

Social Work with Carers

An Evidence Scope

1. Introduction

The *Care Act 2014* sets out parity of esteem for carers. It is a duty to assess carers needs and there is a right to support. Effectively, once identified, the carer becomes a ‘client’¹ or ‘service user’. The principle of individual well-being enshrined in the Act applies to all participants in a living relationship. The inherent challenges to the professional practice of the individual social worker go to the heart of future adult services - social care, health and housing.

Those challenges pose questions for social workers around purpose of involvement, service user/carer focus, methodology, conflicts, advocacy, capacity, safeguarding, resources, coordination and outcomes to name a few. To assist, the [Knowledge and Skills Statement for Social Workers in Adult Services](#)² spells out the role in respect of individuals, families and carers in their communities and wider society. This evidence review of social work practice with adults and carers has been prepared in the light of that statement.

2. Scope

Social work is a unique profession in that it focuses on human rights and social justice with a knowledge base that involves critical analysis of power relationships³. However, in other ways, it is no different to other professions in that it depends on the practitioner bringing their knowledge and skill into applied harness to be effective. Therefore, both evidence of the underpinning knowledge and theory that inform the way of practicing as well as evidence that the activity ‘works’ – or has some tangible benefit or positive outcome for the service user – are necessary to demonstrate value. As a review of the evidence of social work practice with carers the intention is to seek out and add intelligence about its worth and importance.

The intent of the review is to collate the available evidence to support social work practice with carers; making reference to academic literature, government policy and examples of good practice. As well as searching for specific work relating to carers the review was requested to encompass ways of working that support relationship- based practice.

1 The term ‘client’ is used here but is increasingly replaced in professional usage by ‘people who use services and those who care for them’ or services users and carers to distinguish. See section on terminology below.

2 March 2015

3 See the [Global Definition of the Social Work Profession](#)

In the report *The Effectiveness of Social Work with Adults: a systematic scoping review* (Moriarty and Manthorpe 2016) the pros and cons of review methodology are discussed⁴. Whereas this review simply consisted of the efforts of a reasonably knowledgeable and experienced sector professional working at home with publically and freely available browsers and sources of data. Thus similar to what a social worker may be able to do for themselves. As such the review may lack in thoroughness, but has practical credibility and provides a *short-cut* to the research for social workers.

In addition to the limitations of time and availability of data, the scope of the review was contained to *social work practice with adults and carers* (these were, in fact, the initial search terms deployed). Social work with parents, as carers of children, was excluded from the scope excepting work with young carers and with children in need who are in transition to adulthood and their parent carers.

Carers, hitherto, have not been the focus of the individual attention of social work effort and nor has evidence gathering been specific to this field of practice. This review is cognisant that, in defining the carer as the 'client' or service user, it not only redefines the relationship but also opens up the whole spectrum of evidence about the knowledge and research bases available to social workers. As that is accessible elsewhere⁵ the review, which has confined its evidence gathering to the last five years and the materials available on the web in the English language, has a more manageable scope.

Notwithstanding, social work has never been purely about the one-to-one helping relationship between practitioner and 'client'. Included in the pantheon of social work methods are, among others, whole family approaches, group and community work. The critical and reflective social worker seeks to draw on methodologies that change dominant power structures and relations (Fook 2012)⁶. In reviewing the literature, government policies and some case studies it is recognised that there is a rich history of documented evidence in the use of these, and other, methods – most notably, for example, in the application of attachment theory. The review has not replicated these but encompasses some pointers to current utility specific to relationship-based social work with adults – whether service user and/or carer.

Excluded from the scope is the growing body of evidence of the value of support to carers from a range of services provided by social care, health, housing, community support workers, volunteers and peer carers. The review priority is where the roles and tasks are performed by a registered social worker. Included are situations where it is clear that a number of professionals could take the lead and the literature uses a generic term – such as practitioner – and where it is apparent that the roles and tasks are those of social work but are not being undertaken by social workers. The former is exemplified by the Approved Mental Health Practitioner and the latter by the various assessors, support workers and reviewers who perform segments of the social work task in adult services.

