

IMPROVING THE LIFE CHANCES OF DISABLED PEOPLE

Response from the Royal National Institute of the Blind April 2005

1. Introduction

1.1. RNIB welcomes the first general strategy for improving the lives of disabled people. We particularly welcome the commitment from the Prime Minister that **“by 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society.”** The objectives around empowerment, choice and freedom have also been central to the vision of RNIB for many years regarding the lives of blind and partially sighted people.

1.2 We are glad to read that blind people are recognised as an important minority, along with wheelchair users and deaf people. The needs of blind people are often such that they cannot be met by measures intended to serve disabled people in general. The great majority are old or very old and many younger blind people have additional impairments and complex needs. This calls for the provision of specialised services to improve their life chances.

1.3 Many blind and partially sighted people will be able to benefit from personalised payments to obtain support in daily living, employment, etc. But without trained specialist staff, personalised payments will not work by themselves. Our response to the original analysis document gave many detailed illustrations. Few of them have been included in the final report, which may be understandable, given its generalising strategic thrust. Nevertheless we urge that careful attention be given to that response in setting up the new Office for Disability Issues and in operating the pilot scheme on personalised payments.

1.4 We note the claim in the report that disabled people have benefited greatly from the government's measures to help them since 1997. Unfortunately we cannot fully endorse this view as far as blind and partially sighted people are concerned. The mobility component of Disability Living Allowance (DLA) is inadequate to meet the needs of blind and partially sighted people and many of them have their DLA applications turned down on first submission.

Specialist rehabilitation services such as mobility and daily living skills training have developed very unevenly and in many places quite inadequately. As our report *Beyond the Stereotypes* shows, blind and partially sighted people have not benefited proportionately to other groups of disabled people from the welfare to work programmes such as New Deal for Disabled People. It is vital that the new Office for Disability Issues takes this relative case fully into account in seeking to implement the proposed strategy.

1.5 It is regrettable that the report is silent about the way in which personalised payments will relate to DLA. We wish to place on record our view that a system of personalised payment based on assessment of individual need could never be a substitute for DLA. For example, the former would allow for payment of taxi fares where public transport was poor or non-existent. The latter permits a blind or partially sighted person to spend the mobility component on taxis or public transport according to his/ her own judgement.

1.6 From the point of view of blind and partially sighted people it is very unfortunate that the report deliberately gives so little attention to older people. The great majority of blind and partially sighted people are old or very old. Many have complex needs arising from additional impairments and the frailty which comes with old age. It is vital that these needs are taken fully into account by the new Office for Disability Issues in its work to implement this report and the Green Paper on adult social care. "Opportunity" does not become any less relevant simply because a person enters later life.

1.7 We note the emphasis throughout the report on the savings that can be made from the rationalisation of assessments and services. Of course efficiency savings are to be welcomed. However, we wish to place on record our view that adequate services to improve the life chances of blind and partially sighted people will require significant new public expenditure.

1.8 We welcome the proposal to establish an Office for Disability Issues to support improved cross Departmental collaboration and delivery.

Independent Living (Chapter 4)

2.1 We endorse the comments on joined up health and social services. Many blind and partially sighted people have additional impairments and complex needs and would benefit from the integrated health and social services set out here. We also endorse emphatically the need for high quality information about such services, which should be supplied to blind and partially sighted people in the medium of their choice, braille, large print, e-text or audio-recording.

2.2 We particularly welcome recommendation 4.4 which refers to providing appropriate support for independent living:

DH supported by DWP, DfES and ODPM should -- by 2012 -- work towards a new approach to supporting independent living, which delivers support, equipment and/or adaptations".

At present blind and partially sighted people rarely get all the support, equipment and adaptations they need. We have instanced training in mobility and daily living skills. But there are many other needs. Talking book players, CCTVs for people with low vision, access technology such as adapted computers, etc. We are glad to see some of these needs, (including taxis where public transport is very poor) acknowledged on page 78. Repeating once again that many blind and partially sighted people have additional impairments and complex needs, it is important to remember that they may need adaptations to the home, e.g. in the bathroom, which are directly related, not to their sight loss, but for example to limb disorders. Deaf-blind people should be noted as a very important special sub-group and it should be remembered that serious sight loss adds greatly to the problems of people with learning difficulties.

