APPENDIX NATIONAL AND LOCAL EVIDENCE AND RESEARCH

FRIENDSHIP CLUB

Friends make life more fun!

People First Dorset
November 2013
TABLE OF CONTENTS

Governmental Research and Recommendations

1. Department of Health, *Adult Social Care Outcomes Frameworks 2013/14*


3. HM Government, *Caring for our future: reforming care and support 2012*

4. Care Bill, House of Lords, July 2013

5. Improving Health and Lives: Learning Disabilities Observatory
   *Health Inequalities and People with Learning Disabilities in the UK: 2011*

6. HM Government, *Valuing People Now 2009*

7. Prioritising need in the context of *Putting People First*: A whole system approach to eligibility for social care. *Guidance on Eligibility for Adult Social Care, England 2010, Department of Health*

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   *Improving Health and Lives Confidential Inquiry, University of Bristol, Department of Health*
General Research and Evidence


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12. What are Friends For? Rachel Hughes, *A Study looking at the significance of friendship in the lives of adults with profound and multiple learning disabilities*, 2010

13. Loneliness is the only real disability
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14. Social capital, social inclusion and services for people with learning disabilities
*Peter Bates and Fabian A Davis, National Development Team (Ipswich) and Bromley Health Services, Oxleas NHS Trust, Kent*

15. Human Rights of Adults with Learning Disabilities
*Speech by Andrew Dismore, MP for Hendon, Chair of the Joint Committee of Human Rights, 19.3.2009*

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*The Marmot Review, Executive Summary, Strategic Review of Health Inequalities in England post 2010*

18. Effect of social networks on 10 year survival in very old Australians: the Australian longitudinal study of aging
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20. Equal Treatment
*Closing the Gap, Disability Rights Commission (2006)*

21. The Keys to Life, Improving Quality of Life for People with Learning Disabilities
*The Scottish Government, Edinburgh 2013*

22. Five Ways to Wellbeing
*New applications, new ways of thinking, National Economics Foundation (NEF), 2011*

23. Information on Friendships, *Foundation for People with Learning Disabilities*

24. Intelligent Kindness, reforming the culture of healthcare
*John Ballatt and Penelope Campling, RCPsych Publications 2011*
25. Joining the Dots: How all the system elements can connect to drive personalisation and co-production, incorporating individual social and community capacity
   *Lucie Stevens – New Economics Foundation*

26. Living in Sandwell: An Exploratory Study into the Key Issues and Challenges that Affect a Small Group of People with Mild Learning Disabilities
   *Liz Tilly, University of Huddersfield 2008*

27. Working with Communities, Developing Communities
   Guidance for Primary Care
   *RCGP, Royal College General Practitioners, Centre for Commissioning, March 2013*
Local Research and Recommendations


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   *Dorset County Council*

9. Support for people who do not meet the eligibility criteria for adult social care
   *Dorset Learning Disability Partnership Board, DRAFT Report - October 2010*


11. The Dorset Compact, Working Together for Dorset

12. An Introductory Guide to Dorset’s Local Area Agreement 2008-11
    *Dorset Strategic Partnership*

13. State of Dorset 2013, Dorset County Council
Learning Disability Challenges and Campaigns

1. Launch of Real Change Challenge: Mate Crime *Association of Real Change, May 2013*

2. Brandon Trust calls for Government and local communities to do more to tackle disability hate and mate crime, 2013
**Introduction**

This appendix is a summary of relevant White Papers, reports, research, evidence, policy, strategies and theories. They all serve to highlight the need for reducing social isolation, promoting inclusion and supporting health and wellbeing in adults with learning disabilities and their carers through innovative, proven and cost effective initiatives such as the Friendship Club in Dorset.

It is clear that the Government is committed to improving the life chances of people with learning disabilities and the support provided to their families and there is much evidence to support the fact that people with learning disabilities are socially isolated, suffer hate crime, feel excluded in their community, have difficulty securing employment and experience poorer health than the general population. In a stretched financial climate surely we still have a responsibility to respond to such serious issues and address these inequalities with cost effective solutions which reduce reliance on statutory services.

It is evident the Friendship Club is successful not only from the high numbers attending but also from a recent evaluation where members, carers and professionals stated they believe the club supports members to become more confident, independent, healthier, happier, more employable and safer in their community – as well as increasingly visible and accepted by the general public.

What does it take to make an initiative such as the Friendship Club sustainable, a club which meets the needs and benefits many marginalised individuals? These are people many of whom lack the skills to create basic friendships let alone lobby government to have their needs met. There are increasing mounds of evidence highlighting how loneliness and social isolation adversely affect health.

This report reminds us all (government, health, councils, support providers and funders) of why supporting user led, value for money, innovative, result driven projects supported by the voluntary sector and which are proven to work and address the issues contained in this document, must be considered as a serious option as we work together towards solutions based on models of co-production and integrated care.

‘The Adult Social Care Outcomes Framework (ASCOF), with its clear focus on promoting people’s quality of life and their experience of care, and on care and support that is both personalised and preventative, is a key tool to track progress locally and nationally towards the transformation of care and support. It reports there is scope to do more to enhance the quality of life of people with a learning disability, to ensure they are supported to live full and independent lives.

To meet these challenges, councils have been given the freedom to set and act on their own priorities, driven by the needs of local people. As council increasingly look outwards to local people to identify their priorities, and not to central Government for direction, greater transparency based on what care and support really delivers for people becomes even more vital.’ *Rt Hon Jeremy Hunt MP, Norman Lamb MP*

The ASCOF for 2013/14 will support councils to rise to the challenge of delivering key White Paper priorities by providing a clear focus for local priority setting and improvement. The ASCOF is used both locally and nationally to set priorities for care and support, measure progress, and strengthen transparency and accountability.

A key White Paper priority is to drive care that is genuinely integrated, and which seamlessly joins around the needs of people, not the needs of services. Genuinely integrated care requires strong, collaborative leadership, supported by aligned incentives locally. The ASCOF for 2013/14 makes more extensive use of measure which are shared or complementary across the NHS and Public Health Outcomes Frameworks, providing a basis for joint working across the health and care system towards common aims.

The principal vehicles for joint working at the local level will be the health and wellbeing boards, which will bring the whole system together at a local level and will maximise opportunities to deliver integrated social care across the NHS, public health and social care services, and to influence the wider determinants of health.

*This year the ASCOF has been strengthened to reflect key White Paper priorities for care and support – including the promotion of care and support which is integrated and joins up around the needs of the people who use them, and the need to tackle loneliness and social isolation in our communities.*

*The White Paper signalled the Government’s commitment to support active and inclusive communities, which support people to develop and maintain connections to friends and family. As part of this, a commitment was made to include measures of loneliness and social isolation in the ASCOF and Public Health Outcomes Frameworks.*
In response to this, a new measure of social isolation has been included in the framework, which is described in more detail below.

There is a clear link between loneliness and poor mental and physical health. A key element of the Government’s vision for social care, set out in the Care and Support White Paper, is to tackle loneliness and social isolation, supporting people to remain connected to their communities and to develop and maintain connections to their friends and family.

As a result, for 2013/14, the ASCOF includes a new measure on social isolation. Initially, this indicator will focus on social care users and carers, rather than the broader population.

The key aim is to enhance the quality of life for people with care and support needs. The outcome measures are that people are able to maintain a family and social life and contribute to community life, and avoid loneliness or isolation.

Another priority is safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm. This area remains one of the critical development priorities for the future of ASCOF, however defining and measuring outcomes in this domain remains a challenge. The Care and Support White Paper states that a high quality service must be one which keeps people from harm.

The outcome measures are that people are free from physical and emotional abuse, harassment, neglect and self harm. People are supported to plan ahead and have the freedom to manage risks the way that they wish.

UPDATE - Adult Social Care Outcomes Framework 2014/15

A population-based measure of loneliness
The Care and Support White Paper committed to pursue the development of measures of loneliness and social isolation for inclusion in the ASCOF and Public Health Outcomes Framework (PHOF), in recognition of the clear link between loneliness and poor mental and physical health.

As a significant first-step towards achieving this, the 2013/14 ASCOF included a new measure of social isolation, shared with a placeholder in the PHOF. This measure remains in the ASCOF for 2014/15 and draws on self-reported levels of social contact as a measure of social isolation.

There are recognised limitations to this measure:
- This measure is of the users of adult social care services and carers only. However, the problems of loneliness and social isolation are not limited to these groups, and all parts of the health and care system have a role to play in preventing and reducing social isolation and loneliness in the broader population; and,
- Social isolation can only be considered a proxy for loneliness.

Work has therefore been taken forward to develop a population-based measure of loneliness, for inclusion in both the PHOF and the ASCOF, and an assessment has been made of the
survey vehicles available to capture information on people’s reported experience of loneliness. Whilst it has not been possible to develop a new measure of loneliness for the 2014/15 framework, this work will continue over the next year, with a view to including a new measure in the ASCOF in the future.

This measure is proposed to be shared with the PHOF, in recognition that a council’s public health services have a key role in improving outcomes in this area. However it is also recognised that there are a number of other factors, many outside the control of local government, which may impact on a person’s self-reported level of loneliness. The presentation of any new measure in the ASCOF would need to reflect this; for example it has been proposed that any new measure of population-based loneliness could sit as a sub-measure under the existing social isolation measure.

Future developments

Identifying the impact of adult social care

The over-arching measure in Domain One is ‘social care related quality of life’, which is a composite measure drawn from a number of responses made by people to the Adult Social Care Survey. The overall quality of life measure brings together people’s experience of eight outcomes related to social care into a single measure. This is a key high-level measure, which reflects the achievement of outcomes as reported by people who use services.

However, whilst this measure tells us about outcomes for social care users, it does not isolate the impact that care and support services have on those outcomes. The Department has commissioned research from the Quality and Outcomes of Person Centred Care Policy Research Unit to identify whether there is a way in which we could isolate the impact of adult social care on people’s reported quality of life. A number of local authorities are supporting this research, which at present is collecting information through interviews with users and carers. Analysis will be undertaken next year, with a final report in the autumn of 2014. If successful, this work may allow us to develop a new or additional measure for the ASCOF of the specific impact of adult social services on people’s quality of life.

Social isolation

The calculation of the social isolation measure will change from 2014/15. Previously, this measure combined user survey data with the most recent value from the Carers Survey data (as the Carers Surveys is currently a biennial collection). However, from 2014/15, this measure will be calculated for carers and users separately, to increase the usefulness of this data locally. Further detail will be published in the Handbook of Definitions in the spring.

Safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm

The Government’s ambition is to prevent and reduce the risk of adults with care and support needs from experiencing abuse or neglect. The area of safeguarding therefore
remains one of the core priorities of adult social care, and remains a key area of priority for the ASCOF. However, there are significant challenges associated with capturing this type of outcomes information.

A new placeholder was added to this Domain in 2013/14, on measuring the number of completed safeguarding referrals where service users reported that they felt safe. A consultation on this proposed measure highlighted concerns about how this information could be collected in a robust and comparable way, demonstrating that piloting of any approach would be required.

The Health and Social Care Information Centre has since been commissioned by the Department to work with local government to develop a set of questions and a methodology for collecting this information. These questions will be developed and cognitively tested over the next few months, and the methodology will be piloted within a number of councils next year. If this pilot is successful, the ambition is for the collection to be rolled out nationally, and for this placeholder to become a live measure in the ASCOF.

In the first instance, it is proposed that any new collection will support a national-only measure in the ASCOF, as the sample size in some authorities is likely to be too small to enable robust comparison at local level. The Department is working with the HSCIC to identify ways in which the local results could be shared with councils, to provide them with as much information as possible to benchmark their own performance and improve their safeguarding services. The survey would also provide an opportunity for local authorities to gather information to inform the improvement of services locally.

The responsibility to improve and protect our health lies with us all – government, local communities and with ourselves as individuals.

The Public Health Outcomes Framework will set out the broad range of opportunities to improve and protect health across the life course and to reduce inequalities in health that still persist.

The framework will be focused on the two high-level outcomes we want to achieve across the public health system and beyond. These two outcomes are:

1. Increased healthy life expectancy
2. Reduced differences in life expectancy and healthy life expectancy between communities.

These outcomes reflect the focus we wish to take, not only on how long we live – our life expectancy but on how well we live – out healthy life expectancy at all stages of the life course. Our second outcome focuses attention on reducing health inequalities between people, communities and areas in our society.

The Government is creating a new, integrated and professional public health system designed to be more effective and to give clear accountability for the improvement and protection of the public’s health. The new system will embody localism, with new responsibilities and resources for local government, within a broad policy framework set by the Government, to improve the health and wellbeing of the population. It will also give central government the key responsibility of protecting the health of the population, reflecting the core accountability of government to safeguard its people.

Public Health England will be the new national delivery organisation of the public health system. It is being set up to work with partners across the public health system and in wider society to a) deliver support and enable improvements in health and wellbeing in the areas set out in the outcomes framework and b) to design and maintain systems to protect the population against existing and future threats to health.

The NHS clinical contribution is central. But outside the clinical arena the key responsibility for improving the health of local populations, including reducing health inequalities, will rest with democratically accountable upper tier and unitary local authorities. The Health and Social Care Bill will, subject to Parliament, give each unitary and upper tier local authority the duty to “take such steps as it considers appropriate for improving the health of the people in its area”. Elected members in local authorities will take on leadership for public health at the local level. Local authorities will set up statutory health and wellbeing boards to drive local commissioning and integration of all health services, based upon local needs, giving new opportunities to improve the health and wellbeing of local communities right across the life course.
Local authorities will commission public health services on their populations behalf, and put health and wellbeing at the heart of all their activity. They will also take on key roles in supporting the public health system as a whole; thus they will be responsible for ensuring that there are robust plans in place to protect the health of their populations, and will support the NHS with public health advice on clinical commissioning, ensuring that the needs of the whole population are driving local clinical commissioning. Directors of Public Health will be appointed to be the key health adviser for local authorities and to exercise these new functions on their behalf; they will also be statutory members of health and wellbeing boards.

The Public Health Outcomes Framework sets the context for the system, from local to national level. It consists of two overarching outcomes that set the vision for the whole public health system of what we all want to achieve for the public’s health.

The two outcomes are

a) increased healthy life expectancy i.e. taking account of the health quality as well as the length of life

b) reduced differences in life expectancy and healthy life expectancy between communities (through greater improvements in more disadvantaged communities)

These outcomes will be delivered through improvements across a broad range of public health indicators grouped into four domains relating to the three pillars of public health – health protection, health improvement and healthcare public health (and preventing premature mortality), and improving the wider determinants of health.

This framework focuses on the respective role of government, the NHS and Public Health England, and their delivery of improved health and wellbeing outcomes for the people and communities they serve.

These domains include:-

1. **Improving the wider determinants of health.** The objective is to make improvements against wider factors that affect health and wellbeing and health inequalities. The indicators include:-

   a) *Employment for those with a long term health condition including those with a learning disability*

   b) *Social contentedness*

   c) *Older people’s perception of community safety*

Local authorities with their partners, including the police and criminal justice system, schools, employers, and the business and voluntary sectors, will all have a significant role to play in improving performance against these indicators.
2. **Health Improvement.** The objective is that people are helped to live healthy lifestyles, make healthy choices and reduce health inequalities. The indicators include:

a) *Proportion of physically active and inactive adults*

b) *Self reported wellbeing*
We all want to live a full and active life, to live independently and to play an active part in local communities. Supporting people to live this way is a central ambition of the Coalition Government. It is also the purpose of this White Paper. The unfortunate truth is that this is not the life lived by many of those with care and support needs. For them, the daily reality can be a life of dependence, of struggling with daily tasks, of loneliness and isolation.

Across the country, the quality of care and support that people receive can vary considerably. Services that are available as standard in some places are unavailable in others. And all too often, the system only grinds into action in response to a crisis, rather than acting quickly to prevent one.

Our system of care and support, developed in a piecemeal fashion over more than six decades, is broken and in desperate need for reform.

Individuals and their carers should have far better support and they need to be in control of the services they use. The system should be built around the simple notion of promoting people's independence and wellbeing.

But we have to do more than just keep people healthy and out of hospital, as important as that is. We need as a society to understand that people with care needs very much have something to offer. Care and support should not just be about making people comfortable but about helping them to fulfil their potential, whatever their circumstances.

The transformation envisaged by this White Paper and the forthcoming Care and Support Bill will come about only if it is a genuinely collaborative endeavour. We need to dissolve the traditional boundaries that lie between the third sector, private organisations, local authorities and individuals. And we need to listen. In particular, we need to listen to the voices of those using care and support, their carers, their families and their friends. Their views and their insight will be vital if we want to get this right – now and in decades to come.

Rt Hon Andrew Lansley, Secretary of State for Health
Paul Burstow MP, Minister of State for Care Services

This White Paper sets out a new vision for a reformed care and support system. The current system does not offer enough support until people reach a crisis point. The new system will promote wellbeing and independence at all stages to reduce the risk of people reaching a crisis point, and so improve their lives. We will transform people’s experience of care and support, with high quality services that respond to what people want. We will put people, and not institutions, in control.
The Government will help people stay active, connected and independent, through better support in communities. It will develop in a number of trailblazer areas, new ways of investing in services that help people stay active and independent.

Society is not making the most of the skills and talents in communities. Not enough is being done to encourage more active and inclusive communities. Loneliness and social isolation remains a huge problem that society has failed to tackle. Carers have also told the Government that their caring role can mean they experience social isolation and financial hardship. As a society we cannot continue to turn a blind eye to those in our communities who need support.

As well as facing up to current challenges, there is huge potential for care and support reform to benefit wider society and the economy. This includes

a) Promoting people’s wellbeing and independence. Better opportunities for individuals, families and communities to support each other and to plan ahead for their care could help to limit future demand for care and support to help to ensure taxpayers money is used more effectively across health, care and support.

b) Contribution to economy and society. Getting care and support right can enable the people who access care, and their families, to play a more active part in the economy and in communities. This benefits both them as individuals and society.

In Chapter 3 the White Paper promises, ‘I am supported to maintain my independence for as long as possible’.

Communities will be encouraged and supported to reach out to those at risk of isolation, and people will be able to access support which keeps them active and independent.

The Government says it will:

a) support social workers to connect people at risk of isolation to community groups and networks.

b) involve communities in decisions around health and care services.

c) legislate to introduce a clear duty on local authorities to incorporate preventative practice and early intervention into care commissioning and planning.

d) develop, in a number of trailblazer areas, new ways of investing in supporting people to stay active and independent.

This includes strengthening support within communities - supporting active and inclusive communities, and encouraging people to use their skills and talents to build new friendships and connections is central to the Government vision for care and support. Strong communities can improve our health and wellbeing and reduce health inequalities.
Tackling social isolation.

Social isolation and persistent loneliness have a huge impact on people’s health and wellbeing. Social isolation is not something the Government or services can tackle on their own, but can initiate action to recognise and identify the most isolated people. We must work together to tackle social isolation.

The voluntary and community sector is uniquely placed to reach socially isolated people and connect them to befriending services and other networks of friendship and support.

Making prevention and early intervention a core local authority role

As part of this shift to a more preventative approach to care and support, the Government will include a duty of local authorities to commission and provide preventative services in the draft Care and Support Bill.

This means that local authorities will work with their communities to commission support that helps to keep people well and independent.

Building community based support into local commissioning plans.

We want communities to be much more involved in the decisions taken by local authorities and the NHS.

As part of our NHS modernisation, we expect local health and care commissioners to identify how the skills and networks in a community can make an important contribution to the health and wellbeing of local people. This will promote care and support which keeps people active and connected to their communities.

It will mean that care and support draws on community networks where possible, rather than segregating people in formal services. Commissioners will also need to consider how they can further support and nurture these community networks and increase people’s awareness of how they can improve their own health and wellbeing. The Think Local, Act Personal partnership, supported by Public Health England, will establish a collaborative network to support and spread the adoption of community based approaches.

Supporting people to make connections.

Local authorities must empower social workers and other care workers to encourage people to use their skills and talent to build stronger relationships and networks with friends, family and the wider community.
Social workers need to work in partnership with community organisations to connect people to peer support networks and befriending schemes when they might otherwise be at risk of isolation, and to promote greater prevention and early intervention. This will mean people are supported to establish strong connections between themselves and community networks, including peer support, which will help them to stay active and will promote their wellbeing.

We expect local authorities together with their local communities to maximise the potential for spaces and building in a community to act as meeting places or centres of activity. Promoting the innovative use of venues in our communities will help to reduce social isolation and increase connections.

Encouraging supportive networks.

People have enormous amounts to give to their communities in enthusiasm, experience, ideas, time, skills, talent and leadership. We want to make it easier and more attractive for everyone, regardless of age or ability, to contribute to their communities and provide a helping hand to those who need it.

The Financial Context

In the 2010 Spending Review the Government allocated an additional £7.2 billion up to 2014/15 to support adult social care. Whilst we acknowledge this comes in the context of a challenging settlement for local government it provides local authorities with sufficient funding when combined with a rigorous approach to efficiency, to protect people’s access to services.

The reforms set out in this White Paper will deliver a re-engineered care and support system that shifts resources towards prevention and early intervention. This will help to improve people’s health and wellbeing, will ensure that taxpayer funding is used more effectively, and will help to manage the future costs of care and support.

Beyond 2015

This White Paper sets out a long term programme of reform. We will continue to work with our partners across the care and support system in the years beyond 2015 to embed the changes that we have set out. This will mean driving forward with a new culture and purpose for care and support – one that promotes the whole populations health and wellbeing, and empowers people to take the lead in pursuing independent lives and life opportunities.
4. Care Bill, House of Lords, July 2013

To make provision to reform the law relating to care and support for adults and the law relating to support for carers; to make provision about safeguarding adults from abuse or neglect; to make provision about care standards

**General responsibilities of local authorities**

**Promoting individual well-being**

1) The general duty of a local authority, in exercising a function under this Part in the case of an individual, is to promote that individual’s well-being.

