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The contribution of social work and social care to the reduction of health inequalities: four case studies

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Key messages

- Inequalities in UK health outcomes are widening.³ Although the Marmot Review¹ makes few references to social work and social care, it concedes that social care recipients are likely to be among the most disadvantaged of populations.
- There is no systematic body of research evidence that focuses on whether social work and social care has a direct effect on the distribution of health outcomes at the individual or population level.
- However, the health of most users of social care services is already damaged and for many this is a central factor in their involvement with social care services. Social work and care interventions targeted at social care clients, and at the general population, can reduce health disadvantage across the life course.
- To illustrate this, we chose interventions from across the life course. Studies referred to all measured impact on health. They are Sure Start/Children's Centres; the placement of looked-after children with kinship carers; support for parents with intellectual disabilities, and extra care housing for older people at risk of entering care. Research shows that social interventions impact on health disadvantage in individuals and populations, but to impact on health inequality, they must be adequately and sustainably resourced.
- The key message of this briefing is that social work and social care practitioners work with some of the most disadvantaged groups in our society, and this offers many opportunities to improve the lifetime health of those most at risk. The achievement of health benefits and healthcare cost savings requires financial and research investment in the social care sector.¹



Introduction

This briefing argues that support given as social care can help improve health and reduce health disadvantage. Improving access to social care interventions is therefore important to any strategy for reducing health inequality. The concept of health inequalities refers to the avoidable health disadvantage people experience as a result of adverse social factors, such as lack of economic or social capital, or marginalisation. People with higher socioeconomic position in society have better life chances and more opportunities to flourish. They also have better health. The two are linked: the more socially and economically advantaged people are, the better their health. Moreover, a person's social and economic status often develops incrementally: a young person raised without support from parental figures is more likely to develop long-term physical or mental illness, is more likely to miss out on schooling and lack educational qualifications, and is then more likely to be unemployed or in insecure, ill-paid or unfulfilling employment and substandard housing, as well as more likely to suffer ill health and early death: 'Inequalities in health arise because of inequalities in society – in the conditions in which people are born, grow, live, work, and age'.1

These factors, and consequent health disadvantage, particularly affect people who use social care, raising the question of the role of social care in reducing inequality and disadvantage.

The Strategic Review of Health Inequalities Fair society, healthy lives¹ was conducted in the wake of a World Health Organisation (WHO) commission on the Social Determinants of Health,² to form the basis for a strategy for addressing health disparity in England. Inspired by early reports of the Review, the Social Care Institute for Excellence (SCIE) brought together a number of academics who were concerned to evidence and demonstrate the central role that social care and social work might have in contributing to the reduction of health inequality. We found no evidence that social care as currently

organised can reduce social inequality across the board, but we did find examples to illustrate the role of social care in promoting the welfare of all, and alleviating or equalising the health disadvantage experienced by particular groups. Although largely completed before the publication of the Marmot Review in 2010, we believe that this briefing complements that document.

What is the issue?

Despite continuing overall improvements in life expectancy, inequalities in UK health outcomes are wide and widening.3 Differences in average life expectancy between the most advantaged and most disadvantaged local boroughs in the UK increased from 9 to 11 years for men over the decade to 2001.⁴ Differences between sub-districts are even more stark, with men in one district in Glasgow having an average life expectancy of only 54 while the national average is over 75.5 Crucially, however, inequalities do not impact only on the most disadvantaged, but are reflected in a gradient across the population: 'Put simply, the higher one's social position, the better one's health is likely to be.'1 Social care services are by and large delivered to people with social and health disadvantage, a large proportion of whom are already ill and/or disabled. Social work and social care have established experience of working with marginalised groups, and may play an important role in promoting individual and community health and wellbeing. The value base for social work includes a focus on social justice, and individual development and empowerment, which may directly impact on the social determinants of health.⁶ By interrogating the role that social care can play in the health of disadvantaged people across the life course, important evidence-based recommendations for action on health equity can be developed.

Why is it important?

The social determinants of health impact on health status throughout the life span of an

individual. These determinants reflect the conditions of social life which contribute to social inequality: access to material resources and services, locality factors, education, training and employment, and individual factors such as access to social capital and the confidence or esteem to benefit from opportunities. Secondly, many users of social care and social work services have a lifetime history of disadvantaged economic, environmental and social circumstances,4,7 and this may be a central factor in their involvement with social care services. Implicit within this complex understanding of health and health disadvantage is the acknowledgement that health cannot be reduced to physical pathology. According to the WHO, health is not only the absence of disease, but a state of complete physical, mental and social wellbeing.8 Our main topic is therefore the social determinants and physical, mental and social outcomes of a healthy life, and how these might be influenced by social interventions.

The immediate reasons for poor health at the population level include smoking, obesity, excess alcohol consumption, unhealthy diets and lack of exercise. However, there is substantial evidence to counter the argument that health inequalities are merely the product of individual choices. The WHO Commission on the Social Determinants of Health suggests we need to consider 'the causes of the causes'. The choices that people make are themselves influenced by social position and the more adverse the social circumstance the greater the impact of these choices on health outcomes. 10

Socioeconomic position is further influenced by group and area factors. For example, racism or homophobia may exacerbate the relationship between social position and poor health, while there is also evidence that living in certain areas may confer relative disadvantage.¹¹

Poor health should be seen in terms of cumulative disadvantages across the life course.⁶ For example, children and young people who

have experienced abuse or neglect, who are disabled, in local authority care or youth offender systems, and their parents, are among those most likely to die prematurely as a result of poor health and unhealthy lifestyles. 12 People with mental health problems, who have learning disabilities or are disabled, who are addicted to drugs or alcohol, or who are obese, may be storing up poor future health because these circumstances create barriers to economic, environmental and social success, and because their physical health needs may be neglected. 13 As the Marmot Review argues, investment during the early years of life may be the most important priority for reducing health inequalities within a generation. Disadvantage arises across the life course, 14 and the effect of early disadvantage on health may only be apparent in later life. This complicates the task of researching and evidencing the outcomes of social interventions.

While some childhood experiences of relative disadvantage work directly to produce poor health, others work indirectly, by positioning the child for entry into adult life with less social capital and a lower position in the social hierarchy – for example, through lower educational attainment. The lifelong accumulation of risk is the reason childhood is so important for reducing health inequalities. 15,16

Risks can be accumulated through independently occurring factors (e.g. a fall and the loss of a spouse in old age), or through 'clusters' (e.g. low birth weight, not being breast-fed and living in accommodation without a garden), or via 'chains' of correlated factors (e.g. abuse leading to life in care and reduced educational success; a mental health crisis leading to loss of employment in adult life).¹⁷ Key transition points (e.g. from life in care to independence; parenthood; redundancy; entry into residential care) can be critical risk periods when the availability of resources is particularly significant.

There have been no research studies which directly tested whether social work and social

care have reduced inequalities in health at the population level. In principle, however, social work and social care can help reduce health inequalities by improving the conditions across the life course which affect the health chances of the most disadvantaged individuals and groups. This work will include enabling more equal access to resources through the provision or brokering of social care and other services, and increasing opportunities to make and benefit from healthy choices.

In the following briefing, we examine evidence for the potential impact of social care on health inequalities through four illustrative topics which span the life course. We look in particular for evidence that social work and social care delivered through or in partnership with local authorities can have an impact on the social determinants of health. The briefing aims to act as a signpost to some of the relevant literature, but there was no systematic appraisal of the research studies included, and the commentary indicates, but does not test, the research findings. Finally, the lack of direct studies of effectiveness of the social work and social care contribution means we have not been able to examine economic benefits or cost analyses.

Organising this research briefing

The aims of this briefing were to illustrate the impact of social care and social work-led interventions on health inequalities or, where the evidence was lacking, on health disadvantage. Four examples of social care interventions across the life span which research suggested would impact on health inequalities and/or the social determinants of health were identified:

- early years programmes (such as Sure Start)
- kinship care for looked-after children
- parenting programmes for parents with learning difficulties

extra care housing for older people.

A full account of the method used in identifying and organising material for this publication is available at www.scie.org.uk/publications/briefings/files/researchbriefingguidance2009.pdf A structured format was used to extract data from the studies in order to identify and collate relevant sub-topics within each set of papers. For more information, contact info@scie.org.uk

Factors which influence health outcomes are increasingly acknowledged as very broad: 'It is not health services which are the key variables in reducing inequalities: it is the social factors that influence health chances. These are factors which affect the prospects of good health or the likelihood of poor health and reduced life expectancy... the social, economic, environmental and political determinants of health as they affect people'. Our interest was to consider the potential for social work and social care to impact on these intermediary factors, and so facilitate better health and social outcomes. These factors include individual and population variables such as social capital, empowerment, access to services, transport, regional inequalities and responsiveness of services to specific minority needs. The Marmot Review⁹ identified the following key themes as significant to the task of reducing health inequalities:

- 1. reducing material inequalities
- 2. enhancing potential
- 3. empowerment: enhancing social and community capital
- 4. sustainability of neighbourhoods, transport and food systems
- 5. quality and flexibility of work and security of employment
- 6. protecting vulnerable groups
- 7. public sector performance and responsibility
- 8. strengthening the approach to evidence-based policy

To support proposition	Papers included evidence of
Social work and social care can impact on the health of individuals who use services. Because of their relative disadvantage, this is likely to be contributing to more equal health outcomes.	Individual health outcomes Promotion of safety and protection at individual level
Social work and social care can impact on the social determinants of health affecting disadvantaged populations in ways that can be expected to equalise health outcomes or mitigate health disadvantage.	 Individual social capital/empowerment outcomes Promotion of safety and protection at community level Promotion of non-health, potential enhancing outcomes, e.g. education, employment, training, social integration, volunteering
Social work and social care can impact on access to health (and health-related) services by disadvantaged populations and, therefore, is likely to be contributing to more equal health outcomes.	6. Access/use of health services outcomes7. Service delivery or provision issues8. Regional variation; outcomes for marginalised groups.