2.3 RNIB welcomes the call for "user-led organisations" in each locality. RNIB is an "of" organisation controlled by blind and partially sighted people and with a large and growing membership. Our members would wish to be involved in any local user led organisations modelled on existing Centres for Independent Living. We note and welcome the proposal that "The case should be explored for additional resources to be bid for from Spending Review 2006 to facilitate the development of a national network of user-led organisations. However, it is important to ensure that

these organisations genuinely represent the heterogeneity of disabled people.

3. Early Years and Family Support (Chapter 5)

3.1 RNIB welcomes the focus on the vital early stage of a child's development which can impact on future life chances. The government's 10 year strategy for childcare '**Choice for parents, the best start for children**' confirms that 'what happens in the early years of a child's life is critical for later life development'.

3.2 RNIB agrees that early years is a dynamic policy area. **Every Child Matters: Change for Children** is challenging ways of working in children's services. "Improving the Life Chances of Disabled People" must provide the opportunity to ensure that issues for the youngest disabled children are embedded in this changing world.

3.3 RNIB concurs with the judgement that 'the rhetoric of mainstreaming needs to be followed up by specific action to include disabled children'. The evidence from recent RNIB research suggests that young children with a visual impairment, and their families have not been able to benefit fully from the wider reforms of early years policy in relation to equipment, childcare and keyworking and will need specific targeting in the context of child poverty measures. In particular:

3.4 Greater support and guidance on individualized budgets will be needed to give parents the confidence to use these flexibly. The lessons learnt from direct payments should actively feed in to the pilots.

3.5 RNIB welcomes the focus on access for disabled children to free part time places for 3 and 4 year olds, and to the childcare provision outlined in the 10 year strategy. However, evidence from families is that they are not afforded the same choice, flexibility, availability and affordability of childcare as other parents for their children (**Everyone Counts**, Daycare Trust 2005). The planning duty in SENDA which includes early years providers will need to be supported by designated funding.

3.6 RNIB welcomes the proposal that all national evaluations of children's services should include the impact of and on disability.

However, RNIB has concerns as to how the outcomes for disabled children will be monitored at local level to inform national data collection and research. For instance, RNIB welcomes the emphasis in joint area reviews to 'describe what life is like for children and young people growing up in the area and evaluate the way local services, taken together, contribute to their well being'. This is a bold vision and to be applauded for putting the needs of the child at the centre of the planning and provision of high quality services. Yet there are reservations about how this will translate into practice.

3.7 While welcoming the rich examples of evidence to support the key judgements, RNIB has concerns that the framework will lack vision in practice to be a true catalyst for 'change for children' because of the narrow interpretation outlined in the focus of the key indicators. These appear to be a 'best fit' to existing data rather than indicators designed to gather information against the new framework.

3.8 The focus on disabled children in every review is welcomed, but this 'best fit' approach is evident in the key indicators for children with learning difficulties and/or disabilities that relate mainly to the statementing process. Challenging indicators will be required which reflect child and family aspirations and document the level and nature of unmet needs. In this context, RNIB would also recommend a change in emphasis in the report from 'hard to reach families' to 'hard to reach services'.

3.9 In addition, RNIB would like clarification of how the views of disabled children will be represented, especially those children with low incidence high impact needs.

3.10 The EPPE research has a wealth of evidence to offer in terms of quality provision for children in the early years. However, a note of caution should be drawn with regards to the interpretation of this evidence for children with SEN. In the EYTSEN research, the focus is on those children at risk of developing SEN, particularly in the area of communication or behavioural difficulties which can be reduced by early intervention through access to quality early childhood education. It does not address access for young children whose needs are severe, complex and long term. These needs should be acknowledged, particularly if there is an encouragement to children's trust partners to consider how quickly

resources can be progressively shifted into prevention and early intervention, including targetted support within universal settings. Earlier intervention for a blind child will improve the well being of the child and family, but will not reduce long term support costs.

3.11 RNIB is supporting the development of the Early Support developmental profile for visual impairment. However, its implementation must be underpinned by

- Effective systems of early screening and identification of visual impairment, including training for health visitors
- Effective support systems in place in every local authority to provide access to a QTVI within weeks of identification who has been trained in working with the profile in the early years. The interface between this specialist assessment and support and the common assessment framework should be clarified to avoid missed or inappropriate referrals.

3.12 RNIB welcomes a focus on equipment needs through integrated community equipment services to deliver the National Service Framework. The standards set in the National Service Framework for Children, especially standard 8, should be instrumental in driving change. RNIB would welcome clarification on how vigorous the monitoring and enforcing of these standards will be in practice to ensure that there is clearer ownership for children.