The criterion for inclusion in the review was:

- > Knowledge and theory of social work practice with adults (over the age of 18): and carers, young carers and parent/carers of children with particular needs in transition into adulthood
- > Where there has been comment on the effectiveness of that social work
- > Where there is evidence of effective professional work in related professional or multi-disciplinary arenas that has implications for or transferability to social work practice with adults

4 At the time of preparation, this review was unpublished. In the summary it states that the approach to defining effectiveness included changes to quality of life and carers views. It said there was *considerable satisfaction with palliative care social workers among users and carers but there was evidence of unmet need*.

5 SCIE resources and services has 69 entries for 'carers' or 'carers assessments' and 115 that mention 'social work' but none explicit to social work with carers

6 Social Work: A Critical Approach to Practice by Jan Fook (2012)

3. Definitions and terminology

Carers: refers to those people who provide continuing help and support to a relative, partner or friend. Other terms in common usage are caregivers, family carers or family caregivers (in the USA this can refer to foster parents). Sometimes the term ‘carers’ is preceded by the words ‘unpaid’ and/or ‘informal’. These are taken as descriptive of the nature of the role. However, ‘carers’ was used, on occasion in the literature mistakenly, when care worker would be the correct description of a paid and formal role.

Young carer: is defined as a person under 18 who provides or intends to provide care for another person. The concept of care includes practical or emotional support. It is the case that this definition excludes children providing care as part of contracted work or as voluntary work. However, the local authority can ignore this and carry out a young carer’s need assessment if they think it would be appropriate.

Service User: is the term used to encompass people who use services in all ‘client’ groups. The review raises the question of the carer becoming a service user once they are identified. The term ‘client’ features in the literature which is the subject of continuing debate⁷ about the meaning it conveys in terms of the relationship with the social worker. User-led (controlled – Beresford and Croft 2012 NIHR) research provides a *powerful sense of what is stigmatizing...* through user’s experience of language. (Shaw et al eds: 2010)

Social work: there is a **global professional definition**⁸ to give context for this review where the term social work is used to embrace the roles and tasks carried out by a registered social worker.

Other definitions can be accessed from the **Think Local, Act Personal Care and Support Jargon Buster**

4. Research by theme

The themes in *Carers and Personalisation: improving outcomes* (DH 2010)⁹ are:

- > Carers as expert partners
- > Whole family approaches
- > Early intervention and prevention
- > Making self-directed support processes work for carers
- > Market and provider development

Unfortunately, the evidence from searches about social work practice with adults and carers did not neatly cluster around these themes. The most substantial grouping was around the theme of **carers and health care**. There were strands within – client group, disability and health need related – but the largest was around hospital discharge. Social workers in a complementary relationship with doctors, the former concentrating on physiological health, and the latter on social health.

Hospital social work was reported as highly valued but with carers feeling that empowering and person-centred practice was sometimes undermined by the discharge and care management processes (McLaughlin 2016). A review of *Carers as partners in hospital discharge: (ADASS 2010)* was intended to improve carer recognition, support and outcomes within timely and supported discharge processes. The report, resultant of literature searches and direct interaction with carers, found evidence of good practice, but a need to change attitudes and cultures and to understand impact on carers better.

⁷ “Service user” or “client”? Social workers divided on best term – McNicoll in *Community Care* (2012) or *What’s in a Name: ‘Client’, ‘Patient’, ‘Customer’, ‘Consumer’, ‘Expert by Experience’, ‘Service User’—What’s Next?* McLaughlin, BJSW (2007)

⁸ July 2014

⁹ It offers signposts to better practice and outcomes at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/213806/dh_122383.pdf (accessed 050216)

Issues of information for carers, their expectations of a social worker who has to move on to the next patient and the difficulties of reconciling the role of carers and the rights of service users – which can be at odds at the point of discharge (Fowler 2009) – were raised. Guidance for health and social care professionals on the transition from hospital settings to the community or care homes (NICE 2015) stressed the importance of shared information (with carers if the patient consents), communication and multi-disciplinary care planning before admission and as part of discharge.