2) “Well-being”, in relation to an individual, means that individual’s well-being so far as relating to any of the following –
   - physical and mental health, emotional well-being and personal dignity;
   - protection from abuse and neglect;
   - control by the individual over day-to-day life;
   - participation in work, education, training or recreation;
   - social and economic well-being;
   - domestic, family and personal relationships;
   - the individual’s contribution to society.

**Preventing needs for care and support**

1) A local authority must provide or arrange for the provision of services, facilities or resources, or take other steps, which it considers will –
   - contribute towards preventing or delaying the development by adults in its area of needs for care and support;
   - contribute towards preventing or delaying the development by carers in its area of needs for care and support;
   - reduce the needs of care and support of adults in its area;
   - reduce the needs for support of carers in its area.

2) In performing that duty, a local authority must have regard to –
   - the importance of identifying services, facilities and resources already available in the authority’s area and the extent to which the authority could involve or make use of them in performing that duty.

**Promoting integration of care and support with health services etc.**

1) A local authority must exercise its functions under this Part with a view to ensuring the integration of care and support provision with health provision and health-related provision where it considers that this would –
a) Promote the well-being of adults in its area with needs for care and support and the well-being of carers in its area

b) Improve the quality of care and support for adults, and of support for carers, provided in its area.
People with learning disabilities have poorer health than their non-disabled peers, differences in health status that are, to an extent, avoidable. As such, these differences represent health inequalities.

In this report we summarise the most recent evidence from the UK on the health status of people with learning disabilities and the determinants of health inequalities they face.

One in seven adults with learning disabilities rate their general health as not good. These may be underestimates of the poorer health of people with learning disabilities, as carers of people with learning disabilities tend to perceive the person they care for to be healthier than suggested by the results of medical examinations. Health screening of adults with learning disabilities registered with GPs reveals high levels of unmet physical and mental health needs.

The prevalence of psychiatric disorders is also significantly higher among adults whose learning disabilities are identified by GPs, when compared to the general population rates. Reported prevalence rates for anxiety and depression amongst adults with learning disabilities vary widely, but are generally at least as high as in comparison groups drawn from the general population. Anxiety and depression are common amongst people with Downs Syndrome. In one study people with learning disability who lived with their families were found to be more likely to have anxiety disorders whilst those who lived independently of their family were more likely to have personality disorders and overall higher rates of psychopathology.

**Determinants of Health Inequalities**

Research studies have investigated five broad classes of determinants of the health inequalities faced by people with learning disabilities that are, in principle, potentially amenable to intervention.

- Increased risk of exposure (and possibly greater vulnerability when exposed) to well established ‘social determinants’ of poorer health;
- Increased risk associated with specific genetic and biological causes of learning disabilities;
- Communication difficulties and reduced health ‘literacy’;
- Personal health risks and behaviours;
- Deficiencies in access to and the quality of healthcare and other service provision.

Evidence for these determinants of health inequalities is outlined below.

**The ‘Social Determinants’ of Health**
People with learning disabilities, especially people with less severe learning disabilities and people with learning disabilities who do not use learning disability services, are more likely to be exposed to common ‘social determinants’ of (poorer) health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination.

People with learning disabilities also experience a lack of knowledge and choice in relation to healthy eating. Less than 10% of adults with learning disabilities in supported accommodation eat a balanced diet, with an insufficient amount of fruit and vegetables. Carers generally have a poor knowledge about public health recommendations on dietary intake.

Over 80% of adults with learning disabilities engage in levels of physical activity below the Department of Health’s minimum recommended level, a much lower level of physical activity than the general population.

Little is known about inequalities in the sexual health status of people with learning disabilities in the UK. There is, however, evidence to suggest that they may face particular barriers in accessing sexual health services and the informal channels through which young people learn about sex and sexuality.

Wellbeing, health and quality of life are influenced by services other than health services including for example social care, education, employment, housing, transport and leisure services; this may be especially true for people with learning disabilities who may be regular users of these services. Evidence of how these services impact on the health of people with learning disabilities in the UK is scarce and researchers are faced with a number of methodological difficulties.

We are not aware of any recent UK research which specifically measures the impact of leisure services, travel services or education services on the health of people with learning disabilities.

Responding to the health inequalities faced by people with learning disabilities is a critically important issue for primary and secondary healthcare services in England. It is clear that these health inequalities are, to an extent, avoidable. It is also clear that existing patterns of healthcare provision are insufficient, inequitable and likely to be in contravention of legal requirements. Department of Health policies and guidance have continuously emphasised the central role that mainstream health services must play in meeting the health needs of people with learning disabilities.

This briefing paper has drawn attention to:
- Those aspects of health where people with learning disabilities fare particularly poorly;
- Current knowledge concerning the determinants of the health inequalities faced by people with learning disabilities.
Understanding the determinants of health inequalities helps identify potential solutions. Responding appropriately to the health inequalities faced by people with learning disabilities in England demands action on several fronts. These include:

- reducing the exposure of people with learning disabilities to common social determinants of (poorer) health such as social disconnectedness and overt discrimination.
This was a three year strategy for people with learning disabilities setting out:-

- to address what people had told the Government about the support people with learning disabilities and their families need;
- to reflect the changing priorities across government which impact directly on people with learning disabilities;
- the Government’s response to the ten main recommendations in Healthcare for All (2008), the report of the Independent Inquiry into access to healthcare for people with learning disabilities;
- to provide a further response to the Joint Committee on Human Rights report, A Life Like Any Other? (2008)

The vision is that all people with a learning disability are people first with the right to lead their lives like any others, with the same opportunities and responsibilities, and to be treated with the same dignity and respect. They and their families and carers are entitled to the same aspirations and life chances as other citizens.

People with learning disabilities say that relationships are important to them. Yet the evidence is that people with learning disabilities have very limited relationships. 31% had no friends. Reasons for this include services getting the balance wrong between protecting vulnerable people and helping people to have a life. Positive risk taking should be part of everyone’s life.

This strategy emphasises the importance of enabling people with learning disabilities to meet new people, form all kinds of relationships, and to lead a fulfilling life with access to a diverse range of social and leisure activities. There is evidence that people with learning disabilities have limited opportunities to build and maintain social networks and friendships.

The Department for Transport and the Department of Health will ensure national programmes on inclusive transport include people with learning disabilities. We know that people with learning disabilities are less likely to make journeys than non-disabled people because of transport difficulties.

The Department of Health will work with the Department for Media, Culture and Sport to explore how local services can be made more accessible for people with learning disabilities. This is to address concerns that people with learning disabilities are often not connected to their communities or given vocational, social, leisure or learning activities.

The Home Office will work with the Department of Health, the Ministry of Justice and related crime and disorder agencies and third sector partners to support the development and implementation of the Disability Hate Crime Strategy, making sure the specific issues for people with learning disabilities are addressed. This recognises that the lives of people with learning disabilities are still constrained by experience of abuse and
neglect. Many people do not feel safe in their local communities and have been victims of hate crime.
7. **Prioritising need in the context of *Putting People First: A whole system approach to eligibility for social care***

*Guidance on Eligibility for Adult Social Care, England 2010, Department of Health*

Investing in prevention and well-being

Prevention and early intervention are at the very heart of the vision for social care set out in *Putting People First*, and further endorsed in the Care and Support Green Paper. *Putting People First* says that there needs to be a “locally agreed approach....utilising all relevant community resources, especially the voluntary sector so that prevention and early intervention and enablement becomes the norm.” Before setting eligibility criteria for social care, councils should consider their strategy for investing in a more universal approach, which prevents or delays the need for more specialist social care interventions.

The guidance deals later with setting criteria for meeting eligible needs, but councils should also consider the significant benefits of addressing the wider needs of their local community more generally. Low cost interventions may also have considerable impact on day to day quality of life. This could include signposting people to information relating to benefits they may be entitled to or community support groups. Councils should also consider the potential of low – level services in helping carers, of any age, to have a life outside of caring. All of these interventions can support people to maintain their independence and wellbeing and reduce or delay the need for more targeted social care interventions.

To be most effective, preventative strategies should be embedded across the Council, informed by assessment of local needs and created in partnership with other relevant local agencies. Such strategies might include the following:

**Place-shaping and promotion of well-being through universal services**

This involves ensuring that people feel supported, included and able to participate in the community in which they live. It might include activities to address social inclusion such as lunch clubs or befriending; healthy living advice and support; employment advice and support; physical recreation and leisure pursuits; community safety; housing support and transport.

Only a minority of these universal services will be funded through social care and many will be reliant on community – based provision. In considering their local populations needs, councils might therefore wish to consider investment in voluntary and community organisations which can deliver universal and open-access services.

Seventh Report of Session 2007-08, Volume 1. House of Lords, House of Commons, Joint Committee on Human Rights

Extracts from Summary

Despite marked improvements in the past thirty years in the lives of adults with learning disabilities, including the closure of long stay hospitals, there have been a number of recent failures in healthcare, including cases of abuse, neglect and ill-treatment of adults with learning disabilities.

The Committee’s inquiry received evident principally from witnesses in England, and so focuses on the policy framework in the 2001 Government White Paper Valuing People. This is based on rights, independence, choice, inclusion and a programme of change, but progress has slowed and there is a gap between the Government’s policy and the experiences of people in their daily lives.

Evidence to the Committee suggest that adults with learning difficulties are more liable to social exclusion, poverty and isolation, and that efforts to improve their lives have had little impact on some. The evidence suggests that public authorities, including local authorities and PCTs, are not fully committed to the implementation of the Government’s policy in Valuing People and that limited resources are undermining attempts to implement the aims of that policy effectively.

Extracts from Introduction

The first national survey of people with learning disabilities found that adults with learning disabilities are often social excluded, have little control over their own lives, and were “more likely than others to have bad things happening in their lives”.

We have decided to use this inquiry to question whether we are meeting our obligations to respect the human rights of adults with learning disabilities and whether, as a result, adults with learning disabilities in the United Kingdom are likely to be able to lead ordinary lives.

Extracts from Terms of Reference

We called for evidence on how the human rights principles were relevant to the treatment of adults with learning disabilities and how they were treated in their daily lives. In particular we sought evidence on the following issues:

- the possibility for adults with learning disabilities to form and maintain personal relationships with others (such as partners, parents and children) and the positive obligations of the state which arise in this context;

- the opportunities for people with learning disabilities to participate in the life of their local community and the state’s obligation to facilitate participation.
Are people with learning disabilities especially vulnerable to infringements of their human rights? (extracts)

Expectations have traditionally been low for people with learning disabilities, so that the lack of a job, an impoverished home environment, the absence of social relationships, and a lack of privacy and dignity, are often accepted without comment. As Rob Greig, National Co-Director for Learning Disabilities told us:

we need to remember that we are talking about people who on the whole have not only had their rights denied for centuries, but have actually lived in an environment where they have been......taught not to have great expectations in life.

People with learning disabilities are often socially marginalised and isolated. They may live in segregated settings with few, if any, social relationships with people living in the wider community. Infringements of their human rights are thus less likely to be observed or addressed.

The policy context (extract)

We consider that the creation of a culture of respect for human rights will help lead towards a society where everyone, including adults with learning disabilities, is treated fairly, with equality and with dignity.

Why do human rights matter? (extract)

Witnesses told us human rights had a role to play, but that there were a number of barriers to a better deal for adults with learning disabilities. These included failure by Government to secure the effective implementation of Valuing People, lack of funding, and negative attitudes.

Living with a learning disability (extracts)

“I think of life as a person with learning difficulties as being taken to watch a football match, where life is that football match, and never being allowed to join in. People with learning difficulties have the same dreams, inspirations and aspirations as everyone else but we are held back from engaging in life. If you think of your most cherished moments in life, of the things that you still look back on and smile, I expect it is something that people with learning difficulties would get held back from doing”. Andrew Lee, Dorset, People First (Self Advocacy)

We heard examples of good and bad experiences and received evidence on most aspect of life with a learning disability, including:

- Relationships with friends and family and sexual or other personal relationships
Playing a part in the local community

“When group members can’t do something they want to or that is important to them, it is usually not because people don’t respect their rights but is usually down to lack of staff or other support or having no transport.” Summary from a submission from a small self advocacy group.

People told us about their desire for friends and relationships; the difficulties they had in getting out to meet other people (because of lack of support); and the negative attitudes, strictures, lack of opportunities and privacy they confronted if they wanted to develop close personal relationships or get married. Although we accept the evidence of the Minister for Care Services that the State does not have “a duty to provide people who are lonely with a friend”, we are concerned that in some circumstances, the experiences of people with learning disabilities engage their right to respect for private and family life and participation in the life of the community, as guaranteed by the UN Disability Rights Convention. For example, witnesses told us:

We are stuck in at home with not many friends. I would like to go to the pub or to bingo.

We welcome the Government’s recognition in Valuing People that:

Good services will help people with learning disabilities develop opportunities to form relationships, including ones of a physical and sexual nature.

We recommend that the Department of Health revisit this issue in their redrafted Valuing People Now, in light of the evidence we have received.
9. Confidential Inquiry into premature deaths of people with learning disabilities

Mencap wrote a report called ‘Death by Indifference’ in 2007 about 6 people with learning disabilities who should not have died. The Health Service and Local Government Ombudsman looked into the complaints of all 6 families and an independent inquiry also looked at what we can learn from what happened to these 6 people. That Inquiry had some ideas about what to do to make sure people with learning disabilities receive better healthcare. One idea was to set up a Confidential Inquiry to look at why people with learning disabilities sometimes live shorter lives than other people. This report is about what the Confidential Inquiry found.

Included in this report was that of significance in preventing premature deaths was whether a person was married, had a partner or a significant friend. Those whose deaths were amenable to good quality healthcare interventions were less likely to have had such a significant person in their life.
Humans are naturally social. Yet, the modern way of life in industrialized countries is greatly reducing the quantity and quality of social relationships. Many people in these countries no longer live in extended families or even near each other. Instead, they often live on the other side of the country or even across the world from their relatives. Many also delay getting married and having children. Likewise, more and more people of all ages in developed countries are living alone, and loneliness is becoming increasingly common. In the UK, according to a recent survey by the Mental Health Foundation, 10% of people often feel lonely, a third have a close friend or relative who they think is very lonely, and half think that people are getting lonelier in general. Similarly, across the Atlantic, over the past two decades there has been a three-fold increase in the number of Americans who say they have no close confidants. There is reason to believe that people are becoming more socially isolated.

Why Was This Study Done?
Some experts think that social isolation is bad for human health. They point to a 1988 review of five prospective studies (investigations in which the characteristics of a population are determined and then the population is followed to see whether any of these characteristics are associated with specific outcomes) that showed that people with fewer social relationships die earlier on average than those with more social relationships. But, even though many prospective studies of mortality (death) have included measures of social relationships since that first review, the idea that a lack of social relationships is a risk factor for death is still not widely recognized by health organizations and the public. In this study, therefore, the researchers undertake a systematic review and meta-analysis of the relevant literature to determine the extent to which social relationships influence mortality risk and which aspects of social relationships are most predictive of mortality. A systematic review uses predefined criteria to identify all the research on a given topic; a meta-analysis uses statistical methods to combine the results of several studies.

What did the Researchers do and Find?
The researchers identified 148 prospective studies that provided data on individuals' mortality as a function of social relationships and extracted an “effect size” from each study. An effect size quantifies the size of a difference between two groups—here, the difference in the likelihood of death between groups that differ in terms of their social relationships. The researchers then used a statistical method called “random effects modeling” to calculate the average effect size of the studies expressed as an odds ratio (OR)—the ratio of the chances of an event happening in one group to the chances of the same event happening in the second group. They report that the average OR was 1.5. That is, people with stronger social relationships had a 50% increased likelihood of survival than those with weaker social relationships. Put another way, an OR of 1.5
means that by the time half of a hypothetical sample of 100 people has died, there will be five more people alive with stronger social relationships than people with weaker social relationships. Importantly, the researchers also report that social relationships were more predictive of the risk of death in studies that considered complex measurements of social integration than in studies that considered simple evaluations such as marital status.

What do These Findings Mean?

These findings indicate that the influence of social relationships on the risk of death are comparable with well-established risk factors for mortality such as smoking and alcohol consumption and exceed the influence of other risk factors such as physical inactivity and obesity. Furthermore, the overall effect of social relationships on mortality reported in this meta-analysis might be an underestimate, because many of the studies used simple single-item measures of social isolation rather than a complex measurement. Although further research is needed to determine exactly how social relationships can be used to reduce mortality risk, physicians, health professionals, educators, and the media should now acknowledge that social relationships influence the health outcomes of adults and should take social relationships as seriously as other risk factors that affect mortality, the researchers conclude.
"I welcome Lemos & Crane’s report Loneliness and Cruelty. It is a lucid, jargon-free account of ordinary lives disrupted by heartless exploitation and cruelty. It reminds us of the importance of ensuring that people with learning disabilities have informal as well as professional support within neighbourhoods and communities – and how important friends, families and neighbours are in keeping people safe. We shall certainly reflect the report’s findings in our approach to CQC’s inspections going forward.” Dame Jo Williams, Chair of the Care Quality Commission

The issue

There has been a significant shift over the last 30 years away from placing people with learning disabilities in closed residential institutions and towards independent living, supported housing and other community-based accommodation. This shift in policy is to be celebrated. It has given people the promise of independence, freedom from confined horizons and all too frequently from institutional abuse, and freedom for pursuing more integrated and fulfilling lives within the community.

But the society and the communities in which people have found themselves have also changed significantly over the same period of time, becoming in many ways selfish and unwelcoming. Society’s most deprived neighbourhoods and communities – where many people with learning disabilities live independently in social and supported housing – are places where many residents’ self-esteem is chronically low, and where people with learning disabilities have become easy prey for cruel hearts and criminals.

The insight

Loneliness and Cruelty reports on the first phase of an on-going research project working with the Foundation for People with Learning Disabilities and practitioners from housing, care and support, advocacy and police services across the country, supported by Esmée Fairbairn Foundation. For the first phase, 67 people with learning disabilities who live in the community were interviewed about their lives. People greatly value their independence and freedom to express themselves in their own space. But a lot of people feel lonely. One in four people interviewed didn’t have a best friend. And almost everyone had experienced some form of harassment, abuse or related crime in the community.

People experience incidents when they are ‘out and about’ in parks, shopping areas, and on public transport. People also experience incidents in and around their own homes. Neighbours and local residents are among the most common types of perpetrator, as are schoolchildren and young people in groups. ‘Predatory’ groups and individuals who pretend to be friends but who are really taking advantage of people are frequently encountered. Strangers in the street, family members, shopkeepers, work colleagues and care and support workers are also perpetrators.

Verbal attacks – name-calling, taunting, making cruel fun – are the most common type of incident. ‘Paedophile’ is a common term of abuse. Physical attacks, abuse and threats
also occur frequently. ‘Financial abuse’ is common – stealing money, intercepting benefits, making people buy things – as are attacks on property. Other types of incident include emotional exploitation (being promised a romantic relationship only to be used as a source of cash or rent-free lodging), sexual abuse and rape.

Influencing policy and practice

Loneliness and Cruelty sets out a framework for tackling the problems identified that emphasise the importance of developing social capital to address the fundamental and underlying problem of the loneliness and social isolation of people with learning disabilities, as well as continued efforts to achieve criminal justice and equal rights. The policy and practice of over 1,000 providers of social housing, care and support, criminal justice and other community-based service have been influenced by the report.

On-going work for the project includes developing a website that features guidance, projects and resources for practitioners working in the community, and an implementation framework that will enable agencies and organisations to review their policies and procedures to identify action areas that address the problems identified in the report.

Priorities for Action

A. Enhanced social networks for people with learning disabilities

1. Developing friendships and relationships within the community that make people with learning disabilities less vulnerable to harassment abuse and related crime

2. Encouraging person centred interests and activities that enhance lives while also making links with the wider community

B. Stronger prevention and support services from mainstream organisations

C. Creating civic mindedness and safer public spaces
3. Social Care in Crisis – the Need for Reform, Learning Disability Coalition Annual Survey 2012
Anthea Sully, Rachel Bowen

The Learning Disability Coalition (LDC) was formed in 2007 to prevent further cuts to funding for people with learning disabilities. We represent 15 leading learning disability organisations. The aim of the LDC is to make sure there is enough public funding for people with a learning disability to have the same life chances and choices as everyone else.

In January and February 2012 the LDC carried out surveys on local authorities, people with learning disabilities and service providers. Despite the best intentions of local authorities and providers to manage the situation by making efficiency savings based on the consequences of budget restraints, the consistent message is of a struggle to maintain services and people receiving insufficient support, making it a challenge for people with learning disabilities to live the lives they want to lead.

In 2010 the Government allocated £7.2 billion for social care services over the period of the review. This was in recognition of the increasing demand for social care services. It was also an acknowledgement of the very difficult financial position local authorities were put in as they were expected to make cuts of around 28% across their services. The cushion of money for social care was expected to prevent any significant cuts to social care. However, the lack of ring fencing for this funding and the fact that social care has been underfunded and in crisis for many years has meant that this extra funding has done little more than prevent the system from entirely collapsing.

The survey results of service providing organisations and people with learning disabilities show that social care is underfunded and in crisis. People are experiencing cuts to services and are being left isolation and without support – often resulting in costs being transferred to the health system or judicial system as people reach a crisis situation. Local authorities are trying to ensure that an increasing number of people are getting the support they need through a system which is not working for anyone. The message is clear – the system is in crisis and we can’t afford not to reform it.

The financial situation both local authorities and service providing organisations is very difficult, but the most important factor is how this then impacts on the lives of people with learning disabilities and their families. A staggering 50% of people had experienced negative changes to their support.

A high number of people said that they were doing less during the week either because they could no longer afford their day time activities, or their day centre was open fewer hours or was closing altogether. Consequently some people are now stuck at home for most of the week and with no day time activities are becoming isolated, losing friendships and networks of support.

Mild and moderate needs
“People at the less severe end of the spectrum struggle to get any services, even though these are people who typically – without support – will end up in crisis situations and expensive, unnecessary provision. Thinking is very short term”. Provider

More than 5 out of 10 service providing organisations said that funding for people with mild and moderate needs was difficult. 4 out of 10 local authorities identified support for people with mild and moderate needs as facing difficulties in funding.

