

# School for Social Care Research

## Scoping Review

### Prevention and Social Care for Adults with Learning Disabilities

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Janet Robertson



Improving the  
evidence base for  
adult social care  
practice

## The School for Social Care Research

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## SUMMARY

This scoping review was commissioned by the National Institute for Health Research's School for Social Care Research.

The aims of the review were to explore the issue of prevention in relation to adult social care services for people with learning disabilities with regard to:

- Options for preventative actions
- Implications for adult social care practice
- Possibilities for modelling the consequences of preventative strategies

### What is prevention?

Traditionally, it has been common to distinguish between three levels of prevention:

- *Primary prevention* which seeks to eliminate or reduce need by reducing the probability of it initially occurring
- *Secondary prevention* which seeks to eliminate or reduce need by intervening in the early stages of the development of the need in order to reduce the probability of it escalating
- *Tertiary prevention* which seeks to eliminate or reduce need by providing effective support to people who already experience such a need to prevent further disability or disadvantage and, as far as possible, to restore functioning.

However, the recent focus on a 'preventative agenda' in UK social and health care policy has primarily been on shifting activity toward primary and secondary prevention. *Given this focus, this scoping review will only address issues related to primary and secondary prevention.*

There are two logical options for preventative interventions that seek to reduce the need for social care services among people with learning disabilities. First, it may be possible to prevent the development of learning disabilities *per se*. The results of such interventions would be to reduce the number of people with learning disabilities in the population and, over time, the need to use adult social care services by people with learning disabilities. Second, it may be possible for preventative interventions to reduce the need for adult social care services *among* people with learning disabilities.

### Ethical and ideological issues

Discussion of issues of prevention in relation to disability raises a number of contentious ethical and ideological issues. In contemporary English society, which places value on intelligence, independence and literacy, having learning disabilities places people at significant disadvantage. Given that the risk of acquiring learning disabilities is related to childhood exposure to socioeconomic disadvantage and adversity, we believe there are

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strong moral, ethical (and economic) arguments to reduce the exposure of infants and young children to such social and economic inequalities (and thereby reduce the incidence of learning disabilities).

#### Primary prevention

Learning disabilities include an extremely heterogeneous range of conditions or impairments associated with a wide range of genetic, metabolic and environmental causes. Primary preventative strategies aimed at reducing the incidence and prevalence of learning disabilities will need to address the conditions under which children are conceived and grow up (including their pre-natal environment).

■ Key research questions are:

1. To what extent do universal or selective child poverty reduction strategies reduce the risk of children's general cognitive ability meeting the criteria for learning disabilities?
2. To what extent do intensive pre-school intervention/education programmes reduce the risk of children's general cognitive ability meeting the criteria for learning disabilities?
3. What are the characteristics of intensive early intervention/education programmes that are associated with greater reductions in the risk of children's general cognitive ability meeting the criteria for learning disabilities?
4. To what extent do general evaluations of relevant social policy initiatives (e.g. Total Place initiatives, both in affluent and socially deprived areas) report data concerning their impact on the number of children with learning disabilities?
5. What are the social and economic costs and benefits associated with the widespread implementation of such programmes in England?

These issues could be addressed by a combination of systematic review, re-analysis of evaluation data that are accessible, and statistical modelling.

Primary prevention strategies aiming to reduce the need for or use of adult social care services among people with learning disabilities need to be considered in the context of what is known about the determinants of current service use. In some instances, use of specialised social care services by adults with learning disabilities could be prevented by: (1) reducing the prevalence of additional needs (especially those associated with physical or mental health problems, engagement with the criminal justice system) among adults with learning disabilities; (2) strengthening the capacity of informal support networks.

■ Key research questions include:

1. To what extent do intensive pre-school intervention/education programmes and other more generic social policies reduce the risk of children and young people with

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learning disabilities developing additional physical, emotional or behavioural needs that are likely to increase use of adult social care services?

2. What are the characteristics of such interventions that are associated with greater reductions in the risk of the development of such additional needs?
3. To what extent do more personalised systems of support increase the capacity of informal support networks to the extent that the need for formal support is reduced?
4. To what extent do Total Place and general community development initiatives increase the capacity of informal support networks to the extent that the need for formal support is reduced?
5. To what extent do family support services increase the capacity of informal support networks to the extent that the need for formal support is reduced?
6. What are the characteristics of such interventions that are associated with greater reductions in the need for formal support?
7. What are the social and economic costs and benefits associated with the widespread implementation of such programmes in England?

While some of these issues could be addressed by a combination of systematic review, re-analysis of evaluation data that are accessible and statistical modelling, others will require primary evaluative research.

