

WELLBEING STRATEGY 2014 - 2018 WARW CKSH R E ΓH ND EA Δ G **INDEPENDENCE** C Ρ R Ε R F B C KSH ΕI AND G E BOARD 1H Н Н

This evidence review supports the 'Promoting Independence for all' chapter of the Warwickshire Health & Wellbeing Strategy (2014-18).

1 Home Care Independent Living (2014) How to promote independence [online] available from http://www. homecareindependentliving.com/news/157-how-to-promoteindependence [29 July, 2014]

2 Department of Health (Vicotoria) (2014) Aged care in Victora -Help sheet 20: Promoting independence and autonomy [online] available from http://www.health.vic.gov.au [22 September, 2014]

3 Fauth, Hart & Payne (2012) Supporting care leavers' successful transition to independent living https://www. princestrust.org.uk/pdf/NCB_RSCH_9_FINAL_FOR_WEB.pdf [23 September, 2014]

5.

4 Disability Rights Commission (2002). Policy Statement on Social Care and Independent Living. London: Disability Rights Commission.

5 Warwickshire Adult Social Care & Health (2011) Warwickshire Supporting Independence (prevention) Strategy 2011-14. Warwickshire County Council: Warwick.

1.0 What is 'promoting independence'?

The term 'independence' is often used in the context of older people and ageing and how this specific group of the population can maintain independence in their later years when poor health and disabilities are more prevalent. However, promoting independence is important across the life course starting out with babies and young children, running throughout adulthood and into old age.

There are many descriptions of 'promoting independence' and this term will mean different things to different people, professionals and organisations. The following points describe some of the various definitions of promoting independence:

- 1. Encouraging the person in your care to do as much as they can for themselves. Independence is considered one of the most important attributes a person can possess and we should do all we can, within our power, to encourage independence. Once a person loses their independence, they often lose the will to live ¹.
- 2. Keeping or improving physical and cognitive function to fulfil the tasks of independent living, maintaining social connections, and making decisions about their care².
- 3. Learning to take responsibility for yourself and your actions.
- 4. Ensuring young people are prepared and supported to make successful transitions from care into independent living³.
 - All disabled people having the same choice, control and freedom as any other citizen at home, at work and as members of the community. This does not necessarily mean 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations⁴.
- 6. Enabling people to remain in their own home and to live healthy active lives for as long as possible⁵.

The most relevant meaning for Warwickshire is: "promoting independence' is considered an important concept across the life course starting out with babies and young children, running throughout adulthood and into old age. Independence should be encouraged as part of all these events, roles and transitions in order to prevent ill health, disability and dependence on services throughout life".

2.0 Why is 'promoting independence' important?

This paper explores promoting independence from a national and international perspective and looks at research conducted in the last 10 years. It examines the key groups of the population that experience barriers to achieving independence and groups that require intervention to promote or maintain independence. It also reviews evidence of the importance of promoting independence and makes recommendations about the key factors that need to be considered when promoting independence.

2.1 Babies and Children

The early years of life are a crucial period of change; alongside adolescence this is a key moment for brain development. In a report published by the NSPCC in 2013, entitled The 1001 Critical Days – The Importance of the Conception to Age Two Period, it is stated that ensuring that the brain achieves its optimum development and nurturing during this peak period of growth is vitally important. It enables babies to achieve the best start in life and improves choices, attainment, wellbeing, happiness and resilience in later life⁶.

According to Hall and Elliman (2003)⁷, parents who are confident and consistent in their parenting are likely to have confident and secure children who will transition more safely into independence and adulthood. However, poor parenting practices e.g. poor supervision, low involvement in the child's activities, harsh and inconsistent discipline, parental disharmony, high levels of criticism, rejection, neglect and displays of violent temper – are associated with adverse outcomes and later antisocial behaviour, behavioural problems and speech and language problems.

Hall and Elliman continue to talk about increasing the focus on vulnerable children, such as those with complex needs and special educational needs. They describe the importance of identifying these children as early as possible and providing the necessary support and their parents with appropriate information on how to seek help if they have any concerns about their child. 'Families that need the most help are often the most difficult to reach and may not be known to the health services. They include the homeless, transient populations, refugees, asylum seekers, and people with chronic illness or disability (who may be cared for by their own children), substance abusers and people with communication problems such as the hearing impaired. Targeting these families and building a relationship needs more time and extra skills'.

2.2 Looked After Children (LAC)

Moving to independent living and starting the journey into adulthood are landmark steps for most young people. Young people who have been looked after are more disadvantaged and face more difficulties than their peers in achieving independence. According to NICE, LAC have to become independent at a younger age and have to cope with major changes in their lives in a much shorter time and with less support than their peers⁸. Equipping LAC with the skills to be independent in their adulthood is a vital part of the support that they receive from services during their transition and may reduce the occurrence of physical and mental health problems in later life.

