

# OLDER PEOPLE WITH HIGH SUPPORT NEEDS IN HOUSING WITH CARE

Housing with care (HWC) offers a promising model for improving the quality of life of older people with high support needs, but also poses challenges. This *Round-up* covers key messages and practice examples from JRF studies into three aspects of HWC: promoting supportive and positive relationships; boundaries of roles and responsibilities; and affordability, choices and quality of life.

## Key points

- HWC is valued by residents. It can enhance quality of life for those with high and increasing needs, supporting independence, privacy and control, as well as many rights.
- Everyone involved has an ongoing part to play in creating conditions where tolerance, privacy and inclusion can thrive.
- Raising understanding of the lived experience of particular groups, and communicating positive messages about diversity, are key to creating a welcoming ethos.
- Providers can facilitate mutual support and resident-led initiatives through background support.
- Some residents benefit from a 'navigator' – a staff member or family carer to help co-ordinate various aspects of their lives.
- Role confusion can adversely affect residents and can be found across organisational models. A clear shared vision and understanding amongst commissioners, providers and residents of what a particular HWC scheme does, and for whom, is essential. Clarity of roles and responsibilities should be balanced by some flexibility.
- Affordability is specific to individual circumstances and partly subjective. In the context of HWC, there are uncertainties, inconsistencies and complexity. Some housing, care and support costs are ineligible for state subsidy, so reducing residents' incomes below the notional income floor.
- Residents need individualised information about costs, subsidies and state benefits applicable to them, with support and advocacy to navigate the system.

# INTRODUCTION

Housing with care (HWC) offers older people the privacy of their own self-contained home and the security of tenancy or ownership rights, within a community setting. A defining feature is access to care and support (usually with staff on site at all times). Company, social activities, and other services and facilities are also available. However, there is no single model of housing with care for older people, and each scheme is unique. A range of providers and other key players are involved in commissioning and delivering this hybrid of housing, care and support. In some schemes, there are several providers, each delivering different services.

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The Joseph Rowntree Foundation's programme 'A Better Life', launched in 2009, focuses on how to empower older people with high support needs to enjoy better lives. For the purposes of the programme, JRF defines older people with high support needs as 'older people of any age who need a lot of support associated with physical frailty, chronic conditions and/or multiple impairments (including dementia). Most will be over 85 years old. A minority will be younger, perhaps reflecting the impact of other factors linked to poverty, disadvantage, nationality, ethnicity, lifestyle etc. Some of the very oldest may never come into this category.' The community of residents in HWC schemes comprises any combination of people who fall into this group and others who do not.

Three aspects of HWC formed the focus of JRF's studies, each having a significant impact on the quality of life of residents with high support needs:

- how positive and supportive relationships between older people with and without high support needs living in HWC can be promoted (Croucher and Bevan);
- how providers, partner agencies and other stakeholders work together with older people and their relatives to deliver HWC, with a particular focus on boundaries of roles and responsibilities (Blood et al.);
- how affordability and complexities surrounding it affect the decision-making and lives of self-funding older people with high or increasing support needs (Pannell et al.).

This *Round-up* draws out key messages and practice examples from these studies and other relevant research commissioned by JRF.

## What are the issues?

Although the language of 'rights' and 'empowerment' appeared to mean little to residents, Blood *et al.* (2012a, 2012b) found many examples in which the rights of older people with high support needs were being promoted effectively in HWC: the right to family life, privacy, confidentiality, and being treated with dignity and respect. The study also found areas where rights needed to be better understood and promoted; for example, understanding of housing rights amongst social workers, and the right of residents to be consulted and involved in decisions affecting their lives.

### Community life

HWC communities comprise all who live and work there or access the facilities. They are dynamic and ever-changing, so supporting participation and inclusion cannot be seen as a one-off exercise but must be ongoing, and the whole community has a part to play. Scheme managers and provider organisations play a pivotal role in setting the tone. The mix of residents, their reasons for being there,

and their expectations of living there will be unique to each scheme, and play out in different ways in terms of how supportive they are towards people with high support needs.