### Secondary prevention

Secondary prevention of learning disabilities involves the implementation of interventions to people (predominantly children) showing early signs of developmental delay. It is likely that the most effective approach to secondary prevention of learning disabilities will involve the delivery of relatively intensive pre-school intervention and education programmes to children with developmental delay. The difference between primary and secondary prevention of learning disabilities therefore lies not so much in nature of the intervention, but in the targeting of the intervention to children (and the families of children) showing early signs of learning disabilities.

■ Key research questions are:

1. To what extent do intensive pre-school intervention/education programmes reduce the risk of children with early signs of developmental delay having learning disabilities as adults?
2. What are the characteristics of such interventions that are associated with greater reductions in the risk of the development of learning disabilities?
3. What are the social and economic costs and benefits associated with the widespread implementation of such programmes in England?

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While some of these issues could be addressed by a combination of systematic review, re-analysis of evaluation data that are accessible and statistical modelling, others will require primary evaluative research.

Secondary prevention of the need for social care services among adults with learning disabilities involves the implementation of interventions to people showing early signs of the development of additional needs that may lead to need for social care support. As noted above, use of adult social care services among people with less severe learning disabilities is predicted by the co-occurrence of additional physical, emotional and behavioural needs. Interventions that address these needs early in their development may reduce the need for adult social care support in the future. In many, but not all, instances, this may require the delivery of early intervention programmes in childhood.

■ Key research questions include:

1. To what extent do family support services targeted at families who are struggling to support their son or daughter with learning disabilities increase the capacity of informal support networks to the extent that the need for formal support is reduced?
2. What are the characteristics of such interventions that are associated with greater reductions in the need for formal support?
3. What are the social and economic costs and benefits associated with the widespread implementation of such programmes in England?

Few of these issues could be addressed by either systematic review or re-analysis of evaluation data that are accessible. Primary evaluative research is likely to be required.

### Conclusions

A plausible case can be made for the viability and potential effectiveness of primary and secondary prevention of learning disabilities and of the need for social care support among people with learning disabilities. There is, at present, no direct empirical evidence of the social and economic benefits associated with investment in such activities. There are, however, possibilities for estimating some of these costs and benefits using information from a combination of undertaking new systematic reviews and re-analysis of evaluation data that are or could be made accessible.

The vast majority of the options for prevention involve altering the social and environmental context in which children in the UK grow up. Some of these interventions are relevant to all children (e.g., reducing exposure to child poverty and economic inequality). Some are more specific to children with learning disabilities and the families who support them (e.g., early intervention for children with developmental delay, short breaks). Much fewer options are specific to services for adults with learning disabilities.



## BACKGROUND

This scoping review was commissioned by the National Institute for Health Research's School for Social Care Research.

The aims of the review were to explore the issue of prevention in relation to adult social care services for people with learning disabilities with regard to:

1. Options for preventative actions
2. Implications for adult social care practice
3. Possibilities for modelling the consequences of preventative strategies.



## WHAT IS PREVENTION?

Traditionally, it has been common to distinguish between three levels of prevention:

- *Primary prevention* seeks to eliminate or reduce need by reducing the probability of it initially occurring. The mandatory use of safety belts in cars was introduced as a primary preventative strategy to reduce road traffic injuries. The creation of Sure Start areas was introduced as a primary preventative strategy to reduce a range of problems associated with compromised child development.
- *Secondary prevention* seeks to eliminate or reduce need by intervening in the early stages of the development of the need in order to reduce the probability of it escalating. The notion of secondary prevention is fundamental to primary health care services.
- *Tertiary prevention* seeks to eliminate or reduce need by providing effective support to people who already experience such a need to prevent further disability or disadvantage and, as far as possible, to restore functioning. The vast majority of current health and social care expenditure and activity is related to tertiary prevention.

However, the recent focus on a 'preventative agenda' in UK social and health care policy has primarily been on shifting activity toward primary and secondary prevention; 'It means encouraging everyone to have healthy, active and fulfilling lifestyles; supporting people when a care need first arises to stop the problem escalating ....' (Department of Health 2008a; 2010). *Given this focus, this scoping review will only address issues related to primary and secondary prevention.*

Primary and secondary prevention strategies can be further sub-divided:

- *Universal strategies* are delivered to whole populations (e.g., the mandatory use of safety belts, fluoridisation of the water supply).
- *Selective strategies* are delivered to population sub-groups identified on the basis of their increased risk of developing a specific need (e.g., *Sure Start*).
- *Indicated strategies* are delivered to high-risk individuals identified on the basis of early signs of developing such a need (e.g., parenting classes for children with early signs of conduct difficulties).