3.13 “Improving the Life Chances of Disabled People” raises concerns that ‘the children’s workforce is not fully able to meet the needs of the changing disabled children’s population’ and therefore needs strengthening. RNIB supports the focus on joint training outlined in ‘Interagency co-operation to improve the wellbeing of children: children’s trusts’ which confirms that ‘delivering an outcomes-led approach will require innovative thinking about how people are trained, supported, deployed and located to deliver services for children’. Voluntary organisations, such as RNIB, have a long history of providing training to a range of practitioners and parents, supporting the development of specialist services for particular populations of children and practitioners. RNIB would welcome an assurance that the training to support the full range of professionals in their work in children’s trusts will have a robust element on disability, and in particular, low incidence high impact disabilities such as visual impairment.

3.14 In addition, RNIB has concerns as to how Children's Trusts will be supported to work together effectively to jointly commission for disabled children. A comment from the "National Evaluation of Children's Trusts: Phase 1 Interim Report" states that service users need 'a constituency to which to relate, so they can be seen to be accountable and representative of service users in general, not just themselves personally'. This is some times difficult to achieve with a low incidence disability such as visual impairment where there may not be a representative constituency in the smaller children's services authorities.

3.15 RNIB has concerns that a 'consultancy model' is not appropriate for all families in the early days following diagnosis. An evaluation of the RNIB Early Excellence Partnership Project (2005) found that staffing levels in the majority of local authority visual impairment services were insufficient to enable them to provide adequate levels of specialist support to children and their families from birth. Quality provision for young children with visual impairment depends on continued targeted and specialist services to support inclusion in universal services. Every VI service should include early years practitioners with specialist knowledge to work directly with young children and their families. The government should be asked to disapply its policy of delegation of SEN funds to schools in the case of low incidence disabilities such as visual impairment to enable more funding to be provided to LEA VI services to provide this level of service.

3.16 RNIB also has concerns that there is a significant issue missing from the strategy: that of supporting disabled parents and parents to be. Services needed by blind and partially sighted parents include information and advice on practical issues such as equipment and childcare, acting as keyworker between agencies, sign-posting to other organisations and supporting networking between parents. These should be recognised as an integral part of family support, and reflected in "Improving the Life Chances of Disabled People".

For example, RNIB has pioneered the use of teleconferencing to bring the parents of blind or partially sighted children together and this has led to very positive feedback from participants, in terms of information sharing, the peer support involved and the simple

realisation that they are not the only ones experiencing particular issues arising from their children's upbringing.

4. Transitions (Chapter 6)

4.1 RNIB welcomes the importance attached to the transition to adult life. This can be a traumatic and challenging time for the young people themselves and for their families. The identification of the two groups for whom there are particular barriers at this time of transition is very relevant in relation to those having severe visual impairment.

4.2 A significant number of young people who are visually impaired also have other disabilities, including profound and multiple learning difficulties. Impaired sight has a compounding effect on other disabilities. This will be particularly challenging at times when so much new and changing information has to be processed and assimilated using visual channels.

4.3 For young people at the time of transition to adulthood who have no other significant special needs, their visual impairment will necessitate support of a highly specialist, individual nature. This support relies on a high level of understanding and skill from those who may be responsible for provision. This includes the assessment and provision of technology which is both costly and necessitates regular updating and training.

4.4 RNIB endorses the key ingredients for effective support, but also wishes to emphasise that there is a need to address not only service delivery, but also the confusion arising from requirements arising from different legislative strands. For example, at present the ages and frequency at which formal transition planning takes place as defined by the SEN Code of Practice is at odds with that which is prescribed by the framework for Looked After Children, Children (Leaving Care) Act 2000. Such discontinuity is confusing for the individuals and their families and, it militates against the seamless service provision by different agencies and service providers.

4.5 Whilst RNIB endorses the need to remove the "cliff edge" in provision that is experienced by many young people in moving

from children to adult services at the age of 19 years, there is a danger that without very specific guidelines the cliff edge will not be eradicated, but deferred by six years

One final issue around this transition period is the emerging research that tends to indicate that young people with serious sight loss tend to have smaller networks of people who they define as "close" compared to the general population. This may then impact upon them throughout their later life and we therefore feel that more attention may need to be given to the "softer" issues relating to opportunity to develop relationships, sexuality and social networks, as well as the focus on service provision.

