

Alternative Action Plan – Working with Families and People with Learning Disabilities Actions
Draft actions from the November 2022 CB-NSG

Action: What is needed	How it will be done	Who will do it	When it will be done
<p>A joined-up, whole life approach, with improved transition planning between child and adult services</p>	<p>Early intervention to identify current and likely future needs</p>		
	<p>Transition planning¹</p> <ul style="list-style-type: none"> • Integrated transition planning involving representatives of health, education, social care and housing, and both child and adult services • Local authorities to have records of all children within local area that have been identified as having a learning disability (who will require transition planning), and to co-ordinate other services (health, education, care, housing) to begin transition planning at appropriate time • Transition planning to begin by age 13 at the latest • Targets for transition planning to be clearly stated, and establishment of a mechanism for challenge if these are not met 	<p>Local authorities – maintain list of children within local area who have been identified as having a learning disability, co-ordinate health, education, social care and housing to begin process of transition planning</p> <p>Health, Education, Housing and Social Care bodies, inc. representatives of both child and adult services – take active role in transition planning (may require statutory guidance to ensure this occurs)</p>	
<p>Formal right for families to be involved in co-production/conversations with community services and inpatient services</p> <p><i>Care Act (2014) states that carers (e.g. family carers) should be involved in planning and reviewing care and support plans, but other requirements for family involvement</i></p>	<p>Publication of guidelines for involving families in relevant decisions regarding their relatives, including list of areas/decisions where families should be included, guidelines on involving families in a meaningful way, formal recording of family views/recommendation and oversight/accountability processes for if these are not taken into account, and mechanism for families to challenge if not being involved/if views are not being taken into account</p> <ul style="list-style-type: none"> • Should include guidance on care and support plans, EHCPs, decisions around education, 	<p>DHSC, DfE, NICE, in association with families, people with learning disabilities, and charity and advocacy groups</p>	

¹ see page 8 of Cerebra’s [Transition to Adulthood](#) guide for further information on how this is currently supposed to work in England and Wales

Alternative Action Plan – Working with Families and People with Learning Disabilities Actions
Draft actions from the November 2022 CB-NSG

<p><i>are weak and this does not always take place</i></p>	<p>treatment (including inpatient admissions), care, etc</p> <ul style="list-style-type: none"> • Statutory requirement to involve families in C(E)TRs etc <p>Guidelines should state that they are applicable even when a relative is over 16/18 (current cut off points for much family involvement)</p>		
<p>Formal right for families to be provided with information²</p>	<p><i>See 'Legal Actions' document for information on how information about legal rights to be produced and shared</i></p>		
<p>Formal right (based on HRA?) to see relatives – cannot be removed on basis of (e.g.) challenging behaviour</p>	<p>Introduce/amend legislation and/or introduce statutory guidance</p> <p>Should also include right to see ALL areas of unit/care home that they wish to see – cannot be prevented from seeing particular areas including bedroom</p>		
<p>Peripatetic teams that are specifically trained in PBS and in appropriate responses to challenging behaviour that will go to the individual/family, rather than requiring the individual/family to go to them, in order to provide early, targeted support</p>		<p>Local authorities/ICBs?</p>	
<p>Incentives/funding to develop small-scale, community-based services that are tailored to the support requirements of people within the local area</p>	<p>Undertake assessments of what the support needs of people within the local area are</p> <ul style="list-style-type: none"> • Inc. care, education, health, housing 	<p>Local authorities/ICBs (in collaboration with other relevant bodies) – undertake assessment and distribute funding</p>	

² Further discussions around how this could be done took place at the Legal Strategy Meeting in January 2023 – when this table is uploaded to the CBF website we will include a link to the actions table from the Legal Strategy Meeting in this document, however we are still waiting for sign-off on the Legal Strategy write-up

Alternative Action Plan – Working with Families and People with Learning Disabilities Actions
Draft actions from the November 2022 CB-NSG