9. strengthening universal health prevention.

We have focused on the individual and community rather than the societal or structural elements of these priorities, as these are more likely to be affected by social work and social care interventions. These approximately map on to items 2–6 of the above list.

Having found no material which directly evidenced the impact of social work and social care on health inequalities, we sought evidence to support the propositions outlined in the table above, and extracted evidence wherever possible under the headings shown in the right hand column of the table.

For the most part, the findings sections for each example area are organised into headings arising from these categories of evidence.

Early years programmes (31 studies)

Individual health outcomes

Early years programmes have been shown to improve maternal and child health. For example, mothers who attended Webster Stratton's Incredible Years Parent Training Programme reported lower levels of stress and depression, 18 and children with conduct problems presented lower levels of inattention and hyperactive/impulsive difficulties. 19 Investment in the early years is considered 'vital' to reducing health inequalities by Marmot Review, 1 offering higher returns than investment in older children's care.

Sure Start programmes impact on a range of health-related factors. Northrop et al.²⁰ found that parents sought help from Sure Start with

issues such as breast feeding, baby massage and improving confidence for their children. Sure Start home visits have also been shown to improve family health and increase parental confidence.^{21,22} Belsky et al.'s initial evaluation of Sure Start^{23,24} suggested that programmes were less effective for those with poorer social functioning. However, Siraj-Blatchford and Siraj-Blatchford²⁵ found that Sure Start had some success in achieving higher immunisation levels in disadvantaged areas. Children in Sure Start local programme (SSLP) areas were more likely to have received recommended immunisations and less likely to have had an accidental injury in the year preceding assessment.²⁶ However, caution is required in interpreting these effects because of the time difference which may reflect national changes in immunisation uptake. National evaluations have also been hampered by the different stages of implementation of Sure Start programmes at the point of data collection, different local formats and even different aims and functions at the local level. In England, the types of provision with the most positive effects are found to be integrated centres and nursery schools, and the least effective are local authority (social services) day nurseries.²⁷ Similarly, NESS²⁸ and Lord et al.²⁹ reviewed studies and found that broader child developmental outcomes can be produced by integrated Children's Centres, and Children's Centres are now the norm for delivery of early years' support. Benefits reported for children include improvements in social skills and general health.²⁹

Promotion of safety and protection at individual level

The NESS Research Team²¹ found that parents felt there was improved opportunity for safe play and learning. Also, more outside play facilities were mentioned as a key strength in a local area. Safety equipment loan systems were deemed successful by parents. However, Siraj-Blatchford and Siraj-Blatchford²⁵ observe little evidence that home visiting and providing safety equipment help to reduce accidental injury.

Individual social capital/ empowerment outcomes

Sure Start evaluations reveal a range of empowerment and self-confidence benefits in parents and children. The NESS Research Team, 21,22,28 Allen, 31 Anning et al. 32 and Bagley and Ackerley³³ found that Sure Start increased confidence, parenting skills and bonds between parents and children, as well as social capital and empowerment. Children were more confident in socialising with their peers, had a greater independence and improved skills acquisition, such as learning through play. Northrop et al.²⁰ found that parents' perception was that Sure Start improved children's happiness, independence and success. The NESS Research Team²² also found that transforming professional relationships with parents, providing responsive services, strengthening programme ethos, working with communities and understanding local context all increased empowerment. Other literature supports these findings. Lord et al.²⁹ reviewed studies and found that early years provision of all types produces good results on social/behavioural and learning outcomes. However, integrated care and education centres, as well as nurseries, have been shown to promote better outcomes than other settings.³⁴ Such provision is particularly effective for children facing multiple risks or who start at an earlier age.35

Promotion of safety and protection at community level

The literature does not really cover this topic, but does discuss community development and empowerment. Literature supports the idea that community development brings 'added value'. Supportive partnerships, good social networks and local community support have a protective effect and can help parents with rearing children. The NESS Research Team found an increased level of 'community spirit' with parents working together to improve local communities as a result of Sure Start. However, NESS found variation in the extent to which mutual support among parents, parental involvement and

volunteering, and community-oriented actions generated *group* and *community empowerment*.²³ Craig et al.'s case study report³⁷ found that there is a need for SSLPs to develop a wider community development role which could engage local community organisations and encourage them to work at a partnership level. SSLPs could then provide bridging links to other services and enable inclusion of more marginalised communities.

Promotion of non-health, potential enhancing outcomes – e.g. education, employment, training, social integration, volunteering

The impact of early years intervention on later educational and other health-promoting outcomes has been supported in the literature. The 2009 school report by the Office for Standards in Education (Ofsted) shows that Sure Start children had improved attitudes to learning and social development.³⁸ Blok et al.,³⁹ Campbell et al.,40 Hill et al.41 and Melhuish27 agreed that children who received pre-school training earned significantly higher academic scores as young adults. Siraj-Blatchford and Siraj-Blatchford²⁵ note that the Incredible Years programme (Webster-Stratton), Peers Early Education Partnership (PEEP) and Enhanced Triple P -Positive Parenting Programme home visiting all improved children's social behaviour. The NESS Research Team²¹ and Schneider et al.⁴² found that early benefits arose from provision of high quality play and learning experiences. The NESS²⁸ also found that SSLP families showed better home-learning environments than others.

Access/use of health services outcomes

There is considerable discussion in the literature as to the impact of Sure Start on access to services more generally, including debate about the accessibility of Sure Start itself. NESS⁴³ argues that barriers such as geography and age, and the operation of 9–5 'office hours' can also mitigate against access, particularly for working parents. Pearson and Thurston observe that

mainly mothers attend Sure Start and suggest that men may feel uncomfortable attending.⁴⁴ However, NESS²⁸ emphasised that families in Sure Start local areas used more services for supporting child and family development than those elsewhere. NESS²¹ also found that Sure Start promoted better access to professional advice, for example, professional speech and behaviour therapists. Carpenter et al.⁴⁵ found that the quantitative data revealed no discernable short-term effect on the number of child social services referrals or child protection registrations.

Service delivery or provision issues

Recent evidence provides pointers of good practice for more inclusive service provision. Siraj-Blatchford and Siraj-Blatchford's review²⁵ found that families' ability to take advantage of Sure Start provision was negatively related to disadvantage (i.e. there was an under-representation of teenage parents, lone parents and children from workless households). Coe et al. 46 identified barriers to the use of Sure Start to be: lack of transport, cost, language barriers and poor perception (e.g. thinking Sure Start was just for 'disadvantaged people'). Northrop and Pittam²⁰ noted that 'lack of time' stopped people engaging, but that simple solutions such as weekend services improved involvement of working parents. Other practical improvements such as access to a range of professional support under one roof, continuity of midwife, more flexible timings of services, better transport to services, better system of appointments for doctors and better publicity for services have been suggested by parents. 38,47 Arnold⁴⁸ notes the importance of listening to users of Sure Start services and taking action on their suggestions wherever possible.

Regional variation

Access and attendance has been an issue for Sure Start. Craig et al.³⁷ found many examples of poor practice relating to access, including inappropriate use of relatives or peer group

members as interpreters in place of professional translators. The authors suggest that demographic change is occurring more rapidly than previously, and SSLPs need to re-evaluate their services annually, collecting local demographic data, to ensure the inclusion of incoming parents, even coverage and relevant services. Approaches to working with particular groups may need to be tailored closely to the religious and cultural context, or encourage fathers to become involved.

Potentially marginalised groups (i.e. ethnic minorities, children with disabilities)

Minority groups can be particularly vulnerable to inequalities in the distribution and use of care services. Pinney's research⁴⁹ identified considerable barriers for parents of disabled children accessing extra care. She recommends that the take-up of Children's Centre services by children and families with special needs and disabilities should be monitored. Minority ethnic groups may also experience difficulties accessing services. For example, although the Centres that Ofsted³⁸ surveyed found that parents from minority ethnic groups generally made good use of services, six centres (serving communities of mainly disadvantaged white British background) were finding it difficult to secure the trust of these communities. Craig et al.³⁷ and Avis and Chaudhary⁵⁰ found evidence that services stereotyped minority ethnic groups, and/or ignored differences between class and gender within minority groups. NESS argues that creating a team from a varied staff group, and striving to reach all eligible families requires more effective inter-agency working. There is mixed evidence for the use of outreach workers of community origin: several SSLPs observed that outreach workers from a particular community were essential, but other research identified suspicion of workers from within the community arising from fear that they would not preserve confidentiality.^{22,37} Involvement of minority staff in designing centre policy may help encourage

involvement.³⁷ Pearson and Thurson⁴⁴ and NESS²² suggest that 'hard to reach' groups (such as foreign nationals, minority ethnic communities, disabled people and caregivers, people with learning difficulties, very young mothers and new users of services) were more likely to engage if they received home visits. A parent advisory service has shown significant improvements for Bangladeshi families.²² The national Sure Start evaluation report confirmed that ethnically diverse areas need diverse strategies to encourage greater inclusion.