5. Employment (Chapter 7)

5.1 RNIB welcomes the recommendation (7.1) that DWP/DH should develop and launch by 2008 provision for vocational rehabilitation. We agree that the first stage in developing this provision will be to gather a firm evidence base using lessons from Pathways to Work pilots, Job Retention and Rehabilitation pilots, and HSE return to work support models. However we would like to stress that any vocational rehabilitation provision should be accessible and relevant for all. We are concerned that the current pilots are not meeting the needs of blind and partially sighted people as they are aimed at 3 distinct target groups (people with back problems, less severe mental ill health and heart problems). We understand that people with sight loss are not excluded. However, no efforts have been made to reach this group through accessible media and staff are not trained to support them to overcome specific barriers such as access to information, mobility and travel to work, access technology, the need to learn new working methods, employer attitudes - which DWP research has shown to be more discriminatory for this group [1]. It is vital that any new provision takes account of these specific needs.

5.2 We are pleased that a reappraisal of the role of health professionals in new vocational rehabilitation provision is planned. At present GPs lack the training and the tools to accurately assess if a person has the capacity to work. Such an assessment process must take account not only of occupational information to advise an individual with career choice but also local labour market

information to consider the possibility of a person obtaining a job. GPs are not best placed to maintain an in depth knowledge of this information.

5.3 Changes to the Personal Capability Assessment are welcomed. 'Improving the Life Chances of Disabled People' indicates that the Capability Reports piloted as part of the Pathways to Work pilots are carried out by a DWP doctor. Which other professionals are involved in this assessment? Have any assessments been carried out for blind or partially sighted participants?

5.4 A system that targets the right people at the right time without any delays, and which aims to increase recruitment and retention rates of disabled people is exactly what Access to Work should be. We continue to experience challenges as we deliver our Access to Work contracts. For example one of our Employment Officers has recently been advised that clients asking for travel to work support must provide medical evidence stating that that this is required. This is an additional bureaucratic hoop that people with sight loss will need to jump through. The same Officer has been advised that laptops are now considered to be standard equipment for any job requiring the client to work away from the office environment and as such will not be funded through Access to Work. This blanket judgement is likely to discriminate against people with sight loss as they use laptops as a pen and paper substitute. These are two instances in which we believe the current Access to Work programme is not delivering recruitment and retention support to the right people at the right time.

5.5 Although Direct Payment and self-assessment could encourage people to exercise choice and self-control, it will be important that individuals are given the opportunity to understand the range of access solutions available. This is equally true when a person changes job, as some access solutions are context specific. There may be some elements of an assessment that can be transferred to another position but there is no such thing as a generic assessment.

5.6 RNIB is concerned that DWP is again examining options for increasing the employer contribution to Access to Work and uprating this annually. We have written at length about our concerns on this issue and the findings are presented in a report

compiled by the Disability Employment Coalition called 'Access to Work for Disabled People' [2].

5.7 RNIB welcomes the recognition that the employment prospects of all disabled people need to be improved – not just those nearest to finding a job. We support the view that helping people to gain and retain employment should be seen as a process where the individual moves along a continuum of training, work placement, voluntary work and open employment. However we stress that some people will not move all the way along this continuum to open employment. Long term supported employment is a vital option for these people and 'Improving the Life Chances of Disabled People' notes that the need remains within Workstep to offer considerable support to some people to enable them to sustain employment. RNIB also welcomes the recognition that various models including social firms, intermediate labour markets and individual placement schemes provide valuable opportunities for supported employment.

5.8 Tackling employer awareness is a key issue and RNIB is pleased to see that 'Improving the Life Chances of Disabled People' does not simply focus on supply side activity and programmes. RNIB would be happy to work with the DWP Employer Engagement Project and the subsequent employer led campaign to promote the business benefits of employing disabled people. We would also be keen to support DTI if they consult with business and trades unions on the development of an employment standard that encourages good employment practice including the recruitment, management and development of disabled people.

5.9 RNIB supports the use of public sector duty as an opportunity for government departments to lead the way as an exemplar employer in the recruitment and retention of disabled people. Jobcentre Plus is an obvious choice for the Department to play the leading role in establishing policies and practices that demonstrate practical commitment to this duty.

