Acceptability, Costs and Outcomes*. London: Institute of Gerontology King's College

Knickman, J. and Snell, E. (2002) The 2030 Problem: Caring for Aging Baby Boomers, *Health Services Research*, Vol. 37, No. 3, pp. 849-884

Kvale, S. (1996) *InterViews: An Introduction to Qualitative Research Interviewing*, London: Sage Publications Ltd

Lamarca, R., Ferrer, M., Anderson, P., Liestol, K., Keiding, N., and Alonso, J. (2003) A Changing Relationship Between Disability and Survival in the Elderly Population: Differences by Age, *Journal of Clinical Epidemiology*, Vol. 56, pp. 1192-1201

Langlois, J., Maggi, S., Harris, T., Simonsick, E., Ferrucci, L., Pawan, M., Sartori, L., and Enzi, G. (1996) Self_Report of Difficulty in Performing Functional Activities Identifies a Broad Range of Disability in Old Age, *Journal of the American Geriatrics Society*, Vol. 44, No., 12, pp.1421-1428

Lansley, P., McCreddie, C., Tinker, A., Flanagan, S., Goodacre, K., and Turner-Smith, A. (2004) Adapting the Homes of Older People: A Case Study of Costs and Savings, *Building Research & Information*, Vol. 32, No. 6, pp. 468-483

Lefley, H. (1997) Synthesizing the Family Caregiving Studies: Implications for Service Planning, Social Policy, and Further Research, *Family Relations*, Vol. 46, No. 4, pp. 443_450

Litwin, H. (2002) Examination fo the Association of Age, Disability, and Mood Among Jewish Older Adults in Israel, *Aging & Mental Health*, Vol. 6, No. 4, pp. 307-401

Macfarlane, A. (1994) On Becoming an Older Disabled Woman, *Disability & Society*, Vol. 9, No. 2, pp. 255-256

Mason, J. (2005) *Qualitative Researching*, London: Sage Publications Ltd

Maynard, M. & Purvis, J. (1994) (eds) *Researching Women's Lives from a Feminist Perspective*, London: Taylor & Francis Ltd.

McCarron, M., Gill, M., McCallion, P., Begley, C. (2005) Health Co-Morbidities in Ageing Persons with Down Syndrome and Alzheimer's Dementia, *Journal of Intellectual Disability Research*, Vol. 49, No., 7, pp.560-566

McVey, L., David, D., and Cohen, H. (1989) The 'Aging Game': An Approach to Education in Geriatrics, *Journal of the American Medical Association*, No. 262, pp. 1507-1509

Mayhew, L. (2003) Disability-Global Trends and International Perspectives, *Innovation*, Vol. 16, No. 1, pp. 3-28

Melzer, D., Izmirlan, G., Leveille, S., Guralnik, J. (2001) Educational Differences in the Prevalence of Mobility Disability in Old Age: The Dynamics of Incidence, Mortality, and Recovery, *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, Vol. 56, pp.s294-s301

Melzer, D., McWilliams, B., Brayne, C., Johnson, T., Bond, J. (2001) Socioeconomic Status and the Expectation of Disability in Old Age: Estimates for England, *Journal of Epidemiology and Community Health*, Vol. 54, pp.286-292

Moore, E., Rosenberg, M., Fitzgibbon, S. (1999) Activity Limitation and Chronic Conditions in Canada's Elderly, 1986-2011, *Disability and Rehabilitation*, Vol. 21, No. 5/6, pp. 196-210

Morgan, R., and David, S. (2002) Human Rights: A New Language for Aging Advocacy, *The Gerontologist*, Vol. 42, pp. 436-442

(NDA) National Disability Authority. (n.d.) *Aging and Disability: A Discussion Paper*, <http://www.nda.ie/cntmgtnew.nsf/0/FBE570D7C6D435C28025710D004594B9?OpenDocument> (Accessed July 28, 2006)

Northern Illinois University. (n.d.) The Aging Game: Planned for Spring 2005, *Gerontology Student Organization*, www.sa.niu.edu/gerontology/aginggame.htm, (Accessed April 21, 2006)