Kinship care for looked-after children (12 studies)

Individual health outcomes

The discussion of individual health outcomes is limited and tends to focus on mental rather than physical health. For example, although Farmer et al.'s case file review of 270 children⁵¹ (half of whom were in kin and half in stranger foster care) found no difference in long-term health conditions of children placed in kinship compared to foster care, they did find that children in non-kin foster placements were significantly more likely to have emotional difficulties than those in kin care. Similarly, Winokur et al's systematic review⁵² suggests that children in kinship foster care experience better mental health functioning than do children in non-kinship foster care. The majority of the literature on kinship care focuses on behavioural development and placement stability rather than health outcomes.

Promotion of safety and protection at individual level

Farmer⁵¹ and Waterhouse et al.^{53,54} found that children received better placement stability with kin compared to non-kin carers. Sallnas et al.'s investigation of placement breakdown in different placement types⁵⁵ found the lowest rate of breakdown in kinship care and secure

units. Reduced levels of placement breakdown plays an important role in reducing health inequalities, since higher risk of breakdown is associated with young people displaying antisocial/criminal behaviour problems, and experiencing drug/alcohol problems or mental illness. Compared with non-kin placements, kinship placements were found to be more enduring and less prone to breakdown. Aldgate and McIntosh's findings⁵⁶ support this conclusion, and argue that kinship care may be the most appropriate arrangement for children unable to live with their parents. Kinship care placements can provide stability, a sense of belonging and identity, and the chance to maintain meaningful relationships with family members.⁵⁴ However, Farmer⁵¹ notes that the outcomes for carers may be worse. Kin carers receive less support and less monitoring of placements from social services than non-kin carers, especially if under a Residence rather than a Care Order.

Individual social capital/ empowerment outcomes

The literature suggests that children raised by kin tend to have more positive outcomes than those raised by non-kin. However, Cuddeback's synthesis of kinship care research⁵⁷ found a lack of evidence for the perceived benefits of kinship care such as continuity of identity/culture/family and environment/familiarity with child. Nevertheless, Aldgate and McIntosh⁵⁶ argue that although only a few studies have focused on outcomes for children and young people, those that do examine care placements tend to favour kinship care. Attree's synthesis of qualitative studies that addressed children's accounts of living in disadvantage⁵⁸ found that young people describe neighbourhood and social factors such as the continuity of social and community context found in kinship care as mitigating disadvantage.

Aldgate and McIntosh's study⁵⁶ found mixed outcomes for kinship care. They surveyed 32 local authorities in Scotland and found that the most

optimal benefits of kinship care were: children feeling loved, valued and cared for; children being able to maintain a sense of identity and belonging; children feeling settled because they are placed with people they know; children being less likely to be subject to placement moves; and maintaining contact with family and friends. However, they also discuss a number of disadvantages, including: limitations to freedom for children and carers; financial hardship; problems for carers in having to cope with the behavioural difficulties of young people; lack of support from child welfare agencies; overcrowding; ill health of carers; less thorough assessments for kinship carers than non-familial carers; less stringent monitoring of placements; lower reunification rates for children; and children being less likely to be adopted.

Stein⁵⁹ argues that best outcomes depend on the quality of non-kin placements, and these vary widely. For example, some foster placements have an immediate and very positive effect on quality of life, as well as the longer-term wellbeing of young people placed in them. However, others are marked by bullying, sexual harassment, delinquency and misery. Stein concludes that a key determinant of these differences is the quality of the carers – the foster carers, practitioners, heads of home and staff groups. Other factors such as parental substance misuse can also affect whether kinship care is the best solution for the child.

Aldgate and McIntosh argue that the challenge is for social work services to support children in kinship care, along with their carers, so that being looked after by the extended family provides the opportunities and experiences that equip children for a successful adult life. One aspect of this could be involving children in placement decisions. Fox and Duerr Berrick⁶⁰ found that children are empowered if involved in care and placement planning. Similarly, Aldgate and McIntosh discuss Greef's model that places the child and family, not the social worker, at the centre of planning.⁵⁶

Promotion of safety and protection at community level

None of the studies reviewed address the issue of community level safety.

Promotion of non-health, potential enhancing outcomes – e.g. education, employment, training, social integration, volunteering

Winokur et al.'s systematic review⁶¹ found that children in non-kin placements typically display more educational problems than their peers, although it is unclear whether this results from the placement itself, the maltreatment that precipitated it, or child welfare system inadequacies. However, Farmer⁶² studied the characteristics, progress and outcomes of children placed with family and friends, compared these with a similar group of children placed with unrelated foster carers and noted that children in foster care had similar levels of general health, school attendance, emotional and behavioural difficulties as those in kin care. Stein⁵⁹ simply suggests that high-quality placements and the stability of long-term placements for children over 11 are central to children's wellbeing, their satisfaction with schooling and their general happiness.

Access/use of health services outcomes

Winokur et al.⁶¹ showed that children in foster care were more likely to receive mental health services than those in kinship care. However, they additionally suggested that foster parents' 'system involvement' may explain the propensity for children in foster care to receive mental health services. The training and supervision of foster parents may contribute to the identification of mental health problems, and as such contribute to higher levels of service utilisation.

Service delivery or provision issues

Carers may often have to give up caring for kin due to financial hardship and lack of support from

child welfare agencies.⁵⁶ Kinship carers therefore need more support and funding to secure stability for children.⁶³

Regional variation

Aldgate and McIntosh⁵⁶ found that the level and nature of support provided for kinship care placements varied geographically. They note that supporting kinship carers financially is a major issue for local authorities: there is considerable variation in the rates of pay to kinship carers, who are often paid a lower rate than non-kin foster carers. Authorities also use differing approaches to finance based on the status of the carer and that of the child. In addition, welfare benefits legislation is found to be unhelpful and confusing for new kinship carers, as authorities may use several different budgets to provide financial support. Many authorities operate a customised system of financial support, but there is a need for some standardisation for kinship care placements. Similarly, Stein found regional variations in services, including the use of placements, the availability of workers with specialist skills, and access to services.⁵⁹

Potentially marginalised groups (i.e. minority ethnic groups)

Aldgate and McIntosh⁵⁶ found that kinship carers are at a disadvantage in that they are often are financially poor and receive less support from local authorities than non-kin foster carers. For example, kinship carers are often paid at a lower rate than foster careers, or may not receive any funding beyond universal child benefit.

Parenting programmes for parents with intellectual disabilities (24 studies)

Individual health outcomes

'High quality parenting programmes can achieve multiple impacts on inequalities in children's early years, education and health outcomes and parental health and wellbeing.'1 Compared to other parents, parents with intellectual disabilities are more likely to be socially isolated and living in poverty with poor housing. This can have a negative effect on both children's and parents' physical and mental health.⁶⁴ Social care could reduce health inequalities by helping such parents to access better financial and housing support. For example, Tarleton et al.⁶⁵ found that skills that address wider problems (such as avoiding getting into debt) could make a simple but profound impact.

Poor education can also lead to poor health outcomes. Parents with intellectual disabilities are often disadvantaged in terms of sex education^{64,66} and have difficulties understanding the information they receive during antenatal care.64 As a consequence, the health of the mother and child can be put at risk. Parents with intellectual disabilities often lack skills and knowledge related to child health, safety and development. However, Feldman et al.⁶⁷ and Feldman and Case⁶⁸ found that parents can improve their child care and safety skills through audiovisual self-instructional handbooks, and Llewellyn et al.69 found similar benefits from home-based interventions. However, Sheerin notes that services tend to only introduce parenting programmes in extreme cases where children are at risk. 70 Sheerin argues that services need to provide more preventative care and support those parents who may be in need of help but whose children are not known to services as being 'at risk'. Tymchuk⁷¹ suggests that services need to be more integrated to support parents with intellectual disabilities, while Sheerin proposes that nurses from maternity, intellectual disability and public health could work together to design antenatal education programmes appropriate for such parents.

Promotion of safety and protection at individual level

Tagg and Kenny found that despite policy recommendations, there has been a shift from

supporting parents with intellectual disabilities to judging them. 72 Olsen and Wates agree that parents with disabilities frequently perceive services as undermining rather supporting them in their parenting role. 73 In order to prevent themselves being labelled as 'in need', parents with intellectual disabilities may reject help. Booth and Booth note that parents who do not acknowledge care concerns when engaging with professionals are less likely to have their children returned home after removal from parental care. 74 This creates a 'catch 22' situation: parents must first admit their behaviour is putting their children at risk (thereby legitimising social service intervention) in order to have any chance of their family being reunited. Tarleton and Ward similarly found that because parents fear having their children taken away from them, they avoid services and professionals.75 To promote safety, government policy and social services need to address these negative cycles by changing the perception and reality of service intervention from one of judgement to one of support.

