NICE National Institute for Health and Care Excellence

Economic Plan

This document identifies the priorities for economic analysis and the proposed methods for addressing these questions as described in section 7 of The Social Care Guidance Manual (2013).

1 Social Care Guidance

Full title of social care guidance: Care and support for people growing older with learning disabilities

Process for agreement

The economic plan was prepared by the economist in consultation with the rest of the NICE Collaborating Centre for Social Care (NCCSC) and Guidance Committee (GC). It was discussed and agreed on by the following people[a]:

For the NCCSC and GC:

NCCSC economist:	Annette Bauer
NCCSC representative(s)[b]:	Lisa Boardman
GC representative(s)[c]:	Margaret Lally

For NICE (completed by NICE):

Social care technical adviser: Peter O'Neill

Programme manager: Justine Karpusheff

Economic lead: Sarah Richards, post MOC Lesley Owen

Costing lead: Kate Moring

Proposals for any changes to the agreed priorities will be circulated by email to this group. If substantive revisions are agreed, they need to be recorded as addenda to this document (section 0) or as an updated version of the document[d].

[a] This may be done by face-to-face meeting, teleconference, or email as convenient.

[b] This may be the project manager, a systematic reviewer or research fellow and/or the centre director or manager, as appropriate for the NCCSC and guideline.

[c] This may be GC chair, social care lead and/or other members as appropriate.

[d] In case review questions are changed; for example, section 2 requires updating as well as other sections if modelling priorities are affected.

2 Topic priorities identified in the scope

This section contains all topics, or review questions, covered by the scope. These topics usually reflect selected social care issues. Please include a line for all elements of the scope (or review questions), indicating if an area is relevant for economic consideration and if modelling is deemed appropriate to address it[e].

Area[f]	**Relevant?[g]**	**Appropriate for modelling?[h]**
A. (review question 6) Person-centred assessment and care planning	Economic considerations concern the identification of changes in peoples' needs and wants as they grow older which might include a change in care setting. The area is of particular importance for people with learning disabilities as this population often experiences challenges in access to	Medium-high priority for economic modelling and analysis. There is a lack of data of different approaches of assessment and care planning; some data are available on outcomes (and costs) in the absence of assessment and care planning in regards to accommodation **Initial summary of evidence**: Population: Older people with learning disabilities and their carers Potential impact on future costs:

[e] It is important to note that because of the question-by-question approach taken in the systematic review work, no final decision has been made about which literature will be included. Thus, at the moment it is not clear whether and which types of interventions specific to assessment and care planning will be picked up in searches; this means that there might be opportunities for further economic work but those cannot be specified at the moment. We plan to review this during the guideline development process and ensure any updates are recorded in this document

[f] This corresponds to the "Key areas that will be covered " section in the scope, or if available, review questions

[g] Please state if this area is deemed relevant for considering opportunity costs and likely disinvestments. Areas might pose a decision problem directly or implicitly inform the choice between options. Responses should include information on relevance and whether areas are of high or low priority for economic work (see below).

[h] Economic work comprises literature reviews, qualitative consideration of expected costs and effects and/or formal decision modelling. Decision modelling is particularly useful where it can reduce uncertainty over cost effectiveness and/or where a recommendation is likely to result in considerable changes in social care outcomes and/or costs. For further details please see section 7 of The Social Care Guidance Manual (2013). It may not be feasible or efficient to address every relevant decision problem by de novo work. The rationale for choosing areas for cost effectiveness modelling should be described in detail in Sections 2 and 3.

	support and in making future plans.	• Change in care settings that are unplanned and happen in response to crises can lead to inappropriate emergency placements that are costly (Thompson and Wright 2001, Bigby and Ozanne 2004, Bowey and McGaughlin) • Short-term costs for additional support packages increase <u>Potential impact on future outcomes:</u> Getting the right support earlier and access to community resources can lead to health and wellbeing improvements and prevent traumatic experiences linked to unplanned changes in care setting (Bigby 2004, Heller et al 2005, Bowey and McGlaughlin 2007) <u>Existing literature</u>: Studies of different types (usually not RCTs) that investigate impact of care planning practice has direct impact on where older people with learning disabilities live but there is lack of evidence about effectiveness and cost-effectiveness of different care planning approaches <u>Variation in practice</u>: High; services underdeveloped for this population and pathways in practice are complex and sometimes chaotic; there are likely to be examples of good practice, in particular in areas in which personal budgets are available for this population (feedback from Guideline Committee group)

