# Applying citizenship social work with older people and people at the end of life

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Resumen: Este artículo examina cómo pueden restringirse los derechos asociados a la ciudadanía para las personas mayores y las personas en el final de la vida, sobre todo desde posiciones comunitarias conservadores de la ciudadanía, que exigen la participación económica como condición de la ciudadanía y devalúa la dependencia de los demás. Identifica las características de un trabajo de ciudadanía social, que implementa valores comunitarios radicales que favorecen la participación y el compromiso como una fuente de solidaridad en la sociedad. Al ver el envejecimiento como un camino a través de la tercera y cuarta edad de la vida hacia la muerte, con el cambio de la prestación de atención sanitaria y social, el trabajo social ciudadano pretende centrarse en las áreas de la vida donde la pérdida de la ciudadanía está en mayor riesgo. Su objetivo es promover la integración de los cuidados formales e informales, el apoyo a la independencia de las personas mayores a través de servicios generalizados a disposición de todos, en lugar de servicios especializados independientes, centrándose en los servicios esenciales para el mantenimiento de la independencia y la promoción de la participación en actividades creativas y de grupo para mejorar el desarrollo personal y la participación social.

Palabras clave: Ciudadanía, final de la vida, personas mayores, Trabajo social.

Título: : Aplicando el trabajo social ciudadano con las personas mayores y las personas al final de la vida

**Abstract:** This paper examines how the rights associated with citizenship for older people and people at the end of life may be restricted, particularly in conservative communitarian views of citizenship, which demands economic participation as a condition of citizenship and devalues dependence on others. It identifies the characteristics of a citizenship social work, which implements radical communitarian values that favour participation and engagement as a source of solidarity in society. By seeing ageing as a pathway through third and fourth ages of life towards death, with changing health and social care provision, citizenship social work seeks to focus on areas of life where loss of citizenship is most at risk. It aims to promote integration of formal and informal care, supporting older people's independence through generalised services available to all, rather than separate specialised services, focusing on services crucial to maintaining independence and promoting engagement in creative and group activities to enhance personal development and social involvement.

**Keywords:** Citizenship, end of life, older people, social work.

#### CITIZENSHIP AND SOCIAL CITIZENSHIP

Citizenship is a status and identity, enjoyed by most people, denoting their affiliation with a country. What, in this context, does affiliation mean? An individual's citizenship recognises their legal connection with a country (Faulks, 1998) but it implies much more. It includes cultural, economic, political and social belonging and with belonging in this way goes participation, through interaction with others who similarly enjoy that status.

It implies rights and duties that are accepted elements of citizenship. Belonging, rights and duties also imply inclusion for the citizen and exclusion for people who do not possess the same citizenship. Identity is connected with citizenship: people identify themselves and are identified by others as belonging or not belonging to a nation and its cultural, economic, political and social associations. The legal status of citizenship is confirmed by official documentation and by the right to participation in politics and government.

Citizenship exists to provide a structure of social order: it connects a population with a territory and with the right to control of that territory and the economic, political and social life that creates patterns of power relations within that territory. Marshall and Bottomore's (1992) analysis, developed from an earlier theory of Marshall's (1949), linked citizenship with:

- civil rights to legal protection of freedoms and equality
- political rights to vote, stand for election and participate in political processes
- social rights to welfare and participation in social relations with others.

Recognising such rights inevitably implies contested values (Faulks, 1998). One area of difference is the appropriate role for the state in relation to its citizens: what services should it provide to its citizens and on what basis does it make demands of them? Are these services and demands absolute, or are they a form of exchange, in which services are only provided to the extent that citizens make a contribution? If so, the notion of deserts arises: are only deserving citizens entitled to some rights, and how is their entitlement to be defined?

Communitarians argue that citizenship is two-sided: rights go with membership, but so also do responsibilities. Radical communitarians see this as a criticism of individualism and a demand for mutual cooperation, while conservative communitarians see it as a demand for appropriate exchange, so that people only receive the benefits of citizenship if they also make a contribution (Dwyer, 2004: 28-9). The question of concern to social workers then arises: what provision is made for people who through no fault of their own are unable to make a contribution to a society?

Entitlements and exchanges also raise questions about the power relations in a society, because they are provided for only to the extent that their provision can be enforced: powerful people can exclude the less powerful from receiving their entitlement. Marshall's (1949) original analysis was concerned that class divisions in society only offered many working class people second-class citizenship. As well as this, the priorities and social assumptions of a society may exclude people for all sorts of reasons from claiming or receiving social services or social opportunities to which they are entitled by their legal status as citizens. Feminist writers note that women are often excluded by the social assumptions of patriarchal societies from receiving equal citizenship with men (Lister, 2003). Inequalities of this kind arise for ethnic minorities, people with physical and mental disabilities and illness and people in other devalued or stigmatised identities: they may be excluded from 'social citizenship' (Dwyer, 2004), excluded or disadvantaged by their social categorisation.