In addition, Tagg and Kenny found that parents with intellectual disability may find it difficult to understand the importance of outpatient appointments and struggle to attend appointments at specific times. The Lack of private transport and insufficient means to pay for transport, may compound these difficulties. Missed appointments and failure to comply with medication regimes should not be automatically interpreted by professionals as neglect or disinterest in the child. By working closely with families and understanding the family environment, social care workers could support parents by improving communication between parents, health services and the legal system.

Individual social capital/ empowerment outcomes

Campion notes that although for most women pregnancy is a time of joy, for many with intellectual disabilities it is regarded by professionals and family as a time of crisis rather than celebration.⁶⁶ Campion, along with Llewellyn,⁷⁶ found that women with intellectual disabilities often experience disempowerment and an undermining of their right to even consider the option of parenthood: they may be advised to terminate the pregnancy or relinquish the child. Campion notes that if a mother chooses to keep her child, she must prove to child protection professionals even before the birth that she is capable of adequate parenting. Once the baby is born the mother is likely to be closely supervised, perhaps by several different professionals who may give conflicting advice.

Parents with intellectual disabilities may also lack the social support that other parents have. McGraw et al. found that such parents frequently feel socially excluded and may depend on statutory agencies for support.77 Women with intellectual disabilities may also lack positive parental role models.66 Tagg and Kenny argue that environmental factors such as poverty, and a lack of appropriate support to nurture and understand early developmental needs, put parents with intellectual disability at a disadvantage to other parents.⁷² Mothers with intellectual disabilities are more likely to be single parents without a significant other in their lives who can support them. If they are in a relationship, their partners may also have intellectual disabilities and be subject to the same social disadvantages. 64,72 Tagg and Kenny also argue that although abuse of children by mothers with intellectual difficulties is rare, such mothers may be more vulnerable to men who have a history of offences towards children.72

A number of interventions have tried to address the lack of empowerment in parents with intellectual disabilities. Booth and Booth's 'Parents Together' programme⁷⁸ was set up as an independent network to provide support for parents with intellectual disabilities or those expecting or considering having a baby. The project aimed to enable parents by creating

opportunities for them to exhibit their competence, improve their sense of control over their lives, enhance their self-esteem and extend their social networks. Although the programme helped parents work with their problems and to feel better about themselves, it did little to change their situation. Additionally, McGraw et al. 77 found that group intervention improved parents' own views about themselves and allowed them to make new friends but no immediate benefits for their children were found and the intervention did not deliver benefits for the children, nor improve parents' expectations about their children's capabilities, or significantly reduce parental stress. Booth and Booth argue that without an adequate infrastructure from heath and social services, advocacy alone will not relieve the environmental pressures that undermine a parent's ability to cope.74

Promotion of safety and protection at community level

Llewellyn⁷⁹ found that parents with intellectual disabilities receive very little support from the community, and in 2002⁸⁰ confirmed that few mothers could identify supportive ties with friends and neighbours. The challenge for social services is to devise ways in which these mothers can be assisted to develop local, community-based support networks to help with the demanding tasks of parenting.

Promotion of non-health, potential enhancing outcomes – e.g. education, employment, training, social integration, volunteering

Although children raised by parents with intellectual disabilities may be at higher risk of neglectful care due to parenting skill deficiencies, there is a plethora of research that shows that many parents are competent and can improve their skills with training.^{70,72} Such parents have been shown to improve parenting skills through self-instructional pictorial

child-care cards;^{81,82} training on nutrition and feeding;⁶⁷ group learning;⁸³ and home-based training.^{84,85,86} However, these training programmes tend to focus on specific skills rather than addressing the fundamental issues, such as poverty, social isolation and poor service provision, that may prevent parents with intellectual disabilities achieving equal health care for themselves and their children.

Access/use of health services outcomes

Campion found that many women with intellectual disabilities do not have the same access to maternity care choices as women without intellectual disabilities.66 Tagg and Kenny note that parents with intellectual disabilities often miss out on programmes such as Sure Start and experience difficulties accessing resources in community settings.72 Furthermore, Ward and Tarleton discuss how lack of resources can inhibit the provision of appropriate levels of service: parents with intellectual disabilities may not reach local thresholds for community care services, and only show up on services' 'radar' if children are seen to be in need or at risk.87 Their 2007 study found that approximately 50 per cent of parents with intellectual disabilities have their children removed from them, usually as a result of absence of appropriate support. The authors argue that negative or stereotypical staff attitudes in some services may prevent parents with intellectual disabilities receiving appropriate support. To support parents, social services need to introduce appropriate resources and parenting programmes for all parents, and to train staff to address negative stereotyping.

Service delivery or provision issues

Limitations in service delivery and provision outcomes for parents with intellectual disabilities may contribute to inequalities in their health care. Booth and Booth argue that although the rates of removal of children from such parents are high, the investment in the

kinds of services that might enable them to bring up their children is low. 78 Booth and Booth and Ward and Tarleton⁸⁷ highlighted a number of pitfalls in service delivery, which included: the presumption of incompetence by professionals, including fixed ideas about what should happen to children of intellectually disabled parents; tension between the policing and enabling roles of social workers; services de-skilling parents by taking over their responsibilities; blaming the victim rather than addressing deficiencies in social services; lack of trust; and services offering conflicting advice. Furthermore, Tagg and Kenny found that nurses may lack the skills to communicate with a broad spectrum of family units and that parents with intellectual disabilities may miss the subtle messages given by staff, leaving them open to criticism and putting them in a negative light.⁷² Campion's 'Right from the Start' project looked at improving service provision for people with intellectual difficulties. 66 It was suggested that professions such as midwives, health visitors, community nurses, family doctors, psychiatrists and clinical psychologists need appropriate training to support these parents. Together the findings from the literature highlight ways in which social care could reduce inequalities for parents with intellectual disabilities. It is argued that failure to recognise the changes needed in care delivery for parents with intellectual disabilities will perpetuate discrimination and inequalities for adults and children.

Regional variation

This was not raised in the literature reviewed.

Potentially marginalised groups (i.e. minority ethnic groups)

These were not specifically mentioned in the literature reviewed. This may suggest that learning disabled parents of ethnic minority background face even greater obstacles to support in parenthood, or that existing services do not consider that such parents have different needs.

Extra care housing for older people (27 studies)

Definition

For the purposes of this briefing, extra care housing was considered as an alternative to entry to residential care for an older person unable or unwilling to live in their current home. To qualify, the housing provided had to be an individual's home (with separate entry), and not a care home or hospital, with ownership, lease or tenancy arrangements. The accommodation had to be specially designed or adapted to satisfy the care and support needs or owners/tenants, and care and support had to be accessible on site or on call 24 hours a day. (This definition derives from the Care Services Improvement Partnership.) Such communities may be referred to as 'retirement villages'.

Individual health outcomes

Research suggests that extra care housing improves health outcomes for older people. Croucher et al.88 and Brooker and Wooley89 suggest that housing with care can positively impact on health and wellbeing, and may offer better quality of life than other settings. However, people who moved into extra care tended to be less physically and mentally impaired than those who moved into standard care homes. 90 Nevertheless, Croucher found that although many people move to retirement villages because of poor health, they consistently and over time rated their health significantly better than a matched local sample, while the health of the local sample deteriorated.91 Croucher found that security as well as high peer support and a general sense of optimism in the village contributed to residents' physical and mental wellbeing. Croucher further suggests that resident groups can be effectively targeted for health promotion initiatives, and that retirement villages have a significant role in promoting health and wellbeing by reducing social isolation. Brooker et al. found that schemes reduced

residents' hospital stays and improved diagnosed mental health problems. 92 Cantley and Cook found that extra care housing residents report improved or maintained wellbeing, but argue that the current evidence base is limited and further research is needed. 93

Promotion of safety and protection at individual level

Bernard et al. argue that residents feel more secure living in purpose-built retirement villages.⁹⁴ Brooker et al.⁹⁵ and Croucher^{91,96} found that retirement villages improve both independence and security.

Individual social capital/ empowerment outcomes

Evans suggests that beneficial social relationships, access to support and participation in social activities can influence quality of life for older people at least as much as their health status.⁹⁷ Bernard et al. note that although social support may be available, physical and sensory disabilities may compromise full participation and increase isolation.94 Evans and Vallelly suggest that those at risk of social exclusion, including new residents, people without regular family contact and those with impaired mobility, should be offered additional support. 98 Dutton suggests that although some tenants with dementia can be at risk of social isolation and discrimination, there is evidence that people with dementia living in extra care housing have good quality of life.99 However, Cantley and Cook argue that it is still not fully clear whether extra care reduces social isolation.93

Independence can contribute to wellbeing. For example, Brooker et al.,95 Croucher91 and Croucher et al.88 found that retirement villages improve both independence and security for residents. Croucher et al. explain that it is the combination of these that residents value.