The White Paper on Social Care represents a real chance to reform the social care system and create a system which works for everyone – people with learning disabilities, older people and carers. ‘We need better funding to enable people with learning disabilities to have a normal life style live everyone else.’
In 2008 we published estimates of the need for adult social care support among people with learning disabilities in England for the period 2009-2026. All scenarios included in our estimation procedures suggested sustained growth in the need for social care services for adults with learning disabilities over the time period with an average estimated annual growth rate of 1.0% to 7.9% (average 4.2%).

In the new model all scenarios again suggest sustained growth in the need for social care services for adults with learning disabilities over the full time period, with estimated average annual increases varying from 1.2% to 5.1% (average 3.2%). These estimates are marginally lower than, but not as varied as, those we produced in 2008.

All scenarios suggest sustained growth in the need for social care services for adults with learning disabilities over the full time period. However, estimated average annual increases vary from 1.2% (lower estimate, services are only provided to new entrants with critical or substantial needs) to 5.1% (upper estimate, services are provided to new entrants with critical, substantial or moderate needs).

We also estimate that:

- by 2030 the number of adults aged 70+ using social care services for people with learning disabilities will more than double.
5. **Emerson, Intellectual and Physical Disability, Social Mobility, Social Inclusion and Health**

_Eric Emerson, Ros Madden, Janet Robertson, Hilary Graham, Chris Hatton and Gwynnyth Llewellyn, CeDR Research Report 2009:2, May 2009. Paper was commissioned by and was evidence to the Strategic Review of Health Inequalities in England Post 2010 (Marmot Review)_

Disabled adults are at risk of experiencing social exclusion and discrimination associated with their disability (disablism). The direct effects of such discrimination include reduced access to appropriate healthcare. Indirect effects of such discrimination on health operate through increased social exclusion, restricted social mobility and the psychological impact of direct personal experience of disablism actions.

**Recommended Action**

There already exists a plethora of health, educational and social care policies and guidance in England that seek to reduce health inequalities and social exclusion and improve social mobility. All too often, however, these policies pay scant regard to the specific situations faced by disabled people, the apparent assumption being that the benefits of interventions targeted at deprived areas or families will accrue equally across all social groups. There is considerable evidence, however, that behaviour change interventions (whether ‘upstream’ or ‘downstream’) aimed at reducing health inequalities are likely to be more effective if they are tailored to the specific social and cultural contexts faced by ‘high risk’ groups. Without such attention to the specific contexts faced by disabled people there is a real risk that they may fail to benefit from existing ‘generic’ policies. It is also worth noting that the NHS and its constituent parts are under a legal duty to pay due regard to eliminating discrimination and promoting equality of opportunity for disabled people.

There also already exists a plethora of English health, educational and social care policies and guidance that seek to improve the life chances and reduce the disadvantage faced by disabled adults. **We support the general thrust of these developments in health, education and social care, in particular their emphasis on:**

- Prevention and early intervention
- The personalisation of support
- The co-ordination of support
- The devolution of resources and power to disabled people themselves
- The move towards socially inclusive patterns of provision and support

**Disability and Social Exclusion**

Social exclusion has been conceptualised as encompassing participation restrictions in four key domains: consumption; production; political and civic engagement and social interaction. **There is extensive evidence to suggest that disabled people are at significantly higher risk of exclusion in each of these areas:**

a) **Consumption**
b) Production

c) Political and civic engagement

d) Social interaction – as children and as adults disabled people are more likely to have restricted social networks, have looser ties to their local community, to experience bullying and to be victims of hate crimes. The social disconnectedness of some disabled people is exacerbated by the use of segregated and, at times, geographically remote educational and residential services.

**Recommendations for Future Research/Action Development**

There exists a dearth of evidence on the effectiveness of strategies to reduce the health inequalities experienced by disabled people. As such we reiterate the importance of three key recommendations made in the previous section. This includes:

1) The Department of Health to fund a programme of work examining the nature and impact of disablism on health, well-being, social inclusion and social mobility.

A summary of the presentations and discussions from the History of Learning Disability Conference ‘Friendships, Networks and Learning Disabilities: Friends’ stories and stories about friends’ held at the Open University in July 2011. Liz Tilley, lecturer in the facility of health and social care at the Open University and chair of the Social History of Learning Disability Research Group

In July 2011, the SHLD hosted a conference on friendship and learning disability. It was an inclusive event with papers presented by people with learning disabilities, family members, practitioners and academic researchers.

Presentations included five PhD projects focusing on the role of friendships in the lives of people with learning disabilities, indicated that friendship is emerging as a topic central to research and policy agendas.

We heard first hand from a number of speakers with learning disabilities about their experiences of finding friends, but also losing them. People also spoke about the difficulty of sustaining friendships throughout a lifetime of continuously shifting service provision. In some of the life stories that were presented, friendship had remained an elusive aspiration, with bullying and teasing being more familiar experiences of social interaction with one’s peers, staff and the local community. Supportive and respectful relationships had been difficult to find.

Vulnerability without support

Such papers demonstrated how vulnerable to isolation and harassment people with learning disabilities can be if they do not have people around who are actively supporting them to develop and sustain social networks.

Technology

The conference attendee also grappled with the questions of what friendship actually is and whether it can, does and show apply to people with learning disabilities in the same way as the wider population. Gillian Allan led an interesting discussion on this topic, emphasising that friendships cannot be forced and require a natural connection.

The role of technology emerged as another key theme throughout the conference. Some of the younger disabled people who made presentations highlighted the growing importance of social networking sites in helping them to sustain friendships following transitions to new places and services.

Nevertheless, technology is also proving to be a barrier for others. Mobile phones need battery life and credit to be useful. Websites requires access to a PC and an internet connection. Texting and emailing require some reading ability. Some people require support enable them to use technologies in ways that are genuinely useful in sustaining
social networks. For others, technology may hold little appeal, and so alternative means must be found to enable people to find and keep their friends.

**Friendships matter**

Above all, the conference highlighted that friendships really matter to people with learning disabilities. Learning Disability self-advocacy group Central England People First (CEPF) argued that the sustainability and survival of self advocacy may be dependent upon groups developing and sustaining friendships both inside and outside of their organisations.

**Other presenters articulated beyond doubt that good friendships are central to happiness and wellbeing, and a huge support in times of difficulty.** This was especially evident in a presentation by Liz Tilley and the Money, Friends and Making Ends Meet Group. This group comprises people who require some support, but are not eligible to receive services. Their paper emphasised just how vulnerable some people can become - frequently facing crisis in paying for food, fuel or housing, and sometimes lacking the resources and knowledge to address routine issues that then spiral into major problems. Many became friends and have now been supporting one another, and it demonstrated the importance of friendships in helping some people with learning disabilities to get by and manage in the most trying or circumstances.

Postek argued that friends are especially important at transition. Friends help people to experience new things, to develop a values base, to find out what they like and what they don’t; ultimately, to forge identities. But time and opportunities are required to form good and lasting friendships.

**Conclusions**

At the end of the conference there was a lively debate about the extent to which policy makers and service providers should be involved in supporting friendships for people with learning disabilities. Some delegates argued that a ‘friendship strategy’ was an anathema – counter-intuitive and likely to distort the creation of genuine friendships. What is needed instead, they suggested, are credible structural shifts in how support is provided, which would enable people to have the opportunities to develop friendships in more spontaneous ways.

Others suggested that people with learning disabilities require specific support to develop and maintain friendships and that there needs to be greater recognitions by commissioners, managers and frontline staff of the resources and skills required to enable friendships to happen.
Wolfensberger (1983) states that “the most explicit and highest goal of normalisation must be the creation, support and defence of valued social roles for people who are at risk of social devaluation”. One of the most important ways in which roles may be obtained (and retained) is through the development of friendships. (Kings Fund 1982.) According to the popular Oxford Dictionary, friends feel ‘mutual regard and affection’, implying that to have friends can assure one of socially valued status.

Research findings on the number and type of friendships and relationships of people with learning disabilities are not heartening.

**Psychological Well-being**

In addition to social role valorisation, another potential benefit of acquiring and maintaining friendships is the positive relationship between psychological well-being and successful social functioning, reported by a small body of literature. Psychological well-being has been reported to be lower in people with learning disabilities. For example, Thompson *et al.* (1985) administered three self-report measures of depression to 21 people with mild learning disabilities. Their results which showed 52% scored in the clinically depressed range were significantly different from the normal population of whom only 15% are expected to score in the clinically depressed range.

Reiss and Benson (1985) investigated the relationships between levels of social support, perceived stigmatisation and levels of depression in 45 subjects with mild learning disabilities. A powerful negative relationship between social support and depression was found, as well as a positive relationship between levels of perceived stigmatisation and depression. The authors postulate several reasons why they found such a strong relationship between levels of social support and depression. They include loneliness and not being able to cope with stressors because of lack of support. Furthermore, the depression may have resulted in the loss of social support as depressed people may be less rewarding to be with and therefore avoided by others.

Luftig (1989) investigated the estimated ease of making friends, the perceived social competency and loneliness in 73 adults with mild learning difficulties compared to 181 chronological age-matched controls and 132 mental age-matched controls. Compared to the control groups, the group with learning difficulties reported fewer perceived difficulties in making friends, and were less critical of their own social competency skills. However, this group also reported significantly higher rates of loneliness. Unlike the control groups, this group of youngsters with learning difficulties did not see a strong relationship between social competency and loneliness. This apparent lack of insight signifies according to the authors that people with learning difficulties do not only require help in developing their social skills but also need to learn to recognise the importance of these skills.
Opportunities for integration

The acquisition of appropriate social skills and knowledge necessary to engage in meaningful relationships will not necessarily lead to the formation of such relationships. Having the opportunity to meet and socialise with other people is an essential part of acquiring friends and acquaintances. The number of friends that people with learning difficulties have is extremely low and often zero (Felce, 1988; Fleming and Stenfort Kroese, in press). Felce emphasises that although frequency of contact can be measured, it is difficult to obtain a measure of quality of any one relationship, which is necessary in order to define a friendship.

Fleming and Stenfort Kroese evaluated the quality of life of 17 adults who had moved from long stay hospitals to group homes one year previously. The evaluation revealed that there had been an increased in adaptive behaviour, particularly in house bound skills. However, there was low community presence, with few of the activities of the residents being integrated, and with evening outings occurring on average less than once a fortnight. Low staffing ratios and transport problems were cited by staff as being the cause of these difficulties.

Providing a range and balance of activities that may lead to greater community presence and satisfying relationships requires both creativity and persistence by staff. Atkinson’s (1985) survey of 50 people who had moved to independent community based accommodation found that this relatively able group of people participated in a variety of activities, many of which were based in the community. However, many participants in the study described social activities that they used to do. Often an activity was stopped because there was nobody to do it with, suggesting a lack of social ties. Another trend was that of ‘getting stuck’; many of the participants had interests that could have been expanded into a more social or shared activity if the person had the confidence or ‘know how’ to do so. It was also found that although participants mixed with members of their community, this did not always result in actual contact with individuals. The person with a learning difficulty often acquired observer status i.e. tending to watch activities rather than joining in.

Salzberg & Lanford (1981) described a model for providing opportunities for people with learning difficulties to participate in leisure activities and form contacts with non handicapped people. People with learning difficulties were matched to non handicapped individuals depending on their interest and abilities in leisure activities. They were asked to engage in at least one leisure activity per week in an integrated setting. Though this scheme did not specifically aim to help people with learning difficulties to make friends, it did provide opportunities to meet and mix with ordinary people and it gave them opportunities to gain skills in leisure activities. However, long term benefits of this scheme were not evaluated.

There are a number of ways in which opportunities for social contact with the community can be encouraged. However, how effective these schemes are in producing long term, socially relevant benefits for people with learning difficulties has not yet been
established. It must also be recognised that many of their social contacts will still be with other people who also have learning difficulties.

Conclusions

It appears that moving people with learning difficulties into houses in the community will not ensure per se that relationships with others living in that community will be established. Hence, more active policies must be pursued to provide opportunities for people with learning difficulties to form acquaintances and friendships. Such policies may include forms of leisure and activity planning (Cragg and Garvey, 1990) as well as schemes which make use of volunteers for befriending initiatives.

Of course, no number of introductions will guarantee a successful social life, and hence interventions which enable people with learning difficulties to understand and participate in the complex but rewarding dynamics of friendship must not be discarded. Simplistic social skills training packages need to be broadened so as to move beyond the teaching of superficially appropriate behaviours in artificial settings. They should aim to enable people to perceive, understand and respond to the subtler meanings of these behaviours, as they occur in everyday life. Peer mediated learning may well be an important development towards this aim as it overcomes problems of generalisation both in terms of setting as well as the people involved in the social context.
According to this report relationships that are vital to health and well-being are under threat by modern life, which can isolate people from one another and lead to loneliness. UK-wide research carried out for The Lonely Society shows that one in ten people often feel lonely (11%) and half think that people are getting lonelier in general (48%).

**The way in which people now live is impacting on their ability to connect with others**

Old-style communities are in decline and the closure of local amenities have had an impact on people for whom they were a focal point, particularly those living on the margins of society and vulnerable to loneliness, such as those living with a disability.

**Loneliness can affect people of all ages / pressure to be ‘productive’ can lead to loneliness**

The charity’s report suggests that a shift in attitudes is also contributing to loneliness. For some, investing time in social activities is seen as less important than work. Evidence in the Lonely Society shows people feel pressure to be productive and busy, and as a consequence neglect vital relationships with friends, neglecting the basic human need to connect with others.

Often, the social networks of people with learning disabilities consist of paid supporters who come and go, and studies show that up to a third of people with learning disabilities have no contact with friends. Some front-line workers understand the importance of social networks, but it is variable.

**One approach to loneliness is preventative: we can stop loneliness becoming chronic and tackle the needs of groups that are socially excluded and at risk of isolation. But the success of such measures depends on creating a new climate in which we can better manage our need for social connection.**

_British Institute of Learning Disabilities_

_Geraldine Bane, Martin Dooher, Josephine Flaherty, Ann Mahon, Padraig McDonagh and Marie Wolfe (all Research into Action, Galway, Ireland); Marie Deely, Rob Hopkins, Ger Minogue and Martin Curry (all Clare Inclusive Research, Clare, Ireland); Brian Donohoe, Edel Tierney (both National Federation of Voluntary Bodies, Dublin, Ireland); Edurne Garcia Iriate, Siobhain O’Doherty and Stephen Shannon (all National Institute for Intellectual Disability, School of Social Work and Social Policy, Trinity College Dublin, Dublin, Ireland)._ 

The inclusive research network is a group of researchers with learning disabilities, their supporters and paid professional researchers who do research about things important to people with learning disabilities in Ireland.

In this research, we asked people with learning disabilities what they thought about relationships and supports. We asked people in focus groups: (i) what makes a good friend?, (ii) what do you think about having a boyfriend or a girlfriend?, and (iii) what supports do you need to have friends, a boyfriend or a girlfriend? We found people:

- Wanting to have a boyfriend or girlfriend.
- Being embarrassed talking about it.
- Needing more support from family and staff to keep relationships and deal with them.
- Wanting more transport to get around at night and to visit people.

Findings suggest that people with learning disabilities have a diversity of experiences and views on relationships and support needed to keep them. People with learning disabilities taking part in the focus groups identified that they need more support from friends, family and services staff to develop new relationship and keep their existing ones. This support includes both emotional and systematic changes.

People with learning disabilities have said that to keep friends and be independent they needed:

1. Better access to transport

_Discussion and recommendations_

For the first time, we, as people with learning or intellectual disabilities in Ireland, have begun producing our own research about relationships in the last decade.

_Our research says that friendships and relationships are very important. Good friends, for example, can look out for each other and give each other encouragement._

We found that people with learning disabilities sometimes there wasn't the support from families, parents, friends and staff to have and keep their friendships and relationships.

However, we found out in the research that people feel they are treated like children regarding relationships. Evans et al. (2009) and Tattersall et al. (2009) found that staff
needed more training and guidance on how to support people with learning disabilities to have relationships.

However, when we discussed the findings, we suggested that education on relationships would help people with learning disabilities to have relationships. This would help clarify some of the things people in our research were confused about. For example, some people did not know the difference between friends and boyfriends and girlfriends; some people thought that asking out was the responsibility of men; finally, nobody talked in the focus groups about same sex relationships. These themes may reflect common perceptions about relationships in rural Ireland and the need for people with learning disabilities education on relationships.
This study was carried out by a group of researchers, some of whom have a learning disability and some of whom do not. The researchers involved in this project firstly looked at the existing evidence about what makes people with a learning disability happy with their lives, and found that no one had actually interviewed people with a learning disability to find out what makes them happy. They interviewed 23 people who said that they were happy and satisfied with their lives, and completed a Personal Wellbeing Index.

Three main themes emerged; environmental factors, enabling and disability and personal characteristics.

In terms of environmental factors:-

Choice and independence – this was as very important in all elements of life.

Activities - lots of people felt it was important to have somewhere to go and someone to go with, and there needed to be a mix of things to do in the community as well as places to go that were just for people with a learning disability.

Valuable social roles – this was about the value of having a job, a volunteer job or simply having important roles within a community setting.

Relationships – these were also very important.

In terms of enabling and disabling:-

Staff – staff were mentioned as key people who can help people with a learning disability to get out and about, help them manage difficult situations and provide support and care. It is important staff are flexible and can help people access activities, and that is difficult when they can’t do something because no staff can help them.

Family – family were also important in helping this group to do things and to provide support and care, but it was also recognised that sometimes family can cause barriers by not allowing things to happen. Boundaries – lack of transport was seen by many as being a boundary, as was finance.

In terms of personal characteristics:-

The group recognised that some people are just more likely to look on the bright side of life and be positive, and that is important to be able to do that. It is also important to be able to find ways of managing difficult emotions.
Loneliness can be a significant problem for people with learning disabilities who find friendships limited or restricted. This study looks in more details at how adults with learning disabilities understand friendships, and their experiences, through the use of interview.

Research shows that friendship plays an important role in the well-being of all. Further evidence shows has shown that people with learning disabilities find it difficult to maintain friendships, due to factors such as limited opportunities for exposure to difference social groups and settings, lack of opportunity to develop friendships through different contacts, and lack of skills or support to maintain established friendships and social stigma. Attempts have increasingly been made to address the problems of loneliness and isolation faced by people with learning disabilities, with the White Paper ‘Valuing People’ (2001) stating that ‘this is one the greatest challenges’ (p.81).

What has been missing from much of this work is an understanding of the views that people with learning disabilities hold about friendships and this study aimed to do that. Four key themes emerged from the data: the significance of friendships, the effects of friendship on wellbeing, power dynamics and autonomy.

Participants talked about the reassurance and support they get from friends, and also the sense that friendships can make them feel valued. They had an understanding of the different power relationships in their friendships and with others in their lives. They all spoke of negative social situations in which they had felt vulnerable and had sometimes been exploited and made some explicit links between this situation and their learning disability. They were also aware of greater commonalities in their friendships with other people with learning disabilities.

They also spoke about some restrictions caused by services and staff, with some friendships being reported as being ‘banned’, and some friendships only being there because of attendance at a particular centre or other such service. Social interaction was also limited by not knowing what opportunities there are for social interaction, or by not living close to day centres of other places where friendships could form.

Overall the participants had quite conventional understandings of how a friendship should be and the positive and negative experiences that friendships can create. However it was clear that the participants were reliant on others to facilitate friendships, and on services to enable opportunities for social interaction, and that both of these factors can limit friendship opportunities.

What is clear is that services such as dating and friendship agencies are important and should be part of the development of services. Involving people with learning
disabilities in decisions about such services would be an important way of ensuring that their friendship needs are met. It is also important that staff understand the important role they play in enabling friendships, and in being power brokers in social situations.
12. What are Friends For?

Rachel Hughes, *A Study looking at the significance of friendship in the lives of adults with profound and multiple learning disabilities, 2010*

Should we be worried that adults with profound and multiple learning disabilities (PMLD) may be living friendless lives?

Firstly, friendship is generally considered to be one of life’s good things. If we value friendship then surely it must be right that we strive to enable people with PMLD to share in it.

Secondly, Valuing People Now stated that services should be supporting people with learning disabilities to develop friendships, among other relationships. Significantly for people with PMLD, it has also explicitly stated that the Valuing People Now objectives apply equally to all people with learning disabilities.

Another reason has been suggested by some disability theologians (for example, Jean Vanier and Hans Reinders). They have highlighted how people with learning disabilities have suffered, and still suffer, as a result of being considered ‘lesser’ humans. People with PMLD are particularly at risk of this kind of marginalisation because they do not seem to be able to do many of the things that other people can do. For example some do not seem to be able to act intentionally and most do not use speech or sign language.

Friendship, according to these theologians, can put the humanness of people with PMLD on a firm footing. They argue that the essence of humanness is not about having intentionality or using language but about being vulnerable and dependent on our fellow human beings. People with PMLD are very vulnerable and they are highly dependent on others in most areas of life.
13. Loneliness is the only real disability

*Implications and Recommendations for Policy Makers, David Pitonyak, National Association for Developmental Disabilities Directors 2003 Annual Meeting*

To be vulnerable is not to be in jeopardy. To be vulnerable and isolated is the matrix of disaster. *Willard Gaylin, M.D.*

Social policy is not my forte. My brain is quickly overwhelmed by decisions that might affect hundreds or thousands of people. If it involves moving money around from one funding stream to another, or balancing a multi-million dollar budget, count me out. I have worked in the field for 25 years and I still don’t understand Medicaid.

What I do know is that policies implemented on the state or federal level can make a positive difference in people’s day-to-day lives. Everywhere there are examples of people getting services that they need because, among other things, someone figured out how to influence policy in DC or a state capital. I have the luck of knowing some very smart people who do know how this works. They generously offered their time and insight to help better inform this discussion:

The obvious may not be so obvious.

- Many people who experience our services are profoundly lonely. Much of their suffering results from isolation not disability.

  The ultimate success of a service system depends upon its ability to help people to maintain and develop positive, “enduring, freely chosen” relationships. (O’Brien, 1987).

  When people are connected to a social network, they are generally happier, healthier, and better able to adjust to life’s ups and downs.

