

Thurrock Coalition



Response to the Draft Bill on Care and Support and the White Paper

About Thurrock Coalition

Thurrock Coalition is the User-Led Organisation for Thurrock. We are a company that has been set up to ensure that people who live in Thurrock have access to all the information they may require to get the support and care that they need.

Thurrock Coalition is an 'umbrella' company that consists of 4 organisations, all of which follow the Social Model of Disability and aim to improve the lives of disabled and older people living in Thurrock by seeking to remove environmental, attitudinal and physical barriers that exist in society. We connect to over 1500 individuals and organisations with an interest in disability issues. Thus, we have a legitimate and direct interest in the development of new legislation in this area of Adult Social Care.

Summary

We recognise that the draft Care and Support Bill aims to create a single law for adult care and support, replacing more than a dozen different pieces of legislation spanning the past 60 years. These reforms are welcome in order to provide clarity and accessibility in this area of law which is often seen as complex, inequitable and lacking in focus for the timely delivery of quality support that takes into account a person's legitimate expectation of dignity and respect. As and when the Bill becomes law it will have a wide ranging and far reaching impact upon people who use services, both nationally and in Thurrock.

Observations on the Draft Bill

The acknowledgement by Central Government of the Law Commission's recommendations for reform and the need for implementation is also a positive step. We specifically welcome:

- Simplification and amalgamation of existing legislation
- Codification of important principles of good practice and person-centred approaches to care and support planning, focussing upon

personalisation of the whole process, emphasising choice and control and a person's individual well-being

- Drafting regulations that state the precise person-centred methodology of Assessment. Assessments should be needs-led (rather than costs-led) and specialists should be contacted wherever necessary.
- Thurrock Coalition suggests that any regulations dealing with Assessments (of individuals and carers) need to be regularly reviewed and updated where necessary to ensure that the focus upon personalisation is not lost in the interests of efficiency savings.
- Ensuring that all needs are recorded (not just eligible needs in relation to the relevant banding in line with the Fair Access to Care Services (FACS) criteria.
- Local Authorities supporting the wider community and individuals who need extra help and/or assistance in terms of the provision of advice, information, advocacy and signposting (this provides an opportunity for Local Area Co-Ordination (LAC) to help to ensure effective implementation of this principle). There should also be a named individual(s) to be both known to and contactable by individuals concerning advice, information and signposting to services within each Local Authority Area. The recommendation that all services (providing help and care) be codified and categorised in directory form and subsequently given to people who use services will offer re-assurance and increase confidence in the services provided as well as clarity of processes and pathways that the individual may (or may not) wish to undertake. Any advice and information section needs to explicitly state the necessary requirement for the provision of advocacy services to help and support people when a dispute about Local Authority Services arises.
- It is important that any codified outcomes be sufficiently broad but still maintain their effective practical application and can be tailored to the specific individual
- Retention of the legal obligation to offer an assessment of need to anyone who requests it (including carers) as well as the provision for refusal of consent for an assessment to take place in situations where people lack capacity.
- In relation to care plans the recommendation that individuals must always agree with the contents of the care plans and get a copy of it is vital. We are aware of practical examples from Thurrock of people not receiving or indeed approving of the contents of their care plan before a decision is made about service provision at Panel. The individuals are not provided with an early opportunity to disagree with and amend any incorrect information about them.
- Thurrock Coalition suggests that people should get complete copies of all paperwork relating to their commission process, not merely the care plan. All the paperwork is intrinsically inter-related and it is important for a person to have an informed view and expectation of the care and support that they will receive.
- Safeguarding Adults and establishing a Statutory basis for the Board is a positive step

- Provision for an assessment for young people in transition is a positive step. This needs to be linked to the (national) and local Transition strategies to ensure synergy.

We have however collated a number of questions, views, observations and concerns about the Draft Bill for Care and Support. These are as follows:

Under Section 1

The definition of “Well-Being” is indeed comprehensive, taking into account the many tenets that make up an individual’s life and lifestyle. However, the examples of the constituent elements of “well being” (a)-(g) are not easily reflected in how the FACS criteria banding are being supported and interpreted by Local Authorities today. For example Thurrock Council (like many local authorities across the U.K.) only support needs identified as “Substantial” or “Critical” risks to independence. It will have to be (creatively) argued that after exploring the person’s arrangements and talking to carers about why they can’t or won’t help a person to, for example, participate in recreation and/or contribute to society and there is no other way of achieving the outcome, i.e. through the use of taxis etc, then it would be a critical risk to independence if it is not arranged by Adult Social Care at the Council.