		Would an economic model be useful for decision making? In theory an economic model would be useful as there are different approaches of assessment and care planning for different groups that could be compared against each other in terms of costs and outcomes; however, there is a lack of data on the effect of different care planning approaches; however, modelling costs and benefits linked to *planning for* different types of accommodations might be feasible
B. (review questions 3) Information, advice, (advocacy), and training	Economic considerations refer to improved access to services and potentially more appropriate use of health and social care. This area is particularly important for this population because they are less likely to get the support they need and less able to voice their concerns and preferences.	Low priority for economic modelling and analysis. There may be a lack of available data to support modelling; information, advice and advocacy play an important role as part of person-centred assessment and care planning; however, there is a lack of data; the GC will have to make recommendation under consideration of likely costs of such support and possible resource implications. **Initial summary of evidence**: Population: Older people with learning disabilities and their carers. Potential impact on future costs: • There might be longer term cost implications linked to people not getting appropriate information or being unable to get their voices heard; this includes inappropriate choice of care setting or living arrangements;

		• Costs increase for putting appropriate support packages in place <u>Potential impact on future outcomes</u>: • Information, advice, advocacy and training can support behaviour change; there are potential health and wellbeing improvements to service users (and their carers) linked to an increase in self-efficacy, personal control and self-management skills • Information and advice might be able to reduce anxieties for older people with learning disabilities and their carers • Training to unpaid carers and family members to recognise small changes in behaviour, personality or functioning may enable early diagnosis (McCarron 2005) <u>Existing literature:</u> Information and advice addressed in the literature as part of wider person-centred assessment and care planning <u>Variation in practice</u>: Medium; there are legal duties for local authorities to provide information and advice for example about choices of different accommodation and support packages; however, it is less clear how well this is implemented at the moment. <u>Would an economic model be useful for decision making?</u> Yes potentially but lack of data is likely to prevent modelling in this area.

C. (review questions 5, 6) Emotional support	Economic considerations relate to whether potential improvements in health and wellbeing linked to emotional support justify the costs of interventions; emotional support might refer to professional help in form of counselling or to volunteer provided or peer support. This area of intervention is particularly important for this group because they are much more likely to experience mental illness and stigma than other older people.	Low priority for economic modelling **Initial summary of evidence**: Population: Older people with learning disabilities and their carers. Potential impact on future costs: • Costs of mental health interventions are expected to be relatively low compared to physical health interventions; • Reduced levels of psychological distress can reduce the use of some services such as community learning disability services and police (Ali et al 2015) Potential impact on future outcomes: • Older people with learning disabilities are at higher risk of experiencing social isolation, stigma and mental illness and support might lead to important health and wellbeing benefits (Cooper et al 2007, Buckles et al 2013) • Evidence that Cognitive Behaviour Therapy can be tailored to people with learning disabilities and lead to improved mental wellbeing (Jennings and Hewitt 2015) Existing literature available: Evaluative intervention studies from UK (including RCTs and systematic review) but referring to adult population more broadly

		Variation in practice: High Would an economic model be useful for decision making: Yes potentially but lack of evidence specific to this population prevents modelling in this area.
D. (review questions 5, 6, 7) Independent living support including housing adaptations, use of assistive technologies, crises support	Economic considerations include costs, outcomes and economic consequences linked to more independent living; this includes the costs of increased levels of support in persons' homes on the one hand, potential cost savings linked to avoiding unplanned hospital admissions and delaying or preventing care home admission.	Medium priority for economic modelling and analysis. **Initial summary of evidence**: Population: Older people with learning disabilities and their carers; a particular focus might be on people with Downs syndrome Potential impact on future costs: Potential cost savings might be linked to avoiding emergency department visits or unplanned hospital admissions and preventing or delaying admission to a care home or supported housing (McConkey 2006, Easterbrook 2008; HfT 2010) Potential impact on future outcomes: • Peoples preference is usually to remain living in their home and community and relocating can have negative health and wellbeing impacts for some people; people with Downs syndrome have been found to be at higher risk of experiencing negative outcomes linked to relocation (Meehan et al 2004; Patti et al 2010)