  The benefits of our therapies and interventions cannot be sustained in the absence of meaningful relationships. Relationships are a necessary pre-condition to long-term success.

- People who most need relationships are often relationship resistant. Many are experiencing Post Traumatic Stress Disorder as a result of betrayal and abuse. Our high turnover rates are retraumatizing these individuals and it is unethical not to act.

  There is a big difference between coverage and relationships. We keep giving people coverage (and programs and interventions) when they desperately need to be in relationship.

- Caring about someone is not the same thing as taking care of someone. You can’t make people care about one another but the good news is that happens all the time.

- People should not have to “earn” the right to be with friends or family.
Difficult behaviours are often an individual’s only way of creating engagement. We must ask, “Who would the person be if he or she did not exhibit difficult behaviours?”

Social policy is, at best, a blunt instrument. We can promote things that enhance an individual’s chances of forming and maintaining relationships (e.g., we can support families to raise their children at home; we can support the inclusion of children with disabilities in their neighbourhood schools; we can help people to find real jobs for real wages in the real world; we can support home-ownership; we can fund self-directed supports), but the reality is that the tools for the job require a great deal of precision (e.g., someone needs to know each person in a meaningful sense, understand what works and what doesn’t work, provide support over time).

Sadly, most of what we pay for erodes the potential for people to maintain or develop meaningful relationships (e.g., treatment centres for children; “special” classrooms; sheltered workshops; group homes; budgets that are allotted to groups of people rather than individuals).

The people most likely to find courage to stand up for relationships are the ones who understand the importance of relationships in their own lives.

In the fall of 2001, the National Association of State Developmental Disabilities Directors (NASDDD) released a strategic plan to assist member organizations in “building person-centred systems of services and supports for people with developmental disabilities.” On November 13, 2003, the NASDDDS asked me to comment on the goals of the strategic plan. Below are my comments.

**Strengthening System-wide Quality Assurance and Improvement Capabilities**

**Observations:**
- Our current system emphasizes “detached, objective” professionals. What keeps people safe is the presence of people who care deeply, have a commitment to the person over time, and who understand the role of attachment in well-being. While there is no 100% guarantee that a person will be free from harm or exploitation, the odds improve dramatically when a person is surrounded by good, stable, and informed relationships (O’Brien and Lyle-O’Brien, 1993).

- Paid professionals do not stay long. A goal of our service system should be to help people to develop “enduring, freely chosen relationships” (O’Brien, 1987).

- Our quality assurance systems rely on coercion. More often than not, the only thing that is achieved by regulations is that providers engage in activities which "limit legal liability and provide 'feasible deniability.'" Instead of actively pursuing quality, providers "are encouraged to avoid confronting problems"
What matters most to people’s safety...

....is the extent and quality of their relationships. People are safer the more others care enough about their safety and well being to keep a close eye on their situation, to stand up to difficult situations with them, to act imaginatively in response to their vulnerabilities, to negotiate on their behalf with others who control important opportunities, and to struggle with them over situations in which they are contributing to their own problems. Many people with developmental disabilities are more vulnerable exactly because they lack opportunities and assistance to make and keep good relationships. But most current policies and practices ignore these vital relationships issues, and most service dollars are spent on congregating people with developmental disabilities in settings which segregate them. By suggesting that people could be kept safe and well in settings where strangers can drop in to check on quality of life, current approaches to safety fundamentally misdirect attention away from people’s most important safeguard, the safeguard that most service settings are most likely to discourage or disrupt. O’Brien and Lyle-O’Brien (1993)
14. Social capital, social inclusion and services for people with learning disabilities

Peter Bates and Fabian A Davis, National Development Team (Ipswich) and Bromley Health Services, Oxleas NHS Trust, Kent

We have highlighted parts of this paper but recommend the whole paper is read.

Both social capital and social inclusion have emerged as significant concepts for human services in the last decade and yet their inter-relationship remains largely unexplored. This article argues that, whilst they are similar in their vision for a healthy society, they adopt sufficiently different perspectives to stimulate and challenge each other. This can be well illustrated by reference to services for people with a learning disability. Commissioners and providers of learning disability services are encouraged through this article to harness both concepts in order to assist in the process of modernizing services and increasing life opportunities for the people they support. It is argued that it is not possible to understand the full consequences of adopting either theoretical position without an adequate understanding of the other. Examples are given of the implications of this for advocacy services, day opportunities, rural communities, transition and staff training.

The concept of social capital (Putnam, 2000) has become popular just as the English White Paper ‘Valuing People’ (Department of Health, 2001) has required learning disability services to work towards social inclusion. This article points a spotlight on useful insights in both social capital and social inclusion approaches that may help in the development of learning disability services, and notes some of the hazards of an unthinking adoption of either of these frameworks in isolation from the other.

Social inclusion is another fluid term with a variety of meanings (Bates, 2002a). For the purposes of this article, social inclusion means ensuring that people with learning disabilities have full and fair access to activities, social roles and relationships directly alongside non-disabled citizens. Over the past 30 years an informal network of writers (Wolfensberger, 1972; O’Brien, 1987; Falvey et al., 1994; Rusch & Hughes, 1989) have shown how support can be provided so that people with disabilities can be employed rather than attend a sheltered workshop, live in their own home rather than in a hostel, and participate in friendships and community life with a diverse array of citizens, rather than conducting their whole lives within segregated disability services.

Recent policy convergence

We would argue that social capital is an idea whose time has come. It has been enthusiastically adopted by the World Bank, American, European and UK governments, and has permeated the areas of health, education, community care, community regeneration and employment (Mitchell & Harrison, 2001).

Increasing social capital is expected to generate improvements in all the above areas because it is argued that increased civic participation will invigorate government, information flowing through informal networks can enhance job prospects, supportive friendships buffer against distress and illness, reciprocal relationships create a culture
where learning and contribution flourishes, and heightened trust leads to a reduction in crime. As such, social capital theory should be of interest to Local Strategic Partnerships, Learning Disability Partnership Boards, Health Improvement Programmes, Community Safety Partnerships, and a host of other initiatives that directly or indirectly impact the lives of people with learning disabilities.

The 2001 White Paper ‘Valuing People’ (Department of Health, 2001b) introduces person-centred planning (O’Brien, 1987) as a driver to promote service change. The White Paper assumes that the majority of people with a learning disability will want to move towards an independent life in the community, leading to the demise of segregated services. A major part of this change is to be day service modernization by 2006 and the promotion of social inclusion will be an essential component of this change (Love et al., 2002). As a result, many services are looking towards social inclusion advocates and social ‘capitalists’ for a comprehensive and detailed conceptual framework within which to plan and manage such major change.

Thus, developments in learning disability provision, social inclusion and social capital all meet in the growing policy emphasis upon citizenship, so that ‘the world disabled people will occupy will extend way beyond their specialist services’ (Simons, 1998).

Participation in the local community
Those people who have been deliberately segregated in prisons, long-stay hospitals and other institutions are rarely mentioned in social capital thinking, while social inclusion advocates strongly assert that society should find ways of bringing this group back home (Mansell, 1993). A brief glance at policy documents such as Valuing People would suggest that services should promote inclusion, but despite this, current service arrangements often segregate learning disabled people, particularly those with the least natural ability to articulate their interests.

However, bringing people back home demands more than relocating their beds—relationships have to change as well. In both social capital and inclusion thinking, service users are recognized as citizens, and the traditional focus on the relationship between worker and service user is replaced by an emphasis upon the reciprocal relationship between citizen and community:

Two women with learning disabilities wanted to take up yoga. No local groups existed, so the worker found a tutor and a community hall, and put adverts around the neighbourhood. A mixed group of citizens joined and everyone welcomed each other—including the people with learning disabilities. Nine years later the group is still running—long after the worker moved to another job. (Christine Burke, personal communication)

This paradigm shift is also enacted as people are supported to take up open employment and to participate in community Timebanks (Reed & Boyle, 2002) and local exchange trading schemes (Seyfang, 2001). Advocates of social inclusion have rightly highlighted the importance of waged employment as a route to income, status
and relationships, while social capitalists point the spotlight on informal roles and relationships. In addition to the opportunity to earn a wage, people with learning disabilities may participate in the community via education, volunteering or leisure pursuits.

Mainstream learning providers have a renewed focus upon developing citizens’ social and civic skills, and this may lead to a renaissance of non-vocational training to counter the recent emphasis upon developing only those skills that directly contribute to the economy. Such a shift in emphasis would have a disproportionately beneficial effect upon people with learning disabilities.

Similarly, a social capital perspective highlights the benefits of volunteering. For many years, services have arranged a few opportunities for people with learning disabilities to become volunteers in the community. Each placement must find a path between employment (volunteering as work simulation in order to attain vocational experience and skills) and community participation (volunteering as a means to harness altruistic endeavour and build affiliation and membership). Social capitalists helpfully wrest volunteering back from a single-minded attempt to use volunteering solely as work preparation and remind us that volunteering builds community, trust and reciprocity. Care is needed to ensure that volunteering opportunities are safe, rewarding, and respectful and contribute to the formation of social capital (Bates, 2002b).

Reciprocity

The way in which people with learning disabilities are perceived by others can be even more important to their capacity to contribute to the development of social capital and their own social inclusion than their disability. For example, if members of the public label people with learning disabilities as fraudulent, attention seeking, disinterested in civic affairs or unable to make a positive contribution to the community, this will limit their potential for reciprocal relationships with nondisabled community members.

While it can be hard to identify the unique contribution that a particular person enjoys making and for which they will be genuinely appreciated, without opportunity this may never be discovered at all.

Respectful bonding relationships between people with learning disabilities are important, of course, but social inclusion theorists envisage a society in which bridging relationships span all the structural divisions in society (Amado, 1993). An included life with an ordinary home, job and leisure pursuits (rather than segregated in residential units, day centres and ‘group trips’) is a prerequisite for building these socially inclusive bridging relationships. Social inclusion theorists argue that society should nurture relationships between people with a learning difficulty and those without (e.g. Amado, 1993) and assert that everyone can feel at home in mainstream society, while social capital theorists do not make this explicit. Any service would be limited by adopting a social capital analysis alone as this could lead to a diminished vision that confined bonding relationships to those between peers in a day centre and bridging relationships to those that formed between centres, such as at the Special Olympics.

Feelings of trust and safety
Unfortunately, inclusion advocates tend to ignore the shameful reality of bullying, oppression and discrimination that is a daily experience for many people with learning disabilities (MENCAP, 1999). It is curious to note that Valuing People is silent on the matter of bullying, while the Department of Health does require mental health services to address it (Department of Health, 2001a). It is here that social capitalists have the advantage, since their goal of increasing thin trust precisely attends to this agenda. We all have to run the gauntlet of meeting strangers from time to time and negotiate our way through thin trust in order to locate the new friends and colleagues with whom we might enjoy thick trust, but there are extra challenges for visible minorities, and this includes some people with learning disabilities.

Social capitalists task us with addressing these problems by challenging media stereotypes, providing learning disabilities equality training, and actively promoting positive relationships between people with and without disabilities. While social capitalists are developing instruments to measure these things, they have no guidance to offer on which tools are needed to make these changes, so we must look for advice to inclusion advocates, as well as media studies, community development, health promotion and students of the social psychology of stigma.

Inclusion advocates who wish to build links with community development workers may find that social capital is the linking concept that will bring them together.

Social connections
Both social inclusion and social capital theorists invite us to think about people with learning disabilities as citizens who are able to make a contribution to the whole community. This clashes with the current reality, where perhaps only a third of the people utilizing learning disability services have even one non-disabled friend (Robertson et al., 2001). Friendships between people with learning disabilities and non-disabled people must overcome some difficulties, especially where there are inequities in communication skills, disposable income and freedom of choice (Zetlin & Murtaugh, 1988), but can be very rewarding for participants (Newton et al., 1995). Indeed, we think that people with learning disabilities may well have the potential to make an above-average contribution to the community.

Inclusion advocates have been eager to support people with learning disabilities to take up positive social roles, such as householder, employee or student. While lip service has been paid to participation as well as presence in the community, social capitalists insist that attention is given to the quality of social relationships in these settings. Simply achieving the status of a student does not build social capital if there are few opportunities for networking and relationship building. Bridging relationships with non-disabled students are not enhanced if the student is attending a special class, at a special time and taking lunch in a special, segregated cafeteria. Just as important is the support that is made available, for co-location alone does not guarantee the development of friendships. So, for example, poorly skilled job coaches may unwittingly detach learning disabled workers from their non-disabled work colleagues in order to provide intensive task training.
There are also particular challenges that arise from taking a focus on informal and unregulated relationships. A learning disabled customer is legally entitled to fair and equal service from the bar staff, but the Disability Discrimination Act 1995 does not govern the behaviour of other drinkers in the public house. This means that a host of awkward, unfriendly or downright hostile responses may be more in evidence in unregulated social relationships—exactly in those areas that are well covered by social capitalists.

A second reason why discrimination may be amplified in unregulated relationships revolves around the practical transaction with the bar staff. This is governed by clear rules for the encounter (placing an order, pulling the pint, paying for the drink), while the informal connections with other drinkers in the pub are less defined and, consequently, more difficult to negotiate. Similarly, in the workplace, practical tasks may enable people with learning disabilities to demonstrate their abilities at work and so allow social interaction to grow as their competence is recognized, whilst equal opportunities policies constrain potentially negative responses of colleagues. In contrast, unregulated places that are about talking and little else may provide few opportunities for this kind of broader relationship to emerge and so people who don’t seem to fit in may be more comprehensively ostracized. One person said, ‘I have a job, but no-one wants to go out with me in the evenings’. Social capitalists demand that these challenges are addressed.

An analysis of social capital through the life-course reveals how there are particular rites of passage when capital accrues or is lost. A move into residential care, perhaps on the death of a parent, can wipe out stocks of social capital—especially if it involves relocation into a different neighbourhood (Riddell et al., 2001). Indeed, entry into any care system may burn-off social connections, trust and reciprocity. Staff need to be aware that addressing these issues can be just as important as the selection of appropriate accommodation, medication or counselling.

Citizen power
Both social inclusion and social capital theories offer a familiar challenge in this domain—that of increasing service user participation and advocacy.

Traditional services have been characterized by ‘vertical’ relationships in which staff hold power over service users, while social capitalists and service user advocates seek ‘horizontal’ relationships (Riddell et al., 1999).

There are a number of potential pitfalls to watch out for here. As a social capital perspective gains ground, there are the ever-present dangers to be avoided, including:

• preferring ‘white’ social capital over culturally diverse manifestations of relationships, trust and civic participation;
• adding informal community connections to the list of things that it is acceptable to ‘prescribe’ for people using services;
• reproducing traditional power relationships of control and containment within new community locations;
that individuals who do not engage may be blamed for their situation.

From our experience these problems can come about because both social capital and inclusion theorists risk unduly focusing on ‘slotting in’, rather than transforming society. From this standpoint, society is perceived as fundamentally just and stable, so that learning disability services simply need to locate a menu of vacant slots and help the person to decide what they would like to do, learn the correct behaviour and then engage in the social opportunity of their choice. Bourdieu (1983) challenges this perception by reminding us how the ‘old boy’ networks use social capital to maintain their power and control, and advises us that this kind of social capital should be dismantled and replaced by more equitable relationships.

Paradoxically and despite the above we suggest that it is also vital to take an optimistic overview of communities. Reviews of supported employment (Riddell et al., 1997) and volunteering (Bates, 2001b) note that expansion of the service is restricted, not by a shortage of ‘hosts’ willing to offer opportunities to people with learning disabilities, but by a shortage of state funding and therefore support staff. By extension we may assume that there will be plenty of informal social settings that would welcome people with learning disabilities, so long as we could arrange adequate support.

A further example of the synergy possible by taking a dual perspective involves advocacy services. These have devoted much time to supporting people with learning disabilities to engage in formal decision-making processes. Service users have learnt how committees work, how records are kept and distributed, as well as the subtler tasks of lobbying and negotiating with senior managers. Meanwhile, social capitalists have observed that, while the general membership of civic and community associations have been falling, there has been an even faster decline in the number of people willing to take office in these associations. In addition, recent urban regeneration and service improvement strategies have emphasized the value of public consultation and involvement, and sought new methods of reaching traditionally excluded groups. This means that market expansion and labour shortages in these community and civic associations neatly coincides with a new generation of skilled and experienced people who happen to also have a learning difficulty.

Advocacy groups that have traditionally focused on long-term bonding in order to reform the learning disability service could build bridging relationships with local community organizations and campaigns. Some people with learning disabilities might eventually leave the advocacy group in order to join other advocates for the local community improvements that most interest them as citizens.

While there is general approval for specific social roles, such as that of employee or student, taking an active part in civic, political or informal associations does not earn universal praise. Staff operate within a contemporary society that appears to place great store on garden redesign, for example, but which ridicules train spotting. This might result in staff feeling comfortable about arranging a taxi for the learning disabled person who wants to attend the agricultural college, but the same worker may be less willing to arrange transport to a meeting of the local branch of railway
Separating out one’s rights as a citizen from one’s rights as an employee or for that matter as a service user, can lead to contradictory allegiances for staff. A person’s interests or eagerness to write to the newspapers about litter may embarrass the day service staff member or spill over into unwelcome publicity for an employer. Despite this, social capitalists demand that we support people with learning disabilities who wish to vote, contribute to public discussions or agitate for social change.

In addition, those who provide formal or informal civic education should be equally interested in the parallel questions, ‘How do I contribute to my community?’ and ‘How can I transform my community?’ Paulo Freire (1972) and other educators of the liberation school have shown how the task of transforming society can be attempted through alliances between disabled and non-disabled people; that is, through the development of bridging social capital.

Community perception

In a recent training seminar, one day-centre worker described his own leisure time as occupied entirely with solitary visits to the off-licence and watching TV game shows, and therefore he did not see why isolation was a problem for disabled people.

We do not know if staff in learning disability services engage in community life to a greater or lesser extent than the average, but it is likely that the personal attitudes of staff will have a real impact on the lives of service users. This is illustrated by a Department of Health study where inappropriate staff attitudes and behaviour was the most frequently cited barrier to access by disabled people (Disability Matters Limited & NHS Executive, 1999).

This suggests that there is some danger of staff defining service users’ lives by their own personal choice of lifestyle, either by assuming that people with learning disabilities will not be interested in community engagement or by evangelically promoting their own personal interests.

Staff in learning disability services may also favour urban settings, as they appear to offer more venues to people who use services, despite the high transport costs of bringing everyone into a single point. Small, rural communities have fewer events and buildings, but arguably more networks and informal opportunities to connect. When there are more bridging relationships between groups in small communities, positive or negative reputations can also spread quickly, and create or deny a new resident a chance of a fresh start in a new social setting. This means that workers engaged in community relocation should recognize informal networks as sources of social capital and develop strategies in supporting service users to navigate them successfully.

Staff and other allies therefore have a two-fold task: to recognize the unique individuality of the learning disabled person and to similarly recognize the unique attributes of the many available communities to which that person might contribute. Such creative and individualized responses defy simple categorizations and press us...
to create systems that promote artistry, rather than the regimented production of standardized care packages. Since people with learning disabilities are likely to want and need unique arrangements, there is a danger that the introduction of standard monitoring systems will close down their leisure options to those listed on monitoring forms, whilst treating the richness of local human communities as no more than an arrangement of blank, featureless buildings and facilities.

Discussion
As long as many learning disabled people lack a decent home, satisfactory income, good health, meaningful employment, and freedom from discrimination and abuse they are unlikely to view or be viewed as an asset to their neighbourhoods. The complimentary relationship between social inclusion and social capital reminds us that promoting social capital as a human service aim is a legitimate and long-term solution to the isolation and segregation of many devalued groups. However, it is not a panacea and needs bolstering with other approaches.

Social capitalists collect a diverse array of data from whole populations, as illustrated by the range of issues under discussion. As there are a host of comparative indicators already in use with the general population, some of these might also be suitable for collecting aggregate data about people with learning disabilities and comparing findings with the general population in order to discover the size of the ‘inclusion gap’ (Love et al., 2002). However, population-level data is a poor source of guidance for what to offer to named individuals, and so care is needed in interpreting these findings:

Sue lives in a suburb and works long hours in the city. She leaves early each morning and gets home late at night. Almost every weekend she travels to visit friends in other parts of the country. As a result, she does not know her neighbours. Despite her house being often empty, she is safe from burglary as many of her neighbours are unemployed and they maintain a vigorous neighbourhood watch group.

Social inclusion theorists would look at Sue’s connections with her neighbours, while social capitalists look at the whole street and recognize that she benefits from the social capital built up by her neighbours.

At the individual level, those staff who work on developing social capital therefore also need to be skilled in recognizing other factors and have access to the expertise of social inclusion advocates in how to choose, get and keep a home, a job and a social life.

Managers should be aware of the tension and difference in priorities that each theoretical position taken on its own could have on resource allocation, and strike an appropriate balance that supports people who use services and simultaneously invests in the whole community. Service designers need to strike a balance between attempting to develop new ‘social capital or inclusion projects’, and the subtler task of threading the approach through existing services.

Conclusion
If interpreted with care, the concept of social capital provides a helpful additional perspective to learning disability services that are striving to promote social inclusion.
The relationship is reciprocal, however, as inclusion advocates working with learning disabled people have insights and experience that will support the promotion of social capital for the whole community, as well as service users. Finally, many of the issues that have been highlighted in this article apply equally to many other groups who are at risk of exclusion. There is room for further dialogue.
15. Human Rights of Adults with Learning Disabilities

Speech by Andrew Dismore, MP for Hendon, Chair of the Joint Committee of Human Rights, 19.3.2009

Introduction

Human rights matter most to vulnerable people: and adults with learning disabilities are among the most vulnerable in the UK. We began our inquiry – in 2007 – in the light of some shocking revelations about the treatment of adults with learning disabilities. These included years of abusive practices in Cornwall; neglect and institutional abuse in Sutton and Merton; and six deaths in NHS care, described by Mencap in its report Death by Indifference. These tragic events suggested that the human rights of adults with learning disabilities are not well respected in the UK. Indeed, 10 years after the introduction of the Human Rights Act, we still found it necessary to underline in our report, that adults with learning disabilities have exactly the same human rights as everyone else.