# CITIZENSHIP OF OLDER PEOPLE AND PEOPLE AT THE END OF LIFE

The concern about whether minority groups enjoy full social citizenship extends to older people and people at the end of life. Many cultures value older people who are no longer economically active individually as grandparents, ancestors of currently active generations, and collectively as the past history of that society who have made contributions to achieving its present position. Social policy for older people in industrialised societies has usually developed social protection for older people as citizens, based on the assumption that they will retire from the workforce and many will then appropriately require social security, health and social care and other public provision. Citizenship in developed industrialised societies is not always consonant with a high valuation of order people, however, because in a capitalist society, economic participation is an important source of social value. When older people retire and no longer work, they are not part of important networks of communication, support, and relationships and their time are not structured by the need to attend a workplace. Older people may be devalued because some people assume that they are not so important as younger people because they are not so in touch with current ideas, they have retired, so they are not making a productive contribution to society, the main part of their life is in the past, so they are not so important as younger people who need education and development for the future, they need care so they are a drain on family, community and state resources, they have old-fashioned ideas about behaviour, they are irritating and slow (Payne, 2011). Moreover, there is extensive international evidence of abuse and ill-treatment of older people (Cooper et al, 2008). Since dementia is associated with increasing age, older people who experience the multiple medical conditions typical of advancing age may lose rights to treatment because of 'cognitive citizenship' (Graham, 2004). They may be perceived as not able to benefit fully from some treatments, or their lack of capacity to express pain and distress may mean that their need for treatments typical of older age groups such as hip or other joint replacements is not recognised by care staff.

#### CASE EXAMPLE: JOSIE'S ARTHRITIS CAUSES PAIN

A social worker, Karen, visited an elderly client, Melina, who had severe dementia, to the point that she was unable to communicate verbally. It was quite cold in the care home lounge, and Karen asked a care worker to fetch a cardigan from the Melina's own room; respecting Melina's privacy, she usually did not visit clients' own rooms in a care home. As the care worker helped Melina on with the cardigan, Karen noticed that she flinched, so she

asked the care worker whether Melina experienced any pain. The care worker said that she sometimes seemed to find dressing difficult. Karen asked the care home manager to seek medical investigation, and it emerged that Melina was experiencing problems with undiagnosed arthritis, for which he provide treatment.

This case example shows how, particularly with older people who have communication problems or have lost mental capacity through dementia or other illness, respecting cognitive citizenship requires being alert and observant to compensate from the loss of opportunities that come about because an older person cannot fully communicate their wishes and needs.

The social settlement for older people, that is, the accepted expectations about ageing and social provision for older people, is changing across the world. An important reason for this is demographic change. The older population of the world has been growing at an unprecedented rate, from 378 million people in 1980 aged 60 years or above, to 759 million in 2010 and is expected to reach two billion by 2050. By 2005-2010, the annual growth rate for the older population (2.6 per cent) was more than twice that recorded for the total population (1.2 per cent). In the mid-term future, the gap between those two growth rates is expected to widen as the large post-war cohort reaches age 60 in several parts of the world (Department of Economic and Social Affairs, 2011).

These changes raise fears that present assumptions about working life and financing retirement will be increasingly unsustainable, and in turn raise doubts about the position of older people in society, because the degree of their economic dependence on others may increase. Economic dependence arises because most living arrangements assume that employed people within a family support others who are not working. Until the 1950s, people extended their working life as they lived longer. This process ceased and many people now live a long time after the end of the normal period of working life, so older people become dependent on resources accumulated during their working lives or on financing from their family or the state. Longer periods of retirement may mean that pensions and other financial arrangements to support retirement based on past assumptions have increasingly become inadequate. While most older people in the EU, for example, can expect to live healthy and active lives, continuing their former lifestyles and participating actively in social relationships, the opportunity to do so may be restricted by financial problems. Many EU states are making changes in preparation for the impact of these changes, mainly in pension and family policy (Commission of the European Communities, 2009). Pensions are paid for either by financial transfers from the present working population through a pay-as-you-go scheme paid for by taxation or through financial transfers from people's working life, through savings and pensions. However, if increasing periods of post-retirement life mean that the value of pensions or savings decrease, or pay-as-you-go transfers become less affordable because there are not enough people in the working population to pay for increasing numbers of older people, it may be impossible to sustain a reasonable quality of life for older people. Long-term projections suggest that population across the EU will be about the same in 2060 as in 2010. However, during this period the EU will move from having four working-age people (aged 15-64) for every person aged over 65 to a ratio of only two to one. Most of this change will happen between 2015 and 2035, because people born during the post-second world war baby boom will be becoming more frail. The working population will increase until about 2020.