Evans and Vallelly interviewed tenants and managers and found the involvement of family as

well as peer social interaction to be important for wellbeing. 100 Whether they lived locally or further away, family members played a large part in the lives of many, offering practical and emotional support. Burke et al., 101 Evans et al. 102 and Evans 103 found similar findings for many tenants. However, although Cantley and Cook found that extra care enables continued family involvement, they argue that there is less evidence of direct benefits for carers. 93 Researchers highlight a need for more evidence on supporting social wellbeing, including that of carers.

Promotion of safety and protection at community level

Research discussed how, on a personal level, residents felt safer living in purpose-built retirement villages than in their own homes, 104 yet discussion about the promotion of safety and protection at community level was limited overall. One study by Bernard and Bartlam et al. 94 suggests that prior to coming to the retirement village, residents would be too afraid to join clubs that meant travelling after dark. Extra care housing is often seen as a community in itself, in that it offers social, recreational and medical provisions 'in-house'. However, Cantley and Cook argue that there is still not enough evidence to support the claim that extra care provides a fully supportive environment. 93

Promotion of non-health potential enhancing outcomes – e.g. education, employment, training, social integration, volunteering

Croucher suggests that extra care housing facilities promote leisure, education, social engagement and feelings of community with in-house cafes, restaurants, health and fitness suites, computer rooms and small retail outlets making retirement villages 'places to live' rather than care settings. 91 The consultation summarised by Allardice 104 suggests that greater involvement of older people in areas such as design may reduce the institutional feel and promote integration. Evans and Vallelly 100 and

Evans⁹⁷ suggest that wider community engagement promotes older people's well being: tenants who engaged with community activities felt life to be more stimulating. However, Evans argues that opportunities for community engagement can depend on various factors, such as availability of appropriate transport, the quality of pavement access for mobility aids, and available support. Croucher found that the contribution of older people to community life is increasingly recognised, but older people can be inhibited from taking part due to factors including poor health, access issues and information.91 Retirement villages may reduce such barriers. Evans and Vallelly98 argue that facilitating tenants' wider community engagement requires involvement of designers, local planners, service providers and others at an early stage of development.

Access/use of health services outcomes

Cantley and Cook⁹³ suggest that extra care may reduce pressure on other health and social care services, for example by promoting early hospital discharge and reducing the need for hospital readmissions. Kingstone et al. found that due to in-house care, residents required less contact with external services than did the local matched sample. 105 Vallelly et al. agree that extra care housing residents have most health care needs met in-house. 106 Although some extra care residents are admitted to hospital, inpatient stays are shorter than those of the general population. Croucher⁹¹ and Brooker et al.⁹² suggest that since extra care residents are concentrated in one place, health and social care professionals can attend one site, saving time and resources and increasing professional productivity. Consequently, extra care residents have more opportunity to access GP home visits and preventive services such as physiotherapists or chiropodists, preventing more major health care problems developing. Croucher suggests that retirement villages may support service developments which benefit not just residents but other older people locally.

Service delivery or provision issues

Issues that could impact the effectiveness of extra care service delivery include design and management, staff training, whether extra care represents a home for life, and whether care is person-centred and incorporates freedom of choice.

Design and management of extra care housing

Evans and Vallelly argue that when considering the planning, design and management of extra care housing, social wellbeing of tenants should be a priority. 98,100 They find that provision of leisure facilities, gardens, day centres and guest rooms encourages social connectivity. Although larger buildings may have more social facilities and appear to offer some social advantages, 96 they can also present limitations. For example, Bernard et al. found that large establishments intensified isolation for new residents and those with mobility problems, and may disorientate people with mental problems. 104 Croucher found that residents claim that more space is needed for 'living', rather than 'functioning'.96

Balancing security and independence is also a design consideration. For example, Allardice¹⁰⁴ suggests that although security is important, dignity and privacy issues should not conflict: for example, security alarms should be discreet. There is also debate about age-segregated housing. Croucher found that some residents preferred age-segregated living.96 However, Bernard et al. found that 'age clustering' was a concern for some, potentially lowering morale. Croucher also found that since men tend to be the minority in extra care living, more thinking is required regarding activities and spaces that accommodate them. 94 The needs of other minority groups are discussed by Allardice, including gay and lesbian individuals and couples, the projected increase in numbers of couples needing accommodation in the medium term, and other groups such as homeless people.

Staff training

Allardice suggests that staff training and remuneration is key to promoting development of integrated and responsive services, especially where diverse needs are met in the same facility. 104 Other research elaborates on specific skills: counselling, bereavement counselling, 94 promoting social wellbeing 98,100 and issues regarding diagnosis and treatment of dementia and mental illness. 92

Home for life

Croucher et al. assert that 'home for life' is a potentially misleading description, and that 'ageing in one place' will not always be a reality as many older people will need specialist dementia or nursing care.⁸⁸ This is supported by others.¹⁰⁷

Person-centred approach

Evans and Vallelly found that person-centred care provision can contribute to social wellbeing by facilitating key-worker systems. 98,100 Evans suggests that schemes that include key workers benefit resident-staff relationships and can contribute to social wellbeing. 97

Freedom of choice

Croucher notes that choice is central to current policy. 96 Burke et al. found that extra care schemes were largely successful in this, enabling residents to influence changes as well as increasing consultation. 101 Evans 97 found that tenant-organised activities increase empowerment for older people and Cairncross and Bligh, 108 along with Dawson et al. 109 found that the most influential factor that encouraged development of extra care housing was a good working partnership between social services, housing departments and older people themselves.

Regional variation

Evans and Vallelly suggest that locating schemes in rural areas presents challenges in terms of

facilitating tenants' community engagement. P8
Easterbrook and Vallelly acknowledged in their research that differences in scheme success may depend on rural or urban location. Allardice supports this, arguing that older people's care should not be subject to a 'postcode lottery', further noting that access to social and leisure facilities may be especially important in rural areas. Rural extra care housing facilities should consider accommodation for health professionals so that residents have in-house access to these services.

Potentially marginalised groups

Dementia

The literature is unclear about the suitability of extra care housing for people with dementia. Evans suggests that people with dementia may be excluded from research due to perceptions that they are unable to communicate their views meaningfully. Research gaps are noted by O'Malley and Croucher and Dutton, among others.

Minority ethnic groups

Jones found that research into the housing-related needs of black and minority ethnic elders has at best been only partially implemented. Jones argues that the literature on housing and related needs of older minority ethnic groups relates to sheltered accommodation. 112 Jones 112 and Allardice 104 highlight a lack of provision for ethnic-specific extra care accommodation, and suggest that given current emphasis on integration, consideration should be given to the needs of mixed environments and balancing an integrated approach with the need/desire in religious groups for separate provision. People should have choice in relation to later life care. Allardice and the Institute of Public Care¹¹³ also suggest that extra care housing should plan to meet diverse needs, including appropriate advertising, service provision, support, research and incorporation of the needs and aspirations of diverse people who use services. The consultation further argues that the needs of other specific groups such as lesbian and gay

people, homeless and rough sleeping people and released prisoners also need to be addressed. Croucher et al. emphasise that knowledge of how to meet the needs of older people from minority groups remains limited, and represents a gap in the UK evidence base.⁸⁸

Implications from the research

Inequalities in UK health outcomes are widening. Social care practitioners have long worked with people whose health is under threat because of their social disadvantage, many of whom are already suffering from poor physical or emotional health and/or disability. Our analysis suggests that social care and social work practice can improve health status across the life span, and support the central ambition of the Marmot Review 'to create the conditions for people to take control over their own lives'. If social interventions can be effectively delivered to disadvantaged groups, health inequalities will be reduced.

This argument is endorsed by the Marmot Review, which states that adult social care, 'makes a significant contribution to health and to health inequalities'.¹ The Review makes it clear that access to social care services is a health inequalities issue and that sustained, adequate funding, 'the greater integration of health and social care, and joint action on health inequalities' is required to underpin this important aspect of provision. Research that evaluates the impact of social interventions on the distribution of health outcomes will be required to support the strategy.

It is apparent from our four sample topics that the research evidence does not unequivocally support the conclusion that social work and social care achieves health improvements. There are problems to be addressed in the organisation and delivery of services, and in accessing and adapting services for diverse marginalised individuals and groups. The social care sector is

not resourced to pay attention to some of the core social determinants of health and, in particular, to money and housing. For example, programmes aimed at supporting parents cannot compensate for low incomes and environmental deficiencies. Unsupported kinship carers, often elderly themselves and on low incomes, do not have the same level of material support as their paid counterparts, and the value of the continuity, stability and attachment they can offer is therefore compromised. Reduced budgets and increased caseloads within professional social work have discouraged involvement in debt counselling, community engagement and other social determinants of healthy living. A wider definition of health as more than an absence of disease may enable social care staff to re-engage with these issues.