		• Additional support at home might prevent crises for people and reduce self-neglect and help people feeling more able to cope; • There are potential health and wellbeing benefits associated with this; • However, for some people support in their own home might not be safe (in particular for those who need 24 hours support) Existing literature: Literature refers to case studies and studies that investigate associations through statistical analysis; lack of evaluative intervention studies Variation in practice: High; high variety of technological devices which is market driven; and high geographical variation in commissioning models for technologies Would an economic model be useful for decision making? Yes potentially but lack of data prevents modelling in this area
E. (review questions 5, 6, 7) Accommodation types and support packages	Economic consideration refer to the costs of different living options such as residential homes, privately owned homes and supported living; each accommodation type is also linked to different support packages	Medium-high priority for economic modelling and analysis: Simple modelling might be feasible to demonstrate potential cost savings of planning the most appropriate accommodation type and support package **Initial summary of evidence**: Population: Older people with learning disabilities and their carers

		Potential impact on future costs: • Living arrangements have substantial impact on costs; the vast majority of costs incurred by older people with learning disabilities are those related to housing and accommodation; • Residential care more costly than supported living ; • unpaid care costs higher for people living at home • Smaller facilities usually more costly (Hallam et al 2002) Potential impact on future outcomes: • Generally peoples' preference is to live in their own homes and communities; but certain living arrangement might not be safe (risk of accidents and injuries) or put people at risk of deteriorating health outcomes • Supported living not necessarily linked to better outcomes than residential care (Fyson 2007); • Smaller group homes found to be associated with better quality of life for residents with Downs syndrome and dementia (Chaput 2002) Existing literature: Studies (often built on case studies) compare different accommodation types or care settings

		Variation in practice: Medium-high; often not much known about appropriateness of living arrangement and support until crises occurs (Robinson and Williams 2002); provision of supported housing that can accommodate the needs of older people with learning disabilities identified as major gap in provision (Hatzidimitriadou and Milne 2005) Would an economic model be useful for decision making? Yes potentially if model includes care planning different accommodation types and support packages
F. (review question 5) Dementia screening and services	Economic implications to be expected because of improvements in outcomes that prevent deterioration in physical and mental health; there might be economic benefits linked to delayed or prevented care home admissions; there will be also an increase in costs for additional provision. Interventions in this area include person-centred strategies for screening and specialist provision; this might include different service delivery models.	Medium priority for economic modelling and analysis. There may be a lack of available data to support modelling. The GC should be able to make a judgement (informed by published evidence) about the benefits of interventions that are intended to identify dementia early on and increase cognition and everyday functioning; dementia screening might be incorporated as part of general health screening (economic area H.) **Initial summary of evidence**: Population: Older people with learning disabilities and their carers; an important sub-group are people with Downs syndrome (and their carers); this is based on higher rates of dementia for some adults with learning disabilities and in particular in people with Down's syndrome (Cooper et al 2007; Strydom et al 2010).

		<u>Potential impact on future costs</u>: • Screening for dementia is not straightforward or low cost, because of the number and complexity of tests required and the settings where the tests need to take place (feedback from Guideline Committee group) • Impact on unpaid care increases substantially when people with learning disability develop dementia (McCarron et al 2002); • Costs implications linked to increased access to dementia services (Livingstone et al 1997; Nelson et al 2004; Strydom et al 2010); although Guideline Committee group also explained that the support package that people get if dementia is not recognised or supported might be as costly; • Dementia is a predictor for early nursing home admission in people with learning disability and early identification and support might help preventing or delaying admission to care homes and reduce associated costs (DeVreese et al 2012) <u>Potential impact on future outcomes</u>: • Undiagnosed dementia has been associated with higher unmet health and wellbeing needs (Livingstone et al 1997, Nelson et al 2004, Strydom et al 2010); • Diagnosis might lead improved cognition and functioning outcomes