There are two logical options for preventative interventions that seek to reduce the need for social care services among people with learning disabilities. First, it may be possible to prevent the development of learning disabilities *per se*. The results of such interventions would be to reduce the number of people with learning disabilities in the population and, over time, the need to use adult social care services by people with learning disabilities. Second, it may be possible for preventative interventions to reduce the need for adult social care services *among* people with learning disabilities.

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As a result, in the two areas of primary and secondary prevention we will address options for: (1) the prevention of learning disabilities; (2) the prevention of the need for adult social care services among people with learning disabilities.

## ETHICAL AND IDEOLOGICAL ISSUES

Discussion of issues of prevention in relation to disability raises a number of contentious ethical and ideological issues (Louhiala 2004; Shakespeare 2006). It is important, therefore, that we make our position clear. For some commentators, prevention appears to be inexorably intertwined with eugenicist ideologies and practices. We find this approach too simplistic.

First, as Tom Shakespeare has argued, the health conditions or impairments associated with disability may be usefully considered as 'predicaments' (Shakespeare 2006). The vast majority of people would prefer not to experience them and we would have, as a society, legitimate concerns should parents seek to impose such health conditions or impairments on their children. In contemporary English society, which places value on intelligence, independence and literacy, having learning disabilities clearly represents a 'predicament'. We do not accept, however, that the experience of health conditions or impairments associated with disability should alter the human value or rights of the people affected.

Second, it is clear that the risk of acquiring health conditions or impairments associated with disability (and in particular learning disabilities) is often quite strongly related to childhood exposure to socioeconomic disadvantage (Andreias et al 2010; Emerson 2007; Emerson in press; Leonard et al 2005; Leonard and Wen 2002; McLaughlin et al 2010; Roeleveld et al 1997; Shonkoff et al 2009). There are strong moral, ethical (and economic) arguments to reduce the exposure of infants and young children to such social and economic inequalities (Doyle et al 2009; Irwin et al 2007; National Equality Panel 2010; The Marmot Review 2010; Wilkinson and Pickett 2009).

## PRIMARY PREVENTION

### Primary prevention of learning disabilities

Learning disabilities include an extremely heterogeneous range of conditions or impairments associated with a wide range of genetic, metabolic and environmental causes (Einfeld and Emerson 2008). By definition, they emerge during childhood (Einfeld and Emerson 2008). Consequently, any primary preventative strategies aimed at reducing the incidence or prevalence of learning disabilities will need to address the conditions under which children are conceived and grow up (including their pre-natal environment).

#### Genetic counselling and screening

Genetic counselling may, in a small minority of instances, provide information on the risk of conceiving a child with learning disabilities. Pre-natal screening (e.g., for Down Syndrome) is freely available through the NHS. At present, very few of the genetic or metabolic causes of learning disabilities are treatable. One notable exception is Phenylketonuria (PKU), the debilitating consequences of which can be avoided by dietary control. As such, information from genetic counselling and screening is only likely to be of use in assisting parents in decision making regarding conception and the elective termination of pregnancies. These are, of course, highly contentious areas (Louhiala 2004; Shakespeare 2006).

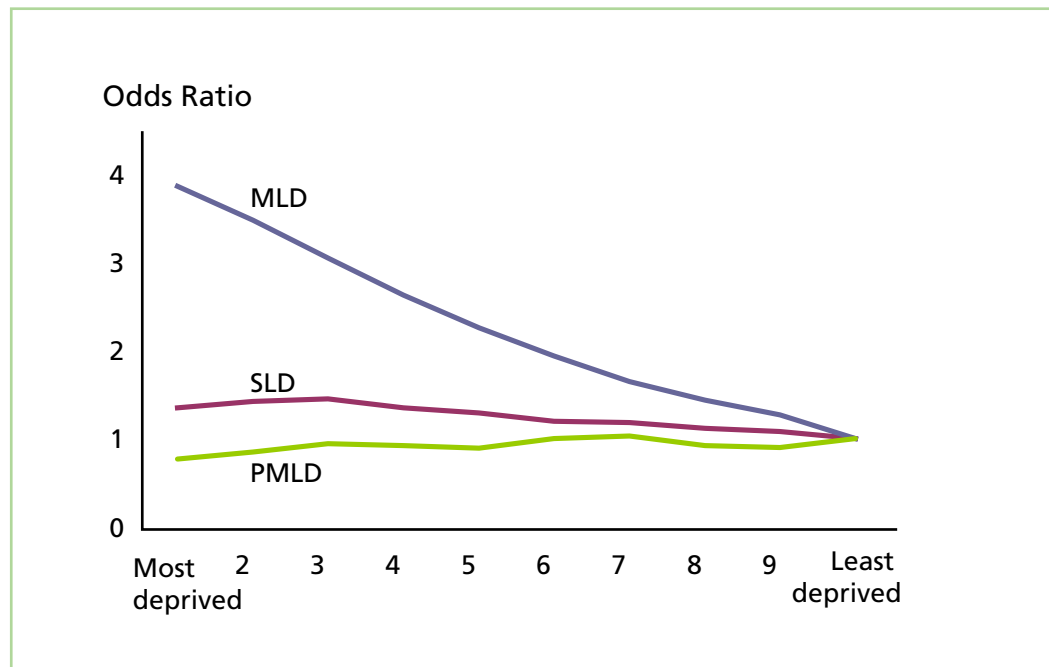
#### Addressing environmental causes of learning disabilities

