



## **Vocational Assessment and Rehabilitation for People with Long-Term Neurological Conditions: Recommendations for Best Practice**

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## Executive Summary

### Introduction

The National Service Framework (NSF) for Long-term Conditions<sup>1</sup> focuses on services for people with a long-term neurological condition. Four clusters of neurological conditions are identified: sudden onset; intermittent and unpredictable; progressive; and stable but with changing needs due to development or ageing. A specific Quality Requirement (QR6) on 'Vocational Rehabilitation' stresses the need for 'appropriate vocational assessment, rehabilitation and ongoing support' to enable people with a neurological condition 'to find, regain or remain in work and access other occupational and educational opportunities'. These recommendations have been developed to assist staff in health and social services with implementation of QR6 and in Jobcentre Plus and other employment services in developing integrated and appropriate services.

### Literature reviews

Research on vocational rehabilitation is reviewed separately for four specific conditions (spinal cord injury, epilepsy, multiple sclerosis and cerebral palsy), representing the four clusters of neurological conditions in the NSF. Each review addresses the following:

- the specific condition and the extent of the employment problem
- factors that contribute to employability (eg impairments, activity limitations, personal factors and environmental factors)
- research on vocational rehabilitation, and
- recommendations for the specific condition.

A summary of the findings across these reviews highlights the extent of vocational need, the factors contributing to these needs, and the success of vocational rehabilitation programmes designed to cater for people with a long-term neurological condition.

### Service summaries

The role of occupational health is outlined, highlighting the need for joint working across neurological/vocational rehabilitation and occupational health services. The range of services provided and commissioned by Jobcentre Plus is described including forthcoming changes to specialist disability employment provision from 2010. The contribution of Local Authorities and Further Education is outlined, reinforcing the need for inter-agency links and support from specialist neurological rehabilitation services.

### Recommendations for best practice

'How to use the Recommendations for Best Practice' notes the wide range of services (government-funded, independent and voluntary) that may be involved in assisting people with vocational needs and the importance of joint working across all agencies.

The Recommendations for Best Practice section has been developed following consultation with key stakeholders. It provides practitioners with detailed guidance on vocational rehabilitation for key general issues and eight identified areas of vocational need experienced by people with a neurological condition. The specific issues addressed include the following:

#### General issues

- assisting people in considering whether to disclose a condition to an employer and in explaining their needs, as and when they decide to disclose

- respecting the wishes and choices of the individual
- conforming with legal requirements of confidentiality, consent and mental capacity
- providing open access and re-access to vocational services through ongoing review.

### **Identification of vocational need/provision of information**

- routine identification of vocational needs by health and social care practitioners
- provision of information and/or referral to relevant information sources
- avoidance of premature judgment about fitness to work without specialist advice
- referral to specialist vocational assessment, rehabilitation and support services.

### **Vocational assessment/employment assessment**

- the wide range of factors to be considered in vocational/employment assessments
- the wide range of assessment components needed for different vocational needs
- the importance of obtaining, sharing and explaining background clinical information
- the need to discuss assessment results with all relevant parties
- provision of summary reports to support benefits applications and reviews.

### **Job retention interventions**

- routine evaluation of the need for a rapid response for those in difficulty at work
- establishing if the person has received occupational health or other specialist advice
- clarifying responsibilities of all parties under the Disability Discrimination Act<sup>2</sup>
- recommended assessment methods for people experiencing difficulties at work
- need for support from Access to Work or referral to Disability Employment Adviser
- meeting with employer and other relevant parties to discuss needs and adjustments
- recommended areas of work adjustments and sources of further information
- support for people returning to education or training
- ongoing monitoring and pro-active review, in liaison with occupational health.

### **Return to occupation**

- rehabilitation interventions to assist the management of work-related difficulties
- consideration of personal and family circumstances, as well as work-related skills
- consultation with specialist vocational practitioners (including occupational health) when return to work (RTW) is problematic
- liaison with employers (and occupational health, when involved) about support needs
- recommendations on RTW, work adjustments, worksite support and review.

### **Withdrawal from work on health grounds**

- the benefit of specialist advice before making a decision to withdraw from work
- specialist occupational health, vocational rehabilitation and/or financial advice
- provision of emotional support and referral to specialist services, as required
- support in finding alternative occupation.

### **Preparation for alternative occupation**

- referral for vocational assessment and/or rehabilitation appropriate to individual needs including specialist vocational programmes for those with complex needs
- proactive advice and support from specialist practitioners to pan-disability vocational providers to explain vocational needs, especially when any risk is identified
- proactive monitoring of people with complex needs on pan-disability programmes

- recommended components of specialist vocational rehabilitation including voluntary work trials and supported placements and ongoing availability of support
- access to neurological and vocational rehabilitation expertise/training.

### **Transition from education to employment or other occupation**

- routine assessment of vocational needs and aspirations of young people during secondary education and advice on sources of assessment, advice and support
- Early referral to Connexions, Social Services Transitions Team or suitable vocational rehabilitation including specialist programmes for those with complex needs
- recommended vocational interventions for young people.

### **Occupational/educational provision**

- guidance and support on alternative occupational or educational opportunities for people currently unable to work, linking in with voluntary groups as appropriate
- pooling of information across agencies and development of new suitable provision
- training and support for providers of occupational opportunities/further education.

## **Implementation**

Recommended inter-agency action to implement the recommendations includes the following:

- local inter-agency review of available services in the context of the NSF for Long-term Conditions' QR6 on Vocational Rehabilitation
- development of local referral criteria and protocols, drawing on these recommendations
- establishment of ongoing service links to discuss vocational needs of specific clients
- review by all relevant professional groups of training in vocational rehabilitation
- inter-agency approach to raising awareness of needs and specialist skills training
- research to identify new and effective vocational rehabilitation for this client group
- regular audit of provision against the requirements of the Disability Discrimination Act (DDA)<sup>2</sup> and the NSF<sup>1</sup>.

There is widespread agreement that effective vocational rehabilitation involves four key players: the employee (or person seeking employment), the (potential) employer, health professionals, and the state-provided specialist employment services (from the DWP in the UK) or other vocational rehabilitation services. Some illustrative key messages for specific professional groups (ie medical practitioners, community therapy staff and Jobcentre Plus work psychologists) are included. Other agencies and professional groups are encouraged to identify the key messages for their respective practitioners.

## **References**

1. Department of Health (2005). The National Service Framework for Long-term Conditions. London: Department of Health.
2. Disability Discrimination Act (1995; 2005). London: HMSO.



# 1 Introduction

**1.1** 'A long-term neurological condition results from disease of, injury or damage to the body's nervous system (ie the brain, spinal cord and/or their peripheral nerve connections) which will affect the individual and their family in one way or another for the rest of their life'.<sup>1</sup>

**1.2** The National Service Framework (NSF) for Long-term Conditions<sup>1</sup> categorised long-term neurological conditions (LTnC) into four broad groups:

- sudden onset neurological conditions, eg traumatic brain injury (head injury); other forms of acquired brain injury such as stroke, cerebral or subarachnoid haemorrhage, cerebral infections (such as encephalitis, meningitis or cerebral abscess), cerebral hypoxia (lack of oxygen to brain) and spinal cord injury
- intermittent and unpredictable neurological conditions, eg epilepsy; certain forms of headache; or early multiple sclerosis where relapses and remissions lead to marked variation in the care needed
- progressive neurological conditions, eg motor neurone disease, Parkinson's disease or later stages of multiple sclerosis, where progressive deterioration in neurological function leads to increasing dependence on help and care from others. (NB dementia for all ages is covered in the NSF for Older People)
- stable neurological conditions but with changing needs due to development or ageing, eg post-polio syndrome or cerebral palsy in adults.

**1.3** The NSF for LTnC<sup>1</sup> set out a number of Quality Requirements including Quality Requirement 6 (QR6) - Vocational Rehabilitation - which states that 'People with long term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support to enable them to find, regain or remain in work and access other occupational and educational opportunities'.

**1.4** The NSF for LTnC QR6 is accompanied by four 'evidence-based markers of good practice':

|    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|----|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. | Coordinated multi-agency vocational rehabilitation is provided which takes account of agreed national guidance and best practice                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| 2. | Local rehabilitation services are provided which: <ul style="list-style-type: none"> <li>• address vocational needs during review of a person's integrated care plan and as part of any rehabilitation programme</li> <li>• work with other agencies to provide: <ul style="list-style-type: none"> <li>○ vocational assessment</li> <li>○ support and guidance on returning to or remaining in work</li> <li>○ support and advice on withdrawing from work</li> </ul> </li> <li>• refer people with neurological conditions who have more complex occupational needs to specialist vocational services</li> </ul> |
| 3. | Specialist vocational services are provided for people with neurological conditions to address more complex problems in remaining in or returning to work or alternative occupation including: <ul style="list-style-type: none"> <li>• specialist vocational assessment and counselling</li> <li>• interventions for job retention, including workplace support</li> <li>• specific vocational rehabilitation or 'work preparation' programmes</li> <li>• alternative occupational and educational opportunities</li> <li>• specialist resources for advice for local services</li> </ul>                         |
| 4. | Specialist vocational rehabilitation services routinely evaluate and monitor long-term vocational outcomes, including the reasons for failure to remain in employment.                                                                                                                                                                                                                                                                                                                                                                                                                                             |

1.5 These recommendations have been written in order to assist those working in health and social services with implementation of QR6 and those in Jobcentre Plus and other employment services in developing integrated and appropriate vocational rehabilitation provision. Vocational rehabilitation is defined as the overall process of enabling individuals with either temporary or permanent disability to access, return to, or remain in, employment.<sup>2</sup>

1.6 Guidelines were published jointly by the British Society of Rehabilitation Medicine (BSRM), Jobcentre Plus (part of the Department for Work and Pensions) and the Royal College of Physicians (RCP) concerning vocational assessment and rehabilitation after acquired brain injury,<sup>3</sup> an example of a sudden onset condition, in 2004. The Recommendations Development Group subsequently reviewed published evidence for vocational assessment and rehabilitation in intermittent and unpredictable conditions, progressive conditions and stable neurological conditions using epilepsy, multiple sclerosis and adult cerebral palsy as examples for each situation. The Group also considered the evidence for vocational assessment and rehabilitation following spinal cord injury. Although this represents another sudden-onset condition, the problems encountered and hence potential solutions are very different from those found following acquired brain injury.

1.7 These recommendations have also drawn extensively on advice from service users (who participated in a User Forum at an early stage in their development), and experts from health and employment settings who were invited to contribute to an initial consultation exercise including a small number of semi-structured interviews exploring specialist provision in this area of work and a second consultation on the draft Recommendations for Best Practice (see Appendix 2 for a list of contributors).

1.8 People with a LTnC have a right to advice and help to maximise their opportunities for employment and it is hoped that these recommendations will assist those working in employment services, health and other services who are trying to ensure this happens.

1.9 The recommendations should be seen in the context of the Disability Discrimination Act (DDA),<sup>4</sup> which applies to people with “a physical or mental ‘impairment’ that has ‘substantial’ and ‘long-term’ negative effects on normal ‘day-to-day activities’”. This includes provision for ‘reasonable adjustments’ to enable a person with a disability to remain in or to obtain employment. Factors to be considered in judging whether an adjustment is ‘reasonable’ including effectiveness, practicality, costs, extent of any disruption, resources, availability of help and the size and type of the business. The Equality and Human Rights Commission have a series of leaflets on the DDA, along with detailed guidance for employers ([www.equalityhumanrights.com](http://www.equalityhumanrights.com) ).

1.10 The following section summarises the published literature concerning the nature and extent of problems experienced by those with LTnC, and the evidence supporting specific interventions to address these.