Novak, M. (1997) *Aging and Society: A Canadian Perspective*, Canada: Nelson

Oliver, M. (1990) *The Politics of Disablement*, London: The MacMillan Press Ltd

Olshansky, S., Hayflick, L., and Carnes, B. (2002a) No Truth to the Fountain of Youth, *Scientific America*, Vol. 286, No. 6, pp. 92-95

Pacala, J., Boulton, C., and Hepburn, K. (2006) Ten Years' Experience Conducting the Aging Game Workshop: Was It Worth It?, *Journal of the American Geriatrics Society*, Vol. 54, pp. 144-149

(PALS) Participation and Activity Limitation Survey. (2001) Statistics Canada (Government of Canada) http://www.statcan.ca/cgi_bin/imdb/p2SV.pl?Function=getSurvey&SDDS=3251&lang=en&db=IMDB&dbg=f&adm=8&dis=2, (Accessed May 27, 2006)

Patja, K., Iivanainen, M., Vesala, H., Oksanen, H., Ruoppila, I. (2000) Life Expectancy of People with Intellectual Disability: A 35_year Follow_up Study, *Journal of Intellectual Disability Research*, Vol. 44, No. 5, pp.591

Patterson, K., and Hughes, B. (1999) Disability Studies and Phenomenology: The Carnal Politics of Everyday Life, *Disability and Society*, Vol. 14, No. 5, pp.597-610

- Participant A. (2006) Interview for MA Dissertation in Disability Studies.
- Participant B. (2006) Interview for MA Dissertation in Disability Studies.
- Participant C. (2006) Interview for MA Dissertation in Disability Studies.
- Participant D. (2006) Interview for MA Dissertation in Disability Studies.
- Personal Communication with fellow Disability Studies MA students. (2006)
- Pound, P., Gompertz, P., and Ebrahim, S. (1998) Illness in the Context of Older Age: The Case of Stroke, *Sociology of Health & Illness*, Vol. 20, No. 4, pp. 489-506
- Priestley, M. (2002) Whose Voices? Representing the Claims of Older Disabled People Under New Labour, *Policy & Politics*, Vol. 30, no. 3, pp. 361-372
- Priestley, M., and Rabiee, P. (2002) Same Difference? Older People's Organizations and Disability Issues, *Disability & Society*, Vol. 17, No. 6, pp. 597-611
- Prince, M. (2003) Canadian Disability Policy: Still a Hit-and-Miss Affair, *Canadian Journal of Sociology*, Vol. 29, No. 1, pp. 59-82
- Prince, M., Harwood, R., Blizard, R., Thomas, A., Mann, A. (1997) Impairment, Disability and Handicap as Risk Factors for Depression in Old Age. The Gospel Oak Project V, *Psychological Medicine*, Vol. 27, pp.331-321
- Putnam, M. (2002) Linking Aging Theory and Disability Models: Increasing the Potential to Explore Aging with Physical Impairment, *The Gerontologist*, Vol. 42, No. 6, pp.799-806
- Reeve, D. (2002) Negotiating Psycho-emotional Dimensions of Disability and their Influence on Identity Constructions, *Disability & Society*, Vol. 17, No. 5, pp. 493-508
- Robert, N., Butler, M., Fossel, S. Harman, M., Heward, C., Olshansky, J., Perls, T., Rothman, D., Rothman, S., Warner, H., West, M., and Wright, W. (2002) Is there an Anti-Aging Medicine?, *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, Vol. 57, pp. B333_B338
- Robinson, S., and Rosher, R. (2001) Effect of the 'Half-full Aging Simulation Experience' on Medical Students' Attitudes, *Gerontology and Geriatrics Education*, No. 21, pp. 3-12
- Saliba, D., Elliot, M., Rubenstein, L., Solomon, D., Young, R., Kamberg, C., Roth, C., MacLean, C., Shekelle, P., Sloss, E., Wenger, N. (2001) The Vulnerable Elders Survey: A Tool for Identifying Vulnerable Older People in the Community, *Journal of the American Geriatrics Society*, Vol. 49, No. 12, pp.1691-1699
- Sanders, C., Donovan, J., and Dieppe, P. (2002) The Significance and Consequences of Having Painful and Disabled Joints in Older Age: Co-existing Accounts of Normal and Disrupted Biographies, *Sociology of Health & Illness*, Vol. 24, No. 2, pp. 227-253