Brueckner, Green & Saggers (2011) looked at the experiences of young homeless people in Australia during their transitions to more permanent accommodation and independent living. The data presented in the study showed that the young people interviewed were keen to become 'normal' occupiers. This included taking part in home maintenance and home improvement activities and also considering how they could own their own home at some point in the future. Even though many of the young people interviewed were able to become 'normal' occupiers, their attempts to be part of a 'normal' home occupying community were seemingly interrupted by the conversations surrounding them, in which they were seen by housing providers, neighbours and others as young people who have not left home the 'right way' and who required social housing

⁶ NSPCC (2013) The 1001 Critical Days - The Importance of the Conception to Age Two Period [online] available from http://www.andrealeadsom.com/ downloads/1001cdmanifesto.pdf [23 September, 2014]

⁷ Health for All Children, 4thEdition, David M. B. Hall & David Elliman, Oxford Medical Publications, 2003

⁸ National Institute for Clinical Excellence (2013) Looked-after Children and young people. London: National Institute for Clinical Excellence

support. This in turn affected their experiences of home and social belonging.

For many of the young people interviewed, their new accommodation was seen as *"a vehicle for gaining independence and an escape from negative pasts. Overall it was a step towards a 'normal' adult life, which they defined as having control, 'being their own boss', and living in a predictable environment that was 'not a drug house' and subject to being 'kicked out'."*9

Cunningham and Diversi (2012) carried out a study to look at the views of young people leaving foster care in the USA. There is much literature in the field which shows that transition from the care system into adulthood can be difficult. However, according to the authors of this study, fostered young people's voices have been largely absent from the body of evidence used in policy-level discussion¹⁰.

It was found that the young people that were spoken to described a transition to adulthood that was immediate and complete, lacking the series of small steps toward autonomy that is common among emerging adults in contemporary societies (Arnett, 2004)¹¹. Young people reported that they struggled to meet their basic needs, describing unemployment, hunger, and homelessness as key issues that they had to deal with. For the young people interviewed, they believed that securing employment was the main conduit to gaining housing and avoiding homelessness. They also reported loss of connections with siblings, foster family members and the affirmation that came in some cases from reunification

from birth parents.

2.3 Disabled People

Historically, disabled people have been treated as being dependent and in need of 'care', rather than being recognised as full citizens. As stated in the Prime Ministers Strategy Unit Report Improving the life chances of disabled people, a new approach to supporting disabled people is needed. The focus should be on the promotion of independent living. Independent living is not just about being able to live in your own home – though that is often part of it for many disabled people. Rather, independent living is about providing disabled people with choice, empowerment and freedom¹².

Dalton and Hoyt-Hallet (2013) explored the occupational deprivation experienced by children with physical disabilities and the use of assistive technology to enable occupation and remove injustices.¹³ Occupational deprivation arises from a person's inability to participate in, or exclusion from, desired occupations for extended periods of time due to factors outside the control of the individual (Whiteford, 2000)¹⁴. This study showed occupational engagement changes for clients with physical disabilities pre and post provision of technology. The study demonstrated how occupational enablement is facilitated through the assessment and use of assistive technology and can reduce the experience of occupational deprivation and social exclusion in children with physical disabilities. Provision of appropriate technology increased independent mobility, academic achievement and expanded their social networks and

Rebiee (2012) explored the relationships between choice and independence by looking at disabled and older people. Rebiee refers to the Government's Personalisation agenda and tested the assumption that giving service users greater choice and control will promote users' independence. The findings show that independence is not a fixed concept, but is relative and multidimensional. These findings are supported by other research which shows that the concept of 'independence' means different things to different people.

2.4 Older People

When they are asked, older people are clear about what independence means for them and what factors help them to maintain it. In a report written by the Audit Commission in 2004, Older people – independence and well-being, the challenge for public services, it is stated that society needs a fundamental shift in the way it thinks

⁹ Brueckner, M., Green, M. & Saggers, S. 2011, "The Trappings of Home: Young Homeless People's Transitions Towards Independent Living", Housing Studies, vol. 26, no. 1, pp. 1-16.

¹⁰ Cunningham, M.J. & Diversi, M. 2013, "Aging out: Youths' perspectives on foster care and the transition to independence", Qualitative Social Work, vol. 12, no. 5, pp. 587-602.

¹¹ Arnett, J. J. (2004). Emerging adulthood: The winding road from the late teens through the twenties. New York: Oxford University Press.

¹² Prime Minister's Strategy Unit (2005) Improving the life chances of disabled people

¹³ Dalton C, Hoyt-Hallett G (2013) Enablement through provision of assistive technology: case reports of two children with physical disabilities. British Journal of Occupational Therapy, 76(2), 108-111.

¹⁴ Whiteford GE (2000) Occupational deprivation: global challenge in the new millennium. British Journal of Occupational Therapy, 63(5), 200-04.

about older people, from dependency and deficit towards independence and well-being. Older people require comfortable, secure homes, safe neighbourhoods, friendships and opportunities for learning and leisure, the ability to get out and about, an adequate income, good, relevant information and the ability to keep active and healthy¹⁵.