## Review of published evidence

1.11 For each of the example conditions; epilepsy, multiple sclerosis (MS), adult cerebral palsy (CP) and spinal cord injury (SCI), literature searches were carried out using the following electronic databases: Allied and Complementary Medicine; British Nursing Index; Cinahl; DH data; Embase; Kings Fund; Medline; Psycinfo; SCIRE. The strength of evidence was assessed using the same method as that used in the NSF for people with LTnC.<sup>1</sup>

1.12 This review has considered the extent of employment problems. We have used the World Health Organisation International Classification of Functioning (ICF) as a framework for the review of evidence and therefore considered how and to what extent factors related to the underlying neurological diagnosis, level of impairment and activity limitation as well as personal and environmental factors impinge on employment.

## Extent of employment problems

1.13 People with epilepsy experience higher levels of unemployment compared to the general population with rates of unemployment up to twice that of the general population. This is particularly the case for those with uncontrolled seizures who are more than twice as likely to experience job

problems compared to those in remission. There is also evidence that those with epilepsy tend to be in jobs that are below their capabilities, uninteresting and poorly paid.

**1.14** With MS, most people are working at disease onset and the main issue is work retention. Only 20 to 30% are still in paid employment by 5–15 years after diagnosis. The common pattern is to move from a high demand job to a less demanding job as activity becomes increasingly limited by the underlying condition. Only 2% of those severely disabled by their MS are employed.

**1.15** Most with SCI are also employed at the time of injury, but the majority are immediately faced with prolonged sick-leave and/or loss of employment. The return to work (RTW) rate after SCI varies according to the definitions used and the time since injury (RTW rate increases with time since injury) and is documented between 21 and 67%. The UK has lower employment rates than other European countries after SCI. Few return to their pre injury job; instead most return to a less physically demanding job and early retirement is often seen. Approximately 30% of people with SCI are working at any given time.

**1.16** With CP, understanding the extent of the problem is complicated by the varied definitions of employment, the inclusion of sheltered work, or part-time work etc. Little UK data are available but employment rates reported in western European countries vary between 20 and 50%.

## Factors contributing to work problems

### Diagnosis and impairments

**1.17** In all four LTnCs, the extent and severity of impairments (signs and symptoms) has been shown to influence employment. Thus, there is an association between frequent seizures and increased risk of employment problems. However, seizure frequency alone is unlikely to be the cause of problems with employment. Intellectual and neuropsychological impairment has been reported to be related to employability, but it is important to remember that medication used to treat epilepsy is associated with many potential adverse effects including intellectual and neuropsychological impairment. Emotional impairments such as anxiety and depression are higher in people with frequent seizures and this can impinge on all aspects of vocation.

**1.18** Early in the course of MS, the symptoms that impact most on the individual's ability to work are fatigue, anxiety and depression. People with MS also describe problems with pain and heat intolerance. It is usually some time (months or years) before overt neurological impairments such as weakness, balance problems, spasticity, sensory disturbance, difficulties with vision, and bladder and bowel disturbances are major determinants of ability to work and even then, severity of impairment does not always correspond to the restrictions in participation.

**1.19** In contrast, there is a clear association between level of SCI, and hence degree of motor impairment and RTW rates. People with paraplegia are more likely to RTW than those with tetraplegia. However, avoidable but frequently encountered secondary medical problems such as urinary tract infections, pressure ulcers and respiratory complications as well as pain, fatigue and perceived stress are reported as reasons for unemployment, particularly in the older age groups.

**1.20** CP is really a group of conditions linked by onset at or soon after birth and usually, an unknown cause. Manifestations may range from those with minor movement disorders to those with profound sensory, motor and intellectual problems who may also be blind and/or have epilepsy. People with hemiplegic CP have the greatest chance of being in competitive employment.

### Activity limitation

**1.21** In people with MS, limitation in mobility may make access to work difficult and movement within the workplace effortful. Poor dexterity affecting handwriting, keyboard use and other manual tasks is frequently encountered. Visual impairment may result in difficulty with reading, writing and many other tasks and, may, for example, preclude changing from, say, manual to office work as motor impairment increases. Slurred speech as a consequence of neurological impairment may interfere with intelligibility resulting in difficulty using the telephone, general communication and poor presentation skills. Urinary and faecal frequency and urgency (with fear of incontinence) may also greatly hamper function in the workplace.

1.22 In SCI, people with greater community mobility and those who are living independently are more likely to RTW. Independent driving is positively associated with RTW.

1.23 In the absence of other health conditions, well-controlled epilepsy seldom limits activity. However, safety and regulations ([www.dft.gov.uk/dvla/](http://www.dft.gov.uk/dvla/)) restrict driving and this is perceived to be a major factor influencing RTW by people with epilepsy. Even where this does not involve driving, access to the workplace may be difficult.

## Personal factors

1.24 In people with epilepsy, personal (or employer) choice may lead to avoidance of stressful situations at work due to fear of precipitating seizures. There is evidence for the interplay of personal emotional factors in people with MS too. Many devote inordinate amounts of energy to working to keep crisis away, waiting until symptoms become severe before addressing the employment obstacles they cause.

1.25 Following SCI, psychological factors are also important. A positive work attitude, internal locus of control, optimism, self esteem, achievement orientation and positive role models are all associated with improved RTW rates. People who increase their years of education after SCI also enhance their employment opportunities.

1.26 In contrast, many with CP miss out on educational opportunities and may leave school with few or no qualifications. They are further hampered by lack of opportunity to socialise normally with their peers and, hence, may have poor social skills. They are thus severely disadvantaged when they first try to enter the job market and this may be the case even in those with little or no intellectual impairment.

## Environmental factors

1.27 Architectural obstacles play a major part in hampering access to work in those with CP, MS or after SCI. These may include physical obstacles to entering the buildings, lack of accessible toilet and other staff facilities, failure to adjust the workspace to accommodate a wheelchair, etc. Transport to work may also be poorly accessible.

1.28 Another poorly recognised factor, particularly amongst those with progressive conditions such as MS is that a mismatch may develop between the job demands and the individual's capacity resulting in excessive fatigue and work instability. Often instead of addressing these problems by advising altering work patterns, health professionals may advise sick leave. This tends to lead to early loss of employment and once unemployed, few achieve a RTW.

## Social factors

1.29 In the UK people with LTnC are protected from discrimination in employment under the DDA<sup>5</sup>. Nevertheless, published literature continues to provide examples of discrimination against those with these conditions. For example, there is evidence that only a quarter of employers would knowingly employ a person with epilepsy. A quarter of discrimination occurs at the stage of recruitment but the vast majority of discrimination occurs after appointment and includes discrimination in promotion and termination, harassment and disciplinary action.

1.30 This is not helped by the fact that many do not understand their legal rights and may be frightened about disclosing their health condition. Disclosure to the employer poses a particular problem for people with epilepsy; many hope to avoid anyone becoming aware of their condition. However employers do need to have the opportunity to enforce sensible workplace restrictions, eg to avoid working at heights or operating potentially hazardous machinery.

1.31 In people with CP, the ability to educate individuals in mainstream rather than special schools seems important. The latter perhaps inevitably offer a reduced range of educational opportunities, but also tend to have poor links to careers advice and pupils may miss out on the work-experience now routine for teenagers in mainstream schools. In short, many severely disabled young people are over-schooled and under-skilled.

1.32 Potential income for this group in particular is often so limited that many may find themselves in the so-called 'benefits trap'.

1.33 Health insurance for all those with LTnC may be difficult to obtain.

## Vocational rehabilitation for people with employment problems

### Access to employment and job retention services

1.34 Many examples of vocational programmes are documented in the literature and these have been shown to improve employment rates.

1.35 Good quality vocational rehabilitation programmes have included a culture of support and encouragement, practical assistance, emphasis on personal preferences, available timely assistance, and flexibility. Providing individualised support and work experience is encouraged. The features of good vocational assessment and rehabilitation programmes included access to a range of health care and employment service professionals such that the team has resources and expertise in the following areas:

- management of the underlying health condition and its potential consequences (eg addressing difficulties with mobility and balance, communication, cognitive and/or emotional problems)
- environmental adaptations and use of assistive technologies. For example, in those with predominantly physical limitations, it may be possible to improve retention of employees by modifications to the workplace, the provision of adaptive or assistive technology, computer training, and vehicle adaptation and special parking
- anticipation of the specific problems associated with a particular health condition. For example, in CP, transition to adulthood is associated with the requirement to acquire a range of new skills and this tends not to happen unless a targeted rehabilitation programme is offered
- good access and the ability to respond rapidly. If an individual develops epilepsy for the first time and is at risk of job loss, perhaps because work necessitates driving, there is a clear need for urgent access to a vocational expert. In general, vocational input should be available rapidly to address new problems which may compromise work. Long term support and reassessment should be available or easily re-accessed if required particularly when the needs are more complex
- communication with other relevant statutory services. Shared responsibility between secondary and primary care is particularly important in people with controlled epilepsy as they are unlikely to be seen frequently in secondary care. In all cases, good links are needed between health and employment sectors
- established links with voluntary/user led organisations who can, in turn, raise awareness amongst their members regarding potential problems, exchange information on how others have circumvented these, and act as a forum to report problems in relation to employment.

1.36 In general, successful programmes have focussed on managing workplace performance rather than reducing the impairment arising from LTnC. There is evidence to support collaboration with the employer as well as the employee. Employers may feel ill-informed, and therefore uncertain what demands may reasonably be placed on the employee with a LTnC and how to accommodate unpredictable absences from work. They may also have specific worries, for example how to respond if their employee manifests problems related to their LTnC whilst at work.

1.37 A number of tools have been developed and validated for monitoring employment difficulties (eg work instability) in people with LTnC. Their use has been recommended to identify those at particular risk of job loss early for targeted vocational rehabilitation.

### Specialised work environments

1.38 **Sheltered workshops** were, at one time, preferred for those with cognitive problems such as adults with CP. However, these are now seen as effectively segregating those with developmental disabilities and have been superseded by the concept of '**supported employment**'. The latter is designed to assist people with severe disabilities in obtaining and maintaining integrated competitive employment through specially planned support. When working well, supported employment enables those with disabilities to learn new skills and enables non-disabled co-

workers/supervisors to work with disabled colleagues, thus facilitating an 'integrated workplace for all employees'. Individual placement allows choice, self determination and empowerment.

**1.39 Collaborative working** is another model whereby people with differing impairments are 'paired' such that their skills complement each others. Groups of individuals may also work together using a similar philosophy eg mobile work crews consisting of 4-8 workers and one supervisor who often perform tasks such as grounds maintenance, house cleaning, janitorial services or other related work and offer another model of supported employment which has in turn led on to the concept of 'social firms'.

## Summary of evidence

**1.40** People with LTnC are less likely to gain employment, more likely to find themselves in poorly paid posts missing out on promotion opportunities and more likely to retire early than their peers. Although specific neurological impairments and their severity affect employment, fear and prejudice also play a major role in compromising work opportunities.

**1.41** Vocational rehabilitation programmes designed to cater for people with LTnC, where available, have been successful in circumventing these difficulties. These have seldom focussed on the treatment of neurological impairments; instead their success has been founded on tackling workplace access, tailoring work patterns and demands to match the attributes of the employee with a LTnC and providing information on health conditions, rights and resources to both employers and employees.

## References

1. Department of Health (2005). The National Service Framework for Long-term Conditions. London: Department of Health.
2. British Society of Rehabilitation Medicine. Vocational Rehabilitation The Way Forward: report of a working party (2nd Edition) (Chair: Frank, AO). London BSRM, 2003.
3. BSRM, Jobcentre Plus & Royal College of Physicians. Vocational assessment and rehabilitation after acquired brain injury Inter-agency guidelines. London RCP 2004.
4. Disability Discrimination Act (1995). London: HMSO.
5. Disability Discrimination Act (2005). London: HMSO.