Thus, a larger population of older people will be practically and economically dependent on a smaller population of working age. In private life, dependence creates ties and psychology and many cultural traditions value interdependence (Sennett, 2003). Liberal political philosophy sees dependence as infantilisation and connects independence with the work ethic: if people work to look after themselves, they contribute to society rather than drawing from it. The concern about dependence among older people is particularly informed by health care services, whose main task is to prevent physical deterioration. This aims to avoid patients becoming practically reliant on informal caregivers or formal services to carry out everyday tasks of life. A range of recent research suggests that policy should move from this medically-oriented preventive stance to a stance of positive maintenance and promotion both of personal independence and also of interdependence between people in a local community (Audit Commission, 2004).

These changes in the present economic system for the dependence of a rising population of older people lead to personal uncertainty for individuals and wider social insecurity. Informal arrangements are used in most societies to sustain older people who are unable to provide fully for their needs. They are based on a system of family and community exchange and reciprocity; family and community citizenship. There is a fear that in many developed countries there is no practical way of continuing this as older people may be cut off from family and other contacts by labour mobility and lack of contact with the means of living. What does this mean for the citizenship of older people who are dependent and no longer able to reciprocate in the implied exchange in developed industrialised societies?

The cultural ideals that value older people highly as citizens in spite of their dependence require a preventive approach to economic and social processes that exclude older people from full participation in society. Adopting a concern for maintaining the citizenship of older people suggests that policy should focus

on preventing dependence by emphasising older people's full participation as a citizen in all the different aspects of their society. Social and health care services should only need to offer help when older people are not able to carry out the everyday tasks of living and cannot maintain social contacts so that they become socially isolated. Such

Similar issues arise for people at the end of life. Although we all die, many people do not dwell on this reality while they are living. Avoiding active discussion of death may be healthy because it allows people to continue with their life tasks. Writers such as Ariès (1974) and Gorer (1965), however, see death as a taboo in twentieth century Western society. The death rate has been reduced by medical advances, so that people do not experience death very often or very early in their lives. It is hidden from ordinary social experience, because the dying process is often managed by healthcare staff in medical settings such as care homes, hospices and hospitals rather than occurring in people's homes. Dead bodies are dealt with in a depersonalised way by specialist professionals such as funeral directors in rarely visited places such as cemeteries, crematoria, and mortuaries. People generally are less inclined than at one time to participate in formal rituals of bereavements and remembrance. Instead of formal mourning rituals, less formal and populist rituals have developed, seen in the funerals and memorials for celebrities.

Awareness of discrimination on grounds of difference may be accentuated in end-of-life care, because dependence on others' care is usually more socially acceptable at this stage of life than dependence that arises from illness or disability. People who are disabled or chronically sick may be seen as partly responsible for their condition or for their dependence, because they have not worked hard enough at rehabilitation or finding a job, or overcoming their disability. This may particularly be so where the disability is less obvious, for example with Deafness, mental illness or controversial illnesses such as chronic fatigue syndrome, which some people do not accept exist. Where people come from an ethnic minority their access to care of all kinds, accessing end-of-life care may be more difficult than people from the majority population. Research on Latina immigrants in the USA, for example, shows that they are dealing with cultural and communication barriers with non-Latino and non-Spanish-speaking doctors, nurses and social workers. This research also highlights matters that may affect migrants to many advanced industrialised countries. Migrants are often affected by geographical distance from families who might support them, or who need to deal with the social tasks of resolving relationships and saying goodbye. Also, migrants may not have full documentation or be fully recognised as legal migrants, and even if there are there may be continuing questioning of their legal status. They may fear that accessing healthcare may lead to deportation or harassment,

and they may not be fully entitled to privately insured healthcare or to state healthcare systems (Smith et al, 2009).

It is important not to exaggerate the extent to which death and dying have become hidden; it does not mean that people do not experience grief. Avoiding public grief and mourning is not unique to modern society, but commonplace in many societies (Walter ,1992). The period when death was a taboo subject in Western society was a specific period occurring in mid-twentieth century after two major world wars and the death of many Jewish people in "the Holocaust," at a time when medical progress seemed set to banish premature death. This has changed with better psychological understanding of death and bereavement and the development of the hospice movement.

