Support for Sight Loss

At our 2019 AGM, Delegates adopted a demand for radically improved rehabilitation and habilitation throughout the UK for people with sight loss. Masterminded by our past President, Professor Fred Reid, Coventry Branch gained unanimous support for their proposal that NFBUK campaign to make this a key demand for government in the UK to accept and enact.

Our aim is to make the lack of adequate rehabilitation and habilitation an important national welfare issue for Government to respond to. This circular presents a plan for us all to campaign together from local council ward level right up to Downing Street. We invite Branches to join us on a five-steps campaign to put this issue on the national agenda:-

1. Find out what facilities are offered locally to support people with “sight loss” and how many people are currently in post to deliver them;
2. Compare our findings with other organisations that might share our concerns to see how we might work together;
3. Raise our concerns with local councillors, council officers, influential people and the public to explain why we need better rehabilitation services;
4. Invite the people we seek to influence to our meetings at every step and hold public meetings to reach out to all who might wish to join us and support our cause;
5. Find out what is the situation in adjoining local authorities and share our knowledge throughout NFBUK to put together an approach to national Government to establish the right for every vision impaired person to receive the services and care and support they need.

'We are aiming to present our demand to national government around the time when it has promised to publish a consultative document of adult social care, i.e. about April or May, 2021.

We elaborate on what is needed at every step later in this circular but, first, let’s remember how the campaign was born. Our campaign guide, entitled, 'SUPPORT FOR SIGHT LOSS: A GUIDE TO ACTION For A NATIONAL REHABILITATION FRAMEWORK' is now available on request. It presents the historical background to the growth of vision rehabilitation services in UK (see Appendix 1). It defines the value of such services at the present day as follows]:

With rehabilitation support, someone with serious sight loss and even blindness can be taught 'mobility', that is to go about safely, both in and out of doors. Indoors, they can be taught to cope with stairs and other obstacles in the home and, out of doors, to go at least as far as their garden gate. Travel in the public environment can be greatly facilitated by teaching someone to use a long cane or a guide dog. Again, no one with serious sight loss need be totally dependent on family or friends for everyday care and support. A rehabilitation worker can teach them to safely make a hot drink, prepare meals and otherwise care for themselves and their homes.

A professionally qualified worker can do much to mitigate the emotional impact of sight loss. It is of enormous help to anyone in that situation to know that there is someone who is on their side and who knows what can be done to make life much easier. This includes provision of information about other types of support: access to education for the young; access to employment for adults; advice and help in applying for welfare benefits such as personal independence payments.

 With all this support and more in place, the sight loss journey, though never a walk in the park, can be a stimulating voyage of exploration, introducing people to new friends, new experiences and new accomplishments.

That is why NFB is calling for a national rehabilitation framework, to guarantee vision rehabilitation to everyone wherever they live in the United Kingdom. Incredibly, such a universal rehabilitation service has never been available, although Britain has had welfare services for the 'blind' since 1920 and a welfare state since 1948. The shocking truth is that access to rehabilitation support has always been a post code lottery.

Central government funding for all local authority services fell by an estimated 49.1 percent in real terms from 2010-11 to 2017-18.

NFB should, then, campaign for early introduction of the long promised Green Paper and make the following recommendations.

(For the list of recommendations please see Appendix 2.)

Way Forward for Campaigning

The Federation instructs all branches to investigate their local authorities' provision of short-term care along the lines of the Coventry report. Branches should be prepared to use freedom of information requests if their council prove uncommunicative.

With an eye to the duties laid down by the Care Act 2014, branches should seek to establish the number of blind/partially sighted people registered with their authority. They should then ask directly:

* How many qualified rehabilitation workers for visually impaired people are employed by the authority to assess and provide for a vision rehabilitation plan within the first 12 weeks of referral.
* how the social care department ensures that people with sight loss above the level required for registration are monitored for reassessment as their sight deteriorates.

We are attaching as Appendix 3 to this circular the Executive Summary written by Fred Reid, on which the strategy for this campaign has been based. You can also request a copy of the complete campaign document in your preferred format.