## 2 Literature Reviews

### Vocational rehabilitation for people with spinal cord injury

#### Background

2.1 The incidence of traumatic spinal cord injury (SCI) in the UK is estimated as 10-15 per million per year. It is estimated that 40,000 individuals in the UK are living following traumatic SCI. The majority of injuries are in young males therefore ensuring return to work (RTW) will have significant advantages to the State as well as to the individual.

2.2 Being employed influences life satisfaction positively. Employees with SCI have greater satisfaction with employment and finances,<sup>1</sup> higher level of activity, fewer medical treatments, fewer depressive symptoms<sup>2</sup> and better overall adjustment.<sup>2</sup> Perceptions of general health, lifestyle, endurance and activity tolerance are all significantly associated with employment status in SCI,<sup>3</sup> and employment has a positive correlation with better community integration.<sup>1,2,4-13</sup>

2.3 The RTW rate after SCI varies according to the definitions used and the time since injury (RTW rate increases with time since injury) and is documented between 21 and 67%.<sup>9,12,14-20</sup> The UK has lower employment rates than other European countries after SCI.<sup>21</sup> Few return to their pre injury job,<sup>19</sup> most return to a less physically demanding job.<sup>22</sup> Approximately 30% of people with SCI are working at any given time.<sup>23</sup> There is little information on hours of work.<sup>22,24</sup>

2.4 RTW does not ensure continued employment – the majority of people with SCI do not maintain their employment in the years after SCI.<sup>25-28</sup>

2.5 There is evidence of a sharper decline in employment in later years, which starts in the fifth decade, compared to sixth and seventh decades in the general population.<sup>25</sup>

#### Factors contributing to work problems

2.6 A number of factors are associated with, or predictive of, post-injury employment. The vocational needs of people with spinal cord injury can be addressed properly by analysing all factors that contribute to the employment problems. These are grouped based on the International Classification of Function.

#### Impairments

2.7 The level of SCI<sup>4,19,26,29-34</sup> and degrees of motor impairment and activity limitation are also associated with RTW rates – people with paraplegia are more likely to RTW than those with tetraplegia, those with higher motor index scores (less impairment)<sup>35</sup> are more likely to RTW, and people with more severe injuries take longer to RTW.

2.8 People injured because of violence due to assault, gunshot or stab injuries are less likely to RTW, whereas those with a medical or surgical aetiology are more likely to be employed.<sup>4,31</sup>

2.9 Poor health is frequently reported as a reason for not working<sup>18,27,29,36</sup> and having fewer medical complications including pain,<sup>37,38</sup> fatigue,<sup>36</sup> urinary tract infection, pressure ulcers and respiratory complications<sup>39</sup> predicts greater likelihood of RTW.<sup>4</sup> Having a psychiatric disorder is a strong risk factor for unemployment.<sup>18</sup> In one study 69% of people who left a post-injury job did so because of health factors.<sup>40</sup>

2.10 Time, energy and perceived stress are reported as reasons for unemployment, particularly in the older age groups, and lack of motivation is reported to hinder work participation.<sup>18,36,41</sup>

#### Activity

2.11 People with greater independence,<sup>41,42</sup> higher Barthel scores,<sup>22,43</sup> greater community mobility and those who are living independently<sup>4</sup> are more likely to RTW. Independent driving is positively associated with RTW.<sup>4,30,33,44,45</sup>

2.12 Higher level education is associated with higher RTW rates,<sup>1,19,22,29,30,32,46-51</sup> though people who increased their years of education after SCI also enhanced their employment opportunities.<sup>19,22,49</sup> Being employed at the time of injury and during the previous post injury year is associated with a greater likelihood of being employed in any given year.<sup>31</sup> People with less physically intense occupations are more likely to RTW<sup>22,34,46</sup> and people returning to their pre injury job RTW in a shorter time interval.<sup>19,22</sup>

2.13 For people with SCI, computer skills are significant predictors of employment and higher earnings, yet many feel inadequate in this area, and training is not universally available.<sup>51,52</sup>

### Personal factors

2.14 There is contradicting evidence on gender, although the majority of studies report higher RTW rates in males.<sup>11,15,19,22-25,46</sup> Older age is negatively associated with RTW; the highest RTW rates are in those injured under the age of 18, the lowest rates in those injured aged 46-61.<sup>4,11,15,22,29,30,31,35,43,46,47</sup> Married people are more likely to RTW,<sup>31</sup> and from US data, caucasians are more likely than minority ethnic groups to RTW.<sup>4,9,24,31,32,35,47</sup>

2.15 Psychological factors are also important<sup>24</sup> – a positive expectation of RTW is associated with successful RTW.<sup>53</sup> A positive work attitude,<sup>24</sup> internal locus of control, optimism, self esteem, achievement orientation and positive role models all affect employment.<sup>9,49,50,53,54</sup>

### Environmental factors

2.16 Lack of work experience, lack of education and training, lack of transportation, architectural obstacles (including lack of accessible toilet facilities, workplace adjustments and accommodation), discrimination, social attitudes and loss of benefits are frequently reported as reasons for unemployment.<sup>27,29,36,41,53,55-62</sup> People with SCI report problems accessing vocational services.<sup>63</sup>

2.17 Indirect evidence from disability groups suggests the National Health Service and employers need to be more responsive to the workplace needs of disabled people.<sup>64</sup>

2.18 Individuals with SCI have a right to non-discrimination in employment practices. There is evidence from non-UK studies that having a disability, and specifically a SCI, is a significant discriminating factor for obtaining an interview or gaining employment.<sup>11,65</sup> From US studies neurological diagnoses were among the impairments of people most likely to allege discrimination regarding issues of lay off and harassment, although 80% of employment discrimination charges were resolved without any finding of discrimination.

2.19 There are differences in patterns of discrimination experienced by people in the US with SCI compared to a group of individuals with other physical, sensory or neurological impairments.<sup>62</sup>

2.20 Replacement of benefits by a low income has been identified as a potential obstacle to RTW.<sup>36,41,56,59</sup>

## Vocational rehabilitation and Interventions

### Return to work

2.21 One retrospective outcome measurement study suggests people who had been treated in a specialist Spinal Cord Injury Centre were more likely to be in paid or voluntary employment than those not treated in such centres.<sup>66</sup>

2.22 People increasing their years of education after SCI enhanced their employment opportunities.<sup>19,22,49</sup>

2.23 Positive expectations regarding resumption of work after a SCI are an important indicator of successful reintegration in work.<sup>53</sup>

2.24 Vocational training or retraining after injury has been associated with improved employment rates.<sup>22,43,49,67,68</sup> People with SCI are interested in receiving vocational services.<sup>63</sup> Many examples of vocational programmes are documented in the literature.<sup>43,69-75</sup> Good quality RTW programmes include a culture of support and encouragement, practical assistance, emphasis on personal

preferences, available timely assistance, and flexibility. Providing individualised support and work experience is encouraged.<sup>76</sup>

2.25 Computer use, Internet use and access groups may give people the necessary computer and internet skills to be used in job seeking and in job performance.<sup>51,52,77-81</sup>

2.26 Home based employment options can be used to bypass many obstacles.<sup>78.</sup>

2.27 Assistive Technology can compensate for functional limitations, overcome obstacles to employability, improve ability to compete for gainful employment and can be important for employment success of individuals with SCI.<sup>51,81-85</sup>

### **Job retention services**

2.28 Work related counselling (covering production and social-interpersonal issues indirect) may help with job retention one year after placement.<sup>86</sup>

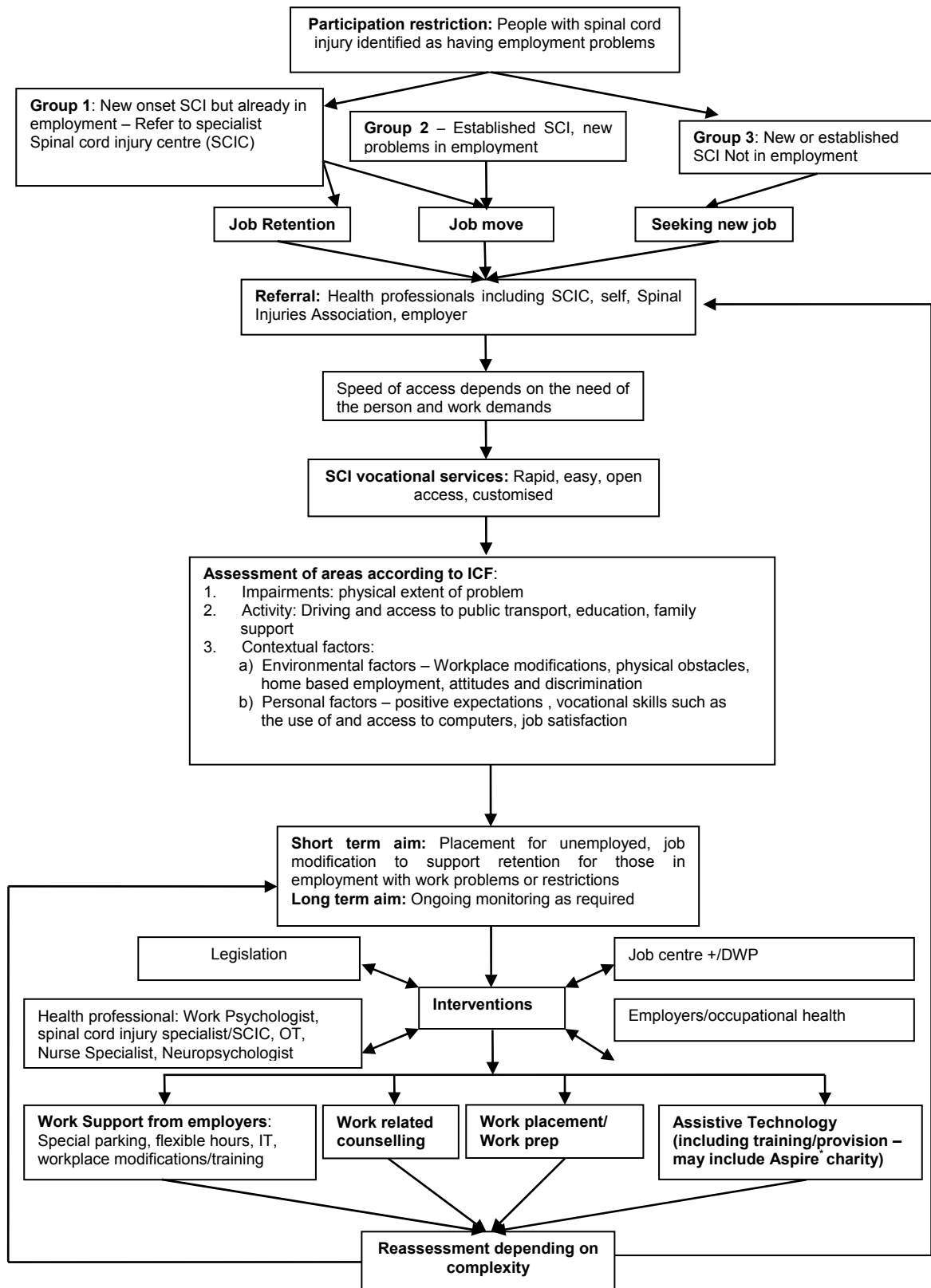
2.29 If people with SCI are experiencing dissatisfaction in employment – it may be an early warning of more significant threat, including leaving the workforce (voluntarily or involuntarily). Some have recommended on the job follow-up services, including assessment of job satisfaction, identifying positive and negative factors affecting that satisfaction, and development of interventions to reduce or remove obstacles to satisfaction.<sup>87</sup>

2.30 It may be possible to improve retention of employees by modifications to the workplace, the provision of adaptive or assistive technology, computer training, flexible scheduling (including working hours, ability to work from home) and special parking.