Sections 2-6

In relation to the provision of advice and information, more information is needed on how this will be supported, sustainably funded and effective capacity maintained.

Where Local Authorities should co-operate with other local organisations, work to integrate services to promote well-being, and improve quality and outcomes (Sections 4-6) more information is needed on how Local Authorities will resource and support the local organisations to ensure long term viability and maintain capacity.

It is not clear how people will get to know what services or support is available to them

Section 7

The elevation of the early intervention and prevention agenda to a statutory footing is beneficial. It is important to realise that such emphasis will reduce distress, crises and increase independence, well-being whilst being a cost effective investment in the longer term

Section 8

In terms of Care and Support – it is not clear what this entails, again it is important not to be prescriptive or exhaustive but including daily living activity, nutrition and social inclusion “indicators” could be useful, but flexibility should be maintained in interpreting what exactly is meant by “Care and Support” and

should be explicitly linked to “Promoting Individual Well-Being” under Section 1. and not just in the Summary of the Bill.

Section 9-30 detailing the process for assessments for care and support

More details are needed around the Regulations (Sections 9-13) specifically how they will be drafted and by whom and when they will be consulted upon. What the implementation timetable will be for bringing any such secondary legislation into force.

In relation to the mandatory elements of the Act (e.g. Section 9 and 17, 19) as it relates to Local Authorities, clarification is needed as to how the additional duties will be funded as well as allaying any concerns about the likely additional capacity that will be required to ensure the duties and obligations are effectively met.

Information should also appear in the Bill on the options available to individuals who disagree with the Care Plan or the level of service or level of needs identified in the Assessment process. What will be the appeals process and who will be responsible for administering it, and ensuring the independence of any decision-maker or adjudicator on the issue(s) in dispute?

Sections 14-16

- What will the threshold for means testing be?
- Please provide some examples of the types of free services referred to in Section 14(4)
- Please provide details on how Sections 14-16 link to the Mental Health agenda, IMCAS and BIAs

Sections 23-30

- How/who/what/ where/when will this information about the assessment and assessment process be provided?
- Surely the person-centred planning should take place as a large part of the assessment – i.e. from the outset, not after the decision to provide a service.
- The right of individuals and carers to ask for a personal budget is a welcome development (Section 24)

The Bill should have explicit provision for a request for a face-to-face assessment in person rather than leaving the methodology at the discretion of the Local Authorities who often opt for telephone assessments which insufficiently address the holistic nature of needs for care and support. The following questions need to be addressed by the legislative draftsmen and policymakers:

- How exactly will the assessment be carried out (principles of person-centred support planning should be used, Section 23-24).
- Who will carry out the assessment? What will be their precise skills, knowledge, experience, understanding and qualifications?
- Where will the assessment be carried out? Consider environmental issues and the impact upon the individual taking part in the assessment.
- Consideration of awareness, capacity and consent issues also need to take place.
- The individual should be made aware of the timescales involved, and at which points they can expect to receive relevant paperwork, sign it off as accurate and be given adequate time to make corrections and alterations where mistakes have been made, what will happen at panel and by which approximate date the care and support is anticipated to be in place.
- Thurrock Coalition suggests the development of a diagrammatical “journey” template for use on a national basis so that individuals can easily identify where they are now on the “assessment pathway” and when they can expect the “journey” to be complete. Use of a national support planning tool or template will ensure good practice and consistency of approach in person-centred support planning
- Thurrock Coalition suggests that any initial assessment in checklist form could be conducted over the phone with the individual voicing their request for a face-to-face full assessment of needs, care and support, the precise “journey” timescales can then be discussed and communicated accordingly.

Section 31-33

- The provision relating to continuity of care when an adult moves as long as the relevant Local Authority has been informed of the move is welcome and allows for good communication between sending and receiving Local Authorities, but will need to be monitored accordingly to ensure vulnerable people are not left without the required care and support.

Section 34-38

The recognition of the importance of the Safeguarding Adults agenda and establishing a statutory basis for the Adult Safeguarding Board is a positive step. However, it is surprising that physical and psychological abuse is not included in the examples given in Section 34.