Sano, M., Aisen, P., Dalton, A., Andrews, H., & Tsai, W.Y. (2005) Assessment of Aging Individuals with Down Syndrome in Clinical Trials: Results of Baseline Measures, *Journal of Policy and Practice in Intellectual Disabilities*, Vol. 2., No. 2, pp.126-138

Sarkisian, C., Hays, R., Berry, S., and Mangione, C. (2002) Development, Reliability, and Validity of the Expectations Regarding Aging (ERA-38) Survey, *The Gerontologist*, Vol. 42, pp. 534-542

Sarkisian, C., Liu, H., Ensrud, K., Stone, K., and Mangione, C. (2001) Correlates of Attributing New Disability to Old Age, *Journal of the American Geriatrics Society*, Vol. 49, pp. 134-141

Saxton, M. (2005) Caring for Aunt Alice, *Journal of Disability Policy Studies*, Vol. 16, No. 1, pp. 61-67

Scudds, R. and Ostbye, T. (2001) Pain and Pain-Related Interference with Function in Older Canadians: The Canadian Study of Health and Aging, *Disability and Rehabilitation*, Vol. 23, No. 15, pp. 654-664

Service Canada. (2006b) *Services and Benefits for You*, <http://www.servicecanada.gc.ca/en/facts/service.html>, (Accessed May 22, 2006)

Seltzer, M., and Krauss, M. (2001) Quality of Life of Adults with Mental Retardation/ Developmental Disabilities who Live with Family, *Mental Retardation and Developmental Disabilities Research Reviews*, Vol. 7, No. 2, pp.105-114

Shakespeare, T. (1993) Disabled People's Self_Organisation: A New Social Movement?, *Disability & Society*, Vol. 8, No. 3, pp. 249-264

Sheehan, M. (2003) Disabilities and Aging, *Theoretical Medicine*, Vol. 24, pp. 525-533

Silverman, D. (2003) *Doing Qualitative Research: A Practical Handbook*, London: SAGE Publications

Simonsick, E., Newman, A., Nevit, M., Kritchevsky, S., Ferrucci, L., Guralnik, J., and Harris, T. (2001) Measuring Higher Level Physical Functioning in Well-Functioning Older Adults, *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, Vol. 56, pp.M644-649

Simons, L., McCallum, J., Friedlander, Y. and Simons, J. (2000) Healthy Ageing is Associated with Reduced and Delayed Disability, *Age and Ageing*, No. 29, pp. 143-148

Stanley, L. & Wise, S. (1993) *Breaking Out Again: Feminist Ontology and Epistemology (Second Edition)*, London: Routledge

Strawbridge, W., Wallhagen M., and Cohen, R. (2002) Successful Aging and Well-Being: Self-Rated Compared with Rowe and Kahn, *The Gerontologist*, Vol. 42, pp. 727-733

The Baltimore Longitudinal Study of Aging. (2005) National Institute on Aging, United States, <http://www.grc.nia.nih.gov/branches/blsa/blsa.htm>, (Accessed August 20, 2006)

The Nun Study. (2006) University of Kentucky, United States,
<http://www.mc.uky.edu/nunnet/faq.htm>. (Accessed August 20, 2006)

Thomson, A., Glasson, E., and Bittles, A. (2006) A Long_Term Population_Based Clinical and Morbidity Review of Prader–Willi Syndrome in Western Australia, *Journal of Intellectual Disability Research*, Vol. 50, No. 1, pp.69-78

Watson, N. (2002) Well, I Know this is Going to Sound Very Strange to You, but I Don't See Myself as a Disabled Person: Identify and Disability, *Disability & Society*, Vol. 17, No. 5, pp.509-527

Weksler, M., and Goodwin, J. (1999) Geriatrics and the Limits of Medicine, *New England Journal of Medicine*, No. 341, pp.768-769

Appendix #1: Vignettes Used in Interview Question #1

Vignette #1: Alice

"I asked her to make a list of everything she hates about ____ ... she gave me this:

Can't get my foot into correct leg of trousers.

Can't reach stuff on shelves.

Slobber when I sleep -need a bib on my pillow.