Throughout our inquiry, I had mixed feelings of admiration, sadness, and anger. Admiration for the huge number of family carers, battling against the odds; admiration for the dedication of professional carers; and admiration for the many people with learning difficulties achieving so much for themselves when given the chance to do so, despite consistently unfair low expectations. I was saddened by the stories of the Lewisham College teenager, who couldn’t go out with her friends, because there was no one to take her and she was not allowed to go out alone.

We learned how people with learning disabilities have been dehumanised through stereotyping for centuries, suffering discrimination and ill treatment, seeing a lack of respect for their rights as part of every day life. How low expectations mean people with learning disabilities are unlikely to have a job; live in poverty; will not have normal social relationships; and continually suffer lack of privacy and dignity.

There is much good practice but there remains a yawning chasm between the policies of ‘Valuing People’ and ‘Valuing People Now’, and everyday experiences.

One of the main ways in which relatively minor changes could have a disproportionately beneficial impact on adults with learning disabilities is supporting social relationships and community participation. We heard how staff rotas in residential accommodation too often determine when adults with learning disabilities can go out and when they must return home. Residents may only be able to go out in a group, accompanied. One told us, “carers’ shifts change at 9pm, so we have to leave the leisure centre at 8.30.” Another told us his carer said he couldn’t kiss his girlfriend, “we’ve got to draw the line somewhere”. Many complained that, “we’re stuck at home”, “we’d like to go to bingo or the pub”, “we’d have to go out in a group”. Maintaining family contact was sometimes difficult, if the person with learning disabilities was placed by the Council out of area.

Tightening local authority eligibility rules have lead to the prioritising of those with complex needs, whilst smaller sums can disproportionately benefit the less disabled. These factors inevitably discourage adults with learning disabilities from forming friendships and relationships, the sort of interaction most people take for granted. In Valuing People Now, the Government has said it will work
with the Care Quality Commission to address this problem. I welcome this; relatively small changes in practice will make a huge difference in the lives of adults with learning disabilities.

Last year a small group of people with learning disabilities and their support workers went to a karaoke night at the Bull and Butcher pub, in my Borough. The manager was hostile, made it clear that he didn’t want them there, and harassed them until they left in distress: an appalling case of discrimination.
Whilst there is increasing support for the principle of people with learning disabilities having greater choice and control over their lives, there is little evidence on how people with learning disabilities feel about living independently. This qualitative study explored the experiences of nine people with learning disabilities who were living alone and receiving minimal or no support at home. Six of these people had previously lived in residential care, whilst the other three had previously lived with partners in the community.

Feelings about living alone were both positive and negative, with most participants feeling they could cope with independent living and valuing being independent, but some still expressing how lonely they could feel at times.

Participants related a range of different factors about the impact of having a learning disability and how that impacted on their ability to live independently in the community. These included experiences of abuse in the community, feeling vulnerable and alone, needing help with domestic activities, social isolation and great feelings of powerlessness leading to them requiring support from mental health services.

The report concludes that if people are to live independently and happily, then there is a need to improve the support to enabling increased social inclusion for people, ensure that levels of received support are suitable and accepted, raising awareness of vulnerability and increasing choice and autonomy for people.
People with higher socioeconomic position in society have a greater array of life chances and more opportunities to lead a flourishing life. They also have better health. The two are linked: the more favoured people are, socially and economically, the better their health. This link between social conditions and health is not a footnote to the ‘real’ concerns with health – health care and unhealthy behaviours – it should become the main focus.

Consider one measure of social position: education. People with university degrees have better health and longer lives than those without. For people aged 30 and above, if everyone without a degree had their death rate reduced to that of people with degrees, there would be 202,000 fewer premature deaths each year. Surely this is a goal worth striving for.

The major task of this Review was to assemble the evidence and advise on the development of a health inequalities strategy in England. From the outset it was feared that we were likely to make financially costly recommendations. It was put to us that economic calculations would be crucial. Our approach to this was to look at the costs of doing nothing. The numbers, reproduced in Chapter 2, are staggering. Doing nothing is not an economic option. The human cost is also enormous – 2.5 million years of life potentially lost to health inequalities.

In November 2008, Professor Sir Michael Marmot was asked by the Secretary of State for Health to chair an independent review to propose the most effective evidence-based strategies for reducing health inequalities in England from 2010. The strategy will include policies and interventions that address the social determinants of health inequalities. The Review had four tasks:

1. Identify, for the health inequalities challenge facing England, the evidence most relevant to underpinning future policy and action
2. Show how this evidence could be translated into practice
3. Advise on possible objectives and measures, building on the experience of the current PSA target on infant mortality and life expectancy
4. Publish a report of the Review’s work that will contribute to the development of a post-2010 health inequalities strategy

Key messages of this Review

There is a social gradient in health – the lower a person’s social position, the worse his or her health. Action should focus on reducing the gradient in health.

Health inequalities result from social inequalities. Action on health inequalities requires action across all the social determinants of health.
Action taken to reduce health inequalities will benefit society in many ways. It will have economic benefits in reducing losses from illness associated with health inequalities. These currently account for productivity losses, reduced tax revenue, higher welfare payments and increased treatment costs.

Economic growth is not the most important measure of our country’s success. The fair distribution of health, well-being and sustainability are important social goals. Tackling social inequalities in health and tackling climate change must go together.

Reducing health inequalities will require action on six policy objectives:
- Create fair employment and good work for all
- Ensure healthy standard of living for all
- Create and develop healthy and sustainable places and communities
- Strengthen the role and impact of ill health prevention

Effective local delivery requires effective participatory decision-making at local level. This can only happen by empowering individuals and local communities.

Reducing health inequalities is vital for the economy
The benefits of reducing health inequalities are economic as well as social. The cost of health inequalities can be measured in human terms, years of life lost and years of active life lost; and in economic terms, by the cost to the economy of additional illness. If everyone in England had the same death rates as the most advantaged, people who are currently dying prematurely as a result of health inequalities would, in total, have enjoyed between 1.3 and 2.5 million extra years of life. They would, in addition, have had a further 2.8 million years free of limiting illness or disability. It is estimated that inequality in illness accounts for productivity losses of £31-33 billion per year, lost taxes and higher welfare payments in the range of £20-32 billion per year, and additional NHS healthcare costs associated with inequality are well in excess of £5.5 billion per year. If no action is taken, the cost of treating the various illnesses that result from inequalities in the level of obesity alone will rise from £2 billion per year to nearly £5 billion per year in 2025.

Six policy recommendations to reduce health inequalities

A framework for action
This Review has twin aims: to improve health and well-being for all and to reduce health inequalities. To achieve this, we have two policy goals:

- To create an enabling society that maximises individual and community potential
- To ensure social justice, health and sustainability are at the heart of all policies.

Policy Objective E - Create and develop healthy and sustainable places and communities

Inequalities in neighbourhoods and communities
Communities are important for physical and mental health and well-being. The physical and social characteristics of communities, and the degree to which they enable and promote healthy behaviours, all make a contribution to social inequalities in health. However, there is a clear social gradient in ‘healthy’ community characteristics.

**What can be done to reduce community inequalities?**

Social capital describes the links between individuals: links that bind and connect people within and between communities. It provides a source of resilience, a buffer against risks of poor health, through social support which is critical to physical and mental well-being, and through the networks that help people find work, or get through economic and other material difficulties. The extent of people’s participation in their communities and the added control over their lives that this brings has the potential to contribute to their psychosocial well-being and, as a result, to other health outcomes.

It is vital to build social capital at a local level to ensure that policies are both owned by those most affected and are shaped by their experiences.

Building healthier and more sustainable communities involves choosing to invest differently.

**Policy Recommendations**

Support locally developed and evidence based community regeneration programmes that:

- Remove barriers to community participation and action
- Reduce social isolation.

**Delivery Systems**

Even backed by the best evidence and with the most carefully designed and well resourced interventions, national policies will not reduce inequalities if local delivery systems cannot deliver them. The recommendations we make depend both on local partnerships and on national cross-cutting government policies.

**Individual and community empowerment**

Linked to the question of whether action should be central or local is the role of individual responsibility, often juxtaposed against the responsibility of government. This Review puts empowerment of individuals and communities at the centre of action to reduce health inequalities. But achieving individual empowerment requires social action. Our vision is of creating conditions for individuals to take control of their own lives. For some communities this will mean removing structural barriers to participation, for others facilitating and developing capacity and capability through personal and community development.

There needs to be a more systematic approach to engaging communities by Local Strategic Partnerships at both district and neighbourhood levels, moving beyond often routine, brief consultations to effective participation in which individuals and communities define the problems and develop community solutions. Without such participation and a shift of power towards individuals and communities it will be difficult
to achieve the penetration of interventions needed to impact effectively on health inequalities.

Conclusions

The central tenet of this Review is that avoidable health inequalities are unfair and putting them right is a matter of social justice. There will be those who say that our recommendations cannot be afforded, particularly in the current economic climate. We say that it is inaction that cannot be afforded, for the human and economic costs are too high. The health and well-being of today’s children depend on us having the courage and imagination to rise to the challenge of doing things differently, to put sustainability and well-being before economic growth and bring about a more equal and fair society.
This Australian study, conducted by the Centre for Ageing Studies at Flinders University, followed nearly 1,500 older people for 10 years. It found that those who had a large network of friends outlived those with the fewest friends by 22%.

### Key Points
The finding that total social networks are protective against mortality suggests overall social integration is important, and reinforces findings from other studies of older people.

Previous Australian studies have not shown an effect of social networks on mortality. However, these studies were generally smaller or did not consider the specific types of social networks that were investigated in this study. Differences in the definitions of social relationships and different analyses may have contributed to the disparities in previous reports. Earlier research has shown social relationships with close friends and/or relatives were protective against mortality in older adults, and subsequent research also pointed to the importance of a confidant in the perceived adequacy of social support. By differentiating between friends, children, and other relatives, we were able to show that it is friends, rather than children or relatives, which confer most benefit to survival in later life. Our finding of a marginally significant effect of confidants upon survival suggests that discretionary relationships, with friends and confidants, as compared with relationships where there is less choice concerning interaction, with children and relatives, have important positive effects on survival. This is consistent with the socio emotional selectivity theory proposed by Carstensen and colleagues, in showing that with age, one’s social choices may become more selective as a means of regulating emotions.

The results from this study raise important questions about how social networks with friends in particular impact upon mortality. The causal relationship between social networks and health is not well understood. A recent review proposed culture, socioeconomic factors, politics, and social change condition the extent, shape, and nature of social networks. In turn, social networks provide opportunities for “psychosocial mechanisms” that include social support, social influence, social engagement, interpersonal contact, and access to financial and health care resources.

Psychosocial mechanisms may have an impact upon health through behavioural, psychological, and physiological pathways. If we consider social networks within this framework, networks with friends may exert an influence upon health behaviours such as smoking, alcohol consumption, and exercise, variables that were controlled for in our analyses.
Friends possibly also encourage health seeking behaviour, which in turn can affect survival. Friends can have effects on depression, self efficacy, self esteem, coping and morale, or a sense of personal control, possibly through social engagement by reinforcing social roles or because interactions with friends stem from choice or selectivity.

In summary, we have shown that better social networks with friends and confidants predict survival over the following decade in a large cohort of older Australian men and women. Strong social networks of discretionary relationships may be important in ensuring longer survival.

Policy implications
Strong social networks of discretionary relationships are important in ensuring longer survival. Strategies to promote the establishment and maintenance of such relationships in later life deserve further attention.
Only 20% of adults with learning disabilities are known to learning disability services.

About one in 20 people with learning disabilities have an unpaid job.

Almost one in three people with learning disabilities say they do not have any contact with friends. One in twenty have no friends and do not see anyone from their family.

Nearly one in three people say they did not feel safe using public transport.

Nearly one in three people with learning disabilities said someone had been rude or offensive to them in the last year. In most cases, the person who bullied them was a stranger.

More than one in ten people with learning disabilities say they never feel confident.

People with learning disabilities are 2.5 times more likely to have health problems than other people.
The Scottish Government has unveiled its new learning disability strategy, making some 50 recommendations to improve the lives of people with learning disabilities, in its Keys to Life, which contains a raft of practical and achievable aims.

The Keys to Life places a focus on ensuring all health professionals can better meet the needs of people with learning disabilities and enable them to be part of their community. It also aims to address the fact that people with learning disabilities live 20 years less on average than the general population.

In addition, the strategy supports the introduction of befriending to prevent people with learning disabilities from being isolated.

Extracts from Report

It is clear that people with learning disabilities of all ages are keen to build social relationships and networks with their peers in the community. However, the experience since The Same As You was launched is that achieving this is very difficult. It requires specialised services with clear delivery models and specific aims and outcomes.

What is needed, at a preventative level is to develop and embed good practice throughout Scotland so that people with learning disabilities have more places to go to have fun, feel safe and able to disclose any anxieties that they may have when they think they are being harassed, bullied or harmed.

Recommendation 33:
That SCLD, in collaboration with ENABLE Scotland, should work with local voluntary services to:

- encourage the setting up and expansion of befriending services and natural networks for people with learning disabilities.

- work with local authorities and NHS Boards to ensure that the planning, commissioning, procurement and implementation of services gives scope for the inclusion of befriending services and natural networks.

- record the number of people receiving befriending services and natural networks in annual eSay statistical returns.

Relationships
The Scottish Government’s publication Growing up in Scotland: Parenting and the Community Context Report recognise that the lack of resources inhibits friendship networks.
From *The Same As You* consultation we know that relationships are of key importance to people with learning disabilities and essential for their wellbeing, but relationships come in many different forms. Being around other people encourages people with learning disabilities to develop their social skills. Developing social skills helps them to make friends and helps them to integrate into the community. People with learning disabilities are less likely to feel lonely or isolated if they have friends, family and carers to support them.

People with learning disabilities should be valued and be able to make friends and build relationships. They have the right to choose their friends and have choice and control in relationship situations. It is recognised that some people with learning disabilities will need support to meet others and build relationships. Relationships take many forms. Each relationship is important to the sense of belonging, social inclusion of people with learning disabilities and important in realising the potential of people with learning disabilities to be all they can be.

**Friends and partners**

Having meaningful relationships is a priority for people with learning disabilities. They may be more prone to abuse and are more likely to be denied the opportunity to conduct their own lives as any adult would take for granted, including the ability to form and conduct relationships. But having the chance to make and sustain friendships and relationships is something that improves their wellbeing and quality of life. Many people with learning disabilities want that chance to have a romantic, sexual and long-term relationship.

Recommendation 34

That by the end of 2013 the Scottish Government in partnership with Equal Futures and other relevant organisations holds a friendship event to help people with learning disabilities to be supported to have more friends.
22. Five Ways to Wellbeing

*New applications, new ways of thinking, National Economics Foundation (NEF), 2011*

*Commissioned by National Mental Health Development Unit and NHS Confederation in 2010.*

The *Five Ways to Wellbeing* is a set of evidence-based public mental health messages aimed at improving the mental health and wellbeing of the whole population. They were developed by NEF (the New Economics Foundation) as the result of a commission by *Foresight*, the UK government’s futures think-tank, as part of the *Foresight Project on Mental Capital and Wellbeing*.

The aims of this work are twofold.
1. To develop an increased understanding about the scope and potential of the *Five Ways to Wellbeing* as a tool to improve population mental health and wellbeing.
2. To review how the *Five Ways to Wellbeing* are currently being used by local and national agencies to help identify future opportunities.

How much is actually known about positive mental health, and how can it be improved?

**Implications of positive mental health**

Recently, a growing body of research has explored both the antecedents and consequences of positive psychological states such as contentment, and fulfilment – often collectively referred to as *psychological wellbeing*. Far from being synonymous with the absence of mental health difficulties, psychological wellbeing has both distinct causes and significant implications across a range of outcome areas. For example, people who report higher levels of wellbeing tend to be more involved in social and civic life, are more likely to behave in environmentally responsible ways, have better family and social relationships at home and are more productive at work. An extensive recent review of literature found that wellbeing is positively associated with various positive health outcomes. Increasingly positive mental states actually *precede* and help to *cause* good outcomes in health and wellbeing. For instance, longitudinal studies of wellbeing have shown that the prevalence of good moods predicts working days lost through illness five years later, likelihood of stroke six years later and of cardiovascular disease ten years later.

**The Five Ways to Wellbeing**

*Connect…*

With the people around you. With family, friends, colleagues and neighbours. At home, work, school or in your local community. Think of these as the cornerstones of your life and invest time in developing them. Building these connections will support and enrich you every day.

*Be active…*
Go for a walk or run. Step outside. Cycle. Play a game. Garden. Dance. Exercising makes you feel good. Most importantly, discover a physical activity you enjoy and that suits your level of mobility and fitness.

*Take notice...*
Be curious. Catch sight of the beautiful. Remark on the unusual. Notice the changing seasons. Savour the moment, whether you are walking to work, eating lunch or talking to friends. Be aware of the world around you and what you are feeling. Reflecting on your experiences will help you appreciate what matters to you.

*Keep learning...*
Try something new. Rediscover an old interest. Sign up for that course. Take on a different responsibility at work. Fix a bike. Learn to play an instrument or how to cook your favourite food. Set a challenge you will enjoy achieving. Learning new things will make you more confident as well as being fun.

*Give...*
Do something nice for a friend, or a stranger. Thank someone. Smile. Volunteer your time. Join a community group. Look out, as well as in. Seeing yourself, and your happiness, linked to the wider community can be incredibly rewarding and creates connections with the people around you.

The *Five Ways to Wellbeing* was developed based on evidence relating to individuals' behaviour. If individuals change their behaviour so as to incorporate more Five-Ways-type activities into their day-to-day lives, the empirical evidence suggests that their subjective wellbeing should improve. However, this does not mean that the focus of interventions need always be the individual. As the examples in the survey responses show, there is considerable scope for using the *Five Ways to Wellbeing* to improve collective wellbeing in a more strategic and indirect way, both in terms of affecting the wider circumstances in which people live to promote wellbeing and by informing processes and ways of working more generally.

The concept of community wellbeing is, at present, somewhat underdeveloped and under-evidenced in the academic literature. It would be interesting for further research and development to explore whether the *Five Ways to Wellbeing* is a useful way to think about flourishing communities. Is there, for instance, evidence that improvements in individuals’ wellbeing within a certain community result in improvements in community-level outcomes? Such evidence, if it existed, would support the intuition of many local policy-makers that the wellbeing agenda is more likely to have a positive impact if focused at the community level rather than at individuals.
23. Information on Friendships, Foundation for People with Learning Disabilities

Friendships are an important part of most people’s lives. They help us feel like we belong and are worthwhile, and they can offer us support when things are difficult in our lives.

Learning how to make friends from an early age is important as it is through friendships that children learn how to deal with everyday life events and social norms. Children who do not have this opportunity” can suffer from emotional and mental difficulties later in life.”

It is commonly accepted that friendships are an important part of most people’s lives. An Australian study, conducted by the Centre for Ageing Studies at Flinders University, followed nearly 1,500 older people for 10 years. It found that those who had a large network of friends outlived those with the fewest friends by 22%.

This suggests that having friends in our lives may actually increase our life expectancy. As adults, friends can often replace family as the most significant people in our lives. Through friends we are linked to other social circles and interests, and we know that we have people who care about us and with whom we can enjoy our lives.

Friendships and people with learning disabilities

Friendships between people with learning disabilities have sometimes been overlooked or seen as less worthwhile by others despite the fact that they are often highly valued by people with learning disabilities. A recent report from the Centre for Disability Research claims that people with learning disabilities are less likely than the general population to have contact with friends and members of their family with whom they were not living.

For those with learning disabilities who do not live with their families, the main people in their lives are their support workers. A 2006 study showed that many people with learning disabilities view their support workers as friends, whilst these support workers often would not classify themselves as such. This highlights how people with learning disabilities can have limited access to meeting new people and developing true friendships, as well as showing the loss experienced when support staff move on taking their ‘friendship’ with them. Just like everyone else, people with learning disabilities need stable and long-lasting relationships in their lives.

The main issue experienced by people with learning disabilities is that of connecting with people to generate and sustain new friendships. This is especially true whilst at school, and immediately upon leaving school. As adults people with learning disabilities may leave the family home for the first time and move into supported living or their own accommodation. This often creates an absence of people in their daily lives which their family/carers used to fill. Everyone can struggle to make new friends as they get older, but for people with learning disabilities this can be compounded by a lack of opportunities to meet new people, especially if they do not have the support to help them to make new connections.
Intelligent Kindness is a powerful new approach to healthcare reform. Ballatt and Campling argue that the NHS is a system that invites society to value and attend to its deepest common interests; it is a vital expression of community and one that can improve if society, patients and staff can reconnect to these deeper values. To do so will improve quality and patient experience, as well as morale, effectiveness, efficiency and value for money.

Relentless regulatory and structural NHS ‘reforms’ have failed to avert scandals and left many health service staff feeling alienated. Industrial and market approaches to reform, whatever their merits, urgently need to be balanced by an applied understanding of what motivates and assures compassionate practice. The authors examine this question from a whole variety of perspectives, including psychoanalytic thinking, group relations, neuropsychology, social psychology and ethology.

The book calls on policy makers, managers, educators and clinical staff to apply and nurture intelligent kindness in the organisation and delivery of care, and offers ideas as to what this approach might mean in practice.

Extracts from the book

Social Capital and Health
It has been established for many years that having friends is good for you and even increases your life expectancy. Harvard Professor of Public Policy and author of Bowling Alone: The collapse and Revival of American Community, Robert Putnam, claims that ‘Joining and participating in just one group cuts in half your odds of dying next year!’

There is also evidence that people in rich countries have fewer friends than in the past. Putnam ‘People watch Friends on TV, they don’t have them’. The extent and quality of relations between people are essential to our social fabric and as such have become a major focus of study. This is what social scientists refer to as social capital – the range and quality of positive connections between individuals and the social networks that embody people’s involvement in community life.