It may be difficult for some people to adjust to the expectations of community life and shared spaces even though these also offer positive opportunities. Different mixes of those with and without care needs can throw up challenges. Some fitter residents, having been 'sold' the idea of a vibrant community, report being uncomfortable and surprised by the number of people with high support needs. Those with high support needs have consistently been reported to be marginalised and isolated within HWC. Groups or individuals with certain characteristics may be subject to discrimination by other occupants. Thus, residents' lives may be enriched or diminished depending on their expectations and whether they feel valued members of the HWC community, able to take part and contribute. Ultimately, whether a scheme is experienced as inclusive and supportive comes down to individual judgement.

### Roles and responsibilities

In addition to tensions within community life, a range of factors contribute to making HWC a complex entity, and these in turn create conditions where roles and responsibilities may be unclear. Blood *et al.* (2012a) identified some of these factors: local authority policies and practice in relation to HWC; the funding that is available for housing, care and support in HWC; monitoring and regulation of these services since HWC is not a single legal entity; the application of 'personalisation' to HWC; different models, sectors and tenures; and different expectations of what HWC is and does amongst residents, families, on-site staff, external professionals, commissioners and regulators.

Despite these complexities, a fundamental strength of the HWC model is that it brings together housing, support and care professionals and their different values and perspectives. Nevertheless, residents' quality of life and rights can be affected for better or worse by the way in which staff from diverse organisations work between themselves and with residents and their support networks. The effect on people with high support needs is likely to be even greater than for other residents. The study found that tensions and lack of clarity about who does what could impact adversely on residents and staff in a number of ways:

- Residents may be confused, not knowing who to approach, leading to stress and anxiety.
- Gaps could result in residents going without a service, experiencing delays and interruptions, or having to ask favours of friends and family.
- Alongside poor staff communication, tasks may be duplicated.
- Staff may go beyond the call of duty to fill gaps, an unsustainable position in the long term.
- An inconsistent, ad-hoc service may result, where some people get a service some of the time while others, sometimes the most vulnerable, slip through the net.
- There may be poor relationships between staff, with silo-working.

These issues may manifest across a range of aspects of HWC: support when someone moves in; supporting residents to take part in community life; tasks relating to the building; when someone has increased or unplanned-for care and support needs; and in relation to providing end-of-life care and safeguarding. Grey areas were found to emerge in particular circumstances: where things are small (e.g. changing a light bulb or applying ointment) and mechanisms for getting them done are unwieldy; when individuals lack capacity to co-ordinate different aspects of their lives themselves; where circumstances change suddenly; where resources are limited; when something is so important everyone assumes someone else is doing it (e.g. stopping a resident with dementia climbing over a fence); where things are difficult and staff lack confidence (e.g. talking about end-of-life planning); when liaison and advocacy with external agencies is needed; and when perspectives differ on the balance between risk and the right to self-determination.

Blood *et al.* (2012a) found similar boundary issues arising at a scheme level in HWC across all four nations and all organisational models.

### Affordability

Of the 78 residents interviewed by Pannell *et al.*, 85 per cent were very happy in HWC. Most reported positive views across different aspects of quality of life. HWC enabled couples to stay together, with partner carers receiving support.

But is this highly valued option affordable to all those who have to pay some or all of the costs themselves? This is not a straightforward question. Affordability is highly specific to individual circumstances, and also a subjective judgement about whether a particular expenditure represents value for money and if it will impact positively on quality of life. In the context of HWC, it is fraught with uncertainties, inconsistencies and complexity. Pannell *et al.* (2012) explored four questions likely to be of concern to people considering moving to, or living in, HWC. They answered them in the following way:

- *Can I afford to stay here?* That depends ... on income and savings, changes for couples when one dies, but also on getting benefits advice; and where I live; and the way my HWC scheme is set up and managed; and what help (if any) I get from benefits (especially leaseholders).
- *Can I get the care and support I need?* Probably ... but if I need it, paying for personal care could be a problem, especially in England; (for couples) HWC helps us to live together, and maybe my partner can continue caring ... depending on health.
- *Will my HWC scheme stay the same?* That is more difficult to predict ... and depends on wider commissioning and funding decisions (if publicly funded) or change of provider (all sectors) ... and whether as residents we will have any control (or even be consulted).
- *Will I be able to stay here until the end of my life?* As a self-funder I may have more choice ... but it also depends on facilities, services and staffing models in my HWC.

