

NATIONAL CENTRE FOR INDEPENDENT LIVING

RIGHT TO CONTROL

Response to consultation on the Right to Control from the National Centre for Independent Living

We have sought the views of our member organisations. Given that the consultation period has been over the summer months this has been done by e-mail

NCIL shares the strong in principle Right to Control in its aim to align funding streams and to shift power from the State to the individual. For NCIL the trailblazers could provide an opportunity to embed a human rights approach such as article 8 a right to family life, in meeting the support needs of disabled people. Yet we are disappointed that, once again, the consultation seems to put choice and control and the outcomes that can be achieved for disabled people last in favour of a focus on procedures and barriers to inform how the trailblazer sites will operate.

The consultation asks about the funding streams to be included in the Right to Control trailblazers and which criteria should be pursued (questions 1 – 3), issues on partnership working (4), legal or regulatory barriers (8), information and support needs (9,10), participation of disabled people in the trailblazers and in the running and commissioning of service (13), lines of accountability between public authorities and service providers (14,15), and support for commissioner (16).

Scope of Funding Streams to be Included

We think – if the goal of aligning funding streams to the benefit of disabled people and to reduce of bureaucracy in the system is to be taken seriously – then social care and access to work will certainly have to be included as a minimum but ideally alongside the funding streams

that were included in the individual budget pilot areas.¹ We also think that it would be useful for the trailblazers to work with the personal health budget pilots where possible. Not only will this serve disabled people well in offering people an holistic approach to meeting support services but will give valuable information for the evaluation.

The Right to Control is essential for independent living to be realised and, to this end, benefit obstacles of any kind should be removed. For instance many disabled people can still be unable to access work in a chosen, careful and gradual approach without losing entitlement to crucial benefits that are there to support such an approach. There is consensus that maintaining all the different processes and forms for all the different local and national government funding streams is unbearably bureaucratic and fosters fragmentation. Pooling funds between health, social care and other funders would not only enhance seamless and joined up provision but also help to reduce and share costs in a fair way.

To many people putting these funding streams together will offer a 'lifeline' and will be an effective means to prevention and early intervention which will have a positive effect on costs, especially to the NHS. This needs to be acknowledged.

The Power Shift from the State to the Individual

The processes behind systems that are there to meet disabled people's support needs are set up in a way that largely keeps control in the hands of professionals rather than to the people supposed to benefit. The recently issued update of the guidance for direct payments shows how far we still have to go to achieve a real shift from the State to the individual. For example 'the individual... is accountable to their local council for the way in which money is spent'. In a market society, the necessary shift in culture can only be driven by a reallocation of

¹ In 2008 an extensive evaluation of the IB pilots by IBSEN (Individual Budgets Evaluation Network) was published www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH089505

resources to the individual and a management system that genuinely works in partnership with disabled people. Power over money is a means to achieve an end which is about much more than just economic wellbeing. It's about having disabled people in the driving seat.

The evaluation of the IB pilot sites have demonstrated how being in control of how your support needs are met can really open up life opportunities.² We urge the Government to build on the findings from the IB sites, take charge and set a clear direction to tackle 'legal barriers, conflicting rules and systems'.

Supporting the Right to Control

Access to independent advice and advocacy is essential if disabled people are to be able to genuinely achieve choice and control. The need for independence should be stressed. Too often advocacy services find themselves in the situation of having to be more answerable to their funders rather to the people using the service. A new approach to advocacy services must be forged that recognises their value and funds without interference. There needs to be independent monitoring to ensure that if an advocacy service has funding withdrawn it is because it has not provided an adequate service not because it has dared to criticise a statutory agency.

Who will Carry the Burden for the Delivery of Right to Control?

We would want to be assured that the evaluation of Right to Control will be based on the extent to which outcomes, agreed with disabled people,

² People receiving IBs were found to be more likely to be in control of their daily lives regardless of age or impairment, and IBs appeared to be cost effective in relation to social care outcomes when compared with traditional social care support. The integration of funding streams however, proved to be problematic and the evaluation called for debate on 'appropriate principles underpinning the allocation of resources'.

have been achieved. We would expect the same co-productive approach to be taken to commissioning and monitoring services.

Such co-production and a clear focus on outcomes still seem to be seen as somewhat extravagant by this consultation which errs more towards a 'divide and rule' approach. The consultation appears to seek to play out those 'who want to do new things with their right to control' against those 'who want to carry on using existing service'. (question 5,6) It is suggested as 'a barrier to Right to Control' when 'there are too few to make a service financially viable'. All of a sudden, choice is seen as no longer a matter for individuals, but disabled people are now actually approached as a group who have to make choices that will apply to the majority. The consultation further seeks to pass onto disabled people the pressure of 'affordability' in relation to 'set up, advocacy and running costs'. (7) All of this not only puts unnecessary strain on disabled people but ignores the evaluation findings of the IB pilots about the cost effectiveness of individual budgets.

NCIL is concerned about the emerging discourse of intimidation. There are numerous anxiety provoking suggestions that existing services (and their beneficiaries) could lose out in a provider market driven by individual choice. The reluctance for outcome driven commissioning, innovation, and the necessary decommissioning of services that operate solely on the basis of economy of scale is a fundamental block against the Right to Control.

Conclusion

To sum up. NCIL is concerned that this consultation overstates the problems with a Right to Control rather than building on the successes that have already been achieved. The fear is that the consultation holds those to account who should actually benefit from the Right to Control. The consultation invites complaints and reasons for not changing rather than embracing everything that has been learnt about the benefits of self directed support so far, and building on those gains by setting out a clear direction for the future. This approach could result in a negative

assessment of the Right to Control and squash further progress. This cannot be allowed to happen. The trailblazers must embrace the value of Right to Control and not be bogged down by problems that those not committed to choice and control choose to put in the way of progress.

National Centre for Independent Living

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