"NOT A BLIND BIT OF NOTICE"

COMMENT

By

THE NATIONAL FEDERATION OF THE BLIND

Of

THE UNITED KINGDOM

On

THE WHITE PAPER

On

ADULT SOCIAL CARE

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1 INTRODUCTION

1.1 In September 2020 The National Federation of the Blind (NFBUK) produced a campaign guide entitle 'Support for Sight Loss' (SFSL), in which it drew attention to the long standing lack of a national framework of rehabilitation for people diagnosed with serious sight loss. Such a service was envisaged, over one hundred years ago,  in The Blind Persons Act of 1920, but has never in fact been made available universally at the point of need. Instead we have a 'post code lottery, in which the quality of rehabilitation varies according to where you live.

1.2 This state of affairs is the more deplorable because, for more than twenty years,  professionally qualified rehabilitation workers have been trained to understand serious sight loss, thereby communicating the skills which people who encounter it need in order to live as independently as possible. 'Living independently' in this context, can mean caring largely for themselves in their own homes, navigating confidently inside, outside and beyond their dwellings, participating actively in civil society and even in the labour market.

1.3 As NFBUK pointed out in SFSL, research by The Royal National Institute of Blind People (RNIB)  has recently demonstrated that, despite the legal obligation laid on local authorities in England to deliver vision rehabilitation,  a substantial proportion of them fail to do so, or deliver it on a basis which falls far short of required standards.

1.4 IN 2020,], Lord Colin Low, an independent Peer in the House of Lords and a distinguished past President of NFBUK referred SSL to the then Minister for Social Care, Helen Whately M.P., this resulted in the Minister's inviting Lords Low and Blunkett, together with the President of NFBUK, Mr. Andrew Hodgson, and the main author of SFSL, Professor Fred Reid, to join her in a virtual meeting to discuss SFSL. The Minister said she had read the campaign guide and would arrange for representatives of NFBUK to discuss it in detail with officials of The Department for Health and Social Care (DHSC). This meeting took place on 6 July 2021. Lord Low participated, together with  Prof. Reid and Mary Naylor MDE, two members of NFBUK with deep knowledge of vision rehabilitation services. Thereafter Reid and Naylor participated in two virtual consultations on 8 and 14 October 2021. with civil servants engaged on preparation of a White Paper on the integration of services, following upon passage of the Health and Social Care bill. That White Paper is still awaited. Meanwhile, the White Paper on Adult Social Care (WPASC) has been published. NFBUK was not asked to participate in consultations on WPASC.

1.5 This note concludes with observations on the consultation process outlined above (see section 5 below). First, however, it must offer critical comment on WPASC from the standpoint of SFSL.

2 CRITICAL COMMENT ON WPASC

2.1 WPASC acknowledges among many other shortcomings, the post code lottery or 'stark geographic variation' (Par. 3.6) in the provision of social care for adults living in their own homes (as opposed to long-term residential care). It goes on to present the Government's '10-year vision' for the reform of the service 'across the whole of England' The vision is for the ultimate delivery of person centred care to everyone who needs it, no matter 'where they live, their age, race, culture, religious beliefs, sex, sexual orientation, gender identity, disability, housing status or their personal circumstances' (par. 2.1).

2.2 No one, least of all NFBUK, would quarrel with these warm words. Nor do we in any way deny that the specific proposals outlined in WPASC for a programme of specialised house building, the roll out of innovative digital care technologies, and the improvement of care delivery would make a difference in the lives of people who need care in their own homes.

2.3 Our problem with WPASC arises from two other features of its content:  first, its omission of any specific reference to blindness or serious sight loss; second, and even more important, its focus on care in the home, almost entirely to the exclusion of rehabilitation or reablement in the fullest sense outlined in 2.1 above. These two features, taken together,  constitute, from the standpoint of NFBUK, a fatal flaw in the vision of WPASC.

3 OMMISSION OF BLINDNESS

3.1 The omission of blindness or serious sight loss from WPASC can be illustrated by reference to the 'stories' concerning four individuals, referred to by fictitious names, who are shown to have benefitted from best practice in adult social care.

3.2 Not one of these stories concerns anyone coping with serious sight loss, far less total blindness.

3.3 'Charlotte's story' refers to a 57-year old survivor of stroke and details how she copes with her mobility and communication challenges by the use of innovative assistive technology (par. 2.10).

3.4 'Will and Jakob's story' refers to the care which 70 year old Will receives (after  treatment in hospital for a hip fracture). His care is provided jointly by his husband, Jakob, supported  by care professionals, including a social worker, physiotherapist and occupational therapist. This helps Will to deal with depression and Jakob to cope with his caring responsibilities (par. 2.11).

3.5 'Joni's story' highlights a 27-year old woman challenged by a combination of intellectual difficulties, epilepsy and dependence on sign language. '24/7 support' by day and night from staff in her own home gives her greater choice in how she lives her life there, as well as access to the community and activities (par. 4.5).

3.6 Finally, 'Matthew and Niki's story' shows how the latter is helped to care for her 50-year old husband, who lives with myotonic dystrophy. Innovative technology enables her and Matthew to stay in communication, control services such as lighting in his home and remember to take medication. Thanks to 'tech', Niki can carry on in the employment she loves while caring for Matthew's other needs )par. 4.41).