Availability of public subsidies for the various housing, care and support charges is central to the question of affordability for many. Yet Aldridge *et al.* (2012) found that there were inconsistencies in the way benefit rules were interpreted, and despite an income floor below which income should not fall, there were various 'trapdoors' through which residents could fall, reducing their income below that level. These included tenure, savings levels, and whether certain housing, care or support costs were eligible for state subsidy or not. In addition, the complexity of benefit rules meant residents not always receiving their entitlements.

Despite higher costs than mainstream housing, HWC was considered good value for money by a majority of interviewees. Age and health influenced whether housing with care was (and would remain) affordable: residents who were very old or in poor health thought their money would probably last; younger residents had to plan over a much longer timeframe so were more anxious. Unexpected changes of circumstances caused concern, especially for couples. At significant risk of affordability problems were couples where one moved into a care home and lower-income private leaseholders with high care/support needs. Various coping strategies and trade-offs were adopted in response to increasing needs and costs.

## What needs to be done?

All three studies identified approaches and practices which addressed these issues to help improve the lives of older people with high support needs in HWC. Provider organisations, local authority commissioners, external organisations and professionals, and residents themselves, all have important parts to play.

### Residents

Resident interviewees said they want: better consultation, with the opportunity to have a real say in how the scheme is run; support for individuals to overcome barriers to participation; and the opportunity to meet with senior managers from provider and partner organisations.

In order to play their part, residents require clarity about their own rights and responsibilities, and the strengths and assets they themselves bring need recognition. As part of a dynamic HWC community, each resident has responsibility for treating others with tolerance and understanding, and respecting others' rights to autonomy, privacy, independence and choice.

'Good neighbourliness' was identified as a key foundation for supportive communities and, in many schemes, residents actively support one another, either purely informally or through more structured resident-led approaches. Often, a number of individuals are recognised to be the driving force behind resident-led activities in schemes; social activities, volunteering or representing residents' views. Croucher and Bevan (2012) give examples:

A resident volunteer group in a sheltered housing scheme offers low level support and social activities to other residents. This is carefully, but informally, co-ordinated by the scheme managers.

Particular individuals are recognised for the contribution they make to their communities. Two 'resident champions' have been identified. Angela had a long-standing interest in computing and introduced residents to the use of computers for connecting with the outside world. Catriona raised funds to enable fellow residents to go on outings. Both expressed considerable personal satisfaction in assisting others, and in both cases, staff provided welcome support, and their attitudes and skills were key in encouraging people to contribute, but not dominate.

Finding meaningful ways to involve residents in decisions affecting their lives, and empowering them to understand and exercise their rights and responsibilities, were found to really matter to older people. Key areas for such involvement were identified as: workforce issues (e.g. staff selection and training); clarifying roles and responsibilities within the scheme; and commissioning processes and decisions. A range of approaches is needed to find out what is important to residents and involve them effectively. These include informal and one-to-one conversations, as well as more formal, group-based mechanisms.

St Monica's Trust consulted widely to develop a wellbeing tree, which highlights six areas of wellbeing: dignity and respect, positive living environment, control and choice, social life, peace of mind, and health and comfort. This is used as the basis for regular review with residents.

Hanover Housing Association develops local agreements with residents based upon a choices framework. This sets out decisions and choices for individuals to make, decisions needing to be made collectively, and those which remain with Hanover.

Family Housing Association in South Wales offers a spectrum of involvement ranging from picking topics for information sessions to participating in policy reviews (including recently cutting jargon from the residents' handbook). Those keen to get more involved can volunteer as Service Assessors, undertaking mystery shopping exercises or peer surveys. There is a real sense of accomplishment for the tenants involved in this initiative.

## Providers

Blood *et al.* (2012a) found no one HWC model to be best at minimising boundary impacts for residents; working for the same organisation appeared neither necessary nor sufficient. Where several providers operate – and especially where there is a change in providers and roles – a lot of effort is needed to make this work and ‘shield’ residents from the potentially negative impact of boundary disputes and grey areas. Scheme staff, especially scheme managers, shape the experience of HWC for older people and it is their flexibility and determination which was found (mostly) to result in a seamless service.

While providers do not have sole responsibility for making the lives of residents with high support needs better, the studies illustrated some important areas where they have a pivotal role.