Appendix 1: Background

* The campaign started in early 2019, when Coventry Branch learnt informally that the number of Rehabilitation Officers for the Visually Impaired working for Coventry City Council had been reduced from 10 to 4.
* They followed this up with a Freedom of Information Request and conversations with other local sight loss organisations
* A report was produced and circulated to local sight loss organisations, the City Council, NFB UK via Fed News and, latterly, the press.
* The Council did not respond to the FOI Request until the report reached the press in March, and even so the response was felt to be inadequate.
* The Branch approached the Council for a face-to-face meeting both pre and post local election and received no response. Members of Parliament were approached and all responded positively, with one offering a meeting to discuss things further.
* The Branch recognises that the Coventry problem exists elsewhere and is likely caused by reductions in funding by national government. There is only so much that can be done locally and it will take national involvement from the Federation to increase government funding. Therefore, the Branch seeks national support.

Appendix 2: RECOMMENDATIONS

1 The legislative enactment of a right to independence and participation in the community'

2 'A universal offer of rehabilitation for all newly blind and partially sighted people.

3 'Rehabilitation to come before a full community care assessment and be offered regardless of an individual's eligibility for long-term care.

4 'Rehabilitation to be available for as long as it is needed.

5 'Social care eligibility criteria that properly recognise the unique barriers to independent living that people living with sight loss face.'

6. 'Any agreed vision rehabilitation support must start within twelve weeks of the person's initial contact with the local authority.'

7 Sufficient funding to support the provision of rehabilitation, calculated by reference to the population of each local authority.

8 A fully structured system for collection of relevant information to enable monitoring implementation of the Convention on the UN Rights of Persons with Disabilities.

9 Effective remedies for breach of CPRD requirements, either for individuals or groups.

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10 Recognition of central government's accountability for UK compliance with the CRPD.

Appendix 3

SUPPORT FOR SIGHT LOSS

A GUIDE TO ACTION

for

A NATIONAL REHABILITATION FRAMEWORK

By

Fred Reid

# SUMMARY

Paras. 1.1-3

People with serious sight loss are not a vanishingly small proportion of the British population. The number of those registered by local authorities as blind or partially-sighted may be misleading in this regard. Research by The Royal National Institute of Blind People (RNIB), suggests that, mainly due to the ageing of the UK population, the number of people with significant sight loss could rise to 2.7 million by 2030 and to 4 million by 2050.

paras 1.4-10

Significant sight loss may occur at any age between birth and end of life. It requires the support of professional workers qualified in vision rehabilitation if we are to achieve the highest possible level of personal independence and a full and satisfying life in the community.

In the light of the facts disclosed, it is recommended that NFB should call for a national rehabilitation framework, inscribed in UK law as a human right, to guarantee vision rehabilitation to everyone wherever they live in the United Kingdom. Incredible as it may seem, such a universal rehabilitation service has never been available, although Britain has had welfare services for ‘the blind' since 1920 and a welfare state since 1948. The shocking truth is, as demonstrated in Part Two of this report, that access to rehabilitation support has always been a postcode lottery.

Paras 2.1.1-5

The Blind Persons Act of 1920 was the first attempt in Britain to create a statutory system of welfare for people with serious sight loss. It indicated the possibility of a national framework of rehabilitation, universally available and free of charge at the point of need.

Unfortunately, it did not succeed in creating this and the aim is still to be fully realised.

Nevertheless, the Act had enduring strengths, namely:

(i) a loose definition of 'blind', which allows today for the inclusion of people with significant sight loss.

(ii) by writing the language of 'welfare' into legislation and making it the responsibility of every local authority, the Act signalled the intention that the new statutory service should be universal.

(iii) the Act pointed forward to rehabilitation, by providing for employment in sheltered workshops, education in residential schools for the blind, care of the elderly blind in residential homes, and the promotion of home visiting services, delivered by professionally qualified 'home teachers of the blind'

Another enduring consequence of the Act was that local authorities found it necessary to maintain a 'register of blind persons' resident in there area. Registration revealed that earlier estimates of the numbers of 'the blind' were serious under-estimates. As registration proceeded, it revealed a very large pool of blind people living in isolation, excluded from employment and any form of income support other than the meagre doles of charity.