2.31 A work experience survey has been validated for use with employees with other conditions and may be relevant after SCI.

2.32 In order to successfully facilitate changes in the workplace, people benefit from knowledge, perceived support, belief of success and confidence they can overcome obstacles. People are more likely to succeed if they perceive their employers as approachable and have the confidence to identify, request and implement change.

## Vocational rehabilitation for people with spinal cord injury (SCI)



\*Further info - Ref 88-90

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## Vocational rehabilitation for people with epilepsy

### Aim

2.33 To enable people with epilepsy to gain or regain work or support job retention or engage in alternative occupation.

### Extent of employment problem

2.34 Epilepsy is a chronic and episodic condition and is a hidden disability. The incidence of epilepsy is estimated to be 40–100 per 100,000 people per year. The incidence has a bimodal distribution with the first peak in neonates and young children and a second peak in old age due to cerebrovascular disease.

2.35 The unpredictable course of epilepsy can have a great impact on the quality of life and finding employment.<sup>1</sup> People with epilepsy experience higher levels of unemployment compared to the general population with rates of unemployment up to twice the general population.<sup>2,3</sup> Rate of unemployment has been reported to vary from 3–49%.<sup>4-7</sup>

### Type of employment problems

2.36 People already in employment also face a diverse range of problems. People with uncontrolled seizures are more than twice as likely to experience job problems compared to those in remission.<sup>8</sup>

2.37 Underemployment is one such problem and is much more likely in those with frequent seizures<sup>2</sup> for example earning a lower salary compared to peers<sup>9</sup> or being in jobs that are below their capabilities, uninteresting and poorly paid.<sup>10</sup>

2.38 Other job problems reported are job modification or alternative placement which may lead to loss of seniority, sometimes with little or no prospect of promotion<sup>10,11</sup> and unnecessary work restrictions.<sup>12,13</sup>

2.39 There may be difficulty advancing career and many people are unable to reach the employment potentials appropriate to their qualifications.<sup>8,14</sup> Refused promotion, transfer to another department or section or exclusion from job related activities such as attending a business conference has been reported by those with ongoing seizures.<sup>8</sup> People in high level jobs too have to prove themselves to employers and colleagues.<sup>15</sup>

2.40 People with epilepsy experience loss of working time due to seizures at work or seizures outside work contributing to sick leave; reduced vocational motivation through avoidance of stressful situations at work due to fear of precipitating seizures and adverse effects of epilepsy medications affecting work performance.<sup>8</sup> Onset of epilepsy during training years disrupts career plans and a late career onset is also seen as a problem with early retirements offered.<sup>13</sup>

### Factors contributing to work problems

2.41 The vocational needs of people with epilepsy can only be addressed properly by analysing all factors that contribute to the employment problems. These factors can be grouped based on the ICF classification.<sup>16</sup>

### Impairments

2.42 Among seizure related variables it appears that frequent seizures increase the risk of employment problems.<sup>2,4,5,14,17</sup> However, seizure frequency alone is unlikely to be the cause of problems with employment. For those with uncontrolled seizures the availability of a work tolerant situation is helpful but for people with infrequent seizures who are unemployed this is likely to be due to a combination of other factors and epilepsy plays no more a role than might any other chronic disease.<sup>18</sup>

2.43 Intellectual and neuropsychological impairment has been reported to be related to employability<sup>19</sup> and neuropsychological assessments are required.<sup>20</sup>

2.44 Emotional impairments such as anxiety and depression are higher in people with frequent seizures<sup>21</sup> and this can impinge on all aspects of vocation.<sup>22</sup>

### Activity

2.45 Education is considered to be important for employment<sup>3,7,23</sup> and occurrence of seizures in childhood has an adverse effect on the level of education.<sup>24</sup> Lower levels of basic education lead to significantly lower employment.<sup>3</sup> Individuals who remain in full time education after the age of sixteen are more likely to be employed.<sup>7</sup> People with educational problems at school and continuing with epilepsy into later life have more job problems compared to those who do not have problems at school.<sup>25</sup>

2.46 Another important activity is driving and restriction of driving is perceived to be the biggest disadvantage by people with epilepsy.<sup>26</sup> Access to work is often a problem as most people with active seizures are not allowed to drive unless they have suffered from nocturnal seizures only in the previous three years. Unemployment has been found to be more in people who do not have a driver's licence.<sup>27</sup> Longitudinal studies have confirmed that those who have a driving licence are more likely to be employed in comparison to those who do not possess a licence.<sup>28</sup> Provision of transport to and from work however, is the least endorsed adjustment made by employers.<sup>29</sup>

### Personal factors

2.47 Disclosure poses a particular problem for people with epilepsy and they are hesitant to disclose their condition to employers. As employers do not make overt statements to the effect that failure to get a job is due to the diagnosis, it is not clear to the applicant if the employer's awareness of the diagnosis plays a part in the decision making.<sup>30</sup> There is also hesitation in disclosure post hire as the perception is that employers use covert rather than overt ways to get rid of the employee when the condition is found out and this uncertainty causes a lot of stress.<sup>30</sup> The UK Disability Discrimination Act encourages disclosure although the stage at which disclosure is made is not stated.

2.48 Unrealistic expectations, feeling of dependency and lower self esteem have been reported amongst those with employment problems.<sup>15,31</sup> Job seeking skills training is important for vocational aspects.<sup>15,32</sup> Vocational interest, perceived and demonstrated skills and strengths, vocational experience, previous work experience and why the person left the previous job as well as job satisfaction are also important and need to be assessed.<sup>22</sup>

### Environmental factors

2.49 Workplace discrimination and negative attitudes continue to be a problem<sup>29</sup> with only a quarter of employers knowingly employing a person with epilepsy. A quarter of discrimination occurs at the stage of recruitment but the vast majority of discrimination occurs post hire and includes discrimination in promotion and termination, harassments and disciplinary action.<sup>33</sup> Accurate figures on discrimination are not available but it appears that 1 in 40 job dismissals occur in those with onset of epilepsy post employment whilst the corresponding figures for people with onset of epilepsy prior to employment is about 1 in 7.<sup>14</sup>

2.50 Epilepsy medication has the potential to affect work performance by impairing concentration or behaviour, decision-making, causing lethargy and may contribute to forgetfulness.<sup>34</sup> Therefore awareness of the role played by epilepsy medication is necessary and appropriate drug regimes should be optimised.

2.51 Shift work may be unsuitable for some particularly when there are frequent shift changes and people are often advised to avoid shift work. Switching from one sleep pattern to another is not easy and may cause shortage of sleep and fatigue thereby reducing seizure threshold.<sup>34</sup> However, there is no conclusive evidence to support this fact.

2.52 Work restrictions may be placed due to security issues or safety issues such as working at heights or operating machinery. However, it can be non specific such as fears about the individual with epilepsy working alone. Work modification may be required in relation to this but unnecessary work restrictions can affect current work and career progression.<sup>13</sup>

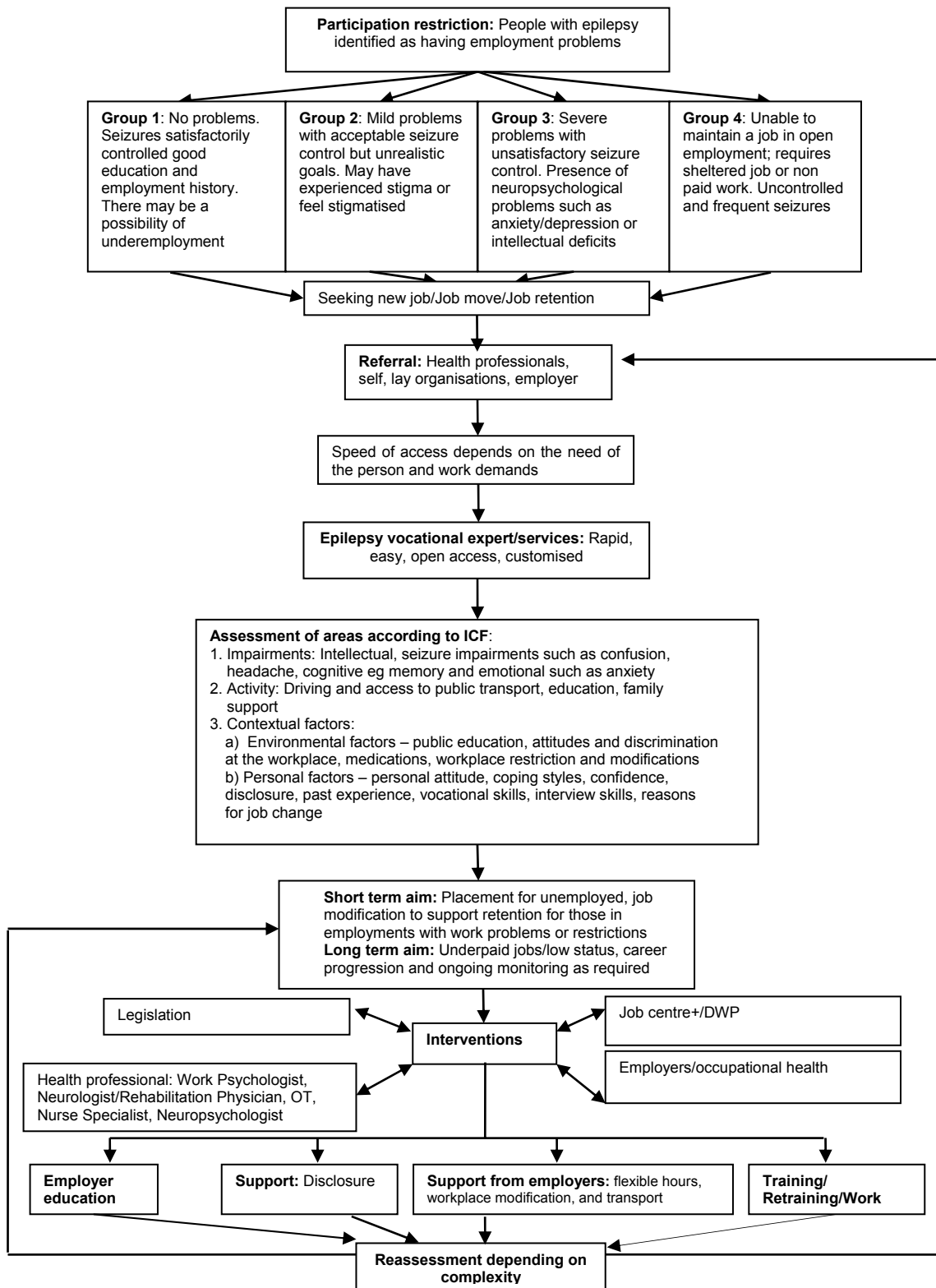
## Vocational rehabilitation for people with employment problems

**2.53** Vocational rehabilitation of people with epilepsy is more successful when undertaken by specialised vocational units catering specifically for epilepsy.<sup>35</sup> The need for a specialised programme to cater specifically for people with epilepsy has been emphasised.<sup>17,20</sup> Vocational rehabilitation programmes such as TAPS (Training and Placement Service) for people with epilepsy have been very successful with placements.<sup>32</sup> The success of TAPS is dependent on a national team providing overall planning, direction and evaluation in combination with local field staff who locate people and offer job seeking skills classes with input from employers, individual and group counselling and both client and employer education. However, ongoing monitoring is required for those who need support with placements as follow ups suggest an increase in unemployment with time<sup>36</sup> particularly in those with difficult seizure control and long periods of unemployment.