### *Ethos of tolerance and respect*

An ethos of tolerance and respect is a fundamental pre-requisite to genuinely inclusive communities, and provider organisations need to embody and promote this. This requires showing a willingness to listen to and support residents; learning from and reflecting on previous experience; and devoting resources to supporting the development of inclusive communities. While opportunities for participation are valued, studies demonstrated that for many residents, autonomy, privacy and choice were important to them. Opportunities for participating in the community life of the scheme should be fostered, but not imposed.

### *Raising awareness and understanding*

Raising awareness and understanding amongst all scheme-based staff and residents of the lived experience of people from diverse groups (e.g. ethnic minorities or LGBT people) or with certain conditions (e.g. dementia) appears to engender greater tolerance and respect.

Accord Housing introduced dementia awareness training with all staff members in schemes and awareness-raising amongst residents. This has resulted in good friendships being sparked between people with and without dementia. Accord also revised their anti-social behaviour policy to reflect the circumstances of people with dementia to create more tolerant and supportive communities.

Anchor’s Older LGBT group is open to staff and residents from across the organisation’s sheltered housing. It aims to make the organisation a safe and welcoming environment for LGBT tenants and staff. The existence of the group helps Anchor make a clear statement about its ethos. It provides a voice for LGBT people within Anchor, supports vulnerable residents, and has been involved in developing equalities and diversity training and online guidance to staff.

### *Background enabling*

Providers can help create an underlying environment which enables residents to take advantage of opportunities to participate. This could include attention to the design of indoor and outdoor spaces to compensate for physical, cognitive and sensory impairments; culturally appropriate facilities and services (e.g. catering); providing support as part of care packages to enable individuals to take part in activities and events (or advocating for commissioners to achieve this); ensuring that hearing aids and glasses work effectively; and staff working discreetly in the background to facilitate privacy and autonomy, as well as encouraging participation in whatever ways residents wish, and enabling supportive networks to grow.

### *Brokerage*

Croucher and Bevan (2012) found that the community as a whole can benefit from someone who acts as broker, recognising what individuals or groups may need and discreetly facilitating the necessary connections. This may involve ensuring that a resident with high support needs is given the opportunity to participate in resident-led activities, introducing residents informally, and identifying people willing to volunteer and matching them to tasks best suited to them while ensuring that no-one is asked to do too much by providing a back-stop.

### *Navigator*

Some individuals with high support needs are unable to consistently take control themselves of accessing services or participating in the community, perhaps due to cognitive impairment or extreme frailty. These residents benefit from someone – a navigator – who plays a co-ordinating role, advocating, liaising and making things happen for them (Blood *et al.* call this role a 'ringmaster'). It may be filled by a partner, family member, scheme manager or other staff member. Providers have a role in facilitating and supporting both navigators and brokers – including their own staff.

### *Welcoming diversity*

In marketing material, scheme information and written policies, organisations have an important role in communicating that the scheme caters for people from diverse backgrounds and varying degrees of support needs, using positive language and images. This helps prospective tenants from disadvantaged groups to feel welcome, while making it clear to others that a diverse range of people are likely to be living there.

Linc-Cymru has developed an information leaflet as part of the welcome pack for incoming residents to clarify that the accommodation is intended for people with a diverse range of needs.

### *Clear scheme information*

Providers also need to convey accurate information to the public, prospective and current residents and external professionals about the scheme. One-off written information is not in itself sufficient. Continual information-giving, awareness-raising and relationship-building with external professionals is needed.

In Denbighshire, North Wales, regular operational meetings helped improve social workers' understanding of HWC. Relatives of residents at the first scheme attended workshops with professionals to describe the benefits of HWC.

### *Workforce and management*

The studies highlighted the central role of front-line staff, making management and workforce issues of fundamental significance. Contributing to workforce and management decisions was important to residents who wanted: friendly staff who genuinely cared about them; continuity and stability of staff team; staff who supported them to be independent and to participate as they wished; and a seamless service with good communication and some flexibility between staff roles.

Addressing these issues on site, and empowering residents to contribute, is largely the responsibility of providers, although commissioners' decisions can also impact greatly on these. Effective leadership, staff support, recruitment, selection, retention and training have all been identified as fundamental to providing residents with a stable staff team who work effectively together, and have the skills and confidence to deliver person-centred support to individuals, and create the conditions for inclusion at an individual and collective level.