There is extensive evidence of marked socioeconomic gradients in the prevalence of learning disabilities, particularly for less severe forms of learning disabilities (Emerson 2007; Leonard and Wen 2002; Leonard et al 2005; Roeleveld et al. 1997). However, recent research in England has documented social gradients across the full range of severity of learning disability (Emerson, 2010a).

When controlling for the effects of local authority, neighbourhood deprivation and pertinent child characteristics (age, gender, ethnicity), children aged 7–15 in England growing up in households that are eligible for free school meals are over twice as likely to be identified as having a Special Educational Need (at School Action Plus or above) associated with Moderate or Severe Learning Difficulty (MLD, SLD) and are 80% more likely to be identified as having a Special Educational Need (at School Action Plus or above) associated with Profound Multiple Learning Difficulty (PMLD).

Living in a deprived neighbourhood is independently associated with risk of learning disabilities (Figure 1). When controlling for the effects of local authority, free school meal eligibility and pertinent child characteristics (age, gender, ethnicity), children growing up in the 30% most deprived neighbourhoods (neighbourhood deprivation based on Income Deprivation Affecting Children Index [IDACI] scores) are three times more likely than those growing up in the most affluent neighbourhoods to be identified as having a Special

Figure 1: Corrected odds of learning disability by neighbourhood deprivation



Educational Need associated with Moderate Learning Difficulty (MLD). The association between neighbourhood deprivation and risk of Severe or Profound Multiple Learning Difficulty is much less pronounced.

But what causes these gradients? The available evidence suggests that they are likely to result from a combination of factors that vary in their significance across childhood.

*In young children*, social gradients in the prevalence of learning disabilities are likely to reflect two processes.

- First, growing up in poverty is associated with increased exposure to a wide range of material and psychosocial hazards (e.g., preterm, low birth weight, foetal growth restriction, exposure to a range of toxins and teratogens, poorer nutrition including reduced rates of breast feeding, poor housing conditions, exposure to less than optimal parenting, poorer pre-school educational opportunities, injury and accidents, exposure to more hazardous neighbourhoods), all of which have been shown to impair the cognitive development of children (Andreias et al 2010; Bergman et al 2007; Conger and Donnellan 2007; Doyle et al 2009; Duncan and Brooks-Gunn 2000; Hertzman and Boyce 2010; Irwin et al 2007; Keating and Hertzman 1999; Laplante et al 2008; Leventhal and Brooks-Gunn 2000; Shonkoff et al 2009; The Marmot Review 2010; McLoyd 1998; Seccombe 2002; Wadsworth and Butterworth 2006; Wilkinson and Pickett 2009; 2007).

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- As a result, children exposed to 'toxic' levels of environmental adversity will be more likely than their peers to have learning disabilities (and in particular mild learning disabilities).
- Second, 'selection effects' involving the intergenerational transmission of socially patterned health conditions or impairments and socioeconomic position are likely to be important. For example, parents with mild learning disabilities are more likely than other parents to: (1) be socioeconomically disadvantaged; and, given the genetic contribution to general intelligence, (2) have a child with learning disabilities (IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities 2008; Maughan et al 1999; McConnell et al 2003; Seltzer et al 2005; Spinath et al 2004).

*In later childhood*, it is likely that socially patterned inequalities in access to higher quality educational activities, experiences and resources may further compromise the cognitive development of children (Bergman et al 2007; Conger and Donnellan 2007; Doyle et al 2009; Duncan and Brooks-Gunn 2000; Feinstein 2003; Irwin et al 2007; Keating and Hertzman 1999; Laplante et al 2008; Leventhal and Brooks-Gunn 2000; McLoyd 1998; Seccombe 2002; 2007; Shonkoff et al 2009; The Marmot Review 2010; Wadsworth and Butterworth 2006; Wilkinson and Pickett 2009). It has been suggested that these social gradients may also reflect the impact of child disability on the social mobility of families as a result of the direct and indirect costs associated with care (Tibble 2005). However, it appears likely that any such effects are small as: (1) there is little, if any, evidence that social gradients in learning disabilities increase with age (Emerson et al 2006); (2) gradients appear to be more pronounced for less severe learning disabilities (see above); and (3) recent research has failed to find any clear associations between child disability and the subsequent poverty trajectories of families (Shahtahmasebi et al, 2010).