**2.54** People with employment difficulties can be grouped based on the degree of employment problems and seizure control.<sup>37</sup> These four groups are:

- Group 1: People with no employment problem. These are people with satisfactory control of seizures, a good education and employment record. There may be problems with under-employment
- Group 2: These are people with mild employment problems. These people have acceptable seizure control but have unrealistic career goals. They may have experienced discrimination or feel that they are stigmatised
- Group 3: These are people with severe employment problems. The seizure control is unsatisfactory and there are neuropsychological issues such as anxiety or depression or intellectual deficits
- Group 4: These are people who are not able to maintain open employment and require sheltered or supported work or are in non paid work. These are people with severe or intractable seizures with possible additional difficulties in learning or additional medical problems that complicate the employment situation.

## Vocational rehabilitation for people with epilepsy



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## Vocational rehabilitation for people with Multiple Sclerosis

### Aim

2.55 To enable people with Multiple Sclerosis to gain or regain work or support job retention or engage in alternative occupation.

### Extent of employment problem

2.56 Multiple Sclerosis (MS) is an inflammatory, demyelinating disease of the central nervous system, with a lifetime risk of one in 400 and the most common cause of progressive neurological disability in young adults.<sup>1</sup> Most people with MS are in full-time education or employment at diagnosis<sup>2</sup> and 90% have a work history.<sup>3,4</sup> People with MS who are working report being healthier, more financially secure, more socially active and experiencing a better quality of life than those who are unemployed.<sup>5-7</sup> As the condition progresses, however, the number of people able to remain in work decreases.<sup>2,4,8-11</sup> Estimates of work retention vary between 20 and 30% employed by 5–15 years after diagnosis.<sup>2,4,12,13</sup> The common pattern is to move from a high demand job to a less demanding job and then to retire.<sup>14</sup> In terms of disability, employment rates are reduced from 82% in early disease to 2% at an Expanded Disability Status Scale (EDSS) score of 8.<sup>15</sup> People with MS are disproportionately unemployed given their educational and vocational histories.<sup>7</sup> Not only is there a lower rate of employment for people with MS than for the general population,<sup>7,16</sup> but people with MS experience some of the highest unemployment rates among groups of individuals with severe and chronic disabilities.<sup>17,18</sup> Forty percent of people with MS who are unemployed report that they would like to return to work (RTW).<sup>8</sup>

### Type of employment problems

2.57 The reasons for unemployment (a participation restriction) have been clearly delineated and may be related to the disease itself (impairment, activity limitation) or, to the working environment (environmental obstacles, both social and physical) and the demands of the job.<sup>2,4,8,11,19</sup> Typically people with MS who are working have higher levels of physical disability than those who are not working but the levels of reported disability are not severe enough to explain the levels of unemployment. A few studies suggest that many people with MS stop working before the onset of significant physical disability.<sup>4,10</sup> There is also some evidence that people with MS don't seek help until an employment crisis develops.<sup>20</sup> It seems clear that many people with MS don't understand their legal rights.<sup>7,21</sup> In the UK people are protected under the Disability Discrimination Act<sup>22</sup> from the point of diagnosis with MS. In the US people with MS are more likely to file discrimination cases about the failure of an employer to provide reasonable accommodation, demotion and terms of employment than the general disabled population but are less likely to allege discrimination in areas of discharge, harassment and hiring.<sup>9</sup>

### Factors contributing to work problems

2.58 The vocational needs of people with MS can be addressed properly by analysing all factors that contribute to the employment problems. These are grouped based on the International Classification of Functioning.<sup>23</sup>

### Pathology

2.59 These include the unpredictable course of the disease.<sup>4,17,21,24,25</sup> In the early stages MS typically has a relapsing remitting course. The approximate rate of relapse is around one relapse every one-two years. A relapse can mean people with MS are unable to work for a period which may be as short as two weeks or as long as six months. Later on the disease becomes progressive and disability more overt. The more disabled the person with MS the more likely they are to be unemployed.<sup>2,8,12,16,19,21,25-27</sup>

### Impairments

2.60 People with MS experience a wide range of symptoms. Early in the disease course the symptoms that impact most on individuals' ability to work include fatigue,<sup>2,7,12,14,17,21,25,28-31</sup> anxiety and depression.<sup>7,17,20</sup> People with MS also describe problems with pain and heat intolerance.<sup>7</sup> People with MS don't report cognitive changes as the reason for change in work status<sup>25,32,33</sup> although concern about memory and concentration difficulties is often cited as a reason for unemployment.<sup>7,19,27</sup> Only two papers<sup>34,35</sup> identify the extent of the cognitive deficits which tend to be mild. The nature of all these deficits is that they represent 'invisible disability'.<sup>21</sup>

2.61 With disease progression people with MS develop weakness, balance problems, spasticity, sensory disturbance, difficulties with vision, and bladder and bowel disturbances.<sup>2</sup> At this point the activity limitation becomes overt. Severity of impairment does not always correspond to the restrictions in participation.<sup>28</sup>

### Activity

2.62 With disease progression people with MS report greater physical disability<sup>4,8,12,25,30,33,35</sup> that impacts on work in the following ways:

- limitation in mobility<sup>2,4,7,12,14,17,21,28,30,31</sup> making access to work difficult and movement within the workplace effortful
- poor dexterity affecting handwriting, keyboard use and other manual tasks<sup>2,14,17,21</sup>
- visual impairment resulting in difficulty with reading both written and on computer screens<sup>12,14,17,31,33</sup>
- urinary and faecal frequency and urgency with fear of incontinence<sup>7,14,17,30,31</sup>
- dysarthria resulting in difficulty using the phone, general communication and poor presentation skills.<sup>20</sup>

### Environmental factors

2.63 **Social:** Many people with MS withdraw from the workplace citing lack of information about legal rights and the support available,<sup>7,21,36</sup> poor support with job retention through workplace accommodations,<sup>2,7</sup> inflexible employment structures<sup>7,17</sup> and lack of employer/colleagues support which may develop into active discrimination.<sup>7,10,17,21,37-39</sup> Physicians may advise unemployment to manage fatigue and other symptoms,<sup>7,11,21,40</sup> and once unemployed, benefits systems may act as disincentives to RTW.<sup>41</sup>

2.64 Women with MS are more likely to withdraw from the workforce.<sup>8,10,21,27,30,37,42</sup> This may reflect the fact that many women have additional responsibilities at home. Support from family and friends is associated with women remaining in the work place.<sup>17,21</sup> Remaining in work may be at the expense of leisure and social activity.<sup>17,20,29</sup>

2.65 **Physical:** Physical obstacles include difficulty accessing work and moving around within the work environment. Other obstacles include hot rooms, open plan offices and inaccessible toilets.<sup>2,7,14,17</sup> Difficulty participating in work related social activities isolates people from their peer group and makes working lonely.

### Work demands

2.66 As physical disability increases physical tasks become too demanding.<sup>17,21,24,43</sup> However, other work demands also pose problems including jobs that require multitasking, long hours and full time work;<sup>14</sup> stressful high demand jobs are problematic for people worried about their health.<sup>29</sup> Eventually there develops a mismatch between the job demands and the individual's capacity resulting in work instability.<sup>4,21,44</sup>

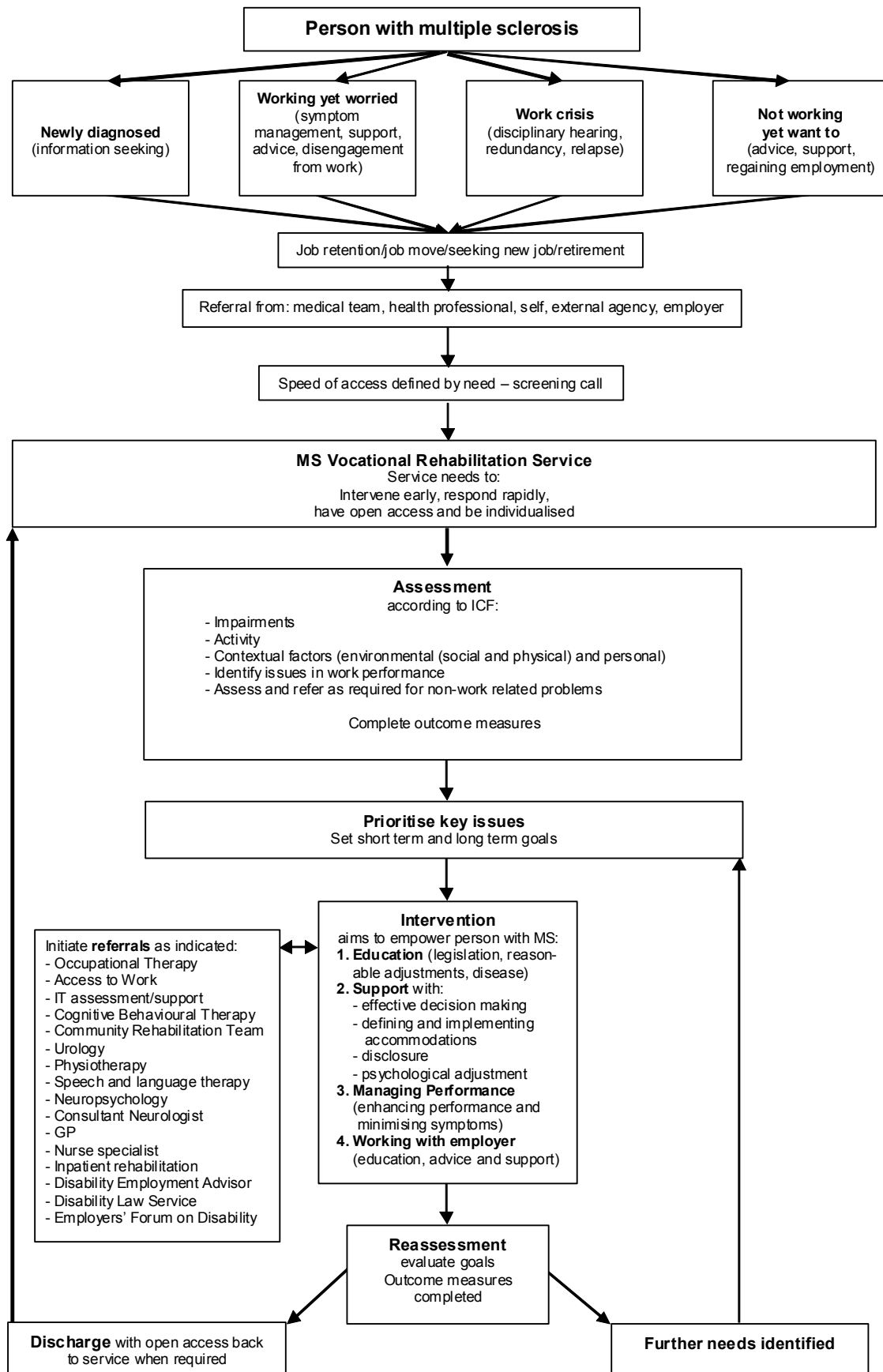
2.67 **Personal factors:** Personal factors have a significant impact on people's ability to cope with workplace demands. High educational levels protect against unemployment,<sup>19,27</sup> the reasons for this have not been clearly delineated but are likely to be related to working in an office-based environment.<sup>4,8,12,14,19,25,30,33,35</sup> Increasing age is associated with increasing unemployment (beyond that of the general population); this is likely to reflect increasing disability.<sup>4,30,33,35</sup>