Can't remember names or words I have known my all my life.

By day fall asleep in chair, then lie awake all night.

My income doesn't allow any extras. I can only hope my money lasts out my life.

Can't get up from toilet, have to wear diapers.

Takes longer to get in and out of the car than it does to get where I am going.

When one pain leaves, another takes its place.

Can't stand up straight.

Can't shampoo and set my hair myself.

Can't remember where I put the list of things I want to remember.

The worst: I have to depend on other people."

(Saxton, 2005)

Vignette #2: Judith

Judith had a history of poli and postpolio syndrome.

She was immersed in the language that developed from the support group and the disability movement. She used some of these resources as tools for helping others who were aging or facing disease.

Her life was a process of physical injury and then healing.

Judith did not focus on her physical strength but relied on an inner strength.

She acknowledged the challenges that she faced with her physical impairments but used her cognitive resources to meet those challenges.

Although she stated that a person must accept the limitations that accompany age, she did not accept being _____. Nor did she intend to be around people who did.

(Harrison and Kahn, 2004)

Vignette #3: Mrs. T

Mrs T suffers from arthritis. She currently only experiences a slight restriction in her mobility and a mild visual impairment. She experiences some pain in her joints but not such that it significantly affects her ability to complete activities of daily living. She cannot walk 400 yards without stopping, and uses public and private transport where possible and necessary.

(King's College London and the University of Reading, 2004)

Appendix #2

This appendix has been omitted from publication for confidentiality reasons.

Appendix #3: Interview Questions

| <u>Interview Questions</u> |
|--|
| 1a) For this first question, state whether you see the individual as -old(er) -disabled -impaired -combination of -none/other -does not matter 1b) How do you think research in general identifies disabled older adults (using the above choices)? |
| 2. I believe your work represents an important area within Aging and Disability research. 2a) How and where do you see your work contributing to the field of Aging and Disability? 2b) Why do you think it is important? |
| 3. A search of current Aging and Disability literature appears dominated by measuring and identifying disability in old age. Other areas, though much less common or explicit, include similar and shared experiences between aged and disabled people, models of successful aging, and aging and health in general. For the following questions, please consider all disciplines, and feel free to be discipline, institution, or individual specific. 3a) Considering either the past and/or present, where do you believe Aging and Disability research have been productive? Unproductive? 3b) Considering either the past and/or present, are there issues you believe Aging and Disability research neglect? If so, i) what are they <i>ie the issues</i> (please rank these according to importance); and ii) who (for example which discipline) should be responsible? 3c) In your opinion, what are the most important directions for future research in Aging and Disability? (please rank these according to importance) |

Appendix #4: Specific Examples Given by Participants for Each Interview Question

Table #1

| <u>Specific Examples given by Participants and Coded into Themes Regarding Productive Aging Research</u> | | | | |
|--|---|---|---|--|
| <p><u>Choice and Control</u> -piloting choice and control for older people (D) -supporting people with dementia to express, and find out what choice means to them, and how to help them express choice, and have it acted on (D)</p> | <p><u>Housing</u> -social and economic benefits in investing in housing adaptations (D)</p> | <p><u>Measuring and Identifying</u> -developing and refining measures of disability (C)</p> | <p><u>Perspective Of</u> -regarding areas/things that older people value in their lives and how they prioritize these (D)</p> | <p><u>Political Economy/ Socio-Political</u> -resources of individuals and they ways society is structured to help/inhibit older people/older disabled people (A) -resources and their impact on the experience of older people/older disabled people (A) -looking at the resources of both individuals and societies, and how these disadvantage people depending on what they have/don't have (A)</p> |
| <p><u>Health</u> -analysis of issues around health (C) -analysis of issues around caregiving (C) -analysis of issues around long term care (C)</p> | <p><u>Methodology</u> -very individual focussed (C)</p> | <p><u>Life Course Supports</u> -looking at benefits in investing in supports across the life-course (D)</p> | <p><u>Theory/Concepts</u> -studies which challenge stereotypes of aging (D)</p> | |