This body of evidence suggests that two broad classes of social policies may be effective in the primary prevention of learning disabilities. First, policies that reduce the odds of exposure to disadvantage (Seccombe 2002) (e.g., by reducing rates of child poverty and/or socioeconomic inequality) or to specific environmental risks (e.g., maternal consumption of alcohol during pregnancy) (Nulman et al 2007) would be expected to reduce the incidence (and therefore prevalence) of learning disabilities, especially mild learning disabilities. Second, policies that help children and families 'beat the odds' when exposed to poverty and/or socioeconomic inequality (Seccombe 2002) (e.g., by providing compensatory support to 'at risk' families or communities in order to enhance their resilience) (Broberg et al 2009; Luthar et al 2006; Luthar 2003; 2006; Luthar and Brown 2007; Luthar et al 2000; Rutter 1979; 1985; 1987; 1999) would also be expected to reduce the incidence (and therefore prevalence) of learning disabilities, again especially mild learning disabilities. It would be important to ensure that any such universal and targeted interventions are inclusive of families at higher risk of having a child with learning disabilities (Emerson et al 2009; National Equality Panel 2010; The Marmot Review 2010), especially families in which one or more parent may have learning disabilities (McConnell et al 2003), and families from some minority ethnic communities (Emerson, in press).

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There is, to our knowledge, no direct empirical evidence to support the first option. This is hardly surprising given the practical and methodological difficulties of undertaking such research. It should be noted, however, that quasi-experimental evidence does exist to suggest that reducing population rates of child poverty is associated with reduced rates of child emotional and behavioural disorders (Costello et al 2003).

There is, however, growing evidence that relatively *intensive* pre-school intervention and education programmes (e.g., Head Start) can have potentially substantial and lasting benefits on children's futures, including on their cognitive ability and attainment (Ben-Itzhak and Zachor 2007; Burger 2010; Chasson et al 2007; Doyle et al 2009; Eldevik et al 2009; Eldevik et al 2010; Guralnick 1997; 2005; Irwin et al 2007; Jacobson et al 1998; Keating and Hertzman 1999; Law et al 2003; McConachie and Diggle 2007; Petitclerc and Tremblay 2009; Ramey et al 2004; Ramey and Ramey 1998; 2004; Reynolds et al 2007; Remington et al 2007; Rogers and Vismara 2008; Shonkoff et al 2009; Spittle et al 2007; Thomaidis et al 2000; US Department of Health and Human Services 2010). However, evaluation studies in this area very rarely report the results in a manner that would make it possible to directly identify the proportion of children in intervention and control groups who would meet the relevant criteria for learning disabilities (scoring more than two standard deviations below the population mean on tests of general cognitive ability). Rather results are typically presented in terms of average gains in test scores.

#### ■ Key research questions

1. To what extent do universal or selective child poverty reduction strategies reduce the risk of children's general cognitive ability meeting the criteria for learning disabilities?
2. To what extent do intensive pre-school intervention/education programmes reduce the risk of children's general cognitive ability meeting the criteria for learning disabilities?
3. What are the characteristics of intensive early intervention/education programmes that are associated with greater reductions in the risk of children's general cognitive ability meeting the criteria for learning disabilities?
4. To what extent do general evaluations of relevant social policy initiatives (e.g. *Total Place* initiatives, both in affluent and socially deprived areas) report data concerning their impact on the number of children with learning disabilities?
5. What are the social and economic costs and benefits associated with the widespread implementation of such programmes in England?

Primary evaluation research would be the most rigorous approach to answering these questions. Such research would, however, be costly and take considerable amounts of time. A shorter-term and less costly alternative would be to address these issues through a combination of systematic review, secondary analysis of existing evaluation data and statistical modelling.



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For example, it may be possible to reanalyse pooled data from previous evaluation studies to determine the extent to which universal or selective child poverty reduction strategies and intensive pre-school intervention/education programmes reduce the risk of children's general cognitive ability meeting the IQ criteria for learning disabilities. If it were not possible to access these data the reduced risk of children's general cognitive ability meeting the IQ criteria for learning disabilities could be indirectly estimated from cognitive gains reported in terms of IQ points.

#### Primary prevention of the need for adult social care services among people with learning disabilities

Primary prevention strategies aiming to reduce the need for or use of adult social care services among people with learning disabilities need to be considered in the context of what is known about the determinants of current service use. Four issues are pertinent to this discussion.