For policy and practice communities

Although social care and social work can do much to improve health, not all people can access the support they need. Barriers of access to all services should be considered by policy-makers. SSLPs, now delivered through Children's Centres, need to develop a wider community development role to enable inclusion of more marginalised families and communities, and be more responsive to local needs.^{22,37} Kinship care remains under-supported, practically and financially, by statutory authorities. Outcomes are therefore compromised and health inequalities may even be exacerbated. Support for kinship carers may be a key factor in improving arrangements which have shown benefits for looked-after children.63

The literature further suggests that, despite policy recommendations, there has been a shift from supporting parents with intellectual disabilities to judging them, which may lead to their rejecting help.⁷² A number of programmes have shown success in enabling such parents to care for their children. These should be expanded to address environmental pressures that undermine coping.

The extra care literature notes that choice is central to current policy. 96 Burke et al. found that extra care schemes that were successful were those that enabled residents to influence change. 101 It is important to develop working partnerships between social services, housing departments and older people, based on 'shared aims'.

For service delivery organisations

Organisations need to address barriers to access. In the early years' literature, factors such as geography, transport, publicity, age and opening hours were barriers to parents' access to Sure Start/Children's Centres. There are simple solutions, such as weekend services, access to a range of professional support under one roof, continuity of midwife, more flexible timings of services, better transport to services, better systems of appointments for doctors and better publicity for services. Craig et al.³⁷ and Avis and Chaudhary⁵⁰ also note that black and minority ethnic families tend not to take up available services. Services were criticised for stereotyping minorities (e.g. by ignoring differences between class and gender within minority groups).

Organisations should also consider that although kinship care can lead to better outcomes for children, these outcomes are compromised if caring leads to financial and support deprivation within the family.

Organisations need to improve sex and child care education for parents with intellectual disabilities and should be mindful of the pitfalls in service delivery for such parents. Organisations need to consider the economic and social deprivation commonly suffered by people with learning difficulties and work to mitigate it.

Extra care organisations could improve care by improving training for care workers, especially in bereavement counselling, treatment of dementia and mental illness. 92,94 Extra care facilities should also consider the suitability of housing for people

with dementia, mental health problems and disabilities, and people of different ethnic backgrounds.

For people using services and their carers

People who use early years care such as Sure Start/Children's Centres can see benefits for themselves and their children. However, the majority of users tend to be female (mothers). More work needs to be undertaken to understand how to ensure the inclusion of males who use services, as well as people from minority ethnic groups and disabled parents.

Although there may be a number of benefits for children in kinship care, research shows that the carers themselves tend to be less well supported than non-familial foster carers. In the UK, kinship care may take place under a Residence rather than a Care Order, thus removing the imperative for social services to provide support. Potential kinship carers may need to be aware of these provisions in order to avoid financial hardship.

For parents with learning disabilities it is clear that programmes can support skills development and maintenance of placement with birth parents. However, the evidence also suggests that without adequate infrastructure to support parents generally, the environmental pressures they are under will not be relieved. Olsen and Wates found that parents with disabilities frequently perceive services as undermining rather supporting them in their parenting role. To support parents with intellectual disabilities, social services need not only to introduce more appropriate resources and parenting programmes for all parents, but to train staff appropriately and address negative stereotyping.

The main finding from extra care research was that it should be available to older people to choose as an option for later life care. Research strongly supports the individual and group benefits of this type of housing environment, although strategies to involve older people in the design and delivery of such facilities were not described and should be developed.

For research

Further implications of this work for the research community include the inadequacy of the evidence base. Firstly, there is an urgent need to develop an epidemiology of social care. It is known that social care service recipients are disadvantaged but there is almost no up-to-date, comprehensive, systematic data examining the populations involved. This is necessary to underscore the link between social conditions across the life course and demand for health services. Secondly, this need is reinforced by the fact that many evaluations do not collect sufficient demographic and socioeconomic data on participants to clarify inequities in access and outcomes between different groups. Thirdly, many outcomes need longer rather than short-term evaluation to show life-course impact, and research needs to be designed to show effects not only on mortality and morbidity, but also on important interim outcomes, such as quality of life, mental and emotional wellbeing, education, child protection registrations or social work referrals. A far more comprehensive appreciation of the social determinants of health would enhance the relevance of outcome measures. Finally, there is an urgent need for research into the cost effectiveness of social work and social care interventions, in order to demonstrate the efficiency of investment in different areas across the integrated field of social and health care.

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Useful links

Centre for Excellence and Outcomes in Children and Young People's Services (C4EO)

A partnership organisation (including SCIE) which delivers evidence and support to the children's sector. Current programmes include evidence reviews on Early Years and Vulnerable (Looked After) Children, which are relevant to some of the themes in this research briefing.

www.c4eo.org.uk

Improvement and Development Agency (I&DeA)

In its health inequalities page, I&DeA promotes the Marmot Review Fair society, healthy lives, along with background to the report and related policy.

www.idea.gov.uk/idk/core/page.do? pageId=16908107

Joseph Rowntree Foundation

A charity that funds a large, UK-wide research and development programme, seeking to understand the root causes of social problems, to identify ways of overcoming them, and to show how social needs can be met in practice. The foundation is a key resource for investigating housing issues for older people. www.jrf.org.uk

Valuing People Now

Valuing People Now publishes guidance on supporting parents with learning disabilities. valuingpeople.gov.uk/dynamic/valuing people115.jsp

Related SCIE publications

SCIE Systematic map report 1: The extent and impact of parental mental health problems on families and the acceptability, accessibility and effectiveness of interventions (2006)

Systematic map report 2: The recovery approach in community-based vocational and training adult mental health day services (2007)

Systematic map report 3: The extent and impact of depression on BME older people and the acceptability, accessibility and effectiveness of social care provision (2008)

SCIE research briefing 9: Preventing teenage pregnancy in looked after children (2005)

SCIE research briefing 12: Involving individual older patients and their carers in the discharge process from acute to community care: implications for intermediate care (2005)

SCIE research briefing 13: Helping parents with a physical or sensory impairment in their role as parents (2005)

SCIE research briefing 14: Helping parents with learning disabilities in their role as parents (2005)

SCIE research briefing 19: What is the impact of environmental housing conditions on the health and well-being of children? (2005)

SCIE research briefing 20: The implementation of individual budget schemes in adult social care (2009)

SCIE Research briefing 32: Access to social care and support for adults with autistic spectrum conditions (ASC) (2010)

SCIE Report 20: Personalisation: a rough guide (2010)

SCIE Report 21: Follow up work to support implementation of the NICE/SCIE guidance on parenting programmes (2009)

References

- 1. Marmot, M. (2010) Fair society, healthy lives: strategic review of health inequalities in England post 2010, London: Department of Health, p 4.
- 2. Marmot, M. (2008)
- Boyle, P.J., Norman, P. and Popham, F. (2009) 'Social mobility: evidence that it can widen health inequalities', Social Science & Medicine, vol 68, pp 1835–1842.
- 4. CSDH (2008) Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health, Geneva: World Health Organisation.
- 5. Hanlon, P., Walsh, D. and Whyte, B. (2006) Let Glasgow flourish, Glasgow: Glasgow Centre for Population Health.
- Bywaters, P. (2009) 'Tackling inequalities in health: a global challenge for social work, British Journal of Social Work, vol 39, pp 353–367.
- 7. McLeod, E. and Bywaters, P. (2000) *Social work, equality and health*, London: Routledge.
- WHO (World Health Organisation) (1948)
 Constitution, Geneva: World Health Organisation.
- 9. Marmot Review (2009) Strategic review of health inequalities in England post 2010, first phase report, 15, London: Department of Health.
- 10. Blaxter, M. (1990) *The health and lifestyle survey*, London: Tavistock/Routledge.
- 11. Braveman, P. and Gruskin, S. (2003) 'Defining equity in health', *Journal of Epidemiology and Community Health*, vol 57, pp 254–258.
- 12. Davey Smith, G. (2003) *Health* inequalities: lifecourse approaches, Bristol: The Policy Press.

- 13. Michael J. and Richardson A. (2008).

 Healthcare for all: the independent inquiry into access to healthcare for people with learning disabilities. Tizard Learning Disability Review, 13(4), December 2008, pp 28–34
- 14. Bywaters, P. (2007) 'Understanding the lifecourse', in M. Lymbery and K. Postle (eds) Social work: a companion to learning, London: Sage.
- 15. Baker, D. (1998) *Mothers, babies and health in later life*, Edinburgh: Churchill Livingstone.
- 16. Graham, H. (2004) 'Social determinants and their unequal distribution', *Milbank Q.*, vol 82, no 1, pp 101–124.
- 17. Ben-Shlomo, Y. and Kuh, D. (2002) 'A life course approach to chronic disease epidemiology: conceptual models, empirical challenges and inter-disciplinary perspectives', *International Journal of Epidemiology*, vol 31, no 2, pp 285–293.
- 18. Hutchings, J. et al. (2007) 'Parenting intervention in Sure Start services for children at risk of developing conduct disorder: pragmatic randomised controlled trial', *British Medical Journal*, 31 March, pp 678–682.
- 19. Jones, K. et al. (2008) 'Efficacy of the Incredible Years Programme as an early intervention for children with conduct problems and ADHD: long-term follow-up', *Child: Care, Health and Development*, vol 34, no 3, pp 380–390.
- Northrop, M., Pittam, G. and Caan, W. (2008) 'The expectations of families and patterns of participation in a Trailblazer Sure Start', Community Practitioner, vol 81, no 2, pp 24–28.
- 21. NESS Research Team (2001) *The impact of Sure Start one year on*, London: DCSF.
- 22. NESS Research Team (2006) Empowering parents in Sure Start local programmes, London: DCSF.