Instead of a single ritualised approach to death and dying, people have a range of frames for viewing death and bereavement: the practical, the spiritual, the biomedical, the lay and the semipsychiatric. In the practical frame, a funeral has to be arranged and money and property sorted out. In the spiritual frame, people reflect and meditate on the meaning of life. In the biomedical frame, reasonable standards of treatment and care are expected, families must visit the sick and support the family and caregivers. In the lay frame, people express their regrets, buy flowers, organize for people leaving work. In the semi-psychiatric frame, people recognize that there will be distress, stress, anxiety and depression and allow for it. A public health frame covers many of the procedures for certifying death and disposing of bodies, a theological frame provides for some of the ritual, and a psychological frame provides for explanations and actions around grief and bereavement.

All social workers, whatever their specialty, help people with end-of-life issues, and the hidden nature of dying presents difficulties with this. People need help as they experience or fear the end of life themselves or as others important to them come toward the end of life. Also, people may have to deal with sudden or violent death, or face the risk or fear of death. These matters are difficult for people for many reasons and they may need help to deal with the changes that dying death and bereavement brings about.

It is clear, therefore that the implications of citizenship for social provision cannot be taken for granted, and as an aspect of the state's provision for its people, social work may be equally contentious. This may even be true in relation to end-of-life care and services for older people, even though we all die, everyone will have older people in their family and among acquaintances and most people age until they reach the phase of life in which they are regarded as within the category of older people. Since social workers are engaged in social services provision for older people and people and the end of life, it is useful to consider how to approach practice, so that it is relevant to maintaining

citizenship for people in this position. The concept of citizenship social work makes an important contribution to achieving this objective.

#### THE ROLE OF CITIZENSHIP SOCIAL WORK PRACTICE

'Citizenship social work' is an approach to social work practice that emphasises the citizenship of social work clients as a value base and a source of direction for deciding appropriate interventions. It may be applied with many different client groups, but emerged from practice with older people (Marshall and Tibbs, 2006; Payne, 2011). Therefore, to understand how it contributes a distinctive approach to social work, it is helpful to explore its origins with that client group. Marshall and Tibbs (2006) describe three main approaches to social work practice with older people.

- Medical or organic approaches, are the mainstream model, reflecting the dominance, noted above, of healthcare practice and research with this client group. These approaches focus on resolving and managing problems that older people experience as ageing processes lead to increasing physical and mental difficulties in their lives. The aim is to reduce or remove physical and mental damage and manage the effects of it on the older person's life. The role of social work in this approach is to contribute to healthcare provision by strengthening the older person's emotional and psychological resources and community, family and practical supports. Interpersonal practice with the older person and informal caregivers is combined with mobilising and coordinating services from the practitioner's agency and elsewhere in the network of formal and informal services.
- Social approaches focus on the impact on the older person's social relationships and surroundings of any physical and mental impairments that they experience. The starting point of this approach is that older people have lived their lives as part of a community with its resources and services. The role of social work is to help older people and people 'age in place', that is, manage the effect of any physical, mental and social impairments that affect them within their social surroundings (Brittain, et al, 2010). A wide range of community services aim to meet the needs of older people alongside others as part of their everyday provision. Where this does not enable older people to live independently, social care services provide substitute help with the activities of daily living in coordination with healthcare services, which maintain and, if necessary, restore older people's mental and physical functioning.

 Citizenship approaches emphasise the right of older people to participate in society and make a contribution to it, in particular using their creativity and other personal emotional strengths. The aim of services is to help people identify and maximise their strengths and contributions to their family, community and society. A citizenship approach to care for older people incorporates citizenship aims in our practice when ageing reduces older people's participation in and contribution to society.

The aim of making these distinctions is to respond to alternative and contending perspectives on the role of social and health care services in older people's lives. The medical model influences most people's thinking on work with older people. It is often taken for granted when professionals and members of the public think about health and social care for older people. Its disadvantage is that it focuses on the role and aims of care services for older people in need of help, when care is not a significant feature of older people's lives for most of the time. The social model therefore draws attention to a broader range of issues and needs that we might be concerned with when working with older people. Using it emphasises the reality that older people, though some may specific care and support needs, are not a separate social group, but are integrated into a wide range of social networks in just the same way as everybody else.

The social model, therefore, contests the medical model because it sees and treats older people as part of normal social relations, while the medical model focuses on a particular subgroup of older people defined by the professional responsibilities of health and social care practitioners. Citizenship social work with older people goes further. It recognises that, in taking for granted a medical model of practice with older people, health and social care practitioners may see older people as needing, and therefore dependent on, care. As a consequence they fail to accord older people rights to self-direction in their lives and in the work that practitioners do. Citizenship practice, therefore, seeks to shift practice towards recognising the importance of promoting an active role in society for older people in general and as part of health and social care practice.

In summary, the alternative and contending perspectives are as follows. The medical or organic model focuses on older people's health and social care needs, when this is necessary. The social model proposes that health and social care services should incorporate that a broader focus on promoting the roles and opportunities of older people for to achieve independence within wider society, incorporating health and social care provision within that. Citizenship practice accepts responsibility for enabling older people to strengthen their contribution to that society.