Three characteristics have been identified in **hospital discharge (transitions) social workers** – first that they managed unanticipated events, second they made good use of a broad and interconnected perspective of the health and care system plus third, relationship building between patient, caregiver and health and care providers was an effective component of that social work. (Fabbre et al 2011)

The value of the social worker in transitions from hospital was recognised as both potentially decreasing financial costs and improving patient outcomes. (Barber et al 2015). The associated benefit to the primary caregiver was not so readily acknowledged. There was little actual evidence of the perspectives of either patients or carers particularly in respect of the increasing numbers people with dementia being discharged from hospital. Here guides to what constitutes effective discharge planning and evidence of what achieves good outcomes were sparse (Mockford 2015). High readmission rates of people with dementia implied one role of social work is to ascertain and communicate the carers understanding of how the service users' needs can be best met. Another was in enabling the caregiver(s) to 'carry on' when the patient had heavy care needs, problematic behaviour or was isolated. Included was assistance with family conflict, for example, about a residential care option. In reality the research showed discharge to often be unplanned, rushed and without proper liaison with social services.

Social workers were considered vital, sometimes underused and overlooked at the point of discharge. The identified contributions of social workers to care transitions were, specifically, informational continuity; patient-health care professional relational continuity; conflict resolution; mediation among family, patient, and health care professional (for example, doctors and nurses); collaboration with family caregivers and community supports; and relocation counselling. The evidence indicated this applied across hospital admission and that *When Things Are Really Complicated, We Call the Social Worker* (Sims-Gould et al 2015 on post hip-fracture care transitions for older people)

Transition emerged as a practice theme, not just in hospital discharge, but across the life course (Blythe 2010, Grant et al 2010). Complex transitions required smooth transfers, adequate support and dedicated professionals (Petch 2010). Understanding transition theory remains an essential in using life course development knowledge in social work practice with adults (Crawford and Walker 2010).

The *Care Act 2014* places a duty on local authorities to assess adult carers, including parent carers of disabled and other children in need, before the child they care for turns 18, so that they have the information they need to plan for their future. This is referred to as a transition assessment. Guidance, advocating a whole family approach, is available to social workers (LGA 2015, SCIE 2015, ADASS/ADCS 2011). Young carers, young adult carers and their families now have stronger rights to be identified, offered information, receive an assessment and be supported using a whole-family approach (Carers Trust 2015).

Partnership building expertise used by practitioners was seen as particular pertinent to transition for a young carer (Heyman 2013). Emotional and practical support from social workers was valued by the mothers of transition-age children with mental illness (Gerten and Hensley 2014) and by men as caregivers to the elderly (Collins 2014)

Support to adults who have **dementia** benefits from a *Manual for good social work practice* (DH 2015) targeted at social workers in day-to-day practice. It suggests an assets or strengths based approach to social work support with the person and their family and/or network of support. The timeline is put forward as a model that can underpin how the social worker supports and intervenes, from early preventative measures through various stages of loss towards end-of-life. The readiness of the carer to have sensitive conversations being an important social work judgement.

The *Manual* is keen that social workers undertaking assessments and support work with carers of people with dementia undertake research themselves. *A Road Less Rocky* (Carers Trust 2012) was flagged up as a good starting point. With three critical points on the timeline – diagnosis, taking up active caring and the decline of the person’s capacity – identified. It considered the social worker assessing the carers needs, sustaining the carers own identity, developing and maintaining their network of support and resources as well as accessing financial and legal advice.

The current evidence to support the *Manual* included works around the strengths based approaches (McGovern 2015, IRISS 2012) which indicate a quality of life gain from ‘we-ness’. The asset based approach to social work had a generic relevance to work in the community with carers beyond, the demands of dementia, and included prevention, care assessment, safeguarding, care management and commissioning (Klee 2014)

Social work with carers of people with dementia, and indeed other **mental health needs**, is dependent on good practice with the Mental Capacity Act where practitioner knowledge and understanding has been found to be variable and a possible impediment to memory work involving the carer. (Iliffe et al 2015). The social work role with carers in adult mental health services has been described as: *intervening and showing professional leadership and skill in situations characterised by high levels of social, family and interpersonal complexity, risk and ambiguity* (Allen 2014)

The questions around consent and confidentiality – knowing what should happen if a carer asks a person’s doctor, social worker or nurse for information – were addressed in references to work with carers. (RiPFA 2016, SCIE 2015, Mental Welfare Commission for Scotland 2013). The management response to increasing involvement of service users (and carers) in mental health services has been deliberated (Rose et al 2014) and carer’s expertise and experience described (Manthorpe et al 2009)

Collaborative approaches, such as circles of support, (NDTi 2014) did not find social work teams the most effective place to access carers or their networks and relied on the community sector to facilitate action research (Jestico 2015, Yeandle 2012). They concluded that social work teams, themselves, were in need of information about the support available to carers. The SCIE **dementia gateway** and **Mental Capacity Act** materials offer a valuable resource to social workers seeking to research how to work with people who use services and their carers which can be supplemented locally and from the active contributions of the ‘online’ community (Young Sam Oh 2015)

Autism is similarly the subject of a social work manual (DH 2015). Like its partner document there is a section on supporting carers. It covers the duties of the Care Act, issues of carer identity, carers networks, parental/carer identity, stigma, recognition and validation plus advice around self-help and having a life.