- 23. Belsky, J. et al. (2006) 'Effects of Sure Start local programmes on children and families: early findings from a quasi-experimental, cross sectional study', *British Medical Journal*, 24 June, pp 1476–1478.
- 24. Belsky, J., Melhuish, E. and Barnes, J. (2008) 'Research and policy in developing an early years' initiative: the case of Sure Start', International Journal of Child Care and Education Policy, no 2, pp 1–13.
- 25. Siraj-Blatchford I. and Siraj-Blatchford J. (2009) Improving children's attainment through a better quality of family-based support for early learning. Knowledge review, England: Centre for Excellence and Outcomes in Children and Young People's Services.
- 26. Melhuish, E.C. et al. (2008) 'Effects of fully-established Sure Start local programmes on 3-year-old children and their families living in England: a quasi-experimental observational study', The Lancet, no 372, pp 1641–1647.
- 27. Melhuish, E.C. and Office, L.N.A. (2004)
 A literature review of the impact of early
 years provision upon young children, with
 emphasis given to children from
 disadvantaged backgrounds: report to the
 comptroller and auditor general, London:
 National Audit Office.
- 28. NESS Research Team (2008) The impact of Sure Start local programmes on three-year-olds and their families, London: DCSF.
- 29. Lord, P., Springate, I., Atkinson, M., Haines, B., Morris, M., O'Donnell, L., Benefield, P., Harper, A. and Sharp, C. (2008) *Improving development outcomes for children through effective practice in integrating early years services: scoping review 1*, London: Centre for Excellence and Outcomes in Children and Young People's Services (available at www.c4eo.org.uk/themes/earlyyears/

- effectivepractice/files/c4eo_effective_practice_scoping_study.pdf, accessed 21 January 2009).
- 30. Hellerich-Tuttle, L. et al. (1996); Smith et al. 2004, cited in Lord et al. (2008), ibid.
- 31. Allen, B.L. (2008) 'Evaluating Sure Start, Head Start, and Early Head Start: finding their signals amidst methodological static, NHSA Dialog: A Research to Practice Journal for the Early Intervention Field, vol 11, no 2, pp 110–132.
- 32. Anning, A., Stuart, J., Nicholls, M., Goldthorpe, J. and Morley, A. (2007) Understanding variations in effectiveness amongst Sure Start local programmes, Nottingham: Department for Education and Skills.
- 33. Bagley, C. and Ackerley, C.L. (2006) "I am much more than just a mum": social capital, empowerment and Sure Start', *Journal of Education Policy*, vol 21, no 6, pp 18–734.
- 34. Sylva et al. (2004), cited in Lord et al. (2008).
- 35. Penn et al. (2004), cited in Lord et al. (2008).
- 36. Cowley, S. (1999) 'Early interventions: evidence for implementing Sure Start', *Community Practitioner*, vol 72, no 6, pp 162–165.
- 37. Craig, G. et al. (2007) Sure Start and black and minority ethnic populations,
 Nottingham: Department for Education and Skills.
- 38. Ofsted (2009) The impact of integrated services on children and their families in Sure Start childrens centres, London: Ofsted.
- 39. Blok, H. et al. (2005) 'The relevance of delivery mode and other programme characteristics for the effectiveness of early childhood intervention', *International Journal of Behavioral Development*, vol 291, no 1, pp 35–47.

- 40. Campbell, F.A., Ramey, C.T., Pungello, E., Sparling, J. and Miller-Johnson, S. (2002) 'Early childhood education: young adult outcomes from the Abecedarian Project', *Applied Developmental Science*, vol 6, no 1, pp 42–57.
- 41. Hill, J., Waldfogel, J. and Brooks-Gunn, J. (2002) 'Differential effects of high-quality child care', Journal of Policy Analysis and Management, vol 21, no 4, pp 601–627; Hill, J., Brooks-Gunn, J. and Waldfogel, J. (2003) 'Sustained effects of high participation in an early intervention for low birth weight premature Infants, Developmental Psychology, vol 39, no 4, pp 730–744.
- 42. Schneider, J., Ramsay, A. and Lowerson, S.A. (2006) 'Sure Start graduates: predictors of attainment on starting school', *Child: Care Health and Development*, vol 32, no 4, pp 431–440.
- 43. NESS Research Team (2005) *Implementing* Sure Start local programmes: an in-depth study, London: DCSF.
- 44. Pearson, C. and Thurston, M. (2006) 'Understanding mothers' engagement with antenatal parent education services: a critical analysis of a local sure start service, *Children and Society*, vol 20, no 5, pp 348–359.
- 45. Carpenter, J., Brown, S. and Griffin, M. (2007) 'Prevention in integrated children's services: the impact of Sure Start on referrals to social services and child protection registrations, *Child Abuse Review*, vol 16, no 1, pp 17–31.
- 46. Coe, C. et al. (2008) 'Sure Start: voices of the "hard-to-reach", Care Health and Development, vol 34, no 4, pp 447–453.
- 47. Wiseman, P.T. and Wakeman, A. (2004) 'Parental review of service uptake during the pre-school period', *Child: Care, Health and Development*, vol 30, no 1, pp 59–65.

- 48. Arnold, R. (2005) Early years and childcare the Sure Start agenda: the Beacon Council Scheme Round 5, Slough: National Foundation for Educational Research. Educational Management Information Exchange.
- 49. Pinney, A. (2007) A better start: children and families with special needs and disabilities in Sure Start local programmes, London: DCSF.
- 50. Avis, M. and Chaudhary, S. (2008) 'Ethnic minority participation in an East Midlands Sure Start', *Community Practitioner*, vol 81, no 8, pp 28–31.
- 51. Farmer, E. (2009) 'How do placements in kinship care compare with those in non-kin foster care: placement patterns, progress and outcomes', *Child & Family Social Work*, vol 14, no 3, pp 331–342.
- 52. Winokur, M., Holtan, A. and Valentine, D. (2009) Kinship care for the safety, permanency, and well-being of children removed from the home for maltreatment, Cochrane Database of Systematic Reviews, issue 1, art no CD006546, DOI: 10.1002/14651858.CD006546.pub2.
- 53. Waterhouse, S., Hunt, J. and Lutman, E. (2008) Keeping them in the family: outcomes for abused and neglected children placed with family or friends carers through care proceedings, London: DCSF.
- 54. Waterhouse, S., Hunt, J. and Lutman, E. (2008) 'Kinship care: the child's perspective', *Seen and Heard*, vol 18, no 3, pp 36–49.
- 55. Sallnas, M., Vinnerljung, B.A. and Westermark, P.K. (2004) 'Breakdown of teenage placements in Swedish foster and residential care', *Child & Family Social Work*, no 19, pp 141–152.
- 56. Aldgate, J. and McIntosh, M. (2006) Looking after the family: a study of children looked after in kinship care in Scotland, Edinburgh: Scottish Government, www.scotland.gov.uk/Resource/Doc/129074/0030729.pdf

- 57. Cuddeback (2004) 'Kinship and family foster care: a methodological and substantive synthesis of the research', *Children and Youth Services Review*, vol 26, no 7, pp 623–639.
- 58. Attree, P. (2004) Childhood disadvantage and health inequalities: a systematic review of the qualitative evidence, Lancaster: Institute of Health Research, Lancaster University.
- 59. Stein, M. (2009) *Quality matters in children's services messages from research*, London: Jessica Kingsley.
- 60. Fox, A. and Duerr Berrick, J. (2007)
 'A response to No One Ever Asked Us:
 a review of children's experiences in
 out-of-home care, *Child and Adolescent*Social Work Journal, vol. 24, no 1, pp 23–51.
- 61. Winokur, M., Holtan, A. and Valentine, D. (2009) Kinship care for the safety, permanency, and well-being of children removed from the home for maltreatment, Cochrane Database of Systematic Reviews, issue 1, art no CD006546, DOI: 10.1002/14651858.CD006546.pub2.
- 62. Farmer, E. (2009) 'Placement stability in kinship care', *Vulnerable Children and Youth Studies*, vol 4, no 2, pp 154–160.
- 63. Broad, B. (2007) 'Kinship care: what works? Who cares?' *Social Work and Social Sciences Review*, vol 13, no 1, pp 59–74.
- 64. James, H. (2004) 'Promoting effective working with parents with learning disabilities', *Child Abuse Review*, vol 13, no 1, pp 31–41.
- 65. Tarleton, B., Ward, L. and Howarth, J. (2006) Finding the right support? A review of issues and positive practice in supporting parents with learning disabilities and their children, Bristol: Norah Fry Research Centre.
- 66. Campion M.T. (1996) 'Right from the start: maternity services for people with learning disabilities', *Disability, Pregnancy and Parenthood International*, vol 16.