Lewin (2013) tested the effectiveness of the Home Independence Program (HIP), a restorative home-care programme for older adults, in reducing the need for ongoing services and promoting independent living¹⁶. 'Reablement services' as they are known in the UK are designed to assist older individuals who are experiencing difficulties in everyday living to optimise their functioning and reduce their need for ongoing care. The focus is on restoring physical independence rather than resolving health care issues, and on helping people to do things for themselves rather than the traditional home care approach of doing things for people that they cannot do for themselves¹⁷. This study showed that individuals who received a restorative home-care programme were considerably less likely to need ongoing personal care services than their counterparts who were randomised to receive 'usual' home care only.

Lucena Ferreira et al (2012) conducted a study to analyse the factors determining active ageing and its relationship to functional independence.¹⁸ According to the authors, ageing may be associated with suffering, increased physical dependence, functional decline, social isolation, depression and a lack of productivity, among other negative factors. It is, however, possible to live with greater a quality of life through independence and autonomy, with good physical and mental health, so that the ageing process is healthy and active. The findings from this study confirmed that for the ageing process to be successful, it should not only be free of disease, but should also present conditions of autonomy and functionality. The more active an individual, the fewer physical limitations exist. Therefore, it is recommended that to be healthy and live an active life, older people need to live an independent life, have a house, an occupation, affection and communication.

Courtney et al (2012) assessed the effectiveness of a "multi-faceted transitional care intervention" for at risk older adults on their functional ability and independence levels through a randomised controlled trial in over 65 year olds with an acute medical admission and at least one risk factor for hospital readmission.¹⁹ The intervention included:

- Individually tailored exercise programmes;
- Follow up care (commencing in hospital) with regular visits from a physiotherapist and a registered nurse;
- Regular telephone follow-up for 24 weeks following discharge.

Results of the trial showed significant improvement in functional ability and independence levels in the intervention group in comparison to the control group. This study provides further evidence to show that promoting independence is an important factor in promoting health and wellbeing.

Woolham, Hughes and Daly (2013) explored the views of older citizens living in Coventry, UK, about their independence, inclusion and well-being and the relationship between these themes. Findings have suggested that whilst most older citizens who were interviewed were independent, able to participate in everyday community activities and were reasonably healthy, happy and comfortable, there were a number of issues that created significant barriers to inclusion and which threatened well-being. These included impaired mobility, lack of access to affordable or accessible transport, a lack of financial resources, impaired social networks, ill-health and lack of access to information. The authors concluded that it would be more beneficial to focus on 'interdependence' rather than 'independence'. This means enabling older people to contribute to the life of the community and for that contribution to be valued and recognised.

15 The Audit Commission (2014) Older people – independence and well-being, the challenge for public services [online] available from http://archive.auditcommission.gov. uk/auditcommission/sitecollectiondocuments/AuditCommissionReports/NationalStudies/ OlderPeople_overarch.pdf [23 September, 2014]

16 Lewin, G. 2013, "A randomised controlled trial of the Home Independence Program, an Australian restorative home-care programme for older adults", Health and Social Care in the Community, vol 21, no 1, Jan 2013, p 69-78, .

17 Social Care Institute for Excellence, Reablement: emerging practice messages [online] available from http://www.scie.org.uk/files/EmergingMessages.pdf [30/07/14]

18 Lucena Ferreira, O.G., Maciel, S.C., Gusmao Costa, S.M., Silva, A.O. & Moreira, M.A.S.P. 2012, "Active Aging and its Relationship to Functional Independence", Texto & Contexto Enfermagem, vol. 21, no. 3, pp. 513-518.

19 Courtney, M.D., Edwards, H.E., Chang, A.M., Parker, A.W., Finlayson, K., Bradbury, C. & Nielsen, Z. 2012, "Improved functional ability and independence in activities of daily living for older adults at high risk of hospital readmission: a randomized controlled trial", Journal of evaluation in clinical practice, vol. 18, no. 1, pp. 128-134.

3.0 Conclusion

It is clear from the evidence reviewed that the concept of promoting independence across the life course is extremely important in order to prevent ill-health, disability and dependence on services throughout life.

Starting out with babies and children, the importance of good maternal health and positive parenting is clear and there is much evidence to suggest that for children and young people to gain independence and have a successful transition into adulthood, the early years are critical.

When working with vulnerable young people, particularly those who are in care or leaving care, the focus should be on early identification and more intensive support. Evidence suggests that care leavers are more likely to have poor educational performance, contact with the criminal justice system, poorer health and be vulnerable to homelessness and unemployment. Therefore, it is important to focus on the transition to adulthood and independence to help prevent negative experiences and crises later on in life.

For disabled people, independence is about choice and control and putting them at the centre of their care. It is also about ensuring that disabled people are provided with relevant assistive technology to enable independent mobility, academic achievement and the development of more meaningful relationships.

The evidence shows that there needs to be a shift in the way older people are viewed and treated. Instead of thinking about older people as 'dependent', society needs to start focussing on promoting 'interdependence' and wellbeing in older people which will in turn help them stay healthy and active and encourage their contribution to the community.

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Warwickshire Health and Wellbeing Board Warwickshire County Council PO Box 43, Shire Hall, Barrack Street, Warwick, CV34 4SX Email: phadmin@warwickshire.gov.uk

http://hwb.warwickshire.gov.uk/