		Existing literature: Literature refers to case studies and studies that investigate associations through statistical analysis; lack of evaluative intervention studies; some literature refers specifically to people with Downs syndrome Variation in practice: High; small number of specialised services that have been developed (Northway and Jenkins 2007; Slevin et al 2011) Would an economic model be useful for decision making? Yes potentially but lack of data prevents modelling in this area
G. (review question 5) Physical activity, wellbeing and health promotion programmes	Economic consideration concern the delay or prevention of the onset of chronic diseases and frailty associated with quality of life improvements and potential reduction in costs for treatment and possibly delay in admission to care homes.	Low priority for economic modelling and analysis. There may be a lack of available data to support modelling. GC should be able to make judgement about benefits of interventions in the context of delivery costs **Initial summary of evidence:** Population: Older people with learning disabilities and their carers Potential impact on future costs: • Existence of physical health problems as major cost drivers (Strydom et al 2010) and more likely in this population so if some problems can be prevented or delayed this is likely to lead to reduction in costs to the NHS

		• Costs of physical exercise interventions relatively low but additional incentives and adjustments might be needed for individuals which might increase costs <u>Potential impact on future outcomes</u>: • Health-related quality of life improvements linked to reduced obesity and there might be also mental wellbeing effect through exercise as well as additional social contacts (if intervention is group based) • More comprehensive interventions (i.e. exercise in combination with nutrition health education) can lead to changes in weight reduction as well as changes in health behavior attitudes and behaviors (e.g., dietary intake) and to a limited extent for improved life satisfaction (Heller and Sorenson 2013) • Reduction in health risks (Aranow and Hahn 2005; Haveman et al 2010) <u>Existing literature:</u> Lack of evaluative intervention studies <u>Variation in practice</u>: High <u>Would an economic model be useful for decision making?</u> Yes modelling would be helpful to understand the cost-effectiveness of different types of interventions in this area but insufficient data available to carry out modelling.

H. (review question 5) Health checks	Economic consideration concern improvements in physical and mental health as well as possible reduction in long-term costs for unplanned emergency treatments and delayed admission to residential or nursing homes.	High priority for economic modelling and analysis. The expected benefit of better knowledge about cost effectiveness in this area is high and data that can inform modelling are likely to be available. **Initial summary of evidence:** Population: Older people with learning disabilities and their carers Potential impact on future costs: • Decisions whether person needs residential care are often made because of health reasons (Williams and Battleday 2007); earlier identification of health problems and access to services might prevent or delay the need for residential care • The identification of health problems might reduce the use of more intensive and unplanned health services and treatments later on (Ryan et al 1997) Potential impact on future outcomes: • Some of the major health risks common for ageing persons with learning disabilities (Haveman et al 2007) might be prevented; • Literature on health screenings and services demonstrates the important role of health checks in identifying previously undetected conditions; conditions include life threatening ones such as cancer and cardio-vascular disease, as well as less serious conditions that are often more common among adults with developmental

		disabilities and could be treated if caught early (Haveman et al 2010; Heller and Sorenson 2013) • Improvements in health after health screening as reported by carers (Barr et al 1999) • Difficulties to differentiate between significant health conditions and normal age-related changes (Bowers et al 2014) Existing literature: Range of international and UK studies that measure outcomes of health checks in terms of their ability to identify previously undetected health needs (Robertson et al 2010); majority of studies refer to adult population more generally but include findings on older people; studies on different ways of providing health checks (e.g. Martin et al 2004; Hunt et al 2001) Variation in practice: Health checks incorporated into GP contracts but how well it works is not clear (e.g. Robertson et al 2010) Would an economic model be useful for decision making? Yes an economic model would be useful to demonstrate the longer term economic consequences and potential cost savings from a government perspective; information from studies on identified health problems might be linked to epidemiological and population data