Table #2

| <u>Specific Examples given by Participants and Coded into Themes Regarding Unproductive Aging Research</u> | | | |
|---|---|--|--|
| <u>Employment/Poverty</u> -in developing analysis or understanding of poverty among US older adults (C) | <u>Health</u> -research on caring/caregiving (A) -focussing on the burden of caregiving (A) - 'successful aging/healthy lifestyles' type literature (B) -restrictive aspects of aging (ie focus on functional independence, physical aging) (D) -in developing social and psychological aspects of aging (D) -in that it's very health oriented (C) | <u>Measuring and Identifying</u> -measuring and identifying disability (A) -measuring and identifying disability (D) -functional-type studies (D) -obsessed with developing more sophisticated ways of classifying impairments (D) -in they take away scarce research resources from areas which would be more productive (D) | <u>Methodology</u> -in that it is often not critical, or is insufficiently critical (B) -in that it is not 'broad' enough (B) |
| <u>Perspectives Of</u> -in asking older adults their beliefs, ideas, or what they would like (C) | <u>Political Economy/ Socio-Political</u> -in discussing social or political environments (C) | <u>Specific (sub)Population</u> -in taking into account minority groups (particularly unemployed/less wealthy) (B) | <u>Theory/Concepts</u> -in the development of theory (C) -in developing any kind of 'big grand theories', especially as a 'replacement' to those which have been heavily critiqued (C) |

Table #3

| <u>Specific Examples given by Participants and Coded into Themes Regarding Productive Disability Research</u> | | |
|--|---|---|
| <u>Health</u> -biomedical/health research around general health issues and trajectories for people who are aging with a lifelong disability (B) | <u>Life Course Perspective</u> -lifelong disability research (B) | <u>Methodology</u> -evaluative research (B) |
| <u>Political Economy/Socio-Political</u> -resources and their impact on the experience disabled people/older disabled people (A) -resources of individuals and they ways society is structured to help/inhibit disabled people/older disabled people (A) | <u>Program/Service Development</u> -service development, demonstration, and pilot-type programs/ research, evaluation, and reflection (esp for those with a lifelong disability) (B) | <u>Theory/Concepts</u> -discussions about issues, topics, and meanings (C) -in developing theory/theories (C) |

Table #4

| <u>Specific Examples given by Participants and Coded into Themes Regarding Unproductive Disability Research</u> | | |
|--|--|---|
| <u>Health</u> -research on caring/caregiving (A) -focussing on the individual's experience of receiving care (A) -in considering health and/or medical issues and realities (P) | <u>Measuring and Identifying</u> -measuring and identifying disability (D) -measuring and identifying disability (A) -health indicators (B) | <u>Theory/Concepts</u> -in addressing aging well, or in particular (C) -in taking the conceptualizations and ideas they have and moving them into more concrete items through research that one can make actual policy decisions around (C) -transferring discussion of issues, topics, and meanings creating some empirical evidence about what we would need to do to change something (C) -in sorting out the issues, topics, and meanings, and what they mean, how to change something, and what the best way to change it would be (C) |

Table #5

| <u>Specific Examples given by Participants and Coded into Themes Regarding Issues Neglected in Aging and Disability Research</u> | | | |
|---|---|--|--|
| <p style="text-align: center;"><u>Health</u></p> <p>-building a better level of knowledge regarding biomedical/health issues in general for people aging with a disability (B)</p> <p>-interface between disability and health (B)</p> | <p style="text-align: center;"><u>Life Course Supports</u></p> <p>-disabled people as part of families and not just care recipients (B)</p> <p>AGING: -benefits in investing in supports across the life-course (D)</p> | <p style="text-align: center;"><u>Methodology</u></p> <p>-qualitative research (A)</p> <p>-longer-term studies (ex actually tracking people's psychological and social experiences/ changes in real-time for a minimum of 5 years) (D)</p> <p>DISABILITY: -focus on individual (C)</p> | <p style="text-align: center;"><u>Perspective Of</u></p> <p>-perspective of disabled older adults (A)</p> <p>-perspective of people with intellectual disabilities who are aging (B)</p> |
| <p style="text-align: center;"><u>Political Economy/ Socio-Political</u></p> <p>-considering a range of resources and structural forces (A)</p> <p>AGING: -focus on larger, societal issues (C)</p> <p>AGING: -political economy models (ie social structures, discrimination, political and social environments, power differentials between groups) (C)</p> | <p style="text-align: center;"><u>Specific Aspects of Aging</u></p> <p>-'middle age' for people with intellectual and other disabilities (B)</p> <p>AGING: -social and psychological aspects of aging (D)</p> | <p style="text-align: center;"><u>Specific (sub)Population</u></p> <p>-class-specific research (A)</p> <p>-ethnicity in relation to both aging and disability (A)</p> <p>-gender-specific research (A)</p> | |