St Monica's Trust consulted residents on what they most valued in staff, the skills and qualities then forming the basis of their recruitment and selection. A number of providers involve residents in selecting staff. The studies gave examples where training includes the lived experience of particular disadvantaged groups (e.g. people from LGBT or BME backgrounds).

At Linc-Cymru, scheme managers have been trained as dementia champions to provide leadership and support to other staff.

The Extra Care Charitable Trust's (ECCT) Enriched Opportunities Programme (EOP) is a multi-level intervention which has been shown to enable cognitively impaired residents and other particularly vulnerable residents to lead enriched, fulfilling lives as part of the community. It combines five key elements: specialist expertise; individualised assessment and casework; a programme of activities and support to participate; specific training and support of all staff; and management and leadership by 'locksmiths'.

### *External resources*

Providers can harness resources from outside the scheme to help make their organisations and schemes as inclusive as possible.

Hear to Help and Hear to Meet – co-ordinated and supported by Action on Hearing Loss, these programmes provide regular practical advice and assistance with hearing aids through trained volunteers, and opportunities for people with hearing loss to meet as a group.

Visibly Better is an accreditation scheme developed by RNIB Cymru aimed at sheltered housing and HWC schemes and focuses on improving services and equality of rights for people with sight loss.

The Scarborough-based OLGA network provides workshops for health and social care providers to raise awareness of LGBT issues with an emphasis on training for all staff, and advice on use of language in printed material.

### *Wider community*

Croucher and Bevan (2012) found considerable mutual benefits in fostering links with the outside community, provided that resident concerns about privacy, and secure separation of living accommodation and communal facilities, were addressed. Open access enabled a wider range of support networks, social interactions and activities, engendered improved understanding of HWC, and promoted schemes to potential future residents. The lives of older people from the surrounding area were also enriched by use of scheme facilities.

The communal facilities at the Joseph Rowntree Housing Trust's Plaxton Court are being used to build links with the wider community. The restaurant serves meals on a pay-as-you-go basis to residents and the public.

### **Commissioners**

Decisions made by commissioners have a significant impact on the lives of residents with high support needs. Residents and their families expressed a wish to be kept aware of, and able to influence, major operational changes; to have a service and staff personalised to their requirements; and to have consistency and stability of the care and support staff team.

A decision to re-tender the care contract or change the approach to funding care, for example via personal budgets, can create anxiety, loss or reduction of a service, or increased personal expense. Yet the studies found little evidence that commissioners consider the affordability implications for residents, and did not always consult residents. To help residents with high support needs to live better lives, commissioners need to:

- recognise residents' wish for continuity and a stable staff group, changing providers and models only when current arrangements are clearly not working and/or cannot continue;
- consider the impact on residents and their families when making changes, consult with them and their providers, planning ahead and allocating sufficient resources to minimise the impact;
- consult with and involve providers and older people in the development of agreements and processes for new HWC schemes;
- look at ways of implementing personalisation so it increases self-determination and choice, rather than creating additional complexity;
- think strategically about the role of the private sector and promote the partnerships needed to make HWC work for leaseholders as well as tenants.

## Partners

All stakeholders involved in HWC need to work effectively together to shape the scheme and support individuals with high support needs effectively.

### *Clarity of shared vision*

To minimise boundary issues, there needs to be clarity from the outset about expectations of HWC. These need to be developed in partnership between key stakeholders: a shared vision as to what the scheme does and does not do, and for whom; residents' rights and responsibilities; respective job roles; and mechanisms for communication and consultation with residents and relatives, and between staff and external professionals.

Residents said they valued a balanced community in terms of care needs, age and gender, and achieving a balance between levels and types of care/support needs was found to help promote a better sense of community, with more activities and more peer support.

Many local authorities and providers work together while a scheme is being built to develop agreements which specify each organisation's responsibilities, allocations processes and eligibility criteria. Where several providers are involved, they work together before the scheme opens to develop operational protocols which clarify roles and boundaries at the interface between organisations. Those that work best manage to effectively communicate what has been agreed to all staff, external professionals and prospective residents.

### *Clarity of staff roles*

All agencies working in, or linked to, HWC schemes have a role to play in delivering what residents and families want from partnerships: support to access appropriate health care; information, advocacy and referral to social services at move-in, or when circumstances change; prompt decision-making; and clarity about whose role it is to co-ordinate the input of other agencies.