I. (review question 4) Supporting carers through information, advice and training	Economic considerations include carers' ability to care for individuals at home but additional resources needed for them to do so; at a minimum this includes information and advice; carers at generally high risk of mental and physical illness because of demands of caring.	Medium priority for economic modelling and analysis. There is likely to be a lack of available data to support modelling. **Initial summary of evidence:** Population: Carers of older people with learning disabilities; particularly important sub groups are: carers of older age; carers of older people with behaviour that challenges; carers of those with severe disabilities, complex health conditions and dementia Potential impact on future costs: • Supporting carers might be able prevent or delay care home admission of the person cared for • Supporting carers is important to prevent their own health deterioration which also has substantial cost implications (for example to the NHS for treatments) Potential impact on future outcomes: • Carers are particularly likely to suffer mental and physical health problems which might be reduced through additional support • Day care provision has been found to contribute most positively to carers' health (Taggart et al 2012); there might be other support options for carers • Information and advice might help carers to feel less anxious about what will happen to

		person they care when they grow older (Ryan et al 2014) Existing literature: Lack of quantitative studies in this area Variation in practice: High Would an economic model be useful for decision-making? Yes potentially but lack of data prevents work in this area
J. (review question 8) End of life care planning	Economic considerations refer to costs and outcomes of different support options provided towards end of life; unplanned end of life support is usually linked to emergency treatment, unplanned and lengthy hospital stays; end of life care planning might reduce some of those costs.	Low priority for economic modelling and analysis. Data is insufficient to carry out modelling. Economic recommendations might need to be made under consideration of aspects of care planning more broadly and under consideration of the costs of end of life care planning. **Initial summary of evidence:** Population: Older people with learning disabilities; an important subgroup are people with Down syndrome Potential impact on future costs: • Unplanned end of life care likely to be associated with increase in costs Potential impact on future outcomes: • Education programmes for frontline staff have shown to support 'ageing in place' for

		people with dementia (McCarthy et al 2009) Existing literature: Lack of quantitative studies Variation in practice: High; people are less likely to access specialist end of life care or hospice (Stein 2008) Would an economic model be useful for decision-making? Yes potentially but lack of data prevents work in this area

3 Planned modelling

This section will specify modelling work prioritised by the GC. It will provide details on how cost effectiveness will be considered for relevant, prioritised areas/decision problems. Proposed modelling work should be listed in chronological order. For each decision model, please state the proposed analytical methods, relevant references and any comments and justifications on, for example, possible diversions from the reference case.

Area F, H [i] (review question 5 [j])	*Outline of proposed analysis*
	Intervention: Health screening (if possible including health action plan and recognising the need for and referral to dementia screening) Population: Older people with learning disabilities (and their carers) Sub groups: Sub-groups include such older people with particular types of learning disabilities such as Downs syndrome and people with comorbid dementia; as far as data allow they will be specifically considered in the modelling and analysis Outcomes: Data on uptake of screening and identification of previously undetected health needs and illnesses will be used to model improved (long-term) health outcomes; we seek to include health-related quality of life and mortality as two important health outcome as well as combined in QALYs. The focus is on outcomes for service users but where this is feasible we will include outcomes for carers where sufficient data is available Costs: The most important costs from a public sector perspective are the costs to the NHS for increased access to health treatments and services. Other economic consequences refer to potential changes in care home admission (if those can be measured). This is in line with the NICE reference case which recommends the inclusion of NHS and Personal Social Services (PSS). Where this is possible we will include costs that incur to the individuals (service users and their carers) for out-of-pocket expenditure and costs of unpaid care. Costs of different health screening strategies will need to be derived based on information about resources inputs from the literature and estimates from GC members. All costs will be presented in inflated to 2015/16 prices. Method: We aim to carry out a cost-consequences analysis reflecting a range of health outcomes. Where appropriate and feasible health outcomes will be presented that can be expressed in QALYs and findings presented in cost per QALY to increase comparability with interventions from the health field (whilst realising that health will only be one of

[i] Key areas relevant for considering opportunity costs and high priority for de novo modelling, as identified in section 3.