In Bowling Alone, using comparative studies of different communities with different levels of social engagement he argues that stronger social capital (the sum total of people’s involvement in community life) is linked to better health and other positive social outcomes.

Social capital, with its implications of connectedness and civic engagement, can be seen as a measure of a society’s success in expressing kinship and kindness. Social capital knits society together and affects the quality of public life. It is based on and contributes to a
sense of trust and reciprocity. It is also linked to equality, in a relationship that is mutually reinforcing.

**Happiness, Health and Kindness**

Fowler and Christakis’ research on the spread of happiness is pertinent to kindness. Their data suggest that people at the core of their local networks seem more likely to be happy, while those on the periphery seem more likely to be unhappy.

Happiness is not merely a function of individual experience or individual choice but is also a property of groups of people. Indeed changes in individual happiness can ripple through social networks and generate large scale structure in the network, giving rise to clusters of happy and unhappy individuals (Fowler and Christakis, 2009).

Happiness is not everything and is worth pointing out that one can be unhappy and still be a valued friend and productive citizen. Happiness does, however, have a positive effect on physical health and is increasingly used as a measure of the overall quality of human lives, rather than economic measure such as GDP (Layard, 2005). Moreover, there is evidence that people who care about the happiness of others and the relief of misery will themselves be happier. In other words, happiness is in dynamic relations to how we treat each other – it is promoted through offering and receiving kindness.

**Political Implications**

Mental and physical health are, then, highly influenced by levels of absolute poverty, by inequality and stress, and by the quality and closeness of the connections in society. Societies and communities that embody kinship to the extent that there is common purpose, active recognition of interdependence and recognition for each other, equality and warm positive interpersonal and group bonds are, very simply, healthier. More importantly, they realise that it pays to be kind – and are willing to invest in it, emotionally, practically and financially.

If improved health is your goal then it is pretty clear what you must to. **Policies across government departments must be directed towards:**

- Eradicating poverty
- Energetically reducing income inequality
- Promoting common identity and purpose
- Communicating the value of, and supporting, combined effort and shared risk
  - Reducing isolation and social divisions
  - Supporting positive connections between people.

The Charity Commission warned in October 2010 that up to £5 billion of funding to charities could be withdrawn. Chairwoman Dame Suzi Leather said:
If you cut the charities you are cutting our ability to help each other, you are cutting what structures our neighbourliness. That is what the Big Society is all about, so you are pulling the rug out from under it.

On the edges of kinship

*The fault in aliens is that those easiest to exploit are the hardest to assimilate* (anonymous)

Powerful political and psychosocial processes influence the extent to which society recognises and responds to its members as kin. There are difficult ‘edges’ at which goodwill and rejection compete for dominance in the public mind. Healthcare staff are frequently working at these edges, which complicate the ‘self-overcoming’ involved in any form of healthcare work. Sometimes the dilemma is pretty obvious – the violent drunk haemorrhaging in an accident and emergency department inevitably arouses conflicting responses; the heavy smoker in need of a lung transplant confronts us with mixed feelings. The continued, often dangerously fluctuating, needs of people with long-term conditions persist in frustrating our instinct and wish to remove suffering and can wear us down. Generosity, and the instinct to turn away, to deprive, even to punish, vie for dominance in our thinking.

These ‘edges of kinship’ are sometimes much more complicated. They may involve attitudes to people who come from outside’ our geographical and social boundary – such as migrants and asylum seekers. Just as significantly, other such ‘edges’ involve the needs of people who are objectively already part of our national ‘kin’ – such as people with profound intellectual disabilities, mental health problems, the old and the dying.

Such groups can arouse inclusive, generous and compassionate responses. They have the capacity, though, to evoke feelings of fear and the wish to reject or deny either things about others or, at the deepest level, about ourselves. The person with an intellectual disability evokes feelings of a fear of dependency and difference. They reflect wider social uncertainty, complexity of feelings, division and discrimination. They reflect profound anxieties about the extent of our resource, material and emotional, and where they should be invested. They confront us all with the limits to our generosity and fellow feeling.

In a mix with our more kindly and generous instincts, our ambivalent, reluctant or even hostile feelings about including ‘the other’ as kind find expression at a policy level, at a service level and at the level of the individual healthcare practitioner. This dynamic requires clear recognition and work to manage the danger to compassionate practice. A common feature of many of the groups at the edges of kinship is that discrimination and abuses in the healthcare of their members are frequently reported. Such occurrences result, often repetitively, in policies and programmes to address stigma, provide education and specify corrective action. There is a danger, however, that these abuses will continue if the complexity of what underpins neglect and brutality is not recognised more thoroughly.
There seem to be a number of overlapping themes which emerge when working on the edges of kinship:

- being confronted with frightening need and experience that threaten to overwhelm, arousing enormous anxiety about our capacity to respond
- difficult feelings, ranging from compassion to anger and hostility
- a profound struggle between the urge to include and exclude
- polarisation of thinking, frequently involving extremes of idealisation and denigration.

These themes operate both at the level of the staff member working with the individual patient and at the level of society addressing the challenges raised by particular categories of patients. Examples from groups clearly on the ‘edge’ can educate our understanding of the difficulties involved in providing healthcare ‘on the edges of kinship’. They also throw light on the challenges to kind and compassionate healthcare more generally.

The trouble with profound need is that it confronts us with the fear that we are not equipped to meet it – in terms of managing to face it, doing anything helpful about it, perhaps even surviving the encounter intact.

In the face of mixed feelings, society is torn between recognising the other as kin, and offering kindness and support, or rejecting their ‘otherness’, and punishing or rejecting them. Policies to promote the social inclusion of people from vulnerable groups tend to underestimate the degree to which this urge to hurt and eject is operating.

Society has traditionally responded to the challenging need and dependency of vulnerable groups by putting people into institutions. People with intellectual disabilities make up 2% of the UK population. Current estimates suggest that 7% of people in prison have an IQ of less than 70 and 20 – 30% of offenders have intellectual disabilities or learning difficulties that interfere with their ability to cope within the criminal justice system (Jacobsen, 2008).

The problems with inclusion travel with people, and so transfer from the public world into institutions. Disturbing trends of neglect and abuse in asylums and similar residential settings have been reported for decades. It seems that the dynamics of institutional life conspire with the concentration of people with challenging needs to provoke neglectful and abusive behaviour, amplifying the tendency to rejection in society at large (Goffman, 1961). The joint report of the Healthcare Commission & Commission for Social Care Inspection (2006) into the care of people with intellectual disabilities in Cornwall, for example, found systemic neglect and abuse. Similar failures have been identified in other areas, such as Norfolk, and Sutton and Merton.

The lesson is clear. The emotional challenge of inclusion, and the behaviours it evokes, do not go away even if we establish institutions to meet and contain difference, disturbance and need. This reality becomes toxic if not managed through
acknowledgment and support for workers, as well as through policy and inspection systems.

The laudable aim to reverse the trend towards institutionalisation expressed in current policies on intellectual disability (DOF, 2009) can invoke serious underestimation of the difficulties in community life for service users, for those close to them and for the community.

Behind this underestimation can lie idealisation of the capabilities and potential of vulnerable people to cope in the community, as well as parallel idealisation of that community. The first is often associated with a varyingly conscious tendency to blame people’s disability on simplistic models of stigma and institutionalisation. The second leads to a minimisation of the sheer hard work involved, at times, in reading and responding to their needs and supporting them in leading fulfilling lives.

It is not difficult to see how such situations evolved. Specialist staff are understandably anxious about the challenges for their patients in the community. They can see themselves as the only ones capable of understanding and responding sensitively to the vulnerable individual. This can involve mistrust of, even contempt for, the capabilities of others, whether or not they are willing or able to respond kindly to people who have an intellectual disability or mental illness. Realism about the limits of people and services is, of course, vital, but this dynamic can lead to a sort of default mistrust. This can undermine and restrict positive work with health and social care colleagues to improve practice and secure their patient’s wellbeing. Where, for example, a carefully designed care plan to help a person with profound disabilities with their eating and drinking fails to be followed in a community setting, this can severely undermine the will of the specialist worker to collaborate. Vicious circles can then result.

Similarly, families, dedicated to a relative with a disability, and aware of a less than easy wider world, can fall into the same position, leading to mistrust of the community and professionals. The idealisation and denigration involved in both these cases can lead to over protectiveness, diminished opportunities and reduced access to services and the world for the person in need.

The danger is that simplistic idealisation leads to people living materially, socially and emotionally impoverished and vulnerable lives, with poor health. Just as seriously, idealisation makes it hard, or impossible, for society or services to recognise or admit it. The complex task of engaging with real people, assessing their needs, evaluating risk, orchestrating resources, monitoring and responding, is undermined.

A dangerous effect of unmanaged splitting processes can be the failure of commissioners and providers of services to achieve an intelligent balance of care and support. In reality, health services and their partners need to ensure the right mix of priorities and resources, balancing the following:
- work to remove barriers and mainstream services
- the provision of an adequate range of specialist services
- risk minimisation and risk taking
- reliance of public support and protection from public neglect or abuse
- managing dependency and promoting independence.

It is dangerous to base ‘efficiency’ plans for specialist healthcare services on idealistic assumptions that social care supports and opportunities for inclusion will be there, when resource limits and public sector cuts mean they will be scarce. Such unrealism is common. The resulting services are difficult environments in which to work. It is hard to maintain open attentiveness, empathy and responsive, responsible, kindness if services are affected by powerful splitting and polarising processes that encourage the denial of key aspect of the personhood and needs of people in vulnerable groups. The fact that these splits are played out a policy level means staff also find themselves trying to reconcile the contradictions in organisational objectives, performance targets and scrutiny from seniors.

Inconveniently, for both staff and patients, the needs of people in vulnerable groups on the edge of kinship require a lot of what the system has increasingly less of: unprejudiced attitudes, kindly concern, time and high levels of interpersonal skill. What is also wanted is a system that adjusts to their needs, rather than the other way round.

**Promoting kinship at the edges**
Members of groups on the edge of kinship, however much they inspire love, compassion, conscientiousness and concern, can be at the same time inconvenient and unwanted, even feared and hated. This reality is hard to face, and to address, especially as it is not going to go away, however much ‘stigma’ and ‘discrimination’ are challenged. As staff work with members of these groups, a core challenge is to remain open to them and their needs, to bear them in mind, despite anxiety and discomfort. Staff must then somehow manage to resist the temptation to split – to idealise or denigrate, to swing between trust and suspicion, to overestimate or underestimate patient or community resources. This temptation is personal, but it is also powerfully built into how society and health services respond to the patient’s needs, and the pressure they put on the worker. At bottom, though, staff have constantly to deal with the lack of fit between the needs of their patients and the wider health and social care system. Often this will involved an encounter with frank discrimination, and almost always it will entail an engagement with culture and processes. The system frequently does not make available the resources patients need, and in fact too often goes about its business in ways that actually work against meeting their needs.

At a time of such pressure on public services, including the NHS, it is difficult to argue for more resources. Somehow, though, the time and space to build relationships with, and to develop and share understanding about, vulnerable people need to be found. Ways of strengthening the continuity of care and supporting them as they encounter the many ‘sharp edges’ in wait for them in the community, and in the health and social care systems, are vital. Recognition of the dynamics at work at the edges of kinship may free up staff, may ‘clear their heads’, so that they can engage more compassionately with the real needs and aspirations of their patients. Managers can help, by resisting the urge to minimise the difficulties of the caring task, to idealise partial solutions,
unreflectingly to demand contradictory priorities, to deny the shortcomings and limits that staff will encounter as they try to serve their patients.
This briefing outlines how within the context of getting 'value for money' it is essential for local authorities to align service strategies in a way that supports community capacity building and builds in preventative approaches. It demonstrates how a focused and coherent approach to outcomes with an explicit requirement for co-production provides commissioners with the opportunity to innovate within public services and how the Putting People First framework supports this.

Addressing efficiency
In the current national climate there is general agreement that public service budgets will become increasingly pressurised. ‘Efficiency’ has increasingly become the driver of public sector reform, with commissioners in a key position to deliver these. ‘Efficiency’ is most commonly assessed in a narrow financial sense. Increasingly though it is recognised that this narrow short-term financial efficiency tends to squeeze out the broader considerations of positive social and environmental outcomes. This is particularly problematic in health and social care where these broader social outcomes might be crucial to making services more effective and so transforming services and cutting costs in the longer term.

Assessing services based on this narrow model can also have the inadvertent effect of narrowing the focus of ‘services’ and preventing more cost saving, because contracts are based on payments for activity, which gives little incentive to provide cheaper or more effective alternatives. The danger in this cost-efficiency game is that it creates a ‘race to the bottom’ in public service provision. This trajectory becomes even more problematic for those commissioning for community capacity building or prevention approaches. Many cost saving approaches assume that services will remain essentially unchanged – doing the same thing, only trying to do it more cheaply. This closes down the space for the far-reaching reforms sought in Putting People First that seek to prevent needs arising, build community capacity and provide better outcomes.

Recognising community outcomes and real ‘value for money’
HM Treasury’s guidance defines value for money as ‘the optimum combination of whole-of-life costs and quality (or fitness for purpose) of the good or service to meet the user’s requirement’. The Treasury Green Book goes on to emphasise that ‘value for money is not the choice of goods and services based on the lowest cost bid’, but that ‘wider social and environmental costs and benefits for which there is no market price also need to be brought into any assessment’.

There is a more holistic approach to value, incorporating social and environmental outcomes. Outcomes are distinct from basic outputs that conventionally will be demanded from a service. By outputs we mean the direct goods or services such as the
training programme provided. Outcomes are wider, less direct effects produced by the services, sometimes co-produced with people using the service such as increased personal well-being, improved social cohesion through broader engagement with the community or greater capacity for communities to support individuals to be active citizens.

The value for money model recognises social inputs including individuals with lived experience, their time and skills and other social resources such as community networks and local social assets such as mainstream services. In this way services can be more cost-effective because they bring in extra resources, in the form of help, support and effort from people who use services, their families and neighbours (co-production). These non-monetary resources are ignored in the current model of financial efficiency because no price is attached. But the possible resources that they represent are huge and their contribution is critical, requiring a broader approach to service design and commissioning. Incorporating these resources into the service design and commissioning process and ensuring that they are tracked against outcomes broadens services to make best use of under-used resources such as citizens’ skills and mainstream services and enables community capacity building based on existing local assets.

Commissioning for outcomes also requires a longer-term focus, which is also more suited to assessing the preventative impact of services. If public services are to become genuinely better and efficient, they must focus on maximising positive outcomes defined in terms of public benefit, rather than merely minimising costs, and move upstream to tackle problems before they become critical. Putting People First recognises that we need radical innovation so that public services can make real inroads into tackling prevention, reducing demand for expensive critical services and ensuring better outcomes.

Whilst co-production is most frequently named in relation to the ‘social capital’ quadrant of Putting People First, in fact, it has a considerable role to play in delivering on all four quadrants. There is considerable evidence that co-production helps to prevent people getting ill, increases their wellbeing and involves those who are seldom heard in society. Co-production is designed to prevent needs arising in the first place, by maintaining and improving the quality of people’s lives and extending the opportunities as well as the capabilities of individuals and communities to look after themselves. It helps people to build stronger social networks, which supports wellbeing and makes communities more resilient. The growing recognition and importance of co-production offers opportunities for to align their Putting People First strategies with other service departments. The increasing need to get ‘value for money’ or ‘more for less’ makes this more strategic configuration of resources critical. It also provides greater opportunity for people qualifying to receive support being seen as active citizens rather than just service users.

Building Community Capacity through Co-production

‘Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where
activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change’

Co-production is an assets-based approach which starts first and foremost with people’s energy, skills, interests, knowledge and life experience. By doing this co-production connects public services with valuable community-based resources and opens up opportunities for improving outcomes without increasing costs. Within services it can help to build a preventative, person-centred and personalised approach to meeting needs. More broadly it can create sustainable change embedded in neighbourhoods by developing and supporting local groups and networks, maintaining or increasing community capacity.

Co-production practice has the following key components:-

1. Building on people’s existing capabilities: altering the delivery model of public services from a deficit approach to one that provides opportunities to recognise and grow people’s capabilities and actively supports them to put these to use at an individual and community level.

2. Reciprocity and mutuality: offering people a range of incentives to engage which enable them to work in reciprocal relationships with professionals and with each other, where there are mutual responsibilities and expectations.

3. Building support networks: engaging peer and personal networks alongside professionals as the best way of transferring knowledge and supporting change.

4. Blurring distinctions: removing the distinction between professionals and recipients, and between producers and consumers of services, by reconfiguring the way services are developed and delivered.

5. Facilitating rather than delivering: enabling public service agencies to become catalysts and facilitators rather than central providers themselves.

Recognising people as assets: transforming the perception of people from passive recipients of services and burdens on the system into one where they are equal and essential partners in designing and delivering services.

Co-production and capacity building beyond health and social care

Putting People First seeks to ‘work towards a single community-based support system focused on the health and wellbeing of local populations.’ This goes far beyond the delivery of goods and services that public services have historically been accustomed to. The policies outlined briefly below also reflect this shift in rhetoric from people as passive recipients of services towards people as ‘active citizens’. In making the most of local resources and in order to capitalize on opportunities to support people to be recognized as active citizens rather than service users it is important that strategies are co-ordinated and mutually supported across departments within local authorities. Some of the policy opportunities include:
The Well Being Power (2000) was introduced to increase local authorities' capability to act on behalf of their areas. It allows principal local authorities in England and Wales to do anything they consider likely to promote the economic, social and environmental well-being of their area unless explicitly prohibited elsewhere in legislation [http://www.communities.gov.uk/]

The Local Government and Public Involvement in Health Act (2007) set out a stronger role for local authorities with an expectation that they would bring local services closer to communities. The intention of this approach is to make local services better co-ordinated and better value for money, with Local Area Agreements (LAAs) as a practical approach to enable and incentivise local agencies to work with their communities in a joined up way. The act included a new duty requiring local authorities to ‘inform, consult and involve’ local people in running local services with the intention of embedding a culture of engagement and empowerment. [http://www.communities.gov.uk/publications/localgovernment/healthact]

Communities in Control: real people, real power (2008) seeks to ‘shift power, influence and responsibility away from existing centres of power into the hands of communities and citizens, often referred to as the ‘double-devolution’ of power from Whitehall to Local Authorities, then from Local Authorities to communities. The White Paper addresses seven key issues: being active in your community; access to information; having an influence; challenge; redress; standing for office; and ownership and control. It concludes that ‘empowering citizens and communities is an urgent task for us all’. [http://www.communities.gov.uk/communities/communityempowerment/communitiesincontrol/]

The previous UK Government’s Foresight Review on Mental Capital and Well-being (2008) concluded that government policies ‘need to nurture the mental capital and well-being in the wider population, so that everyone can flourish in their lives’. Evidence in the report clearly demonstrates that high levels of subjective well-being are associated with better physical and mental health, more effective learning and productivity, and better relationships. The report emphasizes that the UK’s greatest resource is its citizens and identifies the 5 things we all need to do to maintain and improve our well-being (Connect, Be Active, Take Notice, Keep Learning and Give) [http://www.neweconomics.org/projects/five-ways-well-being]

Making co-production real

Co-design and co-delivery can happen at a variety of levels, ranging from strategic, through service specific and at an individual basis, for example in co-designing and co-delivering a personal plan for a good life. It is vital that commissioners can develop feedback loops between these different focuses. For example, in developing a personalised support plan an individual needs to be aware of the existing community resources and networks that are available for them to access. Similarly whole
populations can experience benefits from individuals with support plans playing more active roles in local communities, investing personal budgets within the local economy and ensuring that local resources are well used.

There are various ways in which professionals, people using services and the wider community can interact in the design and delivery of services. Increasingly approaches are employed that support people who use services (and sometimes the wider community) to co-design services, but invariably these are then delivered back to services users by professionals. This may lead to better service design but it does not result in co-production, thereby not capitalising on the skills and resources that people using services and the wider community represent. For the aims of Putting People First to be realised it is essential that people play an active role in both the design and delivery of the support they receive.
26. Living in Sandwell: An Exploratory Study into the Key Issues and Challenges that Affect a Small Group of People with Mild Learning Disabilities

_Liz Tilly, University of Huddersfield 2008_

**Introduction**

The experience of most people with learning disabilities is generally reported as them having a poor quality of life, i.e. excluded from mainstream life, communities, employment, social and political participation and inadequate income for their basic and disability related needs (Bach, 1994; Department of Health, 2001). Valuing People, the Government’s key strategy for people with learning disabilities, however, has social inclusion as a key principle; ‘Inclusion means enabling people with learning disabilities to do those ordinary things, make use of mainstream services and be fully included in the local community’ (Department of Health, 2001:24).

Inclusion means people being able to: participate in, benefit from and contribute to society; claim full human and citizenship rights, access the same opportunities, use the same facilities as other people for education, housing, employment, health and leisure and having the support to do so (Bradley, 2005).

This principle is reiterated in the government consultation paper Valuing People Now: ‘The aim is to support people with learning disabilities to live an ordinary life in the community alongside their fellow citizens as described by human rights legislation and the Disability Discrimination Act’ (Department of Health, 2007:10).

**Who are People with Mild Learning Disability?**

Valuing People (Department of Health, 2001:14) defines learning disability as follows: ‘learning disability includes the presence of:

- A significant reduced ability to understand new or complex information and to learn new skills (impaired intelligence), with:
- A reduced ability to cope independently (impaired social functioning);
- Which started before adulthood, with lasting effect on development.’

Similarly the British Psychological Society (2001:4) defines three core criteria for learning disability;

- Significant impairment of intellectual functioning
- Significant impairment of adaptive functioning
- Age of onset before adulthood

The label ‘learning disabilities’ is used to describe a very wide group of individuals, covering the continuum from those who have profound learning disabilities and have very low levels of functioning and very high level of care needs, through to severe learning disabilities, to those who have only mild learning disabilities. There are no clear dividing lines between people with mild learning disabilities and the general population,
and there is no clear cut off point, so the prevalence rate can vary. Most people with a mild learning disability can communicate using spoken language and reasonable skills to live independently with appropriate support (British Institute of Learning Disabilities, 2007a).