Front-line staff, in particular scheme managers, were shown in the studies to have an important role in protecting residents from boundary disputes, filling gaps, and promoting and supporting an inclusive, tolerant ethos. However, where support from other staff or management was absent, or there were many grey areas, scheme managers could become overwhelmed. It is clear that within schemes, roles and boundaries need to be clarified and effectively communicated, but that flexibility is needed at the edges.

To reduce the risk of issues being passed back and forth between care and housing providers, middle managers from Hanover Scotland and West Lothian Council attend tenants' meetings, and walk around the scheme together, visiting tenants to respond to any complaints.

Aster Living developed a 'typical task table' with their partners using a traffic light approach. They agreed which staff from care, support and housing have lead responsibility for each task (green); who should never be responsible for it (red); and where boundaries can be crossed in exceptional circumstances (amber). This approach is not intended to fetter discretion; a key point about the amber category is that crossing boundaries is temporary and triggers risk assessment and reporting. So, for example, a personal care task such as preparing for attendance at a hospital appointment is green for care, amber for support and red for housing. This increased clarity and flexibility has improved staff confidence and bonding.

#### *Individualised cost and benefit information and support*

In order to make informed decisions in a complex and uncertain situation, residents need accurate information about what the scheme offers, what it costs, what state subsidies will be available, and what the options may be if circumstances change. Information on housing, care and support charges and state benefits need to be individualised since these vary according to individual circumstances. This information should also be provided in a timely manner. For many, whether HWC can be afforded will depend on maximising their income through benefits. All stakeholder organisations should therefore make general information on charges transparent, and help individuals to access benefits advice, support to navigate the system, and advocacy or specialist services as necessary. They may also provide tools to compare costs. Blood *et al.* (2012b), and Copeman and Pannell (2012) provide examples:

The private provider McCarthy & Stone, and the not-for-profit Housing 21 both employ specialist in-house benefits advisers. In addition to taking referrals from staff, these services are publicised through regular newsletters and scheme visits, and they also provide training to scheme staff.

A local charity, St Monica Trust, contracts with the Bristol Citizens Advice Bureau to provide a dedicated benefits advice service in resident's homes. All three approaches ensure that confidential free advice and help with claim forms is available to prospective or existing residents.

Linking up with a specialist local authority or voluntary sector team is another possibility, though probably more likely where social services are involved in referring or nominating residents than for private self-funders.

McCarthy and Stone provides 'comparator tools', which enable an individual to assess the real costs of their current circumstances (housing running costs, maintenance, utilities, care if applicable) with the equivalent costs of living in HWC, with the intention of demonstrating the real cost comparison between remaining in-situ or moving to HWC.

## Conclusion

These studies reinforce the findings of other research: that HWC is a form of housing and support greatly valued by older people who live there, which can enhance quality of life for people with high or increasing support needs. It is a model that supports rights and promotes independence, privacy and control over how residents choose to live their everyday lives.

Residents, providers and commissioners of housing with care are facing complexities, uncertainties and challenges, making the future of the model unclear. Will benefit changes make it less affordable to residents? Will dwindling budgets make it more difficult for providers to be proactive in creating an ethos of tolerance and respect, developing opportunities for community participation, and delivering the seamless, personalised, high quality service that residents want? Will personal budgets result in more personalised support or a less flexible, responsive service? Will HWC become more institutional as residents' needs increase and HWC is increasingly restricted to those with high support needs by some commissioners?

It would be disastrous to let these things happen and, despite austerity, an active programme of development in both the private and social sector offers room for optimism. The good practice examples illustrate what can be achieved despite the challenges.

Many of the approaches outlined in the research, while requiring up-front investment of time, money or effort, are likely to result in improved efficiency and effectiveness, with fewer problems downstream, and in some instances, less expense. To maximise their own resources, residents need access to timely, individualised information, advice and support. Providers and commissioners are advised to consult on, define and communicate a shared scheme vision. They should clarify rights, roles and responsibilities, with some flexibility at the edges, and create opportunities for residents to engage in community life and decision-making individually and collectively, taking into account their aspirations and assets as well as needs.

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## About this paper

This *Round-up* was commissioned as part of the JRF programme 'A Better Life'. It draws together key messages and practice examples from studies into HWC. The author, Sue Garwood, is an independent specialist in HWC.

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