Thus, citizenship social work practice gives social provision and social work a positive focus: facilitating and empowering effective social responses to the issues that societies face. Older people are not just waiting for death: working with them offers an opportunity to empower solidarity in our society. It enables services and practitioners to identify ways in which ageing requires extra help to enable their equality in respect and dignity as citizens to be expressed in the quality of their lives and the opportunities they have to fulfil their human potential.

A life pathway through ageing towards end-of-life and palliative care

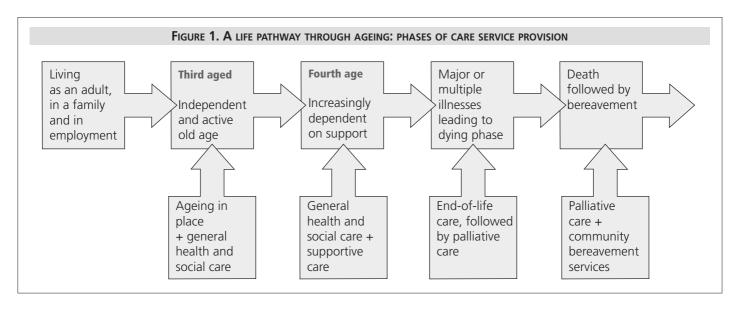
Because everyone will die, and most people who die in developed industrialised societies are in the older age groups, provision for older people is inevitably closely intertwined with end-of-life and palliative care. Palliative care services originally developed, however, as a service for people in the end stage of cancer, later, being extended to other patients where an end stage of treatment may be identified and serious symptoms have to be managed. For example, the World Health Organisation still presents palliative care as a human right concerned with adequate responses to symptom, and particularly pain, management in cancer. This traditional approach to palliative care, in its focus on diagnosed serious illness, fails to recognise that with an increasing proportion of ageing people in the populations of many countries, provision for appropriate care at the end of life also requires integration with broad provision and services for older people. End-of-life and palliative care must increasingly be seen as nested within the life pathways through which people move as they age.

This life pathway to ageing is set out in Figure 1. It begins as people move from being adults in employment, living in a community usually as part of families. The pathway continues as they age towards a phase of life sometimes called the 'third age' when they leave employment but remain independent and

active older people, and 'age in place', that is in their own homes and communities (Brittain, et al, 2010). As they age further, a 'fourth age' develops in which they may become more dependent on informal support and care from people in their family and community, and on formal health and social care services they are usually affected by an increasing number of illnesses and disabilities which leads to. Ageing in place is still important, because being in a familiar social environment helps people to manage their lives more independently, even if they develop dementia and begin to lose their mental capacity (Brittain et al, 2010). Eventually, they move to a phase in which a major illness or multiple disabilities culminate in the failure of one or more major organs and they and others become aware that they are dying. This dying phase leads to death, and is followed by a phase of bereavement for people who have close relationships with them (Payne, 2012).

Associated with this pathway through ageing, people experience a developing range of services; Figure 1 identifies four phases. In the initial state of wellbeing and good health and in the third age, the general role of health and social care services is to care for people with long-term conditions or disability or who are increasingly frail in old age. When a serious illness, a disability or a long-term condition are identified, or frailty begins to interfere with independent living, patients begin to make a first transition into the social role of being a 'disabled', 'frail' or 'sick' person.

Another aspect of general health and social care is additional 'supportive care', which integrates broader social support into medical and nursing treatment. Supportive care has a strong focus on care or treatment for the long-term condition or for increasing frailty, such as heart, lung and kidney failure. As medical treatment has made it possible for people to survive serious illness and disability, supportive care has become an increasingly im-



portant aspect of healthcare. Many serious illnesses can be treated; for example, treatment for many cancers is so successful that patients may become 'cancer survivors' for long periods, even though there is still a cultural memory that leads people to believe that having cancer is a 'death sentence' and they fear a recurrence. Other conditions such as heart, lung or renal failure develop slowly and patients manage them over many years, although they are progressive; that is, worsening over time. Even though this means that patients are aware that they are ill, they develop a way of life which takes into account their illness, perhaps adapting work patterns and relationships to fit in with treatment or periods of increased sickness or disability.

At some point during supportive care, the condition reaches an 'end stage' when it becomes apparent that people are coming to end of their lives, although the long-term nature of the illness may conceal this transition from patients and their families. End-of-life care is an aspect of all health and social care provision in which practitioners assist users of their services to become aware when they are moving towards death, so that they can identify this reality and prepare for dying and bereavement as part of their care. This means that practitioners need to maintain alertness to the need to help people think through and plan for an approaching death.