People with a mild learning disability are frequently ineligible to access learning disabilities services (Learning Disability Commission, 2007), they frequently experience social exclusion from the wider community (Simons, 2000). Prevalence of severe and profound learning disability is fairly uniformly distributed across the country and socio-economic groups, whereas mild to moderate learning disability is associated with poverty. Rates are higher in socioeconomically deprived and urban areas and clusters in families, and has an identifiable cause in only 50% of cases, as opposed to 80% in severe learning disability (Mackenzie, 2005). Higher rates in some social classes suggest that factors such as large families, overcrowding and poverty are significant. It is usually caused by a combination of restricted learning and social opportunities, plus a high rate of low-average intellectual ability and learning disability in close relatives (See 'Contact a Family' website).

There are many difficulties in coming to a definition of this label; people with a mild learning disability are those who have an IQ of 50 to 70, theoretically 2.23% of the population (Whitaker, 2003), with 71 to 130 IQ considered to be within the normal range (Department of Health, 2001). The IQ of 70 is a benchmark simply because it is two standard deviations from the mean IQ of 100.

There is a continuing shift to supporting all people with learning disabilities through non-specialist mainstream services, (Department of Health, 2001; Department of Health, 2007), so inevitably people become less identifiable and are potentially vulnerable and 'fall through the net' (Simons, 2000), and so the label mild learning disability is not well known or used outside of the field of learning disability. People who may be described as having a mild learning disability are often an invisible group in policy and academic research, as most research is focussed on either those with more severe learning disabilities who use specialist services, or research on social exclusion, but not those labelled or recognised as those with a mild learning disability. For many years the focus of research has been on the medical and psychological analysis of needs, rather than on social needs and using an inclusive research method (Walmsley, 2005).

It has been suggested that research undertaken in relation to people with learning disabilities has been slow to involve them directly in the research process (Kiernan 1999). However this group are echoing the demands of women and minority ethnic groups for equal say and opportunities (Beresford et al, 1993), and from the late 1980s there has been a continuous development of participation, citizenship and empowerment, and the rights and responsibilities that go with it. People with learning disabilities are taking an increasingly active role in both research and consultation (Ward, 1997; Atkinson, 2000; Carr, 2004).

It is now widely accepted that they have opinions and the right to express them (Stalker, 1998; Simons, 1999) and furthermore that they are the best informants concerning their
experiences (Chappell, 2000). The methodology selected for this study sought to enable people to communicate their own stories and experiences.

**People with a Mild Learning Disability and their Use of Support and Services**

As local authority budgets become overstretched, people with a mild learning disability are increasingly less eligible to receive support and specialist services, as they are deemed to be too able and therefore do not meet access criteria, yet receive minimal support from other mainstream services.

They are often outside of the employment market and, after leaving special schools, become lost from formal services until crisis situations such as being the victim of crime, a perpetrator of crime, debt, illness, neighbour disputes, bereavement, homeless, pregnant or other situations requiring professional intervention (Simons, 2000; Care and Repair England, 2008; Easterbrook, 2008).

Fair Access to Care Services, the Department of Health (2003) guidance on the eligibility criteria for adult social care, was developed to establish fairer and more consistent eligibility decisions across the country. The framework is based on individuals’ needs and associated risks to independence, and includes four eligibility bands - critical, substantial, moderate and low.

In November 2007 the Learning Disability Coalition (2007a) reported on the withdrawal of services to people with learning disabilities and it revealed that an increasing number of local authorities are rationing support by only providing social care to those people with very high levels of need.

During 2007 the member organisations of the coalition gathered information on local authority funding cuts to learning disabilities services, both those provided in house and by the independent sector. They reported Government spending on social care for people with learning disabilities had increased by 7.2%. However the level of funding from central government had not kept pace with a population that is growing at about 1% per year (Learning Disability Coalition, 2007b). In 2007, 80% of local authorities said their budgets for learning disabilities were under pressure, 70% would only support people whose needs are said to be substantial or critical and 80% of councils planned to tighten their eligibility criteria (Learning Disability Coalition 2007b).

The study took place in March 2008 in Sandwell, a metropolitan borough council, the most deprived borough in the West Midlands and, based on the average ward deprivation scores, is the 16th most deprived in England (National Statistics, 2006) therefore a particularly relevant geographical area to undertake such research given the link between levels of deprivation and numbers of people with a mild learning disability. Using prevalence rates based on entire populations (as compared with people known to services) and applying these across the Sandwell population indicates that locally, there should be approximately 1,698 people with severe learning disabilities and 8,490 with mild learning disabilities in the borough, which is a significant section of the community (Gaughan et al., 2005).
Between 2005 to 2008, Sandwell MBC only funded services to people who would be assessed as being in the substantial band (Learning Disability Commission, 2007a). People who have a mild learning disability are therefore highly likely to be excluded from services provided by funding from the local authority.

Participants

The criteria for participation in the focus groups were that people:

- Lived in Sandwell
- Were aged over 18
- Lived independently with up to five hours ‘of individual formal support
- Described themselves as having a mild learning disability i.e. that they need support to live independently, and have difficulties in numeracy and literacy and sustaining education or work
- Identified they had limited formal and informal support networks

Housing and their Local Area

Local anti-social behaviour was a serious issue experienced by the entire group, both in terms of it happening in the participants’ locality and in them being first hand victims. Some of the examples given from both their past and current experience were having eggs thrown at windows (two participants had experienced this), leaves pushed through letter boxes, seeing people urinate outside, young people hanging about, having windows broken deliberately, drunken neighbours being insulting and neighbours’ children ‘running riot’ with their parents not taking any action.

In addition to anti-social behaviour by local youths, all the participants had experienced problems with harassment and intimidation from at least one and often more neighbours which significantly affected.

Reasons for not Using Community Facilities More

These were due both to issues with the venue or facility; some facilities like swimming baths were considered scruffy and dirty, places are not always family friendly like social clubs. Lack of money was also an issue and those with children also said it was hard to find child care. Some did not do more because they had no one to go with and ‘felt lonely’ if they went by themselves, and also did not like to walk to places on their own. Some had even been excluded by people they thought of as friends, from joining in social and leisure activities with them.

Discussion

The study considered the effects of social deprivation and exclusion experienced by a group of people who have a mild learning disability. It was found that they had limited social networks and informal support mechanisms, few identified role models or people to turn to for advice. Their lives are also influenced by other factors such as the
level of formal support from services and the level of antisocial behaviour in their
eighbourhood. All the group had experienced a range of very difficult and some
traumatic experiences in their past, yet this group of people were only receiving a few
hours of formal support a week. The findings suggest that proactive support is very
important and also there is a need for signposting and advice services.

As with the general population, this study found that anti-social behaviour was a major
issue affecting lives and contributing to their social exclusion, and being a personal victim
of anti-social behaviour was exacerbated by a breakdown in relationships with
neighbours.

The study has also highlighted the importance of identifying people with a mild
learning disability and therefore targeting support to their unmet needs. Some
particular areas of support this group identified were in shopping, and especially using
the supermarket, support in parenting, computer use and travel training to enable
them to have full community inclusion. The findings also suggest that frontline staff
need to be aware of the needs of this group of people, who may not initially present as
having a learning disability, and how they might need support due to their literacy
difficulties or lack of using facilities on an initial visit. It has highlighted a need for
further research to look into the accessibility of community courses in literacy and
computer skills, and advice and guidance services for this group of people, to ascertain
if this group of people are using them and if they are of value, and if not what the
barriers are.

Although not explored specifically, poverty and low income also affected the group,
especially their leisure time. They seldom used the pub and were restricted to free to
enter places, which would have an impact on their inclusion in the local community.

The value of informal networks and friends in the use community facilities, as
identified in other studies (Beart et al., 2001), was highlighted, and shows how this
group can be vulnerable to social isolation if they do not have a circle of friends and
informal support. Finally, it has shown how important it is to enable people with
learning disabilities to be direct informants of the pertinent issues in their lives, and
how, by employing an appropriate method, they are able to share their experiences.
Clinical Commissioning Groups (CCGs) will need the support of local communities in order to ensure success. As commissioning GPs we must proactively work together with all people within our communities.

‘Community Development’ sees the local population as an asset not a drawback, providing answers, not creating problems. Working with and developing communities will make commissioning better, easier and promote more effective results.

Community development professionals work with residents to identify key, local issues and set agendas important to local people. They also work with partners, such as local authorities and the NHS to bring together spheres of health, education, housing and policing in a fresh and innovative way - offering both cost-effective and health-effective results.

This report sets out the background and evidence for the mutual benefits that Community Development can bring for local citizens, primary care practitioners and CCGs. It also uses two case studies as examples of community development projects - the Health Empowerment Leverage Project (HELP) and Turning Point.

What is Community Development?

No society has the money to buy, at market prices, what it takes to raise children, make a neighbourhood safe, care for the elderly, make democracy work or address systemic injustices... The only way the world is going to address social problems is by enlisting the very people who are now classified as ‘clients’ and ‘consumers’ and converting them into coworkers, partners and rebuilders of the core economy.” – Edgar Cahn

This view of Community Development is a form of co-production whereby individuals, communities and public service organisations pool their skills, knowledge and abilities to create opportunities and solve problems.

It is about reaching out to communities, supporting community groups - encouraging and facilitating effective and wide-reaching community activity. Under the guidance of professionals, Community Development will allow local people to:

- identify their own needs and aspirations
- influence the decisions that affect their lives
- improve the quality of their lives, communities and society in general

The positive impact of Community Development will be direct, through the participation of an individual, and indirect through the influence that community participation has on services.
Community Development and Primary Care

The introduction of Clinical Commissioning Groups will create new opportunities for primary care practitioners to work with local authorities and communities. Community Development provides an effective way for these agents to engage with each other proactively to:

- improve health protection
- address health inequalities
- be more responsive in our commissioning duties
- collaborate with statutory agencies
- enhance behaviour change in society
- save money

Working with communities is an essential part of the business plan for every CCG. GPs and CCGs are accountable to communities and, in order to improve and change services, we must engage with the local population, take on board their input, make decisions together and look to them for solutions to societal problems.

The focus of Community Development may not initially be health as the agenda will be set by communities. Local populations lead the collaboration of health, education, housing and policing agencies to best meet the needs of the local area. In doing so we have already seen many examples of innovative solutions to local problems.

Although the impact on health may be indirect, there is evidence that correlates good health with strong social relationships and which are encouraged through Community Development. There is also clear evidence that as communities work together to solve problems that are affecting them, leaders emerge, social capital improves and health benefits are substantial.

Whilst the hub of a Community Development project might not always be a GP surgery - although there are examples where this has been the case - projects do tend to be based in a specific geographical area and so are not dissimilar to the way that GPs and Patient Participation Groups (PPGs) currently work.

In addition, Community Development is an excellent opportunity for PPGs to engage further with local communities. Although the structures and processes of both initiatives are different, their interests are similar.

Community Development – the Health Case

There is substantial evidence to support a link between Community Development projects and improvements in health.

1. Social integration increases resilience against physical and mental health problems
Evidence shows that building links between people - creating social networks between friends, relations, acquaintances - protects both their physical and mental health.

Social networks and more specifically social participation can act as a defence against dementia and cognitive decline in over-65s and research has shown that social links are consistently associated with reduced morbidity and mortality. A meta-analysis in 2010 studied 308,849 individuals’ data over an average of seven and a half years and found a 50% increase in the likelihood of survival for people with stronger social relationships. This makes social networks as important as not smoking, moderate alcohol and regular exercise in terms of good health and is consistent across age and gender. Adversely, low levels of social integration and loneliness have been shown to increase morality. And the most significant difference between those with and without mental health problems is a lack of social participation. Furthermore, there is evidence to suggest that stronger social relationships reduce the risk of depression.

2. **Social networks tackle health inequalities and have wider benefits in society**

As well as being beneficial to physical and mental health, promoting social integration – which has been shown to be weaker in deprived areas- can help to tackle health inequalities. Social cohesion is led by communities coming together in their own interests and a starting point for this is encouraging the participation of local groups.

Areas with stronger social networks have lower crime rates, less delinquency and there is some evidence of higher levels of employment and employability.

3. **Community Development builds social networks**

Community Development projects, such as time banks, increase social contact and therefore promote the health and societal benefits described above.

The Beacon Estate in Cornwall has seen Community Development projects lead to significant improvements in housing, education, housing and policing and overall increased confidence within members of the community. Similar experiences and outcomes have been found in Balsall Health. Another example is the ‘LinkAge Plus’ programme which aims to strengthen social networks for older people whilst simultaneously gaining their input as to how to best improve services. It combines self-help; peer support; social inclusion; participation in activities and advocacy support. The scheme has shown significant improvements in health and independence.

In terms of health inequality, Professor Sir Michael Marmot has said that reducing social isolation through community development is the best way to tackle the issue.

4. **Societal benefits are longitudinal**
Community Development engages and empowers local people, which saves councils time and money and creates more satisfied communities. Communities are able to negotiate new relationships with statutory agencies, helping to develop and improve service delivery.

Research has shown that following Community Development schemes, the quality of public services is resilient in the face of economic and other adversity.

The Dorset Health and Wellbeing Board (HWB) is a strategic partnership board consisting of local organisations that share a collective vision to drive improvements in people’s health and wellbeing. The board is a statutory body, established within the terms set out by Health and Social Care Act (2012). It relates to the population of Dorset, defined as those people living within the administrative boundaries of Dorset County Council. The Dorset Board includes councillors and officers from county and district/borough councils, GPs from the Dorset Clinical Commissioning Group, the National Commissioning Board, Healthwatch, and representation from voluntary and community organisations.

The Joint Health and Wellbeing Strategy (JHWS) is the key document by which the HWB sets out its strategic intentions. The strategy was developed during the course of 2012, following consultation and engagement with multiple stakeholders. The JHWS is based on the assessment of the needs of the local population and on evidence of what is effective in improving health and wellbeing; and this information is presented separately via the Joint Strategic Needs Assessment (JSNA) for Dorset. The strategy does not seek to take on everything at once, but instead sets priorities for joint action that will have a real impact on people’s lives in Dorset.

The strategy for Dorset sets out the following:

- A brief overview of the key issues affecting people’s health and wellbeing in Dorset (taken from the Dorset JSNA).
- Agreed principles, and the ways of working that will be adopted to implement the strategy.
- The vision and aims of the Health and Wellbeing Board.
- Five priorities for action in 2013-14.
- Plans for monitoring progress.

**Principles**

We will commission and provide services and interventions that are cost effective and are built on the best evidence of what works. This is particularly important in service redesign, where a very high degree of certainty is required before disinvesting in, or reorganising an existing service in order to invest in a new service model.

We will prioritise those who have, or who are likely to develop the worst health outcomes. Those with the greatest health and wellbeing needs often require more time and support than others if their outcomes are going to improve. Our efforts and resources will therefore be more concentrated on those with greater needs in line with our vision of reducing inequalities.
We will take a life-course perspective to improving the health and wellbeing of the population. There are measurable inequalities in health and wellbeing outcomes very early on in life with patterns of inequality often remaining throughout adulthood and into old age. Even in a population with an older demographic, it is important to intervene appropriately across the life-course, and maintain an emphasis on the early years that will accrue long-term benefits in population health and wellbeing.

We will seek to develop a sustainable health and social care system through early intervention and prevention. The increasing demands on health and social care services cannot continue to be met simply by increasing the supply of services. Effective preventative community action will be essential in building sustainable health and social care services of the future.

We will continue to assess the health and social needs of the Dorset population to inform our decision-making. Our plans are only as good as our understanding of the issues affecting people’s health and wellbeing. The causes of health and illness are highly complex and far-reaching, spanning personal, social, and environmental factors. Our Joint Strategic Needs Assessment will summarise the breadth of population needs at a county and locality level, and reference more detailed work on particular priority outcomes.

We will work on a whole system basis. No service or intervention exists within a vacuum, or as an end in itself. We need to understand the interrelationships across services and with communities, families and people. The better the alignment of the whole system, the better the improvement in outcomes will be. The emphasis will be on sustainability, operating within environmental limits, and we will not seek short-term gains at the expense of improving outcomes in the long-term. The Board is committed to working in partnership at every level, influencing plans in localities as well working with other county-wide strategic partnerships (for example the Local Enterprise Partnership; cultural, nature and community safety partnerships).

Aims
1. People live in environments that support their health and wellbeing.
2. People, families and communities are enabled to live healthy and fulfilling lives.
3. People with increased risk of poor health are identified early on and are supported to prevent premature problems developing.
4. People living with long-term health problems avoid complications and maintain a good quality of life.

People, families and communities are enabled to live healthy and fulfilling lives.

Our daily habits and behaviours are inextricably linked to our experience of health and wellbeing throughout life. It’s clear that people take personal responsibility for their actions, but it is also important to recognise that health related behaviours are to some degree predictable and dependent on external factors. Many behavioural norms are established very early on in life, either through direct experience or through learning from significant others. By focusing on healthy development in the early years, and
through supporting families to develop healthy patterns of behaviour, health and wellbeing can be improved across the life-course.

Health education is important in informing people about the best course of action to take to prevent the occurrence of premature health problems, but for education to be effective, it requires wider reinforcement. Public policy needs to support people in making healthier decisions by making the healthier choice the easier or more rewarding choice to make.

Similarly, reinforcement comes through our daily experience of the people and communities that surround us. If for example a family moves into a community where they find the majority of children walk or cycle to school, their understanding of the benefits of physical activity is reinforced, and it is more likely that they themselves will do the same. On the other hand, health education which aims to reduce excessive alcohol consumption amongst teenagers will be unlikely to succeed if it is within a social context where parents or peers are binge drinking and misusing alcohol on a daily basis. Promoting healthy behaviours in local communities is not as straightforward as it might first appear. We will support families and carers to give children the very best start in life. We will also invest in health education and health promotion services assisting people in making healthier choices; and we will seek to reinforce this with supportive policies and through collaboration with local communities.

People with increased risk of poor health are identified early on and are supported to prevent premature problems developing.

Risks to health and wellbeing are not evenly distributed across populations, but instead conspire to form patterns of inequality. If inequalities are to be reduced, it is critical that risks are identified early on in their development and, where possible, action is taken to mitigate their impact on health and wellbeing. This requires services to actively seek out groups of people known to be at heightened risk, as they may be the ones least likely to seek help from services or participate in universal screening programmes. The earlier that modifiable risks can be identified and preventative measures put in place, the better the outcomes for health and wellbeing. So, for example, smoking cessation or a reduction in excess weight at a younger age will confer greater benefits in terms of avoiding disease later on.

The ‘NHS Healthcheck’ programme is designed to be proactive in identifying modifiable risks as they relate to cardiovascular disease; however the programme is limited in that it only becomes open to people when they turn 40 years of age. Key risk factors that are possible to modify include: smoking, high blood pressure, overweight and obesity, inactivity, high levels of cholesterol, pre-diabetes, drinking alcohol to harmful levels, drug misuse, work related stress, anxiety and depression.

We are committed to identifying risks as early as possible, including during childhood and will work in a targeted way to bring about reductions in inequalities in health and wellbeing outcomes.
People living with long-term health problems avoid complications and maintain a good quality of life

Over the last century long-term (or chronic) health problems have increased in tandem with improved life expectancy and a reduction in infectious disease. Managing long-term health problems and disability in an effective and efficient way has therefore become a central strategic challenge in the planning of public services.

Preventing the further exacerbation of health problems, or slowing the progression of ill health, remains a central theme of the strategy; helping people to remain as independent as possible, and maintaining purposeful and meaningful lives. Where appropriate, models of care should encourage recovery and functional reablement, giving individuals the skills and confidence to take control of, and manage their own health problems. Importantly, this involves working with, and supporting families, carers and local community groups that are the providers of so much informal care. Health and social care services need to work in unison to provide the right levels of care when it is needed. With increasing demand for care services and no additional resource, it is critical to minimise the use of high dependency, high-cost care provision.

Dorset already has a demographic profile that is older than most other parts of England, and the trend of an ageing population is set to continue for at least a further twenty years. The demand for care is therefore likely to increase over that time. Furthermore, it can be more costly to provide care across rural areas.

Maintaining a sustainable health and social care system which meets the needs of local people in Dorset is of central importance to improving population health and wellbeing. We are committed to working together in facing these challenges, accepting the need for systemic change and innovative new ways of working.

Draft Priorities (2012 – 2015) included:

- to plan and deliver all public services to achieve sustained improvement in health and wellbeing for the whole population and reduce health inequalities at all phases of life and between the various parts of the population. Services for adults should be accessible. These services should not only respond to acute need but should also promote active, responsible and healthy lives. Maintaining good health and wellbeing during adulthood is key to ageing well. Again, services should be designed to meet the needs of those with the greatest need.

- to support the voluntary sector and communities in improving health and wellbeing and reducing inequalities. Over recent years there has been an increasing acknowledgement of the impact that our friends, family, and communities have on our health and wellbeing. Voluntary and community organisations are a key part of this ‘fabric’ of the world in which we live and play a key role in prompting health and wellbeing. Through working with voluntary and community organisations, the Health and Wellbeing Board will seek, together with other partnerships, to promote the strength of local community life in Dorset.
- to protect the public, especially the most vulnerable, from significant risks to their health and wellbeing.

- to plan and deliver health and social care services in a way that not only meets the needs and preferences of individuals but also recognises that demand and needs are growing rapidly and without major reform will exceed the ability of the current system to deliver care in the future. **Support preventative community action**, building on local experience, for example POP. Retain a focus on the quality of services that promote health and wellbeing and safeguards from harm.

- we will commission and provide services that are cost effective and are build on the best evidence of what works.