[j] Two or more review questions may be addressed by a single analysis if appropriate.

	several outcomes). In areas in which it is indicated in the literature that there is no difference in effect between intervention and comparison group we will carry out cost-minimisation analysis. Time horizon: The time horizon will be determined by the available literature. Sensitivity analysis might be used to explore the changes in the estimates of cost-effectiveness following an extension of the time horizons considered. Sensitivity analyses: Probabilistic sensitivity analyses and bootstrapping will be conducted as appropriate and feasible; in particular we will evaluate the impact of including the costs of unpaid care on cost-effectiveness findings if that is feasible. Data sources: UK and international studies which evaluate changes in uptake of screening and number of health conditions captured; populations statistics; NHS reference costs; information about pathways from the policy literature
Areas A, E (review questions 5,7)	Intervention: *Care planning in relation to support packages and accommodation types* Population: Older people with learning disabilities (and their carers) Sub-groups: Sub-groups include such older people with particular types of learning disabilities such as Downs syndrome and people with comorbid dementia; as far as data allow they will be specifically considered in the modelling and analysis Outcomes: It is possible that only differences in costs will be considered as there might be a lack of evidence of differences in health and wellbeing outcomes (measured on standardised scales) Costs: Costs will be derived for care planning and for different support packages and accommodation types where feasible. Important potential costs that will be measured are those of emergency placements. Such cost estimates might be derived from information about resource inputs based on the literature and GC intelligence. Recommendations for interventions in this area strongly depend on the cost perspective; the perspective taken will be a public sector one initially (including NHS and Personal Social Services costs); the impact of including costs to individuals (i.e. costs of unpaid care and out-of-pocket expenditure) on total costs will be examined; Method: It is likely that only simple threshold analysis in form of one ways sensitivity analysis will be feasible; the application of more sophisticated methods (probabilistic sensitivity analysis will be explored depending on data availability; establishing the costs of accommodation types and support packages in a UK context will be an important and challenging part of the cost analysis; it is likely that GC will have to inform this by assumptions on duration and mix of staff; Time horizon: The time horizon is likely to be short-term as there is no evidence on the long-term effects. Data sources: UK and international studies which report consequences of lack care planning; PSSRU Unit Costs for health and social care

4 References

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Plan signed off by Sarah Richards on 03/08/16.

5 Addenda to economic plan

Please state any changes that have been made to the above agreed plan, and the date. If review questions have changed since the economic plan was signed off, include a new list of all review questions as part of the addenda, with a comment and an explanation where questions were inserted, deleted or altered.

Scope area[k] (clinical question(s) [l])	*Proposed changes*	*Date agreed*
Areas A, E (review questions 5,7)	The GC discussed at several meetings about this economic priority area. At the 6th meeting on 23 November 2016 the GC agreed to not carry out modelling in this area. This decision was based on a number of considerations, in particular gaps in evidence. This referred to evidence on the costs of different accommodation types and support packages and associated outcomes for this population. There was currently no research, which investigated this and existing cost estimates were only available either for the general population of older people or for the general population of people with learning disabilities (see for example PSSRU Unit Costs for Health and Social Care). Such cost estimates were only available as averages and not based on individual level data so that further disaggregation was not possible. The GC thought that costs for older people with learning disabilities were different from costs for the general population of older people as well as from costs for people with learning disabilities who were not yet ageing. For example, some people used specialist services (if those were offered locally), which were staffed by people with knowledge in both learning disabilities as well as in ageing-related problems, whilst others used universal services but were likely to get additional support. Generally, the GC thought that arrangements varied substantially between localities and that there was not much information about the	23 November 2016

[k] This should be the key areas relevant for considering opportunity costs and high priority for de novo modelling, as identified in section 3.

[l] Two or more questions may be addressed by a single analysis if appropriate.

	types of support people received so that it was also not possible to estimate meaningful lower and upper estimates. The GC thought this was an important gap in evidence. Additionally, there was no quantitative research on the relationship between different living and support arrangements and health and wellbeing outcomes. The GC reported that the type of living arrangement strongly influenced the level of stress and worry experienced by the person as well as their family. Generally, helping the person to live in their own home was considered the best option, as it would allow people to continue having their social support network. Social isolation was mentioned as an important outcome that was influenced by different accommodation types, which often meant moving away from the community they grew up in or were living over the past few years. Due the identified lack of individual-level data on the costs and outcomes of different accommodation types and support packages, it was concluded that further work was not feasible.	