2.68 Prior experience clearly influences people's response to a diagnosis of MS. The literature comments on people's concerns about disclosure in the work place,<sup>7,12,17,30,36</sup> their reluctance to anticipate future problems<sup>17,20</sup> and fear of income loss.<sup>7,21,45</sup> As a result of these factors people with MS devote inordinate amounts of energy to working to keep crisis away<sup>20,21</sup> waiting until symptoms become severe<sup>17</sup> before addressing the employment obstacles they cause. Managing the psychological adjustment<sup>4</sup> to a diagnosis of MS is challenging. Dealing with this and a high demand job can lead to stress and early withdrawal from the workplace. Levels of stress and people's perceived ability to manage this stress, plus the level of job satisfaction an employee experiences are all indicators to whether someone maintains their employment or not.<sup>46</sup> Little has been written about individual coping styles and how this may impact on work retention in MS.<sup>8</sup>

### **Vocational rehabilitation for people with employment problems**

2.69 Little has been written about the delivery and outcomes of vocational rehabilitation for people with MS in the UK. This may reflect the fact that most government sponsored programmes focus on RTW, whereas for many people with MS the problem is one of work retention. Vocational rehabilitation is being delivered by local teams but this is largely ad-hoc without formalised funding, referral patterns, evidence based interventions, specialist training or outcome measurement. Health care professionals with expertise in MS report themselves poorly equipped to manage work related issues.<sup>7,47</sup> A recent report identified what people with MS wanted from a vocational rehabilitation service and highlighted the need to either improve performance eg physiotherapy to improve mobility, compensate for changing performance eg taking a taxi to work, or modify performance ie by reducing the demands of the task. It also highlighted the need for advocacy and support with disclosure and issues around discrimination.<sup>32</sup> Research has also highlighted the need for timely intervention in people with accruing disability who are in work.<sup>48</sup> Further research is needed to identify the efficacy of different models of vocational rehabilitation, and their cost-effectiveness, and particularly for means of identifying and measuring the effectiveness of interventions that support work retention.<sup>49</sup>

## Vocational rehabilitation of people with Multiple Sclerosis



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## Vocational Rehabilitation for people with Cerebral Palsy

**2.70** People with Cerebral Palsy (CP) differ from those with acquired neurological disorders in that they have a lifetime experience of disability. Thus the term 'rehabilitation' cannot rightly be applied because these people have never been 'habilitated'.<sup>1</sup> Much of the support for people with CP has been designed around a 'myopic' vision that included only the first one-third of a life-span. Very little attention is paid to connecting and developing the remaining two-thirds of a person's life.<sup>2</sup> Few studies have been published that guide interventions to facilitate their well-being, let alone participation in the world of work.<sup>3</sup>

### Understanding cerebral palsy (CP)

**2.71** CP is an umbrella term covering a group of permanent, but not unchanging, disorders of movement and/or posture and of motor function, which are due to non-progressive, interference, lesion, or abnormality of the developing/immature brain.<sup>4</sup> They usually result in disorders of posture or movement.<sup>5</sup>

**2.72** CP is the leading cause of childhood disability. Sixty-five to ninety percent of children with CP now survive into adult life and thus an increasing number of adults with CP need medical care and social support.<sup>6</sup>

### Impairments

**2.73** CP takes a variety of forms, and is typically classified into diplegia, hemiplegia, tetraplegia<sup>7,8</sup> (to reflect the number of limbs affected with spasticity) and the presence of altered movement control (athetosis, dystonia or ataxia;<sup>9,10</sup> or a combination).<sup>10</sup> More recently it has been suggested that there are four groups – spastic, dyskinetic, ataxic and mixed.<sup>4</sup> Physical manifestations may range from mild difficulties with walking and normal manual dexterity to gross spastic quadriplegia.

**2.74** To these lesions may be added intellectual impairments, hearing and visual impairments, athetosis, epilepsy, scoliosis and communication impairments etc.<sup>9</sup> Less commonly, both health and personal independence may be affected by additional impairments eg bladder control and bowel care.<sup>5,6</sup> Comorbidities influencing personal care and life expectancy have recently been summarised<sup>3</sup> and many of these appear to be age-related.<sup>11,3</sup> Many give rise to pain which may be severe.<sup>3</sup>

### Personal factors: growing older with CP

**2.75** In general, walking ability deteriorates with increasing age relating to increased spasticity, balance difficulties, general deterioration with increasing muscle weakness, contractures of the weight-bearing joints and/or osteoarthritis.<sup>12</sup> Deterioration is often noted at puberty but tends to have more impact over the age of 45 when increasing difficulties in working may result.

**2.76** Critical periods in the life of an individual with CP include:<sup>13</sup>

- critical periods of childhood and adolescence (eg time of diagnosis, changing schools etc)
- seeking employment
- leaving home for the first time
- parents ageing and becoming less able to support disabled young people
- times of family crisis etc.<sup>13</sup>

### Transition – period of prevocational training?

**2.77** Although preparation for the world of work begins preschool,<sup>14</sup> the reality hits home in the transitional years - from commencement of secondary education through puberty and up to leaving full-time education.

**2.78** Physical problems faced during transition include increasingly impaired mobility related to the growth spurt.<sup>5</sup> Children with CP, when they leave school, are often immature – physically, emotionally, socially and psychologically; although seldom 'sick'.<sup>13</sup>

## Extent of employment problems

2.79 Those with CP have reduced chances of competitive employment, even as college graduates and they are less likely to move jobs than those who are able-bodied.<sup>15</sup>

2.80 Understanding the extent of the problem is complicated by the varied definitions of employment, the inclusion of sheltered work, or part-time work etc. One study with a control group showed that 55% of those studied with CP in Denmark were not in competitive employment compared with only 4% in the control group<sup>16</sup>. Employment rates in western countries probably vary between 20%<sup>17</sup> and 50%.<sup>18,19,9,20,12,21,22,23</sup> One fifth of a wheelchair dependent group in Sweden were in part-time employment.<sup>24</sup> Employment opportunities for those with physical disabilities in developing countries are probably greatly reduced.<sup>25,26</sup>

## Factors influencing employability

2.81 Successful integration of an individual with CP into work involves the resolution of all the problematic domains in their lives. Factors that enhance or retard employment potential are both intrinsic and extrinsic.<sup>27</sup> There is some evidence that extrinsic factors may be more important than intrinsic ones.<sup>28</sup>

### Intrinsic (relating to the impairments)

2.82 **Clinical subtype of CP.** People with hemiplegic CP have the greatest chance of being in competitive employment.<sup>16,7-9,18</sup> For those with very severe disabilities such as spastic quadriplegia,<sup>1,29</sup> the time available for prevocational or vocational training may be small compared with the (extra) time and effort needed for activities of daily living etc.<sup>30</sup>

2.83 The extent of health problems may create an additional barrier to working.<sup>31</sup>

2.84 **Epilepsy**<sup>7,16,32</sup> can disrupt attendance at training or employment and may be exacerbated during stressful periods of life eg moving away from home.<sup>23,32</sup>

2.85 **Intellectual (cognitive)** difficulties may be present in a third to a half of people with CP<sup>7,9,19,23</sup> and the extent of learning impairment is 'likely to be the most important single personal factor for employment'.<sup>7</sup> However, in the majority, a complex inter-relationship between intelligence, type of CP, level of self-care, and level of education determines future employability.

2.86 **Innate characteristics** such as determination, motivation,<sup>33,14,21,34</sup> maturity<sup>35,23</sup> or career immaturity (lack of awareness of work responsibilities), and (un)realistic assessment of abilities, career interests and social skills also play a role.<sup>35</sup>

2.87 **Appearance, communication, reading, computing and social skills.**<sup>14</sup> Due to communication problems and/or physical appearance, individuals with CP are likely to experience negative reactions from people unfamiliar with the condition<sup>36</sup> – see stigma below.

### Extrinsic – Personal factors

2.88 **Living alone.**<sup>37,5,19,31</sup> Lack of social integration (eg living at home with elderly parents) correlates highly with the degree of employability, school achievement, economic status and degree of social integration.<sup>8</sup> Thus encouraging optimal levels of self-care for these young people becomes essential. However, many children and parents may choose to be dressed within 10 minutes rather than dress independently if it take 75 minutes.<sup>14</sup> Many studies confirm that the majority of those more severely affected remain living with their parents,<sup>17</sup> with restricted opportunities for those with severe disabilities to socialise, meet potential partners etc.

2.89 **Family.** An emotionally supportive family seems very important.<sup>18,19,29,33</sup> Conversely, non-acceptance of the disability by the family of the disabled child may create dependency behaviours and cultural/economic factors interface with implications for working outcome.<sup>14</sup> Some parents are considered as creating obstacles to participation, through overprotection.<sup>24</sup> Others may be employed as personal assistants with very amicable results. Parents of children with CP are less likely to be in full time work and to have lower incomes than a general population of caregivers.<sup>38</sup>

2.90 The level of education is critical<sup>7,15</sup> and in many parts of the world the ability to educate individuals in mainstream rather than special schools seems important.<sup>22,33</sup> Those with high

university/college grades are more likely to be employed but the degree of vocationally-orientated counselling is likely to be important.<sup>15</sup>

**2.91** Educational obstacles to work include inadequate or inappropriate educational programmes, particularly in literacy skills<sup>39</sup> and provision of employment counselling from those with inadequate understanding of the personal nature of disability issues.<sup>40</sup> Educational activities can also be therapeutic and when there is an end-product that can be sold, then self-image is enhanced.<sup>41</sup> Adult education may be vital for those who missed out on aspects of mainstream schooling eg literacy.<sup>37,42,43</sup> College graduates have stressed that social and personal development appears just as important as their academic training.<sup>15</sup>

**2.92** Education for people with severe physical and or intellectual impairments is a juggling act embracing the needs for education, training for independent living, time for physical rehabilitation and counselling as well as preparation for the world of work. Work experience seems important – ‘many severely disabled young people are over-schooled and underskilled’.<sup>44,45</sup> Work placement during education can provide ongoing training covering the acquisition of negotiating skills, the ability to form relationships with co-workers etc.<sup>45</sup> Individual educational needs will vary and need to be provided in both fully integrated and highly specialised schools. There is a consensus about the value of mainstream (or integrated) education.<sup>42,22,33</sup> Factors reflecting the need for special education are the extent of both intellectual and physical disabilities – particularly walking capability.<sup>7</sup> Education needs to facilitate consideration of work potential in areas that the individual finds interesting.<sup>45</sup>

### **Environmental factors - Extrinsic**

**2.93 Access to work**<sup>37,33,42,20,12,46,14,25,35</sup> includes the ability to travel alone and get in/out of a car independently<sup>47</sup> or to drive<sup>46</sup>. Transport obstacles<sup>21,34</sup> may be overcome with use of legislation<sup>48</sup> and with adequate training to give users the confidence to use it.<sup>35</sup>

**2.94 Other factors** include housing<sup>37,20</sup>, the local labour market,<sup>33,40,21,34</sup> limited state assistance<sup>46,24</sup> and the need for personal assistance at work.<sup>2,49</sup>

### **Other obstacles to employment**

**2.95 Income** is often limited and may also contribute to difficulties achieving work<sup>17</sup> and include the so-called ‘benefits trap’.<sup>2,14</sup> Health insurance may be difficult for those with disabilities.<sup>39</sup>

### **Discrimination/stigma**

**2.96** An assumption that a person with a disability is not capable of working<sup>14</sup> may have profoundly disabling consequences<sup>50</sup> and result in social isolation.<sup>8</sup> In America, discrimination appears more common in the retail or service sectors, often in relation to hiring.<sup>51</sup> Negative public attitudes towards assistive technology such as communication aids may play a role.<sup>39</sup>