Section 39-44

Provision for an assessment for young people in transition is a positive step. This needs to be linked to the (national) and local Transition strategies to ensure synergy, clarity, transparency and consistency of approach.

We suggest that further clarity and/or details are needed on exact timescales within which to start the process of planning of the young person(s) concerned, this needs to be timely and perhaps at least 6 months before the young person turns 18. This will avoid any gaps in the provision of the level(s) of care and support required.

Again any support planning needs to be person-centred and needs driven for both young people in need of Care and Support and Young Carers respectively.

Section 45-46

The sections dealing with enforcement of debts, recovery and transfer are useful and the provisions around deferred payment agreements between parties is likely to be beneficial for vulnerable individuals who may require information, advice and support around managing their financial affairs.

Section 49

The mandatory requirement of Local Authorities to maintain a list of sight impaired adults is not new, but the omission of hearing impaired adults in this section is surprising. In addition it is not clear why the requirement to maintain such lists is mandatory in some instances and not simply optional across all impairment types.

Conclusion

It is evident that many sections of the Draft Bill are important codifications of existing laws and principles and contain progressive and useful elements to improve the well-being and experiences of disabled people, their families and carers. A clear pathway through the assessment processes will be beneficial for all parties involved. The active use and positive involvement of the Third Sector and other Stakeholders can only serve to improve multiagency communication, co-operation and co-production to bring about better outcomes for disabled people, people in transition, carers and vulnerable adults.

Further clarification and precise details around responsibilities, funding, capacity, regulations, oversight and implementation timetables are required before the bill can be greeted as a wholehearted success in the field of Social Care

Thurrock Coalition - October 2012

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Observations on the “Caring for Our Future” White Paper The Vision for Care and Support and Strengthening the Third Sector

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Observations on the “Caring for Our Future” White Paper

The recognition of the need for the whole reform agenda to be a “collaborative endeavour” is positive and provides scope for active and meaningful involvement of Disabled Peoples User-Led Organisations, Third Sector Groups and innovative Local Area Co-ordination projects, increasing the connectivity between local groups and local government. The involvement and support for community based organisations in local authority commissioning plans is vital, provided that the people who use services and the networks to which they belong are not only heard but listened to, so that their views, concerns, observations and aspirations can be acted upon. The investment of £3 million over a period of 4 years that aims to promote the growth of disabled people’s User-Led Organisation is welcome, if under publicised initiative. More should be done to increase awareness of this investment and other such projects in the future.

Opportunities from the reforms including helping businesses to grow goes hand-in-hand with building the capacity of the Third Sector and strengthening good communication and co-production with Local Authorities. The Third Sector is paramount to the development and design of new opportunities for services and technologies as they arise.

Strengthening Support within Communities

Too heavy a reliance upon active and inclusive communities without necessary capacity building, support and the necessary funding will be difficult to reconcile where vulnerable and disabled people are isolated and not involved in their local area.

Furthermore, the threat to disabled people's social inclusion and quality of life is likely to be compounded by the Welfare Reform agenda, including the 20% cuts to the DLA (soon to be PIP) budget coupled with the proposed closure of the ILF and efficiency savings within local government. It is difficult to see how the foreword to the White Paper can state that "care and support should not just be about making people comfortable, but about helping people to fulfil their potential, whatever their circumstances" when the cuts in public spending are in themselves likely to severely limit the realisation of potential and indeed the Right of Disabled People to Independent Living as enshrined in Article 19 of the International Convention on the Rights of Persons with Disabilities 2006

Increasing individual choice and control over Care and Support

There is certainly a need for increased choice and control for people who use services over their own care and support plans. We are aware of cases in which people are not being provided with copies of their support plans for sign off and approval before a decision is made upon the contents at Panel. The development and implementation of time banks, credits and similar approaches will benefit many people as the efficiency savings affect many people who currently use Adult Social Care services by improving choice and control, flexibility and skill-sharing in the system. Peer Support Networks should be encouraged and supported to increase their capacity to offer inclusive help, advice and assistance to one another.

Establishing a Care and Support Library to provide a resource for good practice in early intervention and prevention would not only help to improve standards but also to increase consistency on a national level. The main issue of concern will be the maintenance, management and administration of such a system to ensure it is a "living" library, and one which is updated rigorously and responds to changes in policy and law in a timely fashion. How will this proposal fit in with the suggested "Well- Being Atlas" from April 2013 onwards?