	<p>Produce guidance of how to develop small-scale, community-based services</p> <ul style="list-style-type: none"> • Inc. examples of best-practice, and working with existing successful community-based services to develop this guidance <p>Provide a pot of funding which can be used to support the development of these small-scale, community-based services</p> <p>Introduce an oversight/regulatory board to ensure that these services are providing effective and high-quality support, and that the funding to support their development is being allocated effectively</p>	<p>National government/bodies (inc. DHSC etc) – provide funding pot which is distributed to local authorities/ICBs (who in turn distribute to small providers)</p> <p>Relevant government departments, in association with other relevant bodies – publish guidance</p>	
Develop and invest in (local) peer support networks, and support families to share their knowledge and expertise with each other	<p>Provide a pot of funding to develop these networks, including both online and in-person connections and events that can be used to link up family carers</p> <p>Expand the peer support programme which has been piloted in the Black Country, and implement it in other local areas</p>	ICBs/local authorities	
Strengthen the NICE guidelines/make them mandatory		<p>DHSC/government - increase statutory weight of guidance</p> <p>NICE – continue to produce and review guidance, including in association with families and people with learning disabilities</p>	
Training/support for staff and services on how to effectively communicate with families	<i>Other action tables have additional details on what training may be relevant/appropriate and how this can be done</i>		

Alternative Action Plan – Working with Families and People with Learning Disabilities Actions
Draft actions from the November 2022 CB-NSG

Comprehensive record-keeping, including both positive and negative incidents, and evidence of what 'good'/the baseline looks like for the person so that their behaviours etc can be judged against this			
Maintaining consistent staff and ensuring that staff know the person and their needs well	<p>Increase pay of social care workers to increase retainment and reduce reliance on agency staff</p> <ul style="list-style-type: none"> • Provision of support for staff, e.g., mental health support, to prevent burnout <p>Provide pots of funding to do this/increase direct payments which can be used to pay staff</p>	CB-NSG members – identify which, if any, public body has the ability to increase pay of social care workers/provide the funding, and then campaign around this	
Ensure 'reasonable adjustments' are tailored to the individual and their needs	Conduct needs-assessment, sensory assessments etc		
Prevention of blanket policies, particularly re: risk-taking	<p>Produce guidelines setting out that blanket policies are poor practice and that all decisions should be person-centred and least restrictive (e.g., if a person has no history of drugs, there should not be a restriction on what foods etc they can be given on the chance that there may be drugs in them)</p> <p>Perhaps draw on HRA?</p>		
Ensure that all strategies that are supposed to provide therapeutic benefits actually do provide these benefits, and that there is strong evidence underpinning these practices/policies	Conduct assessment of therapeutic benefits of particular strategies, e.g., inpatient units, restraint, medication, PBS etc compared to any negatives, and if there is not a proven (likely) therapeutic benefit, it should not be prescribed	<p>NICE/DHSC/relevant academics and experts</p> <p><i>See 'Evidence-Based Practice Actions' for further details</i></p>	
Opt-in, not opt-out advocacy	<i>See 'Advocacy Actions' document for further details</i>		

Alternative Action Plan – Working with Families and People with Learning Disabilities Actions
Draft actions from the November 2022 CB-NSG

Provision of respite/emergency accommodation to prevent inpatient admission	<i>See 'Housing Actions' document for further details</i>		
Ban on use of restraint and restrictions – these are not therapeutic or beneficial, they are harmful and traumatising	Change/introduce legislation and statutory guidance on what methods can be used that are more appropriate than restraint	DHSC, DfE, NICE, in association with families, people with lived experience and relevant experts (including members of CB-NSG)	
Early planning for discharge and steps taken to (re)prepare an individual to live in the community	<p>Detailed discharge plan drawn up at point of admission and regularly reviewed</p> <ul style="list-style-type: none"> • Includes clear targets, with oversight and action taken if these are not met • (extension of?) section 17 leave to involve experience of community/non-hospital-based activities, with reduced restriction (as would be experienced in the community) 		