Despite its enduring significance, however, the Blind Persons Act had weaknesses as well as strengths. The chief weakness was its permissiveness, which allowed local authorities to devolve responsibility for the delivery of blind welfare services to local charities. The scale of the problem revealed by registration ensured that these could not all cope with the problem of funding even the limited services that could be offered at the time.

Permissiveness and pressure of increasing numbers ensured that blind welfare developed as a postcode lottery, since well-endowed charities could fund blind welfare more generously than others less well-endowed. The tripartite system of funding that developed after 1920 – local taxation, supplemented by grants from central government and subscriptions from charitable donors – was not designed to counteract this tendency.

Paras 2.1.6-8

Before and after the passing of the Blind Persons Act, the National League of the Blind (a trade union which organised workers in sheltered workshops) had argued, with the support of the wider Labour movement, that home teaching services should be the direct responsibility of local authorities and should not be devolved to charities. The League believed that municipal services, funded by local taxation and supplemented by central government, would ensure a common standard of blind welfare throughout the United Kingdom.

This approach was rejected in 1920 as too 'socialistic' but, by the end of the Second World War in 1945, it was gathering support as public opinion turned increasingly towards 'collectivism', which inspired the creation of the welfare state in the years 1943-48. From this developed the four statutory social services: income guaranteed by national insurance; a national health service free at the point of use; a national system of free primary and secondary education; and housing provided by local authorities for affordable rent.

Paras 2.1.9-11

These services were widely thought of as 'universal', but this principle proved elusive in practice, not least in the field of health and welfare, delivered locally. These had grown up over the previous half century as a patchwork of provision delivered by an immense array of different bodies, which included those responsible for 'blind welfare'.

In 1948, there was pressure to unify this patchwork of provision into a ‘fifth social service', to be delivered by one local authority department. The National Assistance Act of 1948 stopped short of such unification, while providing for increased funding and stronger direction by central government.

Increased public funding produced pressure from within blind welfare to transfer responsibility for the service from charities to Local Authorities. Large cities began to lead the way in assuming direct responsibility for blind welfare. Even so, direct provision increased slowly and the postcode lottery persisted.

Para 2.2.2-5

During the two decades after 1948, three policy ideas emerged which supported the unification of health and welfare services. These were:

(i) criticism of the patchwork of health and welfare provision as financially wasteful and administratively inefficient;

(ii) that the welfare state should promote 'rehabilitation' (a term then coming into general use).

(iii) support for the idea that, in an increasingly complex society, the social services should be under the direction of professionally trained social workers.

These issues were taken up in the 1959 'Younghusband Report'. It drew attention to the new emphasis on rehabilitation and was critical of home teaching practice as narrow and atheoretical.

Its main recommendation was that government should fund the training of a greatly increased number of 'general' social workers, who would gradually take over delivery of social services to a wide variety of people in need.

The Report made no recommendation as to the organisation of social services and the new recruits to social work were therefore distributed through the existing patchwork of services. During the late 1950s and early 1960s, however, support grew for the idea of 'care in the community': the delivery of support to people in or close to their own homes.

Paras 2.2.6-7

This issue was taken up by the Seebohm Committee, whose Report (1968) recommended the establishment of a single local authority department, providing at first a family service, which would then develop into a service for the 'wellbeing of the whole community'. This would require research into other needs, such as those of disabled people.

Paras 2.2.7-10

The Seebohm Report disappointed critics on the left and right of British politics. On the left, for example, Prof. Peter Townsend criticised it as a missed opportunity that failed to identify neglected needs in the field of the fifth social service.

NFB responded to Seebohm along similar lines. As an organisation run exclusively by its blind and partially-sighted members, it could reasonably claim to understand their unmet needs. It produced a twelve-point plan, quickly dubbed a 'blind person's charter', the plan called on social services departments to introduce new services specific to sight loss and made many creative suggestions for such service, to be delivered by social workers (both generic and specialist) and by volunteers.

Paras 2.2.8-11

The NFB charter reflected the optimism of the late 1960s that a national framework of rehabilitation for people with sight loss would soon be realised. There were some grounds for this optimism in the trend of public policy. The Local Authority Social Services Act of 1970 set up Social Services Departments (SSDs) broadly on lines recommended by Seebohm. Between 1970 and 1975, Conservative and Labour governments directed significant public funds to their development, declaring their support for care in the community, which should replace long-term institutional care. To this end, central government encouraged SSDs to draw up ten-year development plans and envisaged an annual rate of funding increase for such services of up to ten percent.