- 67. Feldman, M.A., Garrick, M. and Case, L. (1997) 'The effects of parent training on weight gain of nonorganic-failure-to-thrive children of parents with intellectual disabilities', *Journal on Developmental Disabilities*, vol 5 no 1, pp 47–61.
- 68. Feldman, M.A. and Case, L. (1999)
 'Teaching child-care and safety skills to parents with intellectual disabilities through self-learning', Journal of Intellectual & Developmental Disability, vol 24, no 1, pp 27–44.
- 69. Llewellyn, G., McConnell, D., Honey, A., Mayes, R. and Russo, D. (2003) 'Promoting health and home safety for children of parents with intellectual disability: a randomized controlled trial', *Research in Developmental Disabilities*, vol 24, no 6, pp 405–431.
- 70. Sheerin, F. (1998) 'Parents with learning disabilities: a review of the literature', *Journal of Advanced Nursing*, vol 28, no 1, pp 126–133.
- 71. Tymchuk, A.J. (1999) 'Moving towards integration of services for parents with intellectual disabilities', Journal of Intellectual & Developmental Disability, vol 24, no 1, pp 59–74.
- 72. Tagg, L. and Kenny, G. (2006) 'Family nursing and parents who have a learning disability', *Paediatric Nursing*, vol 18, no 2, pp 14–18.
- 73. Olsen, R. and Wates, M. (2003) *Disabled parents: examining research assumptions*, Totnes: Research in Practice.
- 74. Booth, W. and Booth, T. (2003) 'Family trials', *Disability, Pregnancy and Parenthood International*, vol 45.
- 75. Tarleton, B. and Ward, L. (2007). "Parenting with support": the views and experiences of parents with intellectual disabilities', *Journal of Policy and Practice in Intellectual Disabilities*, vol 4, no 3, pp 194–202.

- 76. Llewellyn, G. (1997) 'Parents with intellectual disability learning to parent: the role of experience and informal learning, *International Journal of Disability, Development and Education*, vol 44, no 3, pp 243–261.
- 77. McGraw, S., Ball, K. and Clark, A. (2002) 'The effect of group intervention on the relationships of parents with intellectual disabilities', *Journal of Applied Research in Intellectual Disabilities*, vol 15, no 4, pp 354–366.
- 78. Booth, T. and Booth, W. (1999) 'Parents Together: action research and advocacy support for parents with learning difficulties', Health and Social Care in the Community, vol 7, no 6, pp 464–474.
- 79. Llewellyn, G. (1995) 'Relationships and social support: views of parents with mental retardation/intellectual disability', *Mental Retardation*, vol 33, no 6, pp 349–363.
- 80. Llewellyn, G. (2002) 'Home-based programmes for parents with intellectual disabilities: lessons from practice', *Journal of Applied Research in Intellectual Disabilities*, vol 15, no 4, pp 341–353.
- 81. Feldman, M.A. and Case, L. (1997)
 'The effectiveness of audiovisual self-instructional materials in teaching child-care skills to parents with intellectual disabilities', *Journal of Behavioral Education*, vol 7, no 2, pp 235–257.
- Feldman, M.A., Ducharme, J.M. and Case, L. (1999) 'Using self instructional pictorial manuals to teach child-care skills to mothers with intellectual disabilities, *Behavior Modification*, vol 23, no 3, pp 480–497.
- 83. Heinz, L.C. and Grant, P.R. (2003) 'A process evaluation of a parenting group for parents with intellectual disabilities', *Evaluation and Program Planning*, vol 26, no 3, pp 263–274.
- 84. Mildon, R., Wade, C. and Matthews, J. (2008) 'Considering the contextual fit of an

- intervention for families headed by parents with an intellectual disability: an exploratory study', *Journal of Applied Research in Intellectual Disabilities*, vol 21, no 4, pp 377–387.
- 85. Llewellyn, G. and McConnell, D. (2002) 'Mothers with learning difficulties and their support networks, *Journal of Intellectual Disability Research*, no 46, pt 1, pp 17–34.
- 86. Wade, C., Llewellyn, G. and Matthews, J. (2008) 'Review of parent training interventions for parent with intellectual disability', *Journal of Applied Research in Intellectual Disabilities*, vol 21, no 4, pp 351–366.
- 87. Ward, L. and Tarleton, B. (2007) 'Sinking or swimming? Supporting parents with learning disabilities and their children', *Learning Disability Review*, vol 12, no 2, pp 22–32.
- 88. Croucher, K., Hicks, L. and Jackson, K. (2006) *Housing with care for later life: a literature review*, London: Joseph Rowntree Foundation.
- 89. Brooker, D. and Wooley, R. (2006) *Enriching opportunities: unlocking potential: searching for the keys*, Bradford: University of Bradford, Bradford Dementia Group.
- 90. Darton, R. and Callaghan, L. (2009) 'The role of extra care housing in supporting people with dementia: early findings from the PSSRU evaluation of extra care housing', *Journal of Care Services Management*, vol 3, no 3, pp 284–294.
- 91. Croucher, K. (2006) *Making the case for retirement villages*, London: JRF.
- 92. Brooker, D., Argyle, E., Clancy, D. and Scally, A. (2009). A cluster randomised control trial of a new approach to living with dementia and other mental health issues in extra care housing schemes and villages, Bradford: Bradford University.
- 93. Cantley, C. and Cook, M. (2006) A report on the evaluation of Moor Allerton Care

- *Centre*. Dementia North: University of Northumbria.
- 94. Bernard, M., Bartlam, B. and Sim, J. (2007) 'Housing and care for older people – life in an English purpose-built retirement village', Ageing & Society, 27, pp 555–578.
- 95. Brooker, D.J., Argyle, E. and Clancy, D. (2009) 'The mental health needs of people living in extra care housing', *Journal of Care Services Management*, vol 3, no 3, pp 295–309.
- 96. Croucher, K. (2007) Comparative evaluations of models of housing with care for later life, London: Joseph Rowntree Foundation.
- 97. Evans, S. (2008) Social well-being in extra care housing, Care Services Improvement Partnership, Housing Learning and Improvement Network.
- 98. Evans, S. and Vallelly, S. (2007) *Promoting* social well-being in extra care housing, York: Joseph Rowntree Foundation.
- 99. Dutton, R. (2009) 'Extra care housing and people with dementia: What Do We Know About What Works Regarding the Built and Social Environment, and the Provision of Care and Support? A scoping review of the literature 1998–2008, London: Housing and Dementia Research Consortium.
- 100. Evans, S. and Vallelly, S. (2007) 'Never a dull moment? Promoting social well-being in extra care housing, *Housing, Care and Support*, vol 10, no 4, pp 14–19.
- 101. Burke, S., Bernard, C. and Morris, M. (2008) Delivering a sure start to later life: exploring

- new models of neighbourhood services for older people, London: Counsel and Care.
- 102. Evans, S., Fear, T. and Means, R. (2007) 'Supporting independence for people with dementia in extra care housing', *Dementia: The International Journal of Social Research and Practice*, vol 6, no 1, pp 144–149.
- 103. Evans, S. (2005) Researching older people with dementia in supported housing', *Generations Review*, no 15, pp 3–7.
- 104. Allardice, J. (2005) A 20/20 vision for housing and care: research report; by Jane Allardice, 20/20 Project (ERoSH; Association of Social Alarm Providers ASAP; Centre for Sheltered Housing Studies; National Housing Federation); Jane Allardice Communications Ltd: Electronic format only, 2005.
- 105. Kingstone et al. (2001), cited in Croucher, K. (2006).
- 106. Vallelly, S., Evans, S., Frear, T. and Means, R. (2006) Opening doors to independence: a longitudinal study exploring the contribution of extra care housing to the care and support of people with dementia, London: Housing 21, Housing Corporation.
- 107. For example, Bernard, M., Bartlam, B. and Sim, J. (2007); Cantley, C. and Cook, M. (2006); Dutton, R. (2009) and Easterbrook, L. and Vallelly, S. (2008) 'Is it that time already?': extra care housing at the end of life: a policy-into-practice evaluation; by Lorna Easterbrook, Sarah Vallelly, Housing

- 21; End of Life Care Programme, NHS, Department of Health : Housing 21.
- 108. Cairncross, L. and Bligh, J. (2008) Shared equity: using the private finance initiative to boost extra care housing, London: Care Services Improvement Partnership and Housing Learning and Improvement Network.
- 109. Dawson, L., Williams, J. and Netten, A. (2006) 'Extra care housing: is it really an option for older people?' *Housing Care and Support*, vol 9, no 2, pp 23–29.
- 110. Easterbrook, L. and Vallelly, S. (2008) 'Is it that time already?' Extra care housing at the end of life: a policy-into-practice evaluation, Beaconsfield: Housing 21.

- 111. O'Malley, L. and Croucher, K. (2005) 'Housing and dementia care: a scoping review of the literature', *Health and Social Care in the Community*, vol 13, no 6, pp 570–577.
- 112. Jones, A. (2006). Beyond sheltered accommodation a review of extra care housing and care home provision for BME elders, London: Department of Health; Jones, A. (2008) Meeting the sheltered and extra care housing needs of black and minority ethnic older people, London: Race Equality Foundation.
- 113. Institute of Public Care (2007) Raising the stakes extra care housing report literature review. Oxford: Institute of Public Care.

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