**2.97** Recently, legal mandates in education and environmental access have facilitated positive change for those with CP.<sup>18</sup> Nevertheless, reports of workplace prejudice and denial of learning opportunities to people with CP continue.<sup>39</sup> This may be inadvertent; individuals with CP have commented that their colleagues are ‘too shy to tell me what I am doing wrong’.<sup>39</sup>

### **Employment sector**

**2.98** There are increased opportunities for employment, related to improved technology and home support services.<sup>18</sup> Surveys reveal employment in a variety of sectors,<sup>21,33,34</sup> including light engineering.<sup>35</sup> More recent studies suggest that those with CP are more likely to be employed in offices and using computers.<sup>23,52,40</sup> In Denmark, those in competitive employment were more likely to be working in health and social welfare, offices, information technology and public administration than controls. They were less likely to be employed in commerce or manufacturing.<sup>16</sup> Half to three quarters of those in competitive work were in jobs that relied almost exclusively on the use of computers,<sup>6</sup> which may explain why office work provides the largest source of employment for people with traumatic brain injury and CP.<sup>53</sup>

**2.99** People with CP may have retention rates at six months up to 81%.<sup>53</sup> For those who did not maintain employment at six months, the person initiated separation themselves in 62% of cases, with medical/health reasons being the most common (15%) although a small group resigned to take a better job (8%).<sup>53</sup>

**2.100** Working from home has historically been difficult as supervision and encouragement is not easy to provide,<sup>35</sup> but it does facilitate the ability to work at one's own pace.<sup>40</sup> A minority of those working with CP are self-employed.<sup>18</sup> Usually self employment is an adjunct to benefits received from the government and provides financial benefits, enjoyment of work activities, fulfilment of personal expectations and promotion of societal change.<sup>39</sup> Technological advances assist home working<sup>54</sup> and emails allow for an 'individualised pace in the creation of messages'.<sup>39</sup> Negative aspects to self-employment are the reduction of benefit income<sup>39</sup> and social isolation.<sup>40</sup>

## Vocational rehabilitation (VR)

**2.101** Follow-up is needed for medical reasons,<sup>55</sup> in addition to the need to cope with adults who find life less manageable, meaningful and comprehensible.<sup>56</sup> A pre-existing disability often distracts health professionals from thinking about the development of additional pathologies<sup>5</sup> eg new spinal pathology is a common cause of declining function.<sup>5</sup>

**2.102** Fatigue and muscular/functional weakness may be overcome with aggressive physical rehabilitation.<sup>57</sup> Self confidence can be greatly improved with good rehabilitation, particularly if it reduces time in activities of daily living – a prerequisite to having the opportunity to go to work.<sup>58</sup>

**2.103** Occupational therapy aims to improve self-care which improves the sense of self-worth,<sup>59</sup> developing the necessary skills to perform activities of daily living which lead on to becoming a productive worker.<sup>59</sup>

**2.104** Education needs to be supplemented by programmes that aim to develop self responsibility, emotional stability, and the integrity needed to accept social and civic roles and responsibilities.<sup>43,13</sup> Such programmes can develop from out of school activities such as summer camps, sport and give opportunities for counselling of all members of the family<sup>43,13</sup>. Arranging for these young people to meet adults with cerebral palsy 'with similar disabilities who are now gainfully employed taxpayers and/or are happily married' help both children and parents<sup>43</sup>. Payment to the adolescent for 'chores done can teach concepts of compensation for task completion and quality of work', thus increasing self-esteem.<sup>14</sup>

**2.105** Several tasks have been identified as important in transition planning<sup>10,14</sup>

- separation and individuation from parents/creating new relationships<sup>13</sup>
- development of social skills<sup>13</sup>
- acceptance of responsibility for decisions and behaviour and the consequences<sup>13</sup>
- development of sensitivity to evaluation and feedback
- consolidation of identity, self image<sup>60</sup> and establishment of an adult sexual role
- maturation of vocational choices and development of a career identity, eg getting work experience from school.<sup>10,45</sup>

**2.106** As these areas may not be well addressed, people with CP may present with an unrealistic appraisal of abilities due to limited contact outside family and therapeutic settings.<sup>36</sup> Young people themselves state the importance of including self-care and socialisation skills as part of their education.<sup>61</sup> Although the child's body may mature, the mental, emotional and social state of the child may lag behind.<sup>14</sup>

**2.107** Transitional programmes, often residential, can be utilised to respond to these needs, for both parents and siblings. However on-going support may be required for years after leaving school.<sup>34</sup>

**2.108 Equipment.** This may range from straightforward mobility aids such as lower limb orthoses (splints), walking aids<sup>21</sup> and wheelchairs<sup>55,6,18,48,62,12</sup> to more sophisticated environmental control units.<sup>5,63</sup>

**2.109** Many require specialised seating for adequate support to enable use of their arms freely instead of relying on them for sitting balance.<sup>62</sup> Many users need both powered and manual wheelchairs<sup>12</sup> as access to vehicles and many buildings and activities is too difficult for users of powered wheelchairs.<sup>64</sup> Powered wheelchairs are of enormous value<sup>6,18,27,12</sup> and are often

preferred over manual chairs for greater ease of mobility in order to save energy for the physical demands of their job.<sup>18</sup>

## Communication

2.110 Augmentative assistive technology (AAC) can transform lives by facilitating communication.<sup>27,39</sup> Advances in switching technology facilitate the linking of communication, environmental control and electric wheelchairs.<sup>62</sup> Devices may be unreliable, too slow for the employment market and frequent updates may take a long time to master<sup>39</sup>. Negative public attitudes towards assistive technology eg AAC may contribute towards stigma and discrimination.<sup>39</sup>

**Table 2.1 Recommendations for users of AACs wishing to be self-employed<sup>39</sup>**

|                         |                                                                                                                                                                                                                                                                                                                                                                                    |
|-------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Individuals who use AAC | Take practice jobs<br>Network with future co-workers and employers<br>Demonstrate competence<br>Learn social interaction skills                                                                                                                                                                                                                                                    |
| Educators               | Communicate high expectation<br>Listen to students<br>Set up a mentor programme                                                                                                                                                                                                                                                                                                    |
| Technology developers   | Add cellphone capabilities to AAC devices<br>Add business applications eg calendars, contact databases<br>Develop computer interpreter for dysarthric speech<br>Add automatic device adjustment to changing noise or lighting conditions to AAC devices<br>Manufacture more durable and waterproof devices<br>Provide synthesized speech that communicates personality and emotion |
| Policy Makers           | Legislate to fight discrimination<br>Economic support eg universal healthcare<br>Give individuals control over care assistant funding                                                                                                                                                                                                                                              |

2.111 The techniques that have been used to facilitate employment for those with CP include:

- advocacy<sup>37,13,54</sup>
- job modification eg engineering adaptations or machine/work station modification<sup>2,48</sup>
- personal assistants<sup>40</sup>; may be needed more for personal care tasks rather than in the workplace and may derive from co-workers and/or volunteers<sup>42,37,42,53</sup>
- adjusted working hours<sup>37,53</sup> and financial advice/support for employers as well as the disabled employee
- work trials and work-site rehabilitation/training<sup>13,14,35,36,37,45,48,53,65</sup>
- working from home.<sup>35</sup>

2.112 They are all predicated by the need for appropriate education and prevocational training which includes the development of the skills needed for working.

2.113 Vocational training may occur from home or college, but for some with profound needs, a residential training centre able to accommodate the physical, environmental and psychosocial needs of young people seems desirable and may be provided by the State, the voluntary sector or a combination of both.<sup>1,2,13-15,21,32,34,35,65-69</sup> Many places are specifically designed for (and sometimes run by) CP charities, but others provide training for those with disabilities of different causes.

2.114 Vocational assessment will involve analysis of all the issues raised above and the detailed work up to facilitate an individual gaining employment which may include financial assistance eg with social security benefits, handling of money etc<sup>37,28</sup>, assistance with family issues,<sup>37</sup> medical

insurance,<sup>37</sup> pre-employment paperwork,<sup>37</sup> uniforms<sup>37</sup> and the scheduling of medical appointments, social life, family respite etc.<sup>37</sup> Facilitators of vocational rehabilitation include advocates eg case managers, family, job coaches and vocational counsellors. Job placement will include the need for the cooperation of employers and employees to match the needs of the disabled employee to the needs of the employer<sup>70</sup> and may require modifications to the environment followed by preliminary trials at work and on-going support having commenced work. Worksite support/training may involve issues such as stress management, self-monitoring of behaviour strategies, medication compliance etc.<sup>37</sup> Transport to and from work needs addressing, as will the needs for personal assistants in the workplace (as well as to facilitate independent living at home).

### **Sheltered workshops**

2.115 One careful study of a sheltered workshop with workers having severe intellectual disabilities found that reward payments were counterproductive, and that group counselling had helped them to shift their need for support from the workshop supervisor to their peers, which was considered highly advantageous. One person moved from the sheltered workshop into competitive employment<sup>67</sup>. For some decades it has been clear that, given appropriate training, many 'of the more severely handicapped can hold their own in competitive employment'.<sup>35</sup> Sheltered employment, however, has been widely seen as effectively segregating those with developmental disabilities<sup>37</sup> and has been superseded by the concept of 'supported employment'.

### **Supported employment**

2.116 'Supported employment is designed to assist people with severe disabilities in obtaining and maintaining integrated competitive employment through specially planned supports'.<sup>37</sup> When working well, supported employment enables those with disabilities to learn new skills and enables non-disabled co-workers/supervisors to work with disabled colleagues, thus facilitating an integrated workplace for all employees.<sup>37</sup> Individual placement allows choice, self determination and empowerment.<sup>37</sup>

### **Recent developments in collaborative working**

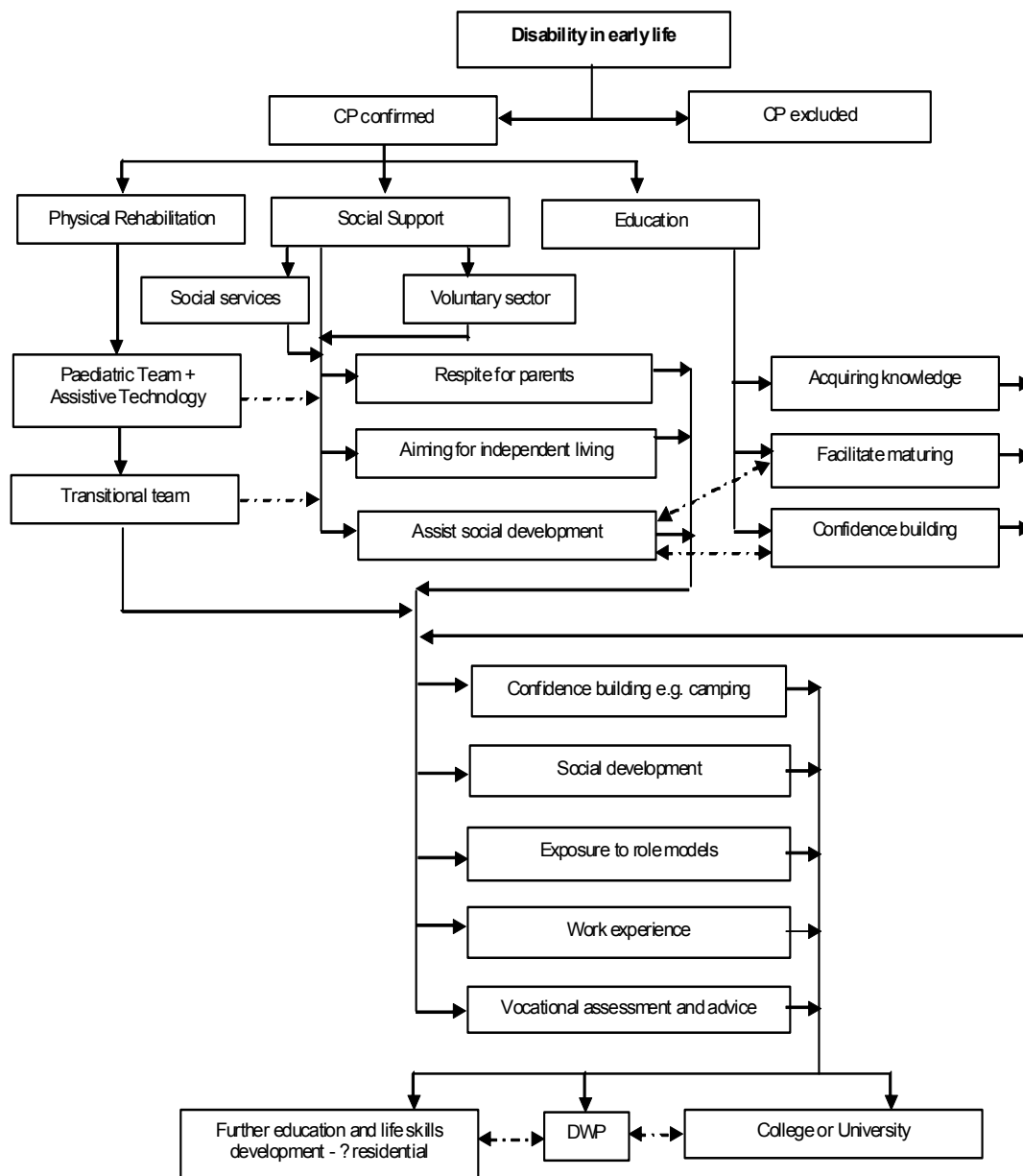
2.117 The use of 'pairing', matching individuals with differing impairments has been reported.<sup>69</sup> Groups of individuals may work together eg 'mobile work crews' consisting of four to eight workers and one supervisor who often perform custodial work, grounds maintenance, house cleaning, janitorial services or other related work,<sup>37</sup> and offer another model of supported employment.

### **Business/Industrial developments**

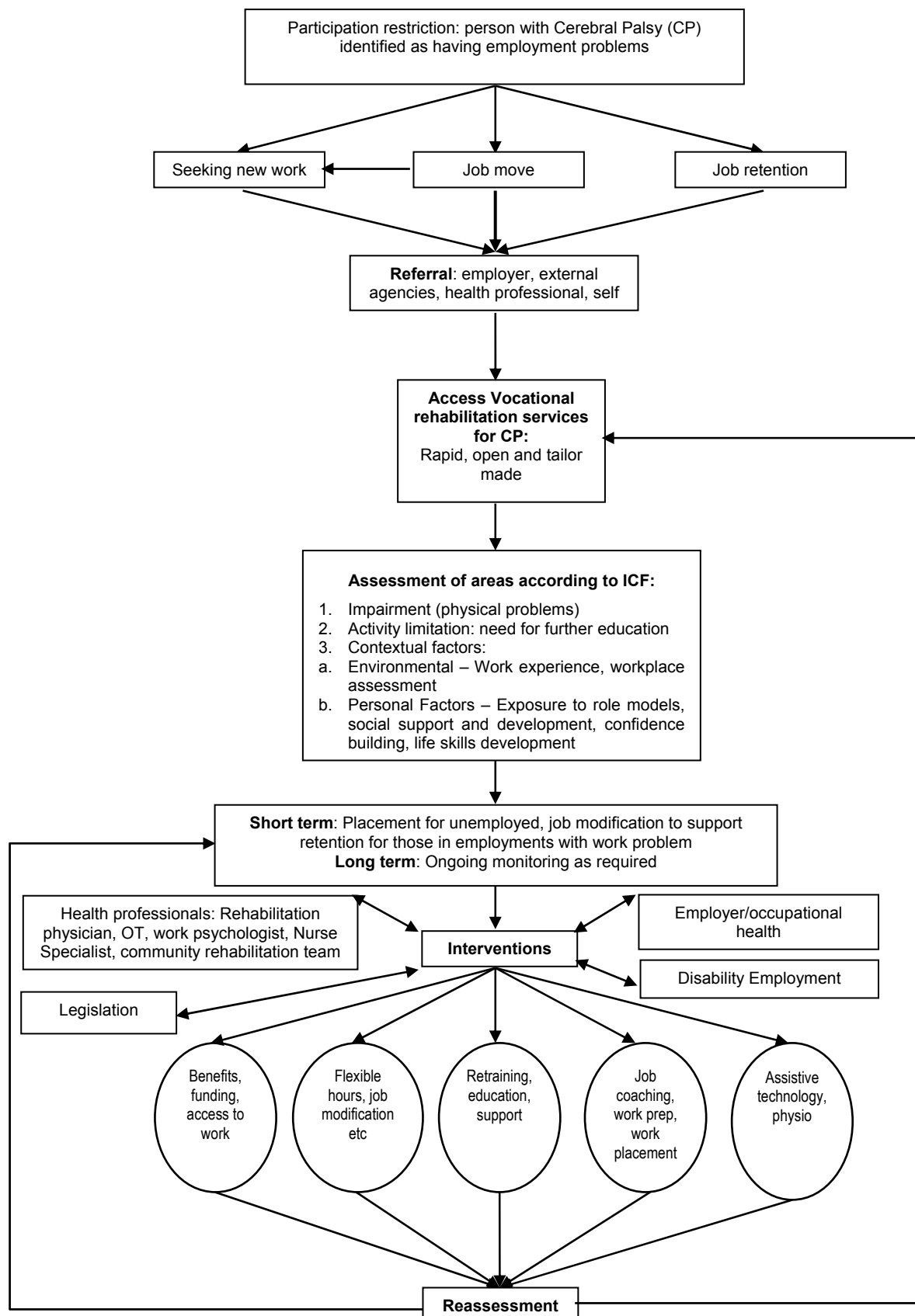
2.118 Programmes have been initiated in Australia and the USA where both able bodied and disabled employees work together in primary manufacturing facilities. Such enterprises may be non-profit making, investing profits in supporting the costs of transportation, and the medical and paramedical support services needed by employees with severe disabilities. One advantage of such a system is that some employees may graduate into mainstream employment, but if such ventures fail, they can 'flow back' into the buffer-zone industry. Another innovative development is to link individuals with complementary skills together within a production facility or sheltered workshop eg linking those with intellectual disabilities with those with cerebral palsy. This enables those with predominantly physical impairments (and impaired hand function) to remind those with intellectual disabilities of the work to be done, with demonstrated increased productivity.<sup>69</sup> Some charities have set up their own factories specifically for those with CP,<sup>35</sup> and in some countries companies have been set up specifically to employ people with disabilities eg Remploy in the UK.<sup>71</sup>

2.119 There is now increasing movement into the establishment of small business enterprises. Thus Social Firms UK aims to create employment opportunities for disadvantaged people through the development and support of Social Firms. Social Firms are market-led businesses that are set up specifically to create good quality jobs for people severely disadvantaged in the labour market.<sup>72</sup>

### Potential routes into sustained employment



### Vocational rehabilitation of people with Cerebral Palsy (CP)



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## 3 Service Summaries

### NHS services

3.1 A wide range of NHS staff are involved in supporting people with long-term neurological conditions (LTnCs). Rehabilitation Medicine (RM) physicians are able to provide expertise and support for those with LTnCs requiring vocational rehabilitation. All RM physicians are now required to train in this area. The RM physician will usually work closely with occupational therapists and clinical psychologists. However, where vocational requirements are more straightforward, any suitably experienced health professional may liaise directly with Occupational Health Services, Disability Employment Advisers or sometimes directly with an employer seeking advice about eg workplace access for someone with mobility difficulties.

### Occupational Health services

#### Occupational Health provision in the UK

3.2 Provision of Occupational Health (OH) for working age adults is not a statutory function for the NHS or employers in the UK and consequently is at the discretion of the employer. However a number of employers in the UK provide such services as an employee benefit and/or to ensure employers are compliant with specific aspects of health and safety and employment legislation. Survey data indicates that 98% of public and 36% of private sector employees have access to an OH professional through their employer. Small to medium sized enterprises (<250 employees) employ about 50% of working adults in the UK but generally have no access to OH support (<5%).

3.3 Several delivery models for OH services exist in the UK including 'in house' provision in many large public and private sector employers (eg services for NHS staff) or by private provider services who may provide comprehensive or ad hoc support, dependent on the contract with the employer. OH services may either be medically led or, more frequently, nurse led with sessional OH physician input. Whilst some practitioners have completed specialist OH physician or nursing training, some advice may be provided by staff with no higher qualification in OH. Consequently the level of OH and clinical knowledge provided by OH professionals varies between employers.

#### Role of Occupational Health services in vocational rehabilitation

3.4 Most OH services act in an advisory capacity for employers and employees. OH advice assists employers in understanding their legal responsibilities to their employee/job applicant under employment and health and safety law, and informing business decisions relating to reasonable workplace adjustments and ongoing employment. OH advice is based on insight into both the clinical aspects of the neurological impairment, and the specific duties and demands of the employee's role.

3.5 OH involvement with employees with a neurological condition is most likely to arise in relation to:

- fitness for employment of job applicants
- fitness for return to work (RTW) of employees experiencing sickness absence
- situations where management concern has been expressed about the health and safety or performance of affected employees.

3.6 Although in practice many employees choose to share their diagnosis of LTnCs with their employer, employers have no legal right to know the diagnosis or clinical detail of an employee's condition. Indeed employees have a right of confidentiality contained within the Data Protection Act<sup>1</sup>. However, the legitimacy of an employer seeking responses to a range of operational questions is accepted within clinical ethical guidance and civil law. These relate to (where relevant):

- likely duration of absence
- likely residual disability on RTW
- likely duration of any such disability
- adaptation in the workplace to overcome the functional effects of disability

- impact of disability on performance and/or attendance
- impact of disability on health and safety
- consideration of alternative employment with the same employer.

**3.7** OH practitioners frame advice to employers on the basis of clinical insight into the employee's condition, frequently by contacting treating and rehabilitation services, and also an understanding of how these employment specific questions relate to the specific demands of the employee's role. Subsequent communication between OH services and the employer, which may include a case conference including therapeutic and rehabilitation professionals, should be framed within the terms of the employment specific issues rather than discussion relating to the clinical detail of the employee's condition. Clarification of the operational questions listed above by the OH professional enables the employer to: determine what can be operationally accommodated to assist the employee in fulfilling their contract; to comply with relevant employment, discrimination and health and safety legislation; and to respect the employee's right of confidentiality over their health details. Information provided to employers by OH services is advisory in nature, and employers are not required to comply, although such advice is normally applied if it can be accommodated within the operational requirements and resources of the organisation.

**3.8** 'In-house' OH services have long term service provision relationships to their employers, as frequently do independent OH service providers. As such, long term follow-up of employees with neurological disorders, particularly if progressive, could in part be undertaken in OH. Long term care planning can include follow up by OH services with re-referral to vocational rehabilitation services if clinical circumstances change.

**3.9** The criteria for the release of occupational ill health early retirement pensions, when in place, differ between schemes. OH services are frequently involved in decisions regarding the release of these benefits and can often provide general guidance to employees regarding the terms of the scheme within the context of their