Yet, when NFB presented its recommendations to the Conservative government in 1974, they were completely ignored. The general explanation for this is to be sought in the challenge to collectivism in the fifth social service, then emerging among commentators on the right of British politics and henceforth amplified by the economic decline of Britain, which began in the later 1970s and continues today.

Paras 2.1-3

This decline was met, from 1976, by calls for reduction of taxation and cuts to public expenditure. This policy began in 1977, under the Labour government of James Callaghan, but retrenchment was carried much further under the Conservative governments of Margaret Thatcher and John Major between 1980 and 1997.

Thatcher was elected in 1979 with a policy to revive the British economy by cutting taxation, shrinking the state and restoring 'Victorian values'. Faced, in 1987, with expenditure on the personal social services that continued to rise in real terms between 1980 and 1997, she decided on a policy of severe retrenchment.

Paras 2.3.4-11

The pressing issues were now the steeply rising cost of residential care for elderly people (whose numbers were growing as a proportion of the population), and the slow development of care in the community which Seebohm had suggested would reduce the cost of residential care.

These issues were taken up in a report which the government commissioned from Sir Roy Griffiths, Community Care: Agenda for Action (1988). The solution, Griffiths argued, lay, not in more funding, but in better management of the available resources.

He criticised as wasteful and inefficient the continuing division of responsibility for social care between the NHS and local authorities and the patchwork provision that still characterised the personal social services.

The solution he recommended was an end to the funding of residential care for the elderly out of NHS funds. Sole responsibility should be transferred to SSDs, which should be given the power to assess care needs, design appropriate provision and oversee their implementation.

At the same time, they should cease to be the main providers of social services and henceforth act as 'brokers' between a variety of providers: NHS, voluntary organisations, hitherto unpaid carers (usually relatives), and commercial organisations.

This reflected opinion, growing in the Conservative party since the 1960s, that 'collectivism' had worked to the detriment of social welfare. It was time to end the drift towards collectivism and restore the 'mixed economy of welfare' that had flourished (so the argument went) in Victorian times.

Significantly, these critics ignored Griffiths' advice that local authorities could not be left to fund the whole of long-term residential care. He recommended a contribution by central government of around fifty per cent. This acknowledgment that market forces must be accompanied by central government planning has been lost in much recent discussion of funding for long term care.

Paras 2.3.12-

The Conservative government enacted Griffith's other recommendations in the NHS and Community Care Act of 1990, but the results projected by Griffiths were not realised.

Over the next three decades, Conservative and Labour governments conducted a series of policy reassessments. These continued to modify the principle of collectivism, but did not end the postcode lottery which had characterised the personal social services, including rehabilitation services for people with sight loss, since 1920.

The governments of John Major continued to pursue the Griffiths philosophy, introducing, for example, Direct Payments in 1996.

The Labour government elected in 1997 under Tony Blair tried to find a compromise, a 'third way', between the market philosophy of Griffiths and collectivism. This aimed at 'modernising' the social services. The term seemed to promise universal rehabilitation services and an end to the postcode lottery. In practice, the promise again failed to be realised.

The principles of the 'third way' were criticised by a King's Fund response in 2006, which drew attention to the continuing lack of proposals to bring the NHS and local authority care into alignment, a separation which had bedevilled all attempts to create a truly universal system of health and social care since 1948.

Paras 2.3.16-17

Further legislative proposals by Labour were thwarted by the financial crash of 2008 and Labour's loss of power in the general election that followed in 2010. Meanwhile, a report of the UK Law Commission on the state of the law relating to care support identified 34 relevant Acts of Parliament which it regarded as incompatible with the human rights of disabled people.

In the wake of this report, the Conservative-Liberal Coalition elected in 2010 revisited the question in a White Paper of 2012. The foreword signed by the Secretary of State for Health, Andrew Lansley, rehearsed the shortcomings of the personal social services, highlighting especially the 'inconsistency' of provision, thus confirming the existence of a postcode lottery.