When doctors make it clear that no further curative treatment is available treatment moves to palliative care, but as with the transition to end-of-life care, patients and families may be unaware of the significance of this changed medical status (Larkin, 2007). Palliative care is a multiprofessional service providing care for people with cancer and other illnesses that have reached an advanced or 'life-threatening' stage predicted to lead to death in the near future. During palliative care, patients move to a 'dying phase' of their condition as their body begins to shut down its physical functioning and major organs begin to fail. The central element of palliative care is specialised medical and nursing care allowing pain and other serious symptoms to be managed. This element then permits care and treatment for emotional, psychological, social and spiritual issues that affect dying people and their families. Palliative care services therefore also support and care for families and other members of the community connected to the patient during the palliative care and dying phases of the patient's life and the period of bereavement afterwards. The emphasis on the psychological and social means that social work is an important contributor to palliative care teams as it is with other healthcare services. This service is called 'palliative' because it relieves symptoms of the illness, and reduces, rather than eliminates, psychological, social and spiritual consequences on people and their families.

When someone dies, their loss disrupts their social networks and family relationships. People may have to deal with emotional

reactions to their loss and also to make practical adjustments in their lifestyle. All this takes place after the dying period in which contact between family members may be hectic. The practical effort of arranging the funeral and the emotional climax of the day of the funeral may bring a later period of reflection. Family support is often important, but there may be family conflict also. This bereavement phase is also included in palliative care, although medical and nursing intervention is often less important and social work more important in this phase.

# IMPLICATIONS OF THE PATHWAY VIEW OF AGEING FOR SOCIAL WORK SERVICES AND PRACTICE

Seeing end-of-life and palliative care as part of the life pathway through ageing raises important implications for social policy and citizenship for older people, and also for social work practice. As people progress through the pathway, their shift into greater dependence may mean that:

- They increasingly lose the physical and mental capacity to exercise their citizenship
- Their dependence means that others begin to question their contribution to society in exchange for citizenship rights.

Citizenship social work argues, first, that the loss of capacity does not mean the loss of the right to age in place and to make the most of the social environment in which an older person lives. It is the responsibility of formal and informal support services to combat any loss of citizenship. Second, seeing dependence as an inability to make economic and social contributions to society is a conservative communitarian position. Citizenship social work takes the radical communitarian position that dependence generates responsibility on services and practitioners to enable older people to continue their involvement in active citizenship. Dependence is not a mark of decline or of lack of responsibility to the community, it is a signal that a community response is required to the needs of one of its members, so that the community's solidarity is enhanced.

Among the implications of this approach in social work with older people is the need for a strong awareness of the pathway through ageing towards death. Citizenship social work requires practitioners to be alert to the need to help people understand and react to the transitions along the pathway, so that older people can be prepared for the changes in their lives and can have the opportunity to complete social tasks that are important to them at each stage. Since, as we have seen, every social worker will deal with the consequences of death, dying and bereavement in the lives of their clients, so all social work, not just

in practice concerned with older people, from time to time requires alertness to raise awareness of and engagement with death, dying and bereavement.

# CASE EXAMPLE: HELPING EDWINA WITH HER MOTHER'S DEATH

Edwina, a woman of 47 with learning disabilities, was supported in specialised housing by a social worker, Georgiana, who learned that Edwina's mother, now in her late 70s, had terminal cancer and was expected to die soon. Care workers at the housing scheme had decided that Edwina would be distressed by seeing her mother's illness, and decided not to arrange any visits to her mother until after the death. Georgiana realised that people with learning disabilities often need repeated information-giving and opportunities to discuss what is happening to understand and manage important events in their lives. She decided that it would be better for Edwina to have increased contact with her mother, so that she could see and understand how ill her mother was, and begin to accept the reality that she was dying. To make the communication easier for Edwina and her mother during in this period of increased contact, she helped them to create a scrapbook together of important events that they had shared during Edwina's life. This gave them a topic of conversation, and a practical and creative task to share. Georgiana was helping both mother and daughter take up their right as citizens to engage creatively with the ageing and dying processes, rather than exclude them from this opportunity to have an important dying experience in their lives.

# FOCUSING SOCIAL WORK PRACTICE ON CITIZENSHIP ISSUES

A range of social networks may form the context of loss of citizenship, and in working with older people and their families, social workers can usefully pay attention to these areas with may limit older people and people at the end of life in taking up their rights:

- Family and neighbours and influences from the community in which they are situated may value and provide for ageing and older people in their midst or may not do so.
- Intimate relationships, friendships, marriage and divorce may facilitate ageing or limit opportunities for successful ageing.
- Employment, retirement and income from both may finance and support successful and creative ageing or make for difficulties.
- Civil and social life, including leisure and recreation, travel and transport, money, political engagement, local govern-

- ment services, personal safety and human rights may all make provision for ageing, retirement and older people or may hinder older people from taking up opportunities.
- Media portrayals of old age and death in newspapers, television and film may stigmatise and devalue ageing and older people or present them positively.
- Health and social care service may present barriers to older people through restricting access and by labelling and stigmatising them as devalued (Thornicroft and Chamberlin, 2006; adapted).