5.10 RNIB welcomes the proposed joint DWP, DfES and DH initiative to develop an online service directory and national helpline. On a smaller scale RNIB has developed an employment information directory and national helpline for blind and partially sighted people and employers. We would be happy to work with

DWP on any new initiative that aims to raise awareness of local service providers.

6. Towards Improved delivery (Chapter 8)

6.1 RNIB welcomes the recommendations in chapter 8 that together will provide an improved delivery system for disabled people:

- A fully developed strategy, timetabled with milestones, communicated widely, and aimed at steady progressive reform to 2025
- A review of provision for disabled people (including older people) leading to a new mix of mainstream, specialist and integrated provision
- More coherent and explicit standards bringing legislation and other rights into a coherent framework
- An incentivised system to promote the effective delivery of services
- A stronger focus within Government on disability issues and to provide oversight of reform delivery
- New arrangements to secure the participation of disabled people in policy design and delivery at all levels.

6.2 Central to the delivery of this programme of change will be the Office for Disability Issues. To be successful it must be able to secure full collaboration between ministers and officials across Departments. This is recognised in the report which envisages it as “a new slim strategic unit, with few executive functions and with an essentially co-ordinating role, providing direct support through its chief officer to the Minister for Disabled People. It would provide a focus within government for disability as a discrete subject and be the means by which departments collectively drive forward the strategy.” The challenge is to make this a reality. Certainly RNIB would welcome the opportunity to contribute to the evolving remit of the ODI

6.3 RNIB has considerable experience of working with Government and would hope to participate in policy design and delivery as set out in section 8.5 of the report. We would also want to participate in the National Forum of Organisations of Disabled

People having moved over the past decade from being a “for” to an “of” organisation (necessitating changes to our Royal Charter).

7. Final comments

As we have previously mentioned, the report gives but passing reference to older disabled people, which is puzzling given the age skew of disability that will be emphasised still further by 2025.

The Social Exclusion Unit interim report on excluded **older people** has the following quote from Lord Rooker,[3]

“The opportunities that allow the majority of the population to have the best quality of life possible must be made available to all including the most excluded. This is just as much about education, employment, leisure and active social roles as it is about health, housing and social care.”

Obviously we would agree with this but cannot see why these issues for older people are not therefore addressed effectively in the Improving Life Chances report. We know that joined up services are key to older people and Government so we hope that older disabled people will not be packed off to be dealt with by some other arm of Government (such as Link-Age) rather than be integrated into general provision for disabled people

A few specific points might be useful. RNIB has recently completed a project supporting older people with serious sight loss in accessing direct payments in a specific local authority. It has been a struggle to ensure that the individuals have been able to make the most of these for a whole range of reasons, amongst them the paperwork involved (which for blind people is hard), the responsibility of actually managing an employee and worries about the carers reliability and background.

For many the autonomy has been worth it but we believe that the direct payments system needs to recognise the specific difficulties that some people may experience in navigating the process. In some circumstances the paperwork and “management” may need to be separated from the individual to allow them to focus on what they want and require the carer, service or equipment to do for them.

The ability of people to get out and about is clearly vital if people are to play a role in the life of their local and national communities. People with serious sight loss are less likely to go out than disabled people in general and have difficulties not experienced by others around use of public transport. Obviously these need to be addressed but public transport is not the only answer as the issue is often getting door to door. What is needed is an adequate recognition of the extra costs incurred through the requirement for taxis or other personal support – either through explicit recognition in the benefits system or through explicit provision through direct payments.

Once again the key issue at heart is the ability of older disabled people to have the same life experiences and chances as their peers who are not disabled. There is no point in getting an increased income through Pension Credit and Attendance Allowance and Council Tax rebate if the end result is still to sit at home day after day without friends or without being able to contribute to your community. This does mean taking specific steps to ensure that older disabled people can be involved (and take the same life enhancing risks where appropriate) the same as anybody else.

The final point to make is that perhaps one outcome of success could be an increase in the numbers of disabled older people being able to volunteer and be involved in the life of their communities. There has been recent funding for younger people to be encouraged into volunteering, what about an equal focus on older disabled people?

References

1. Roberts, S., et al, "Disability in the Workplace: Employers' and Service providers' responses to the Disability Discrimination Act in 2003 and preparation for 2004 changes", Report No 202, London, DWP.
2. Disability Employment Coalition, "Access to Work for Disabled People", 2004, London, Disability Employment Coalition/RNIB
3. OPDM Social Exclusion Unit, Interim Report Excluded Older People 2005, London.