Paras 2.3.18-21

The Care Act of 2014 was presented as a comprehensive solution to this problem.

It is instructive at this point to consider the RNIB Report, ‘Facing Blindness Alone’ (2013), which drew the postcode lottery to the attention of government, as it prepared to introduce the new care legislation to Parliament. It demonstrated that some local authorities failed completely to offer rehabilitation to people with sight loss, while others delivered rehabilitation services under regulations that discriminated against people with sight loss. As a result, the number of blind and partially-sighted people in receipt of rehabilitation support had declined, in recent years, by 48%.

The report suggested that the Care Act of 2014 would provide 'a unique opportunity to ensure that blind and partially-sighted people can in the future access the rehabilitation and ongoing social care that they so obviously need'. It recommended that the Act should provide universal rehabilitation for all newly blind and partially-sighted people, based on a full community care assessment and designed to overcome 'the unique barriers to independent living' that they face.

Paras 2.3.22-25

On the face of it, the Care act 2014 appeared to respond to most of these recommendations by laying new duties on local authorities to broker short- and long-term care and support for people in their own homes, following assessment of needs and preparation of a 'care and support plan'.

Paras 3.1-12

Evidence presented after the passing of the act, however, demonstrated that its provisions were seriously undermined by austerity cuts to public expenditure, introduced as a means of checking the growth of government debt.

In 2018, The National Audit Office (NAO) reported that between 2010-11 and 2017-18, central government funding of local authority services had fallen by an estimated 49.1% in real terms. Local authorities had therefore been forced to cut short-term care services such as rehabilitation, while struggling to meet the ever rising cost of long term residential care.

An RNIB report, 'See, Plan and Provide', published in 2016, showed that 'nearly half' of all local authorities had responded by ignoring the duties laid upon them by the Care Act. In addition, ‘66 per cent of local authorities did not offer an initial specialist assessment to people diagnosed with sight loss’.

RNIB repeated its earlier recommendation that: 'Everyone with a visual impairment must receive a specialist face to face assessment, leading to a plan identifying the outcome of the assessment’.

Other sources confirm the postcode lottery revealed by 'See, Plan and Provide'. Simon Labbett, Chair of the Rehabilitation Workers Professional Network (RWPN), told NFB: 'I am aware of some areas of the country with no [rehabilitation] workers’.

A 2018 report produced by Coventry Branch of NFB drew attention to local information that, under austerity cuts, the number of vision rehabilitation staff of the local authority had been cut from 10 in 2010 to 4 in 2019.

Para 3.13

In addition to the damaging impact of austerity, entitlements to access care have been weakened and rolled back by the Coronavirus Act 2020. Schedule 12 of this Act sets out a range of obligations under the Care Act and associated regulations with which local authorities no longer need to comply. These include the need to assess an adult’s need for care. These ‘easements’ are due to remain in force until March 2022, but there is the potential for them to terminated before that time or extended further at six-monthly intervals. The extent to which local authorities have taken advantage of these ‘easements’ of their obligations is not entirely clear, but Sloan indicates that at one point before July 2020 7 or 8 local authorities had given formal notification that they would be relying on them to reduce their care provision.

The conclusion, then, is inescapable: with nearly half of all local authorities in England wholly falling down on duties towards registered blind and partially-sighted people under The Care Act 2014, it is time to end the postcode lottery. How is this to be done?

Paras 4.1.1-4

'Those who cannot remember the past are condemned to repeat it.'

Parts Two and Three of this report have shown that, over the last hundred years, the United Kingdom has repeatedly attempted to legislate for universal rehabilitation services for people with significant sight loss, only to fall back into some kind of postcode lottery.

The explanation of this cycle of repetition was suggested convincingly in a journal article by Tabitha Collingbourne, in 2014. She argued that The Care Act 2014 was 'a missed opportunity because it did not securely embed the right, inscribed in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD), to live independently and be included in the community’. Historically, British governments had persistently construed 'independent living and care in the community' by reference to a 'welfare' rather than a 'rights' model. The Care Act 2014 was but the latest example of this persistence.