1. The majority of adults with learning disabilities do not use *specialised* social care services for adults with learning disabilities. For example, the administrative prevalence of learning disabilities in education systems is 3-4% (similar to the expected percentage of children with impaired general cognitive ability in the population) (Emerson, 2010a). However, the administrative prevalence of learning disabilities among young adults (age 20–30) in health and social care systems is approximately 0.6% (Emerson and Hatton 2004). It is not known whether adults with learning disabilities who do not use *specialised* social care services for adults with learning disabilities are using other adult health or social care services.
2. Non-use of *specialised* social care services for adults with learning disabilities is highest among people with less severe learning disabilities (Emerson, in press; Emerson and Hatton 2008). Non-use is likely to be determined by a number of factors including lack of need, failure to meet (increasingly stringent) eligibility criteria, reluctance to self-identify as having learning disabilities and lack of awareness of the potential availability of services. The latter is particularly relevant to people with learning disabilities in some British minority ethnic communities (Hatton et al 1998).
3. Use of *specialised* social care services by adults with less severe learning disabilities is likely to be determined by needs additional to the needs associated with learning disabilities (e.g., physical or mental health problems, engagement with the criminal justice system). These additional needs are more common among people with less severe learning disabilities when compared to the general population (Emerson et al 2010; Farrington and Welsh 2007; Maughan et al 1999; Seltzer et al 2005; Tymchuk et al 2001).
4. The majority of social care expenditure for adults with learning disabilities is associated with the provision of supported accommodation services (The Information Centre for Health and Social Care 2009). These include a number of extremely high cost packages



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of support, often involving 'out of area placements' (Emerson and Robertson 2008). The quality and value for money of such placements have been brought into question (Emerson and Robertson 2008; Goodman et al 2006; Hassiotis et al, in press; Perry et al 2007; Ritchie et al 2005). The use of (potentially unnecessarily expensive) supported accommodation options is determined by a range of factors including: the presence of needs additional to learning disabilities (e.g., physical or mental health problems, engagement with the criminal justice system); the lack of availability of appropriate local services; the capacity of informal support networks (Emerson and Robertson 2008; Goodman et al 2006; Hassiotis et al, in press; Perry et al 2007; Ritchie et al 2005).

The above analysis suggests that, in some instances, use of specialised social care services by adults with learning disabilities could be prevented by: (1) reducing the prevalence of additional needs (especially those associated with physical or mental health problems, engagement with the criminal justice system) among adults with learning disabilities; and (2) strengthening the capacity of informal support networks.

#### Primary prevention of additional needs

There is considerable overlap between the social determinants of learning disabilities and the social determinants of the additional physical, mental and behavioural needs of people with learning disabilities (Allen et al, in press; Emerson et al 2009; Farrington and Welsh 2007). As such, the strategies listed in the previous sections (reducing the odds of exposure to adversity and disadvantage, the provision of additional support – especially in the early years – to families and children with learning disabilities who are exposed to adversity) would be expected to both reduce the prevalence of learning disabilities *and* reduce the prevalence of additional physical, mental and behavioural needs among people with learning disabilities. To date, however, no empirical data are available to support this assertion. However, as noted above, quasi-experimental evidence does exist to suggest that reducing population rates of child poverty is associated with reduced rates of child emotional and behavioural disorders (Costello et al 2003). Given that exposure to adversity and risk of mental health problems is very similar in children with learning disabilities and children without learning disabilities (Emerson and Hatton 2007), it appears plausible to suggest that these effects should generalise to populations of children with learning disabilities (Allen et al, in press).

Individual-focused resilience enhancing interventions of perhaps particular relevance to people with learning disabilities include intervention in childhood and throughout the lifecourse that aim to promote:

- positive achievements
- self-esteem
- empowerment
- problem solving
- communication

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- social skills relevant to friendship formation and maintenance
- inclusive social relationships through employment, volunteering and other forms of social participation.

Examples of strategies that may result in such outcomes potentially include:

- having control over a personal budget, with appropriate support for planning
- participation in self-advocacy groups
- supported employment
- participation in artistic and sporting activities
- volunteering.

Unfortunately, whilst such supports/interventions are often advocated, remarkably little empirical research has been undertaken to evaluate their impact. However, a small number (of often methodologically questionable studies) suggest that participation in activities that may help build self-esteem or may give a sense of achievement (e.g., sporting activities, challenging outdoor adventure activities) may be associated with greater well-being (Carmeli et al 2008; Dykens and Cohen 1996; Maiano et al 2001; Ninot et al 2005; Rose and Massey 1993; Weiss and Bebko 2008).

#### **Strengthening the capacity of support beyond services**

Strengthening the capacity of informal support systems may reduce the need for use of adult social care either directly or indirectly. Direct effects would result from the increased capacity of informal support systems to provide the support needed by adults with learning disabilities. Indirect effects would result from changes in the capacity of informal support systems preventing the emergence of additional needs (see previous section).