### CASE EXAMPLES: VALUING AND DEVALUING OLDER PE-OPLE'S SEXUALITY

Felicia lived in a care home for older people provided by religious foundation. She formed a friendship with another resident, Honoria, and this developed into a lesbian relationship. Eventually, they asked to share a bedroom with a double bed. The managers of the foundation took the view that this was unacceptable to their religious values. Felicia's social worker was unable to persuade the managers that the residents' citizenship should give them the right to pursue the intimate relationship that they desired, even though the women's families, while one family was unenthusiastic, were prepared to acquiesce in this arrangement. In addition to their principled opposition, the managers feared that press publicity about scandalous relationships in the home would damage their foundation's reputation. Living in this care home thus restricted the women's freedoms in ways that would not have occurred in their own homes. The social worker therefore applied for them to live together in a sheltered flatlet scheme, where there would be support from a warden and care could be delivered by community services, but the women had greater privacy. The women combined their incomes to be able to afford this move.

This case example shows some of the limitations in intimate relationships that may arise through loss of citizenship rights and barriers to freedom in a social care service, combined with fear about media portrayal of older people's relationships. Fortunately, the women's combined financial resources enabled them to have the flexibility to take up the option of a more independent life in a flatlet, and their family relationships also were not a barrier in this case.

Important principles of citizenship social work in action include:

 Integration of services so that they support one another and interweave formal services with informal family and neighbourhood support through involvement of older people and their families in careful advance care planning (Payne, 2010).

Case example: advance care planning for an older woman Penelope, aged 72, who lived with her son and daughter-inlaw and their two sons was diagnosed with an inoperable brain tumour. She returned home to die, and the family members agreed to care for her for the few weeks that this would involve. They were concerned that they would not be able to manage as Penelope's condition worsened, and the social worker sat down with Penelope's son and daughter-in-law, discussed the range of services that would be available and planned in detail how they could apply for each as Penelope got worse. A few weeks later, the son approached the social worker to say that his sons were being noisy and disruptive in the house, and asking them to respect the need for quiet had not worked; neither had remonstration. The social worker found that the sons were being kept away from Penelope, in order to protect them from seeing how ill she was becoming, and she suggested that they visit her in her room regularly for an agreed period and watch television or play games with her. His involvement allowed them to talk to their parents about their fears about an unpleasant death for Penelope, and allowed them to feel involved in her care, rather than just trying to get them to be restrained in their behaviour.

Identifying generalised, low-cost services, where older people can be involved alongside younger age-groups, as opposed to specialised care services, where they are separated into specialist provision, can be improved to maintain independence and dignity for older people.

### CASE EXAMPLE: IMPROVING LEISURE SERVICES

An association for older people responded to a consultation about leisure services in the area. They complained that although theoretically older people could use the local swimming pool to maintain and improve their health, a lot of younger users wanted to plough up and down the pool and this made it more difficult for frailer and less confident swimmers to use the pool. They asked for special sessions for older people to be introduced. A social worker reported that a hidden factor was that some older people were embarrassed because their bodies were not so conventionally attractive as some of the 'ladies in lycra' using fitness equipment in the same building, and this also put them off. The centre also introduced special fitness session for older people as a result.

Ensuring that healthcare, housing and social security services are appropriate and work well together since these are the priority domains for quality of life among older people and therefore for social work intervention and participation. Increasingly the effectiveness of services can

be enhanced by using assistive technology and telecare as part of care for older people. Telecare uses telecommunications technology to monitor vital signs or safety and security in the home, or to provide information and support. It includes video or audio surveillance devices, or radio call buttons on a necklace, so that older people can feel safe even though they are alone for part of the day (Payne, 2012). Effective telecare interventions include automated vital signs monitoring (for reducing health service use) and telephone follow-up by nurses (for improving clinical indicators and reducing health service use)(Barlow et al, 2007).

 Enabling older people to take part in creative and group activities so that they can continue with personal self-development and education, and to feel involved with other people.