- we will continue to assess the health and social needs of the Dorset population to inform our decision making. **Our plans are only as good as our understanding of the issues affecting people’s health and wellbeing. The causes of health and illness are highly complex and far-reaching, spanning personal, social, and environmental factors.**

- we will work on a whole system basis. **No service or intervention exists within a vacuum. We need to understand how services work together and with communities, families and individuals. The better the system works together then the better the improvement in health and wellbeing will be. The emphasis will be on sustainability. We will not seek short term gains at the expense of improving outcomes in the long term.**

- we will prioritise those who have, or who are likely to develop the worst health priorities. **Those with greatest health and wellbeing needs often require more time and support than others if their health and wellbeing is going to improve.**

- we will seek to develop a sustainable health and social care system by intervening early to help prevent the need for services. **Effective preventative community action will be essential in building sustainable health and social care services in the future.**

- we will set up a clear system to measure progress of agreed priorities. **It is only through evaluation and by measuring changes in outcomes that we can learn about whether we have made a difference and about what works. We also need to understand who is benefitting most.**

Co-ordinating an effective delivery system through Joint working. It is important that new partnership structures build on established, as well as emerging joint arrangements.
A Joint Strategic Needs Assessment (JSNA) is a way the local NHS, in partnership with local authorities and other public sector partner’s work together to understand the current and future health and wellbeing needs of its local population and identify our future priorities. The production of the JSNA is a statutory responsibility of The Director of Public Health, Director of Children’s Services and Director of Adult Social Services.

The term learning disability usually refers to a group of individuals who have a history of delayed development, a failure to achieve the level of behaviour and social functioning expected for their age, and in who there is evidence of significant intellectual impairment. People with learning disability often have a wide range of health and social care needs. In addition, people with learning disability often physical or developmental disabilities, mental and physical ill-health and a range of behavioural problems that require services.

Not only does this group of people have significant needs compared with the population as a whole for health and social care, but they may face a number of barriers in being able to access such services. A 2010 review of the literature around inequalities in health and people with learning disability found extensive evidence that people with learning disability and chronic health problems are less likely to present to services such as primary and secondary care compared with non-learning disabled people with similar chronic health conditions.

Finally, health outcomes for this group of people have been shown to be much poorer across a range of conditions compared with the population. From this perspective, ensuring that people with learning disability are able to access and take advantage of health and social care services to meet their additional needs will be an important step in reducing the inequality in health currently experienced by this group.

What is known about the local population?

There is no definitive record of the true number of people with learning disability locally, or nationally. This is because most estimates are derived from counting numbers of people in contact with services rather than the true number that might be living in the population with a learning disability. In addition, severe learning disability in childhood will be more likely to be recognised than mild to moderate learning disability, so many people with milder forms of learning disability may go unrecognised. In addition, people with learning disability without significant health or social care needs may never be recognised by services, and so the real prevalence may be higher than that estimated based on service contacts.

Based on national estimates of prevalence, it is expected that around 2.5 per cent of school aged girls and 4 per cent of school aged boys with have a learning disability. Of these, 0.4 per cent of girls and 0.6 per cent of boys with have profound and multiple learning disabilities.
Overall, there are an estimated 17,429 people of all ages with some degree of learning disability. However, there are currently a total of 2,869 people known to primary care on GP QoF registers – 16 per cent of the total estimated population estimated to have some degree of learning disability.

**What are the main inequalities that we know about?**

People with learning disabilities face some important health inequalities. Above all, numerous studies have shown that they suffer poorer health than their non-learning disabled peers. These differences in health status are largely avoidable.

In addition to the specific inequalities in health status outlined above, people with learning disability are also more likely to experience inequality in terms of their exposure to social determinants of health, including poverty, poor housing, unemployment, social isolation and discrimination. This population is also less likely to have good nutrition and a sufficient intake of fruit and vegetables, and take the recommended amount of physical activity.

**How well are services currently meeting needs?**

This is quite difficult to judge for a number of reasons. First, even among the known local population with learning disability there is likely to be evidence of substantial unmet need for health and social care services. For example, national reviews of inequalities in health status have identified that this group is much more likely to suffer poorer health, and hence have unmet needs. In simple terms, individuals with significant health and social care needs will only be identified once they present, and the professional recognises that need and acts on it.

There are also many more people with a degree of learning disability living in the community who are not currently on GP registers or in receipt of support from social care providers. For some people this will be because they have a mild learning disability, with no significant health or social care needs. However, for others, they may have significant health and social care needs but are not recognised because they may not always access services or receive the right approach in understanding their needs.
The ‘Local Account’ was introduced in 2011. At the time the Government suggested that this might be the way performance of adult social services is presented and the way in which the service is held accountable to the local community.

The Government wants to see a shift towards local assessments and accountability. In other words, local people will rate our performance and we will answer to them if our performance isn’t good enough. The audience for the ‘Local Account’ will be local people, but more specifically, Healthwatch who represent local people.

Healthwatch was established on 1 April 2013 and it will be the new independent ‘consumer champion’ for health and social care in every area of England. A ‘consumer champion’ is someone who stands up for customers, in this case, NHS patients and people who use social care services. Healthwatch replaces the organisation known as LINks (Local Involvement Networks).

**Learning Disability Services in Dorset**

In 2012-13, Dorset County Council asked the Local Government Association to run what is called a ‘Regional Peer Challenge’ to help improve performance in Learning Disability services. ‘Regional Peer Challenge’ is not an inspection, it is designed to help an authority assess current achievements and identify areas for development and improvement. In March 2013, the Peer Challenge team arrived and spent three days meeting and talking to councillors, officers, staff in partner organisations, people using our services and carers. They also reviewed documents produced by the council.

They asked the following key questions:

- Does the council have a clear strategy (a plan of action) for Learning Disability services in Dorset?
- Is the council doing everything it can to get value for money when it plans and buys services?
- Does the council have the right structures in place to enable it to respond to the growing demand for services and to enable it to work in partnership with the National Health Service (NHS)?
- Is the council doing enough with partner organisations (service user groups, service providers, doctors, hospitals etc.)?
- Does the council have the right mechanisms in place to ensure they get feedback about the service?
- Are there new and different ways of delivering services that the council could adopt?
The Peer Challenge team praised the council for some of its excellent projects, including the Sturminster Newton Bungalow, the Friendship Club and developing the Shared Lives scheme. They were impressed by the ‘huge commitment of staff and councillors to provide excellent services for people with a learning disability’.

The Peer Challenge team asked the council to consider or ‘reflect on’ the following:

• The excellent projects that are in place are small and merely additions to mainstream services – is it time to make them more widely available?

• Staff in the council do not know where the council stands in respect of the externalisation of services’; in other words, should the council ‘make services or buy services’ – is it time to be clear about this?

• Generating income and self-unders (service users who pay for their own care) – is it time to think again about the charging policy?

• The plan of action for finances is dominated by making savings in the current year – is it time to improve this for the longer term?

• Services are geared towards reducing the number of people who are in crisis – is it time for staff to develop a more planned approach to their work?

Our Priorities for 2013/14

• Strengthen communities through the provision of a range of community and cultural services;
• Continue to improve the way we safeguard adults in vulnerable circumstances.

How Bournemouth and Poole plan to work together to provide health and social care services for adults with learning disabilities 2012 – 2015. Bournemouth Borough Council, Borough of Poole, NHS Bournemouth and Poole

This plan is about how the Borough of Poole, Bournemouth Borough Council and NHS Bournemouth and Poole want to work together to provide health and social care services for adults with a learning disability.

Valuing People (2001) definition of learning disability includes the presence of:

- a significant reduced ability to understand new and complex information to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.

We made a list of 12 Big Aims and 12 areas of work that we want to happen over the next 3 years. We then asked people to tell us what they thought about them. The Big Plan has now been updated to show what people told us is important to them.

We now have 14 Areas of Work.

The 3 biggest priorities for people with a learning disability are -

- Staying Healthy
- Where people live
- Relationships
5. Joint Commissioning Strategy 2010-13, Update September 2012

Dorset Services for Adults with a Learning Disability
NHS Dorset, Dorset County Council

Background
The three-year Adult Learning Disability Joint Commissioning Strategy was endorsed by the Learning Disability Joint Commissioning Board, Dorset County Council and NHS Dorset between July and September 2010. The action plan set out 21 priorities for development (Appendix A) that followed the five areas of the national learning disability strategy Valuing People Now (2009):

- Including Everyone
- Personalisation - starting with the individual and their family
- Having a Life
- People as Citizens
- Making it Happen

This report provides a progress update on developments over the last 2 years and, where appropriate, recommendations for revising the action plan.

The national economic and political context has changed considerably since the Dorset strategy was first drafted. There was a change of Government in May 2010 which brought in a new approach to inspection and performance monitoring. There is a new model for the NHS, with major organisational change taking place. There are significant budgetary pressures with Dorset County Council needing to reduce spending by around £60m over three years. Inevitably these pressures have led to both statutory agencies reviewing internal processes and implementing reorganisations. However, it is vital that the actions in the strategy are implemented in a continued drive to improve outcomes for people with a learning disability and their carers.

Having a Life
- Reduce the proportion of people placed annually in residential care and consider "settled accommodation" options for people placed in residential care both in and out of county
- Increase Shared Lives, supported lodgings and shared ownership opportunities
- Implement the Day Services Strategy through the appointment of Community Co-ordinators in all areas
- Improve health support in both primary and secondary health services
- Create more opportunities for people to be valued in their communities such as paid employment, voluntary work and time banking schemes.

What has happened? (extract)
The Friendship Club received a Big Lottery Grant of almost £300,000 over 3 years that has enabled them to run events throughout Dorset. Membership is now nearly 700 with 400-450 regular attendees. More young people are attending, many who have lost contact with each other since leaving school or college.

This strategy sets out the high level ambitions and principles that will govern the NHS Dorset Clinical Commissioning Group from 1st April 2013.

We are delighted that the NHS Dorset Clinical Commissioning Group has been successfully authorised and is now fully established as a statutory body. We are looking forward to building on the robust legacy inherited from the former NHS Bournemouth and Poole Primary Care Trust and the NHS Dorset Primary Care Trust including the strong relationships with partners and providers.

The shadow organisation has already been actively engaged in the development of the local Health and Wellbeing Boards with the Local Authorities in Dorset. As we continue our work to help people in Dorset to lead healthier lives, this collaboration will become increasingly more important as we continue to explore opportunities to commission services together and to work innovatively to develop a more integrated approach to the delivery of services.

**Our Mission - Supporting people in Dorset to lead healthier lives**

As leaders and using our clinical understanding we will drive continuous improvements in services throughout Dorset to support people to lead healthier lives for longer.

**Strategic principles**
- Services designed around patients
- Preventing ill health and reducing inequalities
- Sustainable healthcare services
- Care closer to home
This strategy sets out what the NHS Dorset Clinical Commissioning Group and Dorset County Council want to achieve for carers, and is a long term plan of action designed to achieve particular goals. Those involved in developing the strategy recognise that it can only be effective if we work together for the benefit of carers and use resources wisely.
Reviewing progress
Priorities of the national strategy

We are reviewing and planning against the priorities in Recognised, Valued and Supported; next steps for the carer’s strategy, under the following headings:

Identification of carers
- supporting our communities to become more aware of carers’ needs
- helping people realise that they have become a carer
- reaching out to people who may not recognise that there is support available

Information, advice, assessment, support services and personalisation
- getting information and advice on the health care needs of both carer and cared-for, accessing benefits, support available, financial and employment issues
- encouraging carers and the person/s they care for to have their needs assessed, and providing services

Our proposals for 2013-16

Carers have similar needs regardless of where they live and who they care for. These are:
- recognition as a carer
- information, advice and support
- their own health and wellbeing needs to be addressed
- the opportunity for a break from caring if they need it
- an understanding of what they are entitled to
- to have professionals working with them who are kind and caring and acknowledge and support their role.

Priorities
During 2013-2016 we will develop the services and support that we give to carers in the following ways:-

Supporting carers to remain physically and mentally well
- Develop health checks for carers
- Improving support in hospital discharge plans
- Raise the profile of Safeguarding, through training and information
- Increase opportunities for short breaks
- Encourage development of social activities to enable carers to take a break
8. Learning Disability Database 2008

Dorset County Council

The purpose of the Learning Disability Database was to obtain information about the population of Dorset with a recognised learning disability. This information will be used to inform the planning of services, through the work of the Learning Disability Partnership Board sub-groups and via the joint commissioning Strategy for services for people with a learning disability.

The focus of the database was to enable people with a learning disability to have greater independence and choice in their lives, and to play a full part in their local communities and society.

Findings

8 out of 10 people did not have an in case of emergency card, and just over half of these people would like to have one.

People were asked what their top 5 evening activities were. The most popular were a) going to the pub b) group activities c) live music and concerts d) cinema e) visiting friends and e) friends visiting them.
9. Support for people who do not meet the eligibility criteria for adult social care

Dorset Learning Disability Partnership Board, DRAFT Report - October 2010

In common with all Local Authorities, Dorset County Council applies FACS criteria (Fairer Access to Care Services) when assessing the needs of disabled and vulnerable people. At present only people assessed as having substantial or critical needs under these criteria are eligible to receive services from the local authority. This arrangement extends to services for people with a learning disability. The Department of Health recently reissued FACS guidance - Guidance on Eligibility Criteria for Adult Social Care, DH, and February 2010

There are 2 areas in particular that have been flagged up by adults with a learning disability and their families as priorities for people who do not meet FACS criteria:

friendships/relationships and housing.

Through Dorset People First, the Learning Disability Partnership Board has used Development Fund money to pilot and roll out a Friendship Club across Dorset, which is open to anyone with a Learning Disability. It organises regular gatherings in local community venues where individuals can guarantee to find someone to talk to, as well as events that people purchase tickets for. There is a leader at the event, but those that need support bring their own. Currently membership stands at 420 and is still growing. Up to one third of members are not users of adult social care services.

Appendix A
Support for people who are not eligible for adult social care support.

Fulfilling Lives
The Friendship Club is open to all.
- Trying to support those who want to do more/take a leading role in the club (a lot of these people are outside the criteria) and sending representatives to Dorset V, new Mencap group etc.
- Not over-protecting club members!
- Educating providers of services in the community (e.g. pub and café staff) and club members about how to handle various situations (advice sheets to pub staff, etc).
- Good volunteers are vital to the Club’s work.

Action Plan
NETWORK – FRIENDSHIP
Where to go for Company, Share activities, Arrange meeting up/events, Someone to live with, Relationships, Peer support, Awareness of Abuse
ACTION
Tools to network with, Groups to network in, Communities learning from a) Outreach from centres b) Care providers/PAs trained in Community connecting, Shared resources held in the community
NAME OF PERSON RESPONSIBLE
Roll out through Day Services and Friendship Club
BY WHEN
Ongoing
Notes of Big Discussion on Friendships and Relationships
South West Region Forum, 2008

Notes of the big discussion on Friendships and Relationships – main points

Some people have got good relationships. We need respect for them and for a range of relationships.

You need good support with a relationship but sometimes we are afraid to tell people about it. Some people need special help to have their relationship and this should be provided.

Risk assessment can really get in the way! Getting ‘permission’ to have a relationship from staff is difficult to do.
There is not enough private space.

We need to speak up about relationships and peer advocacy can help.

It’s difficult to keep in touch with friends when you leave college.

People in 24 hour care find meeting friends difficult.

Getting out in the evenings is really important but not easy to stay up late.

Transport and support is not easy especially in the evening.

Hate crime stops people going out.

My ideal thing to do with my friends is

Going out dancing, getting married, going to the football, going out with my friends, Hard Rock Cafe to meet Lindsay Lohan – she’s hot!, a BBQ, night out with my special lady, go out to the pub
11. The Dorset Compact, Working Together for Dorset

The Dorset Compact is a commitment to positive partnership working between the public sector and the voluntary & community (or ‘third’) sector. It is an expression of the desire of third sector organisations and public bodies to work better together for mutual advantage and community gain.

In 1999 Dorset became the first county in the country to adopt a joint Compact agreement between public bodies and the third sector. It was updated four years later, in 2003. This revised version has been written to reflect policy developments at local and national level, to strengthen the links with the Dorset Strategic Partnership and to improve implementation of the agreement. For information about the Dorset Strategic Partnership, go to www.dorsetforyou.com/dsp.

Effective partnerships are essential to the achievement of our long-term strategic aims for Dorset, including the development and delivery of the Community Strategy and the Local Area Agreement. The Compact provides a framework in which to develop and maintain these effective partnerships.

The Compact sets out a number of shared principles, and provides specific guidance on the following issues:

- Consultation
- Funding
- Volunteering
- Support for third sector organisations (‘infrastructure’)
- Equality and diversity

The Compact principles

The following principles have been agreed as a basis for a Compact way of working:

- Partnership - the public and third sectors have distinct but complementary roles and there is added value in working together towards common aims and objectives.

- Mutual value and respect - the public and third sectors have different forms of accountability and are answerable to a different range of stakeholders, but common to both is the need for integrity, objectivity, accountability, openness, honesty and leadership.

- Interdependence – both sectors are interdependent, in that the contributions of both sectors are necessary to the achievement of our shared goals. This does not conflict with the principle that the public sector should respect the legal independence of voluntary and community organisations. Similarly, the third sector should respect the statutory obligations of the public sector.
• *Equality of opportunity* - both sectors recognise the importance of promoting equality of opportunity for all people, challenging and reducing inequalities, and celebrating diversity.

• *Building sustainable, cohesive communities* – both sectors are committed to empowering communities and developing sustainable community cohesion.

• *Shared responsibility* – both sectors have a shared and equal responsibility for implementing the Compact principles and ensuring it is regularly promoted and reviewed.

These principles should underpin partnership working between the two sectors *at all times.*

**Volunteering**

Volunteering is the commitment of time and energy for the benefit of the community and society and can take many forms. It is freely undertaken and not for financial gain. Although the UK does not have one common national definition of volunteering, it is generally described as “an unpaid activity where someone gives their time to help an organisation or an individual who they are not related to” (Volunteering England). Individual volunteers make a huge contribution to local organisations and the quality of life for local people in Dorset.

Volunteering is not a cheap option. The recruitment, training, reimbursement, support and management of volunteers costs money. All partners recognise the need to invest in volunteering, and volunteering infrastructure, and to follow best practice in order to ensure that there are sufficient resources to make volunteering a positive, safe experience.

Public bodies will seek to create opportunities to promote employee volunteering and create opportunities for volunteering within their own organisations. Third sector organisations will implement good practice in the involvement and management of volunteers.
What is the Local Area Agreement (LAA)?
Dorset is currently implementing its second Local Area Agreement, it runs for a period of three years from 2008 – 2011. The LAA is enshrined in the Local Government and Involvement in Public Health Act 2007. It is an agreement between central and local government which brings together local priorities to make Dorset a better place to work and live. The LAA involves partners such as the police, the Primary Care Trust and representatives from business and the voluntary and community sector. Dorset’s LAA sets out 33 key priorities known as designated targets; these are improvement targets which are agreed by the Dorset Strategic Partnership (DSP). These targets are chosen from the National Indicator Set laid out by central government. Dorset’s LAA improvement targets support the achievement of the following;

- Affordable, sustainable and appropriate housing
- Developing Dorset’s economy
- Improved access to services, employment and leisure
- Safeguarding Dorset’s environment
- Addressing Dorset’s demographic challenge
  - Ageing population
  - Children and young people
- Safer communities
- Building strong and inclusive communities
- Better health and well-being
- Creating well-being through culture

Improvement targets include:

- Environment for a thriving third sector
- Percentage of people who feel they belong to their neighbourhood
- Participation in regular volunteering
- Perceptions that people in the area treat one another with respect and dignity
- Engagement in the arts
One in four people experience poor mental health during their life and many of these will have two or more psychiatric disorders, with an associated rise in functional disability and reliance on statutory services. Local partners will all play a part in reducing discrimination associated with mental illness through promotion, prevention, early intervention, and community services. Developing real partnerships with service users and carers is key to supporting recovery and ensuring a good quality of life.

Increased survival rates among young people with severe and complex disabilities and reduced mortality among older adults with learning disabilities will result in further demand for health and social care services. Housing aspirations for people with a learning disability have also changed over time and the preferred option of young people leaving the family home is now supported living packages in the community. The percentage of people with learning disabilities in paid employment is low in Dorset and the target for 2013/14 is to achieve six per cent of adults with a learning disability in paid employment. Public sector organisations, being the largest employers across the county, should be challenged to improve their low recruitment levels of individuals with a disability in line with corporate objectives.

The Government’s vision is that all adults with autism are able to live within a society that accepts and understands them. In terms of future demand, around 50 children in each school cohort are being identified as having an ASC (Autistic Spectrum Condition). A service review found that there are pockets of good practice and that some people with ASC pan Dorset are able to, and do, access good quality services that meet their needs. However, it also provided evidence that good practice and access to appropriate services is not consistent.

Whilst research in Dorset commissioned by the DCMS127 shows above average engagement and participation in cultural and sporting activity here, this is proportionally greater amongst the affluent population, whilst people in more deprived circumstances and young people tend to be under represented. Women are most likely to perceive barriers to cultural activities.
1. Learning Disability Challenges and Campaigns

1. Launch of Real Change Challenge: Mate Crime
   
   Association of Real Change, May 2013

   In May 2013, the Association for Real Change launched the second in a series of challenges – Mate Crime: A Challenge for Providers to identify the issues that people with learning disabilities face and the steps providers can take to address them.

   Jacqui Bell, Chief Executive of the Association for Real Change said “We are pleased to be launching the second challenge. Raising awareness of mate crime and ensuring that people with learning disabilities are safe and confident to make the most of the same opportunities that you and I have is something that is extremely important to us.

   “Friendships are a basic human need, but making good, genuine friendships is never easy and there are people out there who try to take advantage. Through the Mate Crime Real Change Challenge we’re asking the learning disability sector to step up and actively encourage the reporting of mate crime and enable the people they support to make friends safely”.

2. Brandon Trust calls for Government and local communities to do more to tackle disability hate and mate crime, 2013

   Learning Disability charity Brandon Trust has called for the government to do more to tackle the issues of disability hate and mate crime as a survey has revealed widespread ignorance of both among the general public.

   A UK wide survey involving 2,000 adults was carried out on behalf of the charity. It found that 72% of those questioned did not know what disability hate crime was and only a quarter (23%) said they would report such a crime to the police if they witnessed it.

   More worryingly, 92% of those asked did not know what mate crime was. Additionally 9% said they had witnessed someone with learning disabilities being bullied.