Social policies whose implementation may have direct effects would include providing additional support to families supporting a child or adult with learning disabilities through, for example, increasing the availability of disability-friendly child care arrangements and increasing the availability of short-breaks for children and adults with learning disabilities (Emerson et al 2009; Robertson et al 2010). The current move toward more personalised health and social care (Department of Health 2007; 2008a; 2009a; 2009b; 2009c; 2010; Robertson et al 2010) may make a significant contribution in this area as families diversify the support they use beyond existing social care services to a wider range of non-service supports.

They would also include policies that served to develop more inclusive communities. These would range from policies that sought to directly address disablism and other forms of discrimination (e.g., on the basis of race or ethnicity) (e.g., through social marketing) and thereby reduce the stigma associated with learning disabilities (and other forms of discrimination faced by people with learning disabilities) through to social policies that strengthen social capital through, for example, reducing economic inequality (Emerson et

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al 2009; Equalities Review 2007; Equality and Human Rights Commission 2008; National Equality Panel 2010; The Marmot Review 2010). Such policies, given the association between exposure to disablism and well-being, are also likely to reduce the prevalence of additional needs (see above) (Emerson 2010b).

Again, however, whilst such supports/interventions are often advocated, remarkably little empirical research, especially high quality research, has been undertaken to evaluate their impact (Robertson et al 2010). As a result, the likely effectiveness or efficiency of such approaches is unknown.

#### ■ Key research questions

1. To what extent do intensive pre-school intervention/education programmes and other more generic social policies reduce the risk of children and young people with learning disabilities developing additional physical, emotional or behavioural needs that are likely to increase use of adult social care services?
2. What are the characteristics of such interventions that are associated with greater reductions in the risk of the development of such additional needs?
3. To what extent do more personalised systems of support increase the capacity of informal support networks to the extent that the need for formal support is reduced?
4. To what extent do Total Place and general community development initiatives increase the capacity of informal support networks to the extent that the need for formal support is reduced?
5. To what extent do family support services increase the capacity of informal support networks to the extent that the need for formal support is reduced?
6. What are the characteristics of such interventions that are associated with greater reductions in the need for formal support?
7. What are the social and economic costs and benefits associated with the widespread implementation of such programmes in England?

While it is possible that some of these issues (e.g., the impact of intensive pre-school intervention/education programmes) could be addressed by a combination of systematic review, re-analysis of evaluation data that are accessible and statistical modelling (see above), addressing most of these issues will require either significant investment in primary research or the development of systems for the collection of routine operational social care information that could be pooled to address some of these issues. For example, if operational social care information systems are capable of tracking service use by individuals over time (e.g., through use of NHS numbers) it would be possible to pool data across agencies to examine the association between the introduction of specific policies and practices (e.g., short breaks for disabled children in Pathfinder sites) and subsequent changes to service use.

## SECONDARY PREVENTION

### Secondary prevention of learning disabilities

Secondary prevention of learning disabilities involves the implementation of interventions to people (predominantly children) showing early signs of developmental delay. It is likely that the most effective approach to secondary prevention of learning disabilities will involve the delivery of relatively intensive pre-school intervention and education programmes to children with developmental delay (Ben-Itzhak and Zachor 2007; Burger 2010; Chasson et al 2007; Doyle et al 2009; Eldevik et al 2009; Eldevik et al 2010; Guralnick 2005; Guralnick et al 1997; Irwin et al 2007; Jacobson et al 1998; Keating and Hertzman 1999; Law et al 2003; McConachie and Diggle 2007; Petitclerc and Tremblay 2009; Ramey et al 2004; Ramey and Ramey 1998; 2004; Remington et al 2007; Reynolds et al 2007; Rogers and Vismara 2008; Shonkoff et al 2009; Spittle et al 2007; Thomaidis et al 2000; US Department of Health and Human Services 2010; Wadsworth and Butterworth 2006). The difference between primary and secondary prevention of learning disabilities therefore lies not so much in the nature of the intervention, but in the targeting of the intervention to children (and the families of children) showing early signs of learning disabilities.

A key issue for all early intervention programmes is the identification and targeting of those behaviours, skills and capabilities that have the greatest impact on accelerating further development (e.g., communication skills, problem solving and help seeking) of independence and well-being. To our knowledge little consideration has been given to identifying these key or pivotal behaviours in the context of reducing future need for social care.

#### ■ Key research questions

1. To what extent do intensive pre-school intervention/education programmes reduce the risk of children with early signs of developmental delay having learning disabilities as adults?
2. What are the characteristics of such interventions that are associated with greater reductions in the risk of the development of learning disabilities?
3. What are the social and economic costs and benefits associated with the widespread implementation of such programmes in England?