Table #6

| <u>Specific Examples given by Participants and Coded into Themes Regarding Future Direction of Aging and Disability Research</u> | | |
|---|--|--|
| <p style="text-align: center;"><u>Choice and Control</u></p> <p>-advocacy for older people with intellectual disabilities (ex end of life care, quality of care, housing) (B)</p> <p>-choice and control of older population as a whole (B)</p> <p>-how to support the choices and decisions of older people with intellectual disabilities (B)</p> <p>-service system ‘monitoring’ for older people with intellectual disabilities (B)</p> | <p style="text-align: center;"><u>Employment/Poverty</u></p> <p>-aging and disability policy outcomes related to labour force participation or non-participation (C)</p> | <p style="text-align: center;"><u>Independence</u></p> <p>-challenging “forced dependency” (for ex through institutionalization) (D)</p> <p>-people’s beliefs and attitudes towards independence, what people need to maintain independence, and how that changes over the life course (D)</p> <p>-understanding what dependence and inter-dependence in old age actually mean (D)</p> |
| <p style="text-align: center;"><u>Life Course Perspective</u></p> <p>-disability from a life course perspective (C)</p> <p>-looking at people from a life course perspective (C)</p> <p>-maintaining, recording, and releasing the life histories of older people with intellectual disabilities (B)</p> <p>-social and economic development over the life course (C)</p> | <p style="text-align: center;"><u>Measuring and Identifying</u></p> <p>-good measures and variables to understand aging with disability (C)</p> | <p style="text-align: center;"><u>Perspectives Of</u></p> <p>-perspectives of disabled older adults regarding policy and service developments which effect them (B)</p> |
| <p style="text-align: center;"><u>Political Economy/Socio-Political</u></p> <p>-complex interconnections such as finances, community, social support structures (A)</p> <p>-experiential experiences and perspectives of people with various disabilities and combinations of differential experiences and resources (A)</p> <p>-resources and how these impact on a person’s experience (A)</p> | <p style="text-align: center;"><u>Policy</u></p> <p>-comparative work between policies and countries and their respective experiences (A)</p> | <p style="text-align: center;"><u>Support Networks</u></p> <p>-family and informal support networks (B)</p> |

Table #7

| <u>Specific Examples given by Participants and Coded into Themes Regarding Responsibility for Aging and Disability Research</u> | | | |
|--|---|--|---|
| <u>Disability Studies</u> -disability (A) -disability (B) -disability (C) | <u>Gerontology</u> -gerontology and social gerontology (A) -gerontology (B) -aging (C) | <u>Governing Bodies</u> -funding councils themselves (D) -government departments (D) | <u>Health and Medicine</u> -sociological approaches to health and medicine (A) -medicine (C) -occupational therapy (C) -public health (C) |
| <u>Public Policy</u> -public policy (C) | <u>Other</u> -many people (D) -many disciplines (C) -researchers themselves (D) | | |

Appendix #5: Frequency of Consensual Themes Across Three of the Four Interview Questions

Table #8

| <u>Frequency with which Themes were Consensual across Productive/Unproductive Research, Issues Neglected, and Future Directions Data</u> | |
|---|-----------|
| Theme | Frequency |
| Health | 9 |
| Measuring and Identifying | 7 |
| Life Course Perspectives | 6 |
| Methodology | 6 |
| Political Economy/Socio-Political | 6 |
| Perspectives Of | 5 |
| Theory/Concepts | 2 |
| Choice and Control | 2 |
| Employment/Poverty | 2 |
| Specific Aspect of Aging | 2 |
| Specific (sub)Population | 2 |
| Housing | 1 |
| Independence | 1 |
| Policy | 1 |
| Program/Service Development | 1 |
| Support Networks | 1 |