3.7 The failure of WPASC to include any stories of people facing the challenges of blindness or serious sight loss fundamentally limits its value as a vision of best practice across the field. A full review of care in the home would have included stories about people with blindness or serious sight loss, 45% of whom have been shown to share the impairments mentioned above. Such a comprehensive treatment would have shown in precise detail how best practice care and support requires input from a worker specialised in impairment specific rehabilitation. Instead, WPASC gives the impression that all rehabilitation needs can be met by input from occupational therapy, physiotherapy and general social work. It is well known that the training of physiotherapists, occupational therapists and general social workers lacks the content required to enable people to recover from the mental trauma of sight loss and to acquire proficiency in the use of assistive technologies. The technologies here in question are impairment specific and by no means the same as those which can be of benefit to people with vision, however serious their other cognitive or physical challenges.

4 THE FATAL FLAW IN WPASC

4.1 This omission of any reference to impairment specific rehabilitation, taken together with its exclusive focus on care in the home is the fatal flaw in WPASC. This claim may be illustrated by another 'story', which comes from the life and career of a distinguished member of NFBUK, sadly recently deceased. Sylvia ()not her given name) was totally blind, extremely hard of hearing and her mobility severely limited by skeletal deformities acquired before birth. After leaving a special school at age eighteen, she lived at home, cared for by her parents. Approaching age thirty, she grew aware of this restrictive dependency and aspired to a measure of independence. To achieve the level of independence she attained, she received training from a vision rehabilitation worker, who trained her to use impairment specific technologies. Unable to hear synthesised speech, she used a refreshable braille display connected to her computer to access information online.  Thus equipped, she was able to read philosophy and law at university and went on to employment by a local authority as an advocate on disability rights. For this she needed training in further impairment specific skills,  notably the use of the long cane as a mobility aid.

4.2 Sylvia's story serves to make the point about the fatal flaw in WPASC. This consists in using a restricted model of 'care'. As we pointed out in SFSL, this is the 'welfare model, inherited from the distant past, but most directly from the National Health Service established in 1947. The welfare model (referred to in WPASC as 'wellbeing' [par. 1.1) abstracts the 'care' element from the hospital service and projects it forward into the life of the patient at home.

4.3 [This is a restrictive view of care services in at least two important respects. First:  for some, perhaps many disabilities, and certainly for sight loss, it fosters dependency and limits the horizon of independence towards which rehabilitation should strive. Second (and closely related to the first):  It envisages  the user of adult care services as a beneficiary rather than a citizen with rights. The 'legal rights' conferred under the Care Act 2014 (regarded in WPASC as the 'foundation' of reform' par. 2.1), are not rights to independent participation in the community. They are, at best, rights to apply to designated authorities for assessment and provision of care, subject to resources of funding and trained personnel. This falls far short of the 'rights' model of 'care and support', inscribed in the Convention on the Rights of Persons with Disabilities (see SFSL , par. 4.1.2-4.2.8).

4.4 Under the 'rights' model, rehabilitation would not be restricted to care in the home, since the rights to independence and full participation in the community clearly include mobility beyond the home and even activity in the labour market. Given the appropriate training and support, We believe that many people with disabilities, and certainly people with sight loss, are capable of pursuing these activities well into later life. This is the ambition which WPASC fails to register.

5 ISSUES OF PROCESS IN THE PRODUCTION OF WDPASC.

5.1 Returning to the issue of process:  as stated above (1.4), NFBUK was not asked to participate directly in the consultations leading to the production of WPASC. Reference to its Annex A, moreover, will reveal that reference to organisations concerned specifically with blindness or serious sight loss was extremely limited. We can find in this annex no reference to RNIB, Blind Veterans UK or to Visionary. This has clearly led to the omissions and flawed conceptualisation to which we have been drawing attention here. In the colloquial parlance of our title here, WPASC reads as though its authors had taken not a blind bit of notice of the concerns raised in SFSL.

5.2 As also stated above, NFBUK was invited to participate in consultations regarding the White Paper on implementation of The Health and Social Care Bill now progressing through Parliament. Reid and Naylor, who represented NFBUK directly in these consultations, felt reassured that the view they presented, derived from SFSL, was carefully noted by officials present and would be considered during further work of preparation. Later, we were also assured that the views which we presented for the White Paper on The Health and Social Care Bill would be passed to officials in charge of WPASC.

5.3 It now seems painfully clear that none of this has happened in the order we anticipated. Preparation of the two White Papers as described means that the important case presented by NFBUK was never considered by officials preparing WPASC. Perhaps such confusion was inevitable, given the extremely short deadline for production of the White Paper on The Health and Social Care Bill.

5.4 In view of the foregoing, we must end this note by repeating that the omission of detailed consideration of vision rehabilitation fatally weakens WPASC as a comprehensive review of the shortcomings in current provision for care and rehabilitation.. Sadly, that work remains to be done and it is to be hoped that the case presented in SFSL will be given due consideration in the promised White Paper on implementation of The Health and Social Care Bill.

Prof. F. Reid,

10 December 2021