While some of these issues could be addressed by a combination of systematic review, re-analysis of evaluation data that are accessible and statistical modelling, others will require primary evaluative research (see p7).

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### Secondary prevention of the need for adult social care services among people with learning disabilities

Secondary prevention of the need for social care services among adults with learning disabilities involves the implementation of interventions for people showing early signs of the development of additional needs that may lead to need for social care support. As noted above, use of adult social care services among people with less severe learning disabilities is predicted by the co-occurrence of additional physical, emotional and behavioural needs. Interventions that address these needs early in their development may reduce the need for adult social care support in the future. In many, but not all, instances, this may require the delivery of early intervention programmes in childhood.

Some examples of potentially effective approaches to secondary prevention are given below:

- The implementation of annual health checks for children and adults with learning disabilities within primary care systems may help detect illnesses prior to them becoming fully symptomatic and opens up the possibility of earlier and more effective treatment (Lennox et al 2008; Robertson et al 2010; Webb and Rogers 1999). This is likely to become increasingly relevant given the increasing longevity of people with learning disabilities in order to detect as early as possible the common diseases of old age that can have a significant social care impact.
- Early intervention for people with learning disabilities who show evidence of the development of behavioural difficulties may help avoid the escalation of severity and persistence of such difficulties (Allen et al, in press; Emerson and Einfeld, in press). Given the early emergence and persistence of behavioural difficulties (Einfeld et al 2006; Emerson and Einfeld, 2010; Murphy et al 1999), early intervention will in the majority of instances involve intervening in (early) childhood (Allen et al, in press; Emerson and Einfeld, in press). There now exists a growing body of evidence to support such approaches from within the general population (Boisjoli et al 2007; Dishion et al 2008; Offord and Bennett 2002; Tremblay 2006; Webster-Stratton et al 2008; Webster-Stratton and Taylor 2001), and (to a much lesser extent) among children with learning disabilities (Allen et al, in press; Emerson and Einfeld, 2010; McIntyre 2008a; 2008b; Wacker et al 1998).
- Providing additional support to families who are struggling to support their son or daughter with learning disabilities may increase their capacity to cope and consequently avoid or postpone entry into supported accommodation services (Emerson et al 2009; Robertson et al 2010).
- Improving the health of carers (e.g., by introducing annual health checks for carers, short breaks for children) (Department of Health 2008b).

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- Increasing the potential for people with learning disabilities to enjoy a healthy lifestyle and thereby minimise the chances of certain types of care need arising (Department of Health 2008c; Krahn et al 2006; The Marmot Review 2010). Again, this is likely to become increasingly relevant given the increasing longevity of people with learning disabilities and their consequent risk of suffering common diseases of old age that can have a significant social care impact.

It will be important, of course, to ensure equality of access to any such interventions. This is likely to be particularly important given that those groups in society who often have the greatest need for support (e.g., one parent families living in poverty, people from certain minority ethnic communities) have the greatest difficulty in accessing support.

#### ■ Key research questions

1. To what extent do family support services targeted at families who are struggling to support their son or daughter with learning disabilities increase the capacity of informal support networks to the extent that the need for formal support is reduced?
2. What are the characteristics of such interventions that are associated with greater reductions in the need for formal support?
3. What are the social and economic costs and benefits associated with the widespread implementation of such programmes in England?

Few of these issues could be addressed by either systematic review or re-analysis of evaluation data that are accessible. Addressing most of these issues will require either significant investment in primary research or the development of systems of the collection of operational information that could be pooled to address some of these issues. The latter option (sometimes referred to as 'practice-based evidence') offers substantial potential benefits. For example, the routine collection of outcome data by *In Control* sites opens up the possibility of pooled analyses of policy impact and, perhaps more importantly, the identification of personal and contextual factors that may influence the extent of impact.

## CONCLUSIONS

A plausible case can be made for the viability and potential effectiveness of primary and secondary prevention of learning disabilities and of the need for social care support among people with learning disabilities. There is, at present, no direct empirical evidence of the social and economic benefits associated with investment in such activities. There are, however, possibilities for estimating some of these costs and benefits using information from a combination of undertaking new systematic reviews and re-analysis of evaluation data that are or could be made accessible.

The vast majority of the options for prevention involves altering the social and environmental context in which children in the UK grow up. Some of these interventions are relevant to all children (e.g., reducing exposure to child poverty and economic inequality). Some are more specific to children with learning disabilities and the families who support them (e.g., early intervention for children with developmental delay, short breaks). Much fewer options are specific to services for adults with learning disabilities.



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