The review uncovered an interesting document that concerned people with learning disabilities and challenging behaviour going into hospital (NHS England 2014). Written for family carers, it offered the description of the social worker's role as to: *assess your loved one's whole situation and what life was like before their admission – their history, their relationships, their home life, their occupation, their wishes*. Called *Getting It Right*, it said all people with learning disabilities will have a named worker (social worker or nurse) and that the social worker may be the responsible clinician.

Professionals in the field of **learning disability** have advice for clinical commissioning groups (RCGP/RCP 2012) that failed to mention social work but nonetheless offered useful guidance. It was one of the few references to people with learning disabilities caring for other people with and without disabilities themselves. It flagged life change awareness as having important implications.

Useful materials were found about effective community learning disability teams putting the individual and their surrounding family or carers at the heart of a service (National LD Professional Senate 2015). The carers strategy demonstrator sites identified the benefits of workers from voluntary organisations assisting social workers undertake carer's assessments (Yeandle 2011). A good practice project (DH 2013) with people with learning disability included a case study with an organisational model based on Attachment, Object Relations, Developmental, Systemic and Trauma theories – essentially a psychotherapy based service, rather than social work, but with transferable practice lessons.

There were similar findings in the fields of domestic violence (Alridge 2013), prison welfare (Age UK 2011), substance and alcohol abuse (Galvani 2015, Manthorpe et al 2015, Walter et al 2015, Wadd 2014, Galvani and Forrester 2011), veterans (Patel 2015), post-traumatic stress disorder (NICE 2005), sensory impairment (Rabiee 2015, Balen 2013) and palliative care (Alcide and Potocky 2015, Ewing 2015, Hansen 2015, Karla et al 2014, Beresford et al 2006). Common factors identified for social work practitioners working with adults and their carers were those of information, advice and guidance – having the specialist knowledge or knowing where to signpost people – assessment and the processes of carer-directed self- support, using the knowledge and skills to work with the whole network of relevant people (family and carers), understanding of life change and course, transition with particular reference to loss and bereavement. In situations of multiple and complex needs the distinction between service user and carer blurred and could change circumstantially. The question of separate social workers for people in such relationships (Swetenham et al 2015) or the introduction of a carers advocate (SCIE, *Care Act 2014*) have received consideration.

Assessment is key to all social work practice and work with carers equally puts assessment at the core of personalised practice. The significant potential of social work to ensure sustainable and effective support over the longer term, in forming relationships and undertaking comprehensive and sensitive assessments in partnership with (older) people and their carers has been documented. (Milne et al 2014 in making the case for gerontological social work)

Guides to learning and practice in assessment are now mostly in need of updating because of the requirements of the Care Act 2014. Here **SCIE** is the primary source of knowledge and theory not just on assessment and eligibility but also on advocacy, safeguarding and transitions from childhood. That said the '**out of date**' assessment materials on the SCIE website were timeless where they promote carer's perspectives and involvement in their assessment. Tools available to assist had amongst them the Carers Support Needs Assessment Tool (CSNAT) which has been researched in palliative medicine. It was said to have delivered benefits through a change in practice to an identifiable, separate assessment process for carers, facilitated by practitioners but carer-led. Used routinely with all carers, the CSNAT was considered to have the potential to normalise carer assessment and support, facilitate delivery of carer identified support and enable effective targeting of resources. (Ewing et al 2015)

Personalisation and carer's assessment go hand in hand in the processes of managing self-directed support. Practitioner tasks that were identified - carer involvement in service user's assessment, carer's assessment, resource allocation, support planning, ongoing management of personal budgets and reviews. Some of the implications for practice - assessing the emotional impact of caring, when should practitioners be separate for service user and carer? awareness of resources to support carers and of how the resource allocation system operates, understanding 'inappropriate assumptions', need for clarity and consistency. (Mitchell et al 2013, NIHR)