# CASE EXAMPLE: THE ART GROUP AND HENRY'S RELATIONSHIPS AT HOME

Henry, age 85, was quite disabled and isolated at home, and so was referred to attend an older person's day centre. He was doubtful about this at first, but became involved in mosaic work, which he thought was more 'masculine' that basket work or painting activities. Eventually, he created mirrors with mosaic surrounds for family presents and a mosaic coffee table for his grandson's bedroom in the colours of his grandson's favourite football team, which he displayed proudly (Butchers, 2008). He said that this craftwork enabled him to give something tangible back to family members for the time and trouble they took in looking after him. He also found that he was able to talk about his craftwork and people he met at the centre, whereas previously he never met anyone or did anything new, so he had no sources of conversation when family members of neighbours visited him.

Many medical and healthcare practitioners do not understand social provision well and see it as a low priority compared with their other responsibilities. Because of a focus on their specific responsibilities, they may not be aware of the possibilities of stimulating ageing in place and ways in which older people's independence can be supported. Reporting back on social work actions is a crucial aspect of practice, so that they can see what is happening with their patients, feel more confident in and see results from social work involvement. Seeing successful work on emotional and psychological issues affecting older people and people at the end of life helps to strengthen healthcare provision, recognise citizenship and makes healthcare professionals more aware of and accepting of potential social work contributions. Among the difficulties is that staff unfamiliar with social care services may not be aware of possible options.

# CASE EXAMPLE: PLANNING SUPPORT TO REDUCE RISKS OF ABUSE

Henrietta was a frail woman in her 80s, living in her daughter's home, who was admitted to hospital for treatment of some symptoms of cancer. Nurses noted that she had severe bruising, and one of Henrietta's sons said to the doctor that he feared that his sister was misusing Henrietta's money. The doctor consulted a social worker, who suggested he had a private interview with Henrietta to find out her views. She said her daughter was rough with her, but she did not understand the money issue, and wanted to return from the hospital to her daughter's home. Therefore, the social worker had a discussion with the daughter, who was finding it expensive to care for her mother, and had used money from her mother's purse to pay bills. No discussion about finances had occurred when Henrietta had moved into her daughter's home: the daughter had not wanted to worry her about this, but now it was proving problematic. The social worker reported back to the doctor, and hearing what he had found out, suggested that he arrange for a physiotherapist to train the daughter in lifting and moving Henrietta. These procedures were not intuitive for the daughter, and the social worker arranged for a community physiotherapist to visit the home to reinforce the daughter's learning by providing additional training on the spot. The social worker explained to the doctor that she would sit down with the daughter and son to plan finances for the family, to ease the additional burden of Henrietta on the family finances. In discussion with the daughter, the social worker arranged for a community nurse to visit regularly, and planned with the nurse that the social worker, nurse, physiotherapist and a community doctor would organise their visits so that a professional saw Henrietta every alternative day, and could check to see if there were any problems. The doctor afterwards said to the social worker that he had not realised how coordinating changes in Henrietta's arrangements at home could help to reduce the risk of physical and financial abuse taking place.

This case example shows how concern for both emotional and practical issues, and coordinating health and social care services can free even quite frail older people to 'age in place'; it also demonstrate the importance of reporting back on social care issues to healthcare staff who may be unaware of what can be achieved.

#### CONCLUSION

Citizenship is a legal and social status that is part of the formation of a social order in any nation, by associating civil, political and social rights with emotional and cultural belonging. It is a controversial status, since in a conservative communitarian philosophy, citizenship is part of an exchange in which citizens receive rights and services provided by the state in return for an economic and social contribution. Since older people follow a pathway in which they become progressively economically and then socially less active as part of a community, eventually reaching dependence and death, this conservative position may lead to their entitlement to the benefits of citizenship being questioned and their capacity to make economic and social contributions to society declines. A radical communitarian position, however, proposes that community cooperation and engagement with older people and end-of-life care builds community solidarity. End-of-life and palliative care, with their emphasis on transparency about dying and participation of families and communities in caring for dying people, further illustrate the radical communitarian view that engagement is a more appropriate response to dependence than exclusion.

A citizenship approach to social work contests dominant medical and social models of provision by ensuring that social work practice focuses on identifying and strengthening the contributions that older people and people at the end of life can make to their families and communities and promotes their participation in community and family life. It focuses particularly on areas where older people and people at the end of life may experience barriers or limitations in taking up their citizenship in society. These include family and neighbourhood relationships, intimate relationships, restrictions and opportunities offered by employment and income, engagement in civil and social life, the influence of media and barriers in health and social care services to older people and people at the end of life taking up full participation in society.

The principles of citizenship practice include focusing on integration of formal and informal services to provide effective support for freedom and advance care planning, enabling older people and people at the end of life to take part in generalised rather than specialised services, finding ways of using healthcare, housing and social security as well as new technology to enhance citizenship rights and enabling older people and people at the end of life to take prat in creative activities and personal development opportunities to enhance their social engagement with society.

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