Care, Support and Housing

The establishment of a new care and support housing fund to support the development of specialist housing is interesting, but how this will fit in with existing arrangements such as Home Improvement Agencies, the Disabled Facilities Grants and adherence to Lifetime Homes Standards needs further clarification. The critical role of good quality, safe housing and allowing for people to remain in their own housing that meets their needs cannot be underestimated in terms of maintain good physical and mental health and well-

being. People need to be supported to look at the various housing options effectively in a way that suits them that also enables them to maintain independence and remain active.

Better information and Advice

The White Paper makes reference to “Better national care and support information” and that “from April 2013...the Government will provide a clear, universal and authoritative source of national information about the health, care and support system.” However, it is not clear what the precise format will be, whether it will be piloted. Also, the emphasis upon providing funding to local authorities (of £32.5 million over 2 years) for better online information and support does not appear to take account of the fact that 1 in 4 adults in the U.K have never used the internet and 39% of those people without internet access are over 65.¹

It is also not clear how the proposed “national , easy access directory of care providers” will be administered and maintained.

Assessment, Eligibility and Portability

The proposal for a national minimum threshold for eligibility is beneficial but it is unclear why this is not being implemented until 2015 particularly given the efficiency savings and welfare reforms that are likely to result in more disabled, older and vulnerable people needing some form of Adult Social Care support before a crisis develops.

Carers’ Support

When will the road map setting out action to support carers to remain in the workforce be published? The contribution of carers to the U.K. should not be under estimated².

Improving the quality of care and support

The focus upon improving the quality of care provision through creation of quality profiles, better transparency, consultation, listening, implementing and providing advice and information is useful provided that regulation and monitoring is consequences for failure are enforced.

¹ Statistics from: <http://www.21stcenturychallenges.org/60-seconds/what-is-the-digital-divide/>

² The work of unpaid carers makes a significant contribution to the United Kingdom. [Carers UK](#) has recently estimated that carers save the tax payer an estimated £119bn per year (Carers UK, 2011), equivalent to £2.3 billion per week. Research by Carers UK found that 72% of carers were worse off financially as a result of becoming carers and many struggle to make ends meet (Carers UK, 2008). The reasons cited for this include the additional costs of disability, giving up work to care, the inadequacy of disability benefits and the charges for services. The Princess Royal Trust for Carers (2011) report that carers aged 60-64 experience the most financial difficulty, often juggling work with caring responsibilities for more than one person. Available at: http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=546

A better local care market

Stimulating and encouraging a diverse local market is good, in particular the focus upon quality, outcomes for the individuals concerned and value for money along with recognition of the need to stop commissioning practices that place the provision of care support under tight constraints, potentially violating dignity and fundamental human rights.

A skilled workforce.

This section of the White Paper is to be congratulated. It elaborates upon opportunities for Co-production between Workforce Development teams in Local Authorities, care providers and User-Led Organisations. Thurrock Coalition is one such example where the Third Sector engaged with people who use Council Services to develop Quality Outcomes and Service Standards by which Adult social Care staff will adhere to in terms of their skills, knowledge and experience.

Personalised Care and Support

Any help for people to arrange their own care and support needs to be fully independent from National or Local Government so as not to jeopardise the impartiality of its service provision to its client base. Any support planning must be wholly person centred and brokerage organisations must be impartial in all aspects of the work that they do.

Integration and Joined-Up Care

Clarification is needed as to how these proposals fit in with the Continuing Health Care (CHC) funding agenda. Several people who use services have expressed concerns around flexibility issues and well as issues surrounding consent and the consequences (for their Independent Living Fund (ILF) and their existing Direct Payment provision) in refusing CHC assessments. People feel less in control as soon as health become involved.

Better integration at key transition points

Post discharge support needs to be holistic, timely and personalised if it to be at all effective. Any support plan needs to reflect this and a full assessment should replace the temporary plan as soon as possible in all circumstances.

Beyond 2015

Please clarify when the further details on the precise implementation programme will be made available so as to ensure that consultation, feedback and participation of all interested parties can take place for the benefit of the health and well-being of people who use Adult Social Care Services in England.

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