Within these processes **direct payments** has attracted attention with suggestions of social worker reluctance and lack of imagination. There are, in theory, few restrictions to the use of payments to support carer's or to curtail innovation (Dittrich 2013). The Care Act 2014 was anticipated (Carers Trust 2012) to:

- > Improve quality of access and information and advice about personal budgets for carers
- > Ensure carers are informed and supported throughout self-directed support processes
- > Ensure take up of both direct payments and managed options for carers and that carers are offered a range of flexible options to support agreed outcomes
- > Examine whether one off payments are appropriate and flexible enough for meeting all carers' needs, particularly for those carers who have regular and substantial caring roles over longer periods of time

The **whole family approach** was a familiar theme, already mentioned in respect of young carers and social work with children in transition, in the research (LGA 2015). Advice was offered on learning about forming relationships with carers (SCIE 2016) and there appeared to be a clear appetite for evidence that relationship-based practice actually works (Cooper 2015). Texts about relationship-based social work *getting to the heart of practice* (Wilson et al 2011, Ruch et al 2010) flourish. Recent interest has centred on attachment theory - a stalwart in child and family social work (Shemmings 2016) - having application to relationship based social work with adults and their carers (RiPFA 2015, Bennett 2011) promoting positive change (Baim and Morrison 2011) across the life course (Howe 2011).

Family group conferencing, along with mediation as whole family approaches, were found to have particular applicability to adult safeguarding social work. (SCIE 2012). An International and multi-professional bibliography has been specifically researched (SCIE 2012) - it covered the effectiveness of social work practice, weighted towards children and families, but includes items on intergenerational mediation, public mental health care, the role of the social worker in family mediation, rehabilitation, frail elders, decision making and placement outcomes, building social responsibility, elder caregiving, *Helping Older Adults and Their Families Develop and Implement Care Plans*, social worker attitudes, cultural responsiveness, involving the extended family and domestic violence.

There is useful advice to carers about reporting abuse and neglect, if they are victims themselves or if they intentionally or unintentionally cause harm or neglect to the person they support (ADASS 2011). Financial abuse, linked both to carers and care workers, is a particular concern of social workers (Law Society 2013)

A Hampshire pilot project using family group conferencing with elder abuse has been evaluated (Tapper 2010). Work was undertaken on mediation and family group conferences in adult safeguarding to inform the review on No Secrets (Hobbs and Alonzi 2013). It included an overview of the research and practice literature. In Northern Ireland there are standards for family group conferencing (Family Group Conference Forum 2010) and in the USA standards for family care givers of older adults (NASW 2010).

Workforce learning

Social care practice with carers is raising many questions about job roles and their effectiveness (see the NIHR research programme 2010 to 2013) but this was not social work specific. The fragmentation of the social work role was identified and the perspectives of workers have been gathered (Manthorpe and Moriarty et al). There was found to be a wealth of materials available from [Skills for Care](#) in respect of work with carers. Among these were materials about carers in the workforce – burnout, caregiver identity and distress amongst social workers who are themselves carers was a concern (Moriarty 2015, Grant et al 2014, Wu and Pooler 2014).

Integration of carers experiences, involvement and participation in the development of social work practice and learning has attracted researchers (Open University in Scotland 2013). The expert partner standing of carers was recognised by educationalists (SCIE 2009, Ager et al 2005), as co-researchers (Littlechild 2015), in practice (Warren 2007) and in respect of cultural competence and homophily (Manthorpe et al 2011). The *Caring with Confidence* programme aimed to provide support to 37,000 carers and to create a network of training providers. In respect of social work practice, it showed that just 5% of participating carers got their information about the programme from social workers or local authorities (53% carers organisations). It recommended that: *Local health and social care partnerships should ensure health professionals and social workers have regular opportunities to refer carers who would benefit from it to training support* (Yeandle and Wigfield 2012).

5. Gaps in the evidence

It is safe to say that social work practice with adults and carers is under-researched. The Care Act 2014 elevates the status of carers, which on the one hand opens up the knowledge and theory base of social work to a wider range of service users and on the other exposes gaps. What is open to benefit practice with carers are the whole family and relationship-based approaches born of attachment and loss, as well as transition and life-course, theories. The gaps in knowledge and theory are around context, adaptability and extension related to social work specifically with carers.