Moreover, the Act failed to provide adequate redress mechanisms. Collingbourne described such as there were as 'monumentally opaque' and 'inadequate’ when judged against international human rights standards.

Paras 4.2.1-3

Collingbourne's analysis is based on the CRPD. This Convention is a human rights treaty which makes clear how existing human rights should be understood and implemented in the disability context.

The UK government became a party to this treaty in 2009 and thus committed itself to implementing all the rights set out in it. The UK's progress has been reviewed by the UN Committee on the Rights of Persons with Disabilities (UN CRPD Committee), whose 2016 Report took account of representation by organisations of people with disabilities.

The Committee found that austerity measures had indeed resulted in breaches of disabled people’s rights under a number of articles, including Article 19 of the CRPD. Article 19 is the right to live independently and be included in the community (which is the focus of Collingbourne’s article).

The government published a response to this enquiry which, instead of setting out plans for tackling the problems, rejected the Committee’s conclusions and insisted that there had been no breach of human rights. A year later, the UN CRPD Committee examined the UK’s progress in implementing the rights set out in the CRPD and again expressed concerns about the UK’s implementation of Article 19, the right to live independently and be included in the community.

Paras 4.2.5-8

These concerns and recommendations of the CRPD Committee on the UK’s implementation of Article 19 provide purchase for campaigns by the NFB for a national rehabilitation framework.

Three other Articles of the CRPD – 26, 20 and 4 – should also be taken into account and used in any such campaign.

The title of Article 26 is ‘habilitation and rehabilitation’. Broadly it sets out rights to access rehabilitation services which are designed to maximise the independence of a disabled person and tailored to their particular needs and circumstances.

Article 20, on ‘personal mobility’ is concerned broadly with ensuring that disabled individuals have access to the equipment, assistance, skills and training (including long canes and guide dogs) they need in order to get around independently.

Finally, Article 4 of the CRPD on ‘general obligations’ includes a number of commitments relevant to rehabilitation, including the training of professionals and staff working with persons with disabilities in habilitation and rehabilitation programmes.

Paras 4.3.1-4

The broad conclusions of this Campaign Guide are as follows:-

NFB campaign for a national rehabilitation framework must be informed both by the lessons of history and by the current disability human rights context as reflected in the CRPD and the ongoing work of the CRPD Committee.

In devising care and support plans, SSDs should be aware that rehabilitation services will often need to be combined with appropriate support provided by sighted people. Notwithstanding this recommendation, it should be fully understood that the provision of such support without rehabilitation would produce dependency rather than independence. In short, the interlocking provision of rehabilitation, support and care forms the ground upon which independence and participation will be realised.

In 2015, government undertook to produce a Green Paper setting out its proposals for the funding of adult social care. It is still awaited, though the present government included the undertaking in its election manifesto of 2019. At the time of writing this Campaign Guide, further delay has been announced on account of the coronavirus pandemic. Further delay is deeply frustrating. Whatever solution is finally proposed, however, for the funding of residential care, the Green Paper should provide an opportunity to revisit the question of the relationship between short- and long-term care. Universal short-term care (including rehabilitation)will reduce the cost of residential care.

NFB should, then, call for production of the Green Paper and, in doing so, require that the following recommendations be included:

RECOMMENDATIONS

1 The legislative enactment of a right to independence and participation.

2 A universal offer of rehabilitation for all newly blind and partially-sighted people.

3 Rehabilitation to come before a full community care assessment and be offered regardless of an individual's eligibility for long-term care.

4 Rehabilitation to be available for as long as it is needed.

5 Social care eligibility criteria that properly recognise the unique barriers to independent living that people living with sight loss face.

6 Any agreed vision rehabilitation support must start within twelve weeks of the person's initial contact with the local authority.

7 Sufficient funding to support the provision of rehabilitation, calculated by reference to the population of each local authority.

8 A fully-structured system for collection of relevant information to enable the monitoring of the implementation of rehabilitation-related aspects of the CRPD.

9 Initiatives to collaborate with other relevant disability organisations to ensure that rehabilitation-related concerns are included in future shadow reports to the CRPD Committee.

10 Effective remedies for breach of relevant CRPD requirements, either for individuals or groups and the recognition of central government's accountability for UK compliance with the CRPD.