

Cycles of Adaptive Strategies Over the Life Course

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ABSTRACT

An increasing number of Australia's ageing population are aging with long-term physical impairments. This study explored the life experiences of this group using a qualitative approach. In depth interviews were conducted with 10 disabled Victorians, aged between 51 and 84 years and an inductive thematic analysis undertaken. A relationship was found between the adaptive strategies; participants developed as they moved through life phases and impairment stages. The implications of the emergence of a cyclical process of adaptation across the life course and particularly in respect of aging, delivery of aged care services and social workers in this sector are discussed.

KEYWORDS *disability, long-term physical impairment, impairment progression, life course perspective, identity, positive aging, secondary health conditions, adaptive competence, qualitative research, aging of people with disabilities*

People aging with long-term physical impairments must be differentiated from those who acquire impairment as part of the aging process (Putnam, 2002), because of differing physical reserves (Mosqueda 2004 a) and life experiences. The growing number of people ageing with long-term impairments will influence gerontology in at least three ways:- the range of diagnostic conditions amongst the elderly will increase (Putnam, 2002), parameters of ageing with long-term impairments will need to be developed (Hitzig, Eng, Miller & Sakakibura, 2011), and service models will be expected to incorporate the principles of the United Nations Convention on the

Rights of Persons with Disabilities 2008 (CRPD). Difficulties associated with aging of people with physical disabilities, include the probability of impairment progression, secondary impairments and impoverished opportunity to build resources.

Many governments used chronologic age to define old age and associated retirement from the workforce (Roebuck, 1979). While this may be bureaucratically useful, it makes little sense given the importance of social and cultural context and understanding of aging processes. For example, social theories of aging (Putnam, 2002), biomedical definitions (Beers, Jones, Berkwitz, Kaplan, & Porter, 2000), and ideas about successful or goal oriented ageing (Baltes & Carstenson, 1996) or positive ageing with inherent quality of life indicators (Gabriel & Bowling, 2004).

This study defined ageing as beginning at the time the individual attained fifty years, due to the vulnerability to risk factors because of physical impairment. A similar approach was used by Heslop and Gorman (2002, p. 2) in sub-Saharan Africa, who suggested that:-

The meaning of old age is not a chronological definition but the changing roles accompanying physical change and reduced capacity to contribute and maintain a livelihood (2002).

Australian Context

In many western countries both the proportion of the population who have a disability and who are aging are increasing (AIHW, 2007; ABS a, 2010; ABS b, 2010). For example, in Australia it is estimated that in 2010 4,026,413 people or 18.5% of the total population had a disability. Although the Australian population has aged more slowly than other industrialised countries, because of the influx of younger people under immigration programs (McCallum & Kobayashi, 2001), life expectancy continues to rise (ABS, 2012) and the percentage of Australians aged 65

and over is expected to increase to 24% of the total population by 2036 (AIHW, 2007)..

This study explored the experiences of people who were coping with ageing as well as long-term physical disabilities. The concept of disability used was as defined by the United Nations Convention on the Rights of Persons with Disabilities (CRPD):

... disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society. (UN, 2008).

Participants in the study were resident in Victoria, a south-east mainland Australian state, with a population of 5,640,900 persons (ABS, 2012), 13.7% of whom 65 years or more (ABS, 2010).

Method

A qualitative research approach was used to explore the experiences of a small group of ten Victorians, fifty years older or more, who had lived for at least forty years, with physical impairment. They defined themselves as ageing by answering invitations, posted in two disability issues newsletters and two disability oriented email discussion lists, to participate in a study of ageing while living with disability.

A qualitative approach was chosen to enable the respondents' experiences, feelings and thoughts to be explored. Approval to conduct the research was given by La Trobe University Ethics Committee. Data were collected through two in depth interviews with each participant which used open ended questions to initiate discussion about their involvements with aging. Data were coded and analysed to discover thematic relationships.

Open coding was used to discern information units or concepts (Strauss & Corbin, 1998. p.102). An example was the stated reaction of each participant to their major impairment episode or, in the case of those impaired as children, their first awareness of difference from their non-disabled peers. Conceptual themes were “recognised” (Minichiello, 1995. p.255) such as each participant’s perception of a challenge to his/her identity. Concepts were interrelated and recast as categories (Strauss & Corbin, 1998. p. 102). One example was participants’ use of the terms ‘lazy’ or ‘bad’ to denote a paralysed limb or other physical inability or a sense of non-performance thus ascribing negative meaning to impairment.

Categories included causal conditions, strategies, conditions, context and consequences (Creswell, 1998). The example of ‘badness’ might be personally felt by an individual who lived in a stigmatizing society. Subcategories occurred giving more “clarification” (Strauss & Corbin, 1998. p. 101) for instance participants with less education had reduced opportunities for employment. Axial coding occurred when connections were made between categories and subcategories. Unexpected often occur in this phase (Strauss & Corbin, 1998, p.203), One finding in this study was participants’ reluctance to seek gerontological advice. Selective coding revealed the central category, or “essence” of the research findings (Strauss & Corbin, 1998. p.146), which was the emphasis by participants on their desire to preserve control of their lives as people with long term disabilities.

Trustworthiness of this study was achieved by planned processes to develop credibility, transferability, dependability and confirmability of findings and processes (Erlandson, 1993). Credibility and dependability was supported through transparent and supervised methodology, prolonged professional engagement with gerontology

and disability advocacy fields and a comprehensive literature review (Lincoln & Guba, 1985, Creswell, 1998).

Purposive sampling also assisted transferability (Erlandson, 1993; Lincoln & Guba, 1985). Thick description was used to assist other researchers to carry out further studies “across contexts” (Erlandson, 1993. p. 32). Confirmability which ensured the study was “internally coherent” (Erlandson, 1993.), was achieved through an audit trail of the process of data collection and analysis

Table 1 presents some descriptive data about the respondents. Four men and six women, aged between 51 and 84 years, all had physical impairments caused by different medical conditions. Two were immigrants.

Please insert Table 1 here

The insider status of the first author, who conducted all the fieldwork, as a person with long term physical impairment allowed for easier development of rapport with participants. The ‘*epistemology of insiderness*’ is a term coined by Reinharz to describe the intertwining of life experience and work (1992, p. 260). Tacit knowledge which included experiential culture common to the first author and participants, was conveyed in verbal shorthand exchanges Lincoln & Guba (1985). Being an ‘insider’ can raise ethical issues in regard to both confidentiality, and the ability of the researcher to be open to new findings and loss of objectivity (Breen, 2007). However insider status was a positive attribute because the practitioner was intimately connected with the field (Lee, McGrath, Moffat & George, 2002).

Findings

Participants varied greatly in their education, employment and voluntary work.

Table 2 gives a brief description of respondents' backgrounds.

Insert Table 2 about here

At the time they were children, mainstream schools did not allow for disability.

For example, Diana remembered 'I used to go the school steps on hands and feet...and then in high school I yanked myself up on the railings'.

Some participants had changed careers during the course of their lives. Jack, for example, who had developed back trouble doing farm work, said:-

I started to build up my confidence in doing photos... I taught myself. Then the phone started to ring because I had this byline in the paper. I got a lot of orders. So I went into photography full-time.

Cycles of Adaptation

Participants were aware of negative changes in their abilities, impairments and health conditions as they progressed through their life course. During each life course phase they dealt with normative social expectations in a context of rapid social changes and the slow development of anti-discrimination legislation.

Victorians lived through sluggish growth of policies enabling actualization of the rights of people with disabilities. This was partly due to Australia's social context, as the nation engaged with two world wars, two regional wars, economic cycles and a slow move from conservative to socially progressive governments. Table 3 provides description of key social and policy events in relation to the life course phases and related impairment stages of participants.

Impairment is not an unchanging circumstance. All participants experienced highly significant stages of their impairments which occurred at the onset of impairment, at the time of stabilised partial recovery, when impairment progression or loss of physical abilities were manifested in middle age and finally during ageing where new health conditions became evident.

Similarly all participants reported similar adaptive strategies associated with life course cycles and impairment stages.

The four cycles identified in this research were:

1. Childhood and early adulthood: a drive to independence as soon as possible after dealing with their respective reactions to impairment.
2. Adulthood: achievement of valued social roles.
3. Middle age: maintenance of roles while experiencing some impairment progression.
4. Ageing: maintaining an identity as a person with disability while dealing with new and increased impairment.

Figure 1 has a triangular form indicating the adaptive strategies that evolved in response to challenges. Spiraling arrows indicate a cyclical climb to new learning which leaves room for regressive and progressive movement.

Cycle One

During the first cycle, participants were physically and emotionally challenged by surviving the onset of impairment or, in the case of children impaired from birth, the time they recognised their difference from peers. The first goal pursued by post-survival participants was to gain as much self-control of their bodies and lives as possible. Their adaptive strategies ranged from working through emotional reactions

to searching for enabling therapy and education. Development of self-determination and self-management skills were integral to pursuit of role goals. For example, Janice said 'a whole lot of magic keeps you alive learning how the body and porphyria works. It was absolutely the key to my survival.'

By the end of Cycle One informants had adapted to living with long-term impairment and had developed coping strategies which included viewing disability as part of their identity.

Cycle Two.

The second cycle began when participants had reached a plateau of recovery and had begun to realise their potential. At this impairment stage, participants developed adaptive strategies that enabled them to take on major roles, which becoming economically independent, family formation, home ownership, employment, and community participation. Education and employment, paid or voluntary, were crucial to informants' perception of positive social roles. Diana spoke about employers:

If they want you because you're good that just kills the disability issue. I think the struggle is to be better than to be as good as most times.

Adaptive strategies were used to minimise assumptions about impairments by non-disabled peers and authority figures as scrutiny of real or assumed weaknesses, by significant others, was believed to lead to discrimination.

Participants met their role obligations by exercising strong self-control. They used dissociative techniques such as compartmentalisation and suppression, to separate themselves from pain, fatigue and stress. Over time, these became

maladaptive when informants pushed themselves to the limits of their physical and emotional reserves.

Cycle Three.

The third cycle occurred when participants were confronted with unexpected loss of functional abilities, at a time when they were fully engaged in active lives.

For example, Alfred often travelled by air but suddenly found he was unable to walk through an airport. He said:

I realized that if I didn't stop and lean against the wall I'd fall down...there was a significant change.

Participants coped by learning new skills, modifying personal goals, and seeking information on management of their conditions. This was hampered as sources of informed advice had dwindled with the retirement of their former disability experienced health practitioners.

During this phase participants were more comfortable with identifying part of themselves as disabled. They were proud of achievements and most had become informal or formal advocates assisting others to gain a sense of self-worth. Anna, for example, volunteered in an adult literacy program, choosing 'to work with the difficult ones, some that couldn't go in a group straight off because they were so scared.'

Cycle Four.

At the time of the study, the fourth cycle was unfinished for participants, although one person died at the age of 81 shortly after it's' completion. This cycle saw development of new social responsibilities as participants moved into intergenerational roles as grandparents and carers of ageing relatives. They experienced ageing vicariously and directly.

The impairment stage was characterised by adverse physical changes requiring further adaptation. Some had secondary health conditions of arthritis or osteoporosis. Others had developed disorders apparently unrelated to their impairments including cardiovascular disease.

Unlike other stages participants were unable to determine the origins of their health concerns but did not seek specialist geriatrician advice because they believed their physical impairments were responsible for functional decline. For example Barry said:

I was very tired and angry. I was slower at doing things, slower at writing and I think I was physically exhausted. I don't know what the cause was.

Adaptive strategies changed. Participants did not want to be submerged within the ranks of the ageing as they perceived their self management and social roles as threatened by the nature of aged care services. Participants only engaged with community based aged care programs to access subsidized funding of mobility aids and home modifications.

Participants were fearful that loss of physical abilities would lead to loss of independence. They did not use dissociative techniques to the same extent as earlier in life. They adapted by planning strategies to retain essential activities. Their growing need for information on ageing concerns, was frustrated by the perceived dearth of professionals who understood impairments and ageing. Fragmentary help was obtained from local health professionals, complementary medicine and the occasional impairment specific service provider. A strategy revisited, was to seek peer knowledge, and support from friendly networks and disability related newsletters.

All adapted by investing energy into supportive networks. Some looked to chronological peers as role models. They were concerned with enriching their lives. Most had thought about their eventual deaths. For example, Alfred expressed concisely the hope of many participants 'the main thing really of course is that one's companion is with one.' All sought to maintain their social roles within their families and friendship circles until life's end.

Discussion

Similar to Trieschmann and Zarb, this study identified the importance of personal financial resources, community based care, maintaining independence and control over social circumstances to people ageing with long-term disabilities. However, there were five main differences between this study and research by Trieschmann (1987, 1992) and Zarb (1993, 1996).

Use of a life course perspective, as delineated by Arber & Evandrou (1993), identified influences and associated coping strategies that occurred at different life phases. Similar to research involving people with spinal cord injury or polio (Campbell, Sheets & Strong 1999; Bruno, 2002; Halstead, 2006), participants in this study expected their capacity to remain close to their peak level of recovery throughout their lives. When they lost some physical abilities during middle age at a time when they were fully engaged with work, parenting, and community activities, they were unsure of the causal factors. This study has helped to illustrate that impairments are not static, and are affected by lifelong stressors. It also challenges propositions about accelerated or early ageing of people with long-term physical impairments.

The notion of premature ageing has also been challenged by researchers who have studied polio (Mulder, Rosenbaum & Laton, 1972; Howard, Wiles & Spencer, 1988; Sorenson, Daube & Windebank, 2006), multiple sclerosis (Molti, Goldman & Benedict, 2010), muscular dystrophy (Herman, Pinto, Merkies, de Die-Smulders, Crijns & Faber, 2010), and cerebral palsy (Hemming, K., Hutton, J. & Pharoah, P. (2006) who have instead conceptualized mid and later life changes as impairment progression. Although Zarb didn't use the term 'impairment progression' he reported accounts of general deterioration closely associated with the time of disability onset but unrelated to chronological age (Zarb, Oliver & Silver, 1990; Zarb, 1993).

Distinguishing impairment progression from secondary health conditions and ageing processes (Thompson, 2004 b), is important so that the cause of functional loss is investigated, treated and offset wherever possible and to prevent further complications (Charlifue, Lammertse & Adkins, 2004; Jensen, Molti, Groah, Campbell, Charlifue, Chiodo, Forcheimer, Krause, 2012). For example osteoporosis, which is a condition that can be diagnosed and treated, poses a greater risk at an earlier age for mobility impaired people (Garland, Stewart, Hu, Rosen, Liotta, & Weinstein, 1992; Haziza, Kremer, Benedetti & Trojan, 2007). Similarly, life stage related health concerns for women relate to menopause (Kalpakjian, Tate & Quint, 2004).

This study identified changes in adaptive strategies as people moved through four life cycles and different impairment stages. Trieschmann noted a need for people with disabilities to maintain a personal equilibrium but did not explore adaptive strategies in relation to the life course (1987).

Importantly, participants in this study perceived themselves as disabled rather than as aged. They had coped with stigma and neglect of their rights to equal

opportunity and were proud of their achievements. They were competent in managing their impairments, although all were concerned about realising their goal of aging positively.

Policy and Practical Implications

The significance of this study is the uncovering of how participants adapted to life stage challenges and impairment changes. The task for service providers then becomes one of developing assistive strategies to enhance the strengths of people with disabilities. Participants identified as disabled, rather than as aging and demonstrated expertise in managing their primary impairments. They would be best served by gerontological professionals who collaborate with people with disabilities to develop positive aging goals and programs.

Positive aging, or aging with quality of life, is possible for people with long-term disabilities but the rigid separation of disability and aged care service systems, which has been exaggerated in Australia by the new National Disability Insurance Scheme (Baker 2013), hampers the application of theories and tools applicable to the field of aging, such as goal substitution (Steverink, Lindenberg & Ormel, 1998). These can be equally useful for people with disabilities who are aging.

Role of social workers

People aging with long-term physical disabilities will come into contact with geriatricians, social workers and other allied health personnel. Trust issues will occur as people with disabilities learn to deal with 'new' professional health workers who may not comprehend the struggle that life has been and the essential compromises that have been struck.

Social workers, engaged in relevant research and social policy formulation concerning aged care, are vital in delineating and advocating for at risk populations. Social workers can explain the socio-cultural context of these people to colleagues in other professions, service providers and program developers. There has been a revolution in rights for people with disabilities that should be used by social planners to make aged care inclusive (Minkler & Fadem, 2002). Understanding the quiet struggle for human rights is an essential part of the social work role.

Social workers must always articulate the political aspects of the personal and the personal aspects of the political (Ife, 2008, p.182).

Given people with disabilities are aging, there is urgent need to develop an active interface between respective knowledge and skills within the disability and aged care sectors, to encourage fulfillment of life goals.

Conclusion

The significance of this study is the clarification of issues confronted by people with physical disabilities as they enter and move through their ageing life phase. Impairment progression, secondary health conditions and age related problems need to be differentiated and appropriately treated. This study, albeit with a small group, indicates factors which, if enhanced, enable positive ageing. These dynamic influences include recognition of their expertise in impairment management, acknowledgment of their identities as influenced by the disability experience, and their strong desire to continue self-actualisation of chosen social roles. Although impairments remain and ageing processes continue to occur, sensitive interventions by targeted programs, which enlist and advance self-management skills, can help this population to age in place and maintain their quality of life. The rights of people with disabilities have been further acknowledged by the Australian ratification of the

UN International Convention on the Rights of Persons with Disabilities, which means that people aging with disabilities not only deserve better aged care, they are entitled to it.

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Table 1.

Characteristics of participants¹

| | Age at first interview | Gender | Medical diagnosis | Date of onset of impairment | Age at onset | Country of birth | Arrival in Australia |
|---------|-------------------------------|---------------|---|------------------------------------|---------------------|-------------------------|-----------------------------|
| Alfred | 84 | M | Polio | 1921 | 2 years | Britain | 1947 |
| Beth | 72 | F | Polio | 1954 | 21 years | Australia | N/A |
| Anna | 78 | F | Paraplegia from spinal cord injury | 1954 | 26 years | Australia | N/A |
| Janice | 60 | F | Porphyria with neurological impairment | 1964 | 18 years | Australia | N/A |
| Barry | 67 | M | Cerebral ataxia | 1941 | Infancy | Australia | N/A |
| Cathy | 57 | F | Cerebral Palsy | 1951 | Birth | Australia | N/A |
| Jack | 67 | M | Cerebral Palsy | 1941 | Birth | Australia | N/A |
| Sushila | 55 | F | Cerebral Palsy | 1953 | Birth | South Asia | 1961 |
| Diana | 58 | F | Polio | 1948 | 15 months | Australia | N/A |
| Dennis | 51 | M | Severe childhood autosomal recessive muscular dystrophy | 1954 | 5 ½ years | Australia | N/A |

¹ All names are pseudonyms

Table 2.

Education, employment pre-and post 'retirement', unpaid work pre- and post 'retirement'

| | Highest Education level | Employment | Unpaid work pre-retirement | Date of retirement | Unpaid work post-retirement |
|---------|--|--|--|--|---|
| Alfred | Ph D | Research scientist – 1947-1985 | Parent | 1985 | Emeritus professor, Writing research papers, grandparent |
| Beth | Diploma of Teaching | Teacher, adult literacy coordinator | Home tutor, Literacy teacher, Raised family, convenor church women's groups | Gradual change of activities | Set up visiting program aged care hostel, also served on the hostel planning committee, aged care visiting; grandmother |
| Anna | Diploma of Nursing, Bachelor of Special Education | Nurse teacher | Peer and sexuality counselor. Founding member of Paraplegic & Quadriplegic Association of Victoria | 1989 – 1991 when nurse education was transferred to universities | Reader to Braille technicians |
| Janice | Part Bachelor of Science | Public Service | Raised family, joined condition support group, studied science | | Founded / maintains Porphyria Association, research & advocacy |
| Barry | Library technician Diploma of Tourism | Public Service | Raised family, scouting | 1994 | Recreation and tourism for people with disabilities |
| Cathy | TAFE business studies | Workshop employee, office worker | Church office volunteer | N/A | Disability advocacy |
| Jack | mid high school | Farm worker, photographer | Young Farmers Association, Disability rights advocacy | Gradual change of activities | Disability rights advocacy |
| Sushila | Bachelor of Arts. Diploma of Community Development | Casual disability rights work | Advocacy, peer sexuality counsellor | N/A | |
| Diana | Diploma of Arts | Artist, office work, Metro access worker | Arts access | N/A | |
| Dennis | Year 8 | Casual disability rights advocacy | Disability rights | N/A | |

Table 3.

Summary of adaptive strategies used to meet challenges within cycles.

| Cycles | Impairment stage | Social context | Social challenge | Emotional reaction to recognition of impairment | Adaptive strategies |
|---|--|--|--|--|---|
| <p>Cycle One. Childhood and early adulthood: drive to independence after Impairment.</p> | <p>Onset or recognition of impairment.</p> | <p>1920's – 1950's pre and post World Wars 1 & 2 veteran rehabilitation and general infrastructure development.</p> <p>Immigration promoted to enable economy building.</p> <p>Polio epidemics.</p> | <p>Eugenics theories.</p> <p>Institutionalisation.</p> <p>Poverty caused by difficulty in obtaining education and employment for people with disabilities.</p> | <p>Anger.</p> <p>Depression.</p> <p>Resignation.</p> | <p>Strive to survive, and formation of physical goals.</p> <p>Search for a cure and information about the impairment.</p> <p>Use of family support.</p> <p>Search for information and education</p> <p>Search for resources.</p> <p>Definition of desirable social roles and associated goals.</p> |
| <p>Cycle Two. Adulthood: achievement of valued social roles.</p> | <p>Maximum use made of available physical and psychological abilities.</p> | <p>Mid 1950's to 1980.</p> <p>Cold war and nuclear threats involving USSR, America and allied nations' economies.</p> <p>Immigration encouraged.</p> <p>Rights based legislation for example the Racial Discrimination Act 1975.</p> | <p>Civil rights discourse not fully extended to people with disabilities.</p> | <p>Anger at perceived discrimination.</p> <p>Anxiety about possible reactions by other people to perceived impairment.</p> <p>Pride at attaining roles and many goals.</p> | <p>Minimisation of impairments when facing relevant social systems such as employment.</p> <p>Strong self-control of impairment effects so as to portray, as far as possible, normal functional abilities.</p> <p>Dissociation from physical difficulties.</p> <p>Achievement of some social roles.</p> |

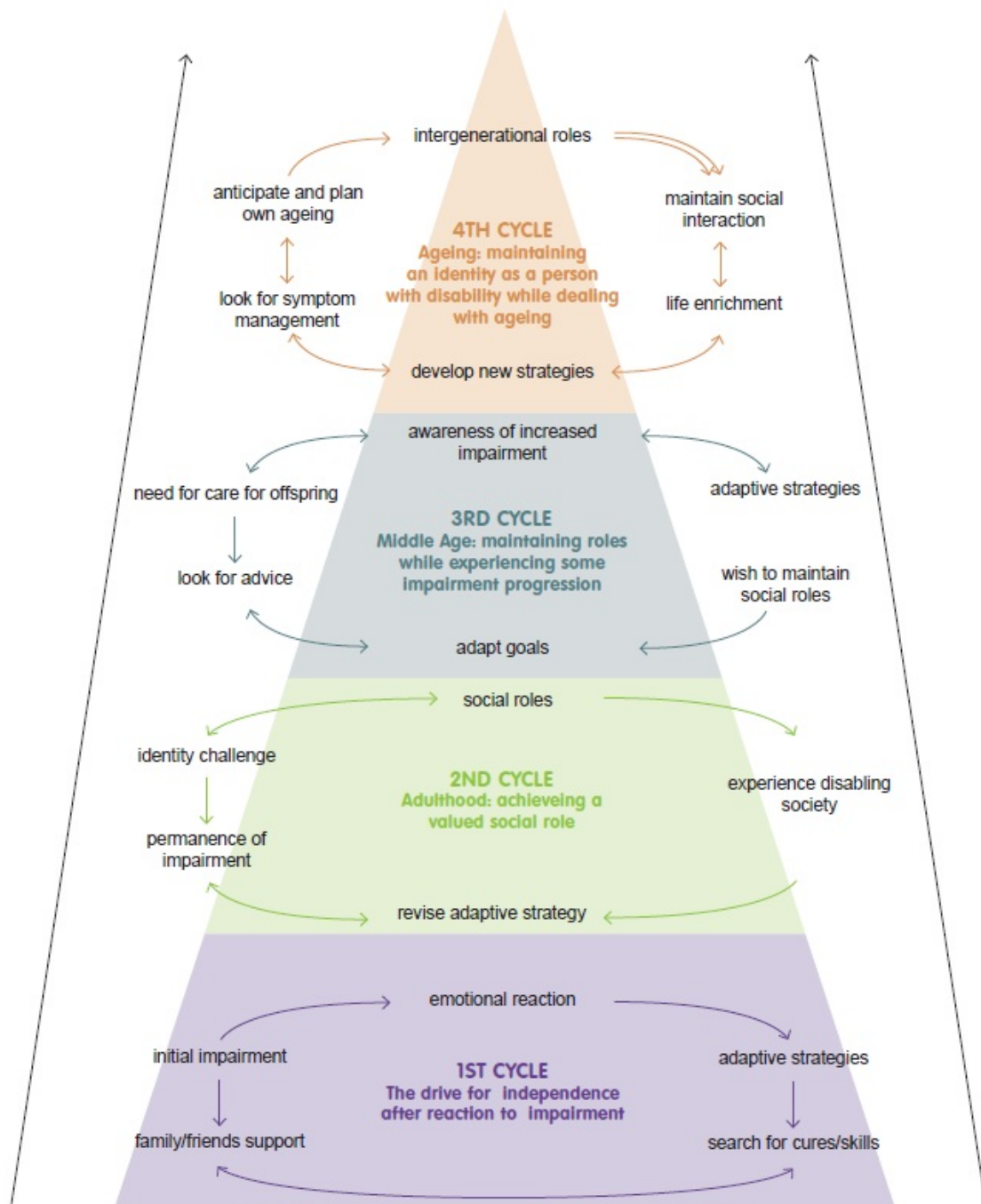


Figure 1. Representation of life stages and adaptive cycles