Evidence of the effect of social work support and intervention with carers in adult's services appears meagre. The current position is descriptive, in places intuitive and in need of confirmation in terms of positive outcome and cost-effectiveness. The impact/risk assessment for the Care Act posited that the simplification of the law would both free up social work (and lawyers) time and, after training, build their legal confidence. Thereby it would enable them to take on the additional duties in respect of carer's assessments and support. There is a need to research how social workers are spending their time as the new legislation beds in.

There is a need to understand better how social work knowledge and skills are deployed related to a service user in their circle of support. Why, when and how is personalised and separate support provided for a carer? What are the criteria – risk, complexity, cost – for work with carers being undertaken by social workers? How are models of practice emerging that cater for the segmentation of the roles and task of social work? Whole family approaches imply a team effort, hitherto met by the care management/coordination role of social work, but now there is a systems leadership responsibility emergent for social work which requires research.

The literature review is suggestive that the therapeutic impact of social work warrants evidence gathering and documentation. Transition is not just about the smooth management of complexity it involves a process of personal change and development. If a social worker can help a carer make these transitions – a child becoming an adult, a move to independence, a breakdown of a relationship, personal trauma, the onset of chronic illness, bereavement – and then carry on making a positive contribution then it should be known how this has been achieved. Research into the use of knowledge, theory and method will allow replication of success.

There are many specific client groups, settings, processes and methodologies that warrant research into the effectiveness of social work time and effort with carers. Perhaps the priority should be placed on situations where there are clearly multiple and complex needs (co-morbidities) in individuals, families and communities. How social workers support people in symbiotic relationships that facilitate mutual caring and protect people in parasitic relationships where there is a risk of harm are questions posed.

The review revealed scope for research into the social worker-carer relationship – what benefit is there in bonding? How does similarity breed connection? How can cultural dissonance be overcome? How does the social worker protect themselves from burnout when they are a carer themselves? What do carers say they want from social workers? Essentially it is necessary – possibly adopting the appreciative enquiry¹⁰ approach successfully used to develop safeguarding social work practice – to ask: what works? There are few robust evaluation studies currently available and no systematic research studies were found on cost-effectiveness.

10 See Safeguarding, Attachment and Appreciative Inquiry, Research in Practice (2015)

6. Summary messages and emerging themes.

- > There is a lack of knowledge amongst social workers about the needs of carers and their experiences. A lot of the materials prepared and circulated by carers organisations and service providers (including the NHS) are useful for social work practitioners. A good example is the NHS materials on going into hospital
- > Social workers should keep abreast of local resources and services for carers. They should know where to refer carers for specialist knowledge and information
- > Carers should be treated as expert partners by social workers. However, the social worker must know what should happen (the process), the law, the duties and powers, and people's rights.
- > It is a social work task to 'keep an eye on the ball' of who the 'client' or service user is and the possible conflicts of interest with the carer. Whole family approaches may require co-working, a separate social worker for the carer or the involvement of an advocate. Individual's best interests in a family group or circle of support have to come through. Social work practice with carers involves complexity of relationships and warrants having practice standards.
- > The interface between social workers working with adults and those working with children involve the same families, carers and young carers. Effective personal transition for the carer should not be impeded by organisational issues.
- > The role of the social worker as care coordinator seems readily accepted in multi-disciplinary settings in the community – less so in health settings/hospitals. There is a systems leadership role emerging for social workers that could be of benefit to carers in their communities
- > The tendency to segment social work roles and tasks, particularly in work with older people, means that carers may have to relate to different non-social workers for assessments (including their own), care plans, support and reviews. This can shift the coordination responsibility onto the carer and create risk of breakdown.
- > The NHS and CCGs are alert to the needs of carers when commissioning specialist and general health services but less so to the role of social work
- > Carers can make effective trainers of social workers and the carer experience should be integrated into the curriculum
- > There is a risk of stress and burnout in social workers who are themselves carers – they have another life
- > The applicability of theory and research on relationships – attachment, loss, transition, life-course and resilience for example – to social work and social policy is well-established relating children. Yet, its usefulness for enhancing the understanding of adults and carers, as individuals, families, groups and communities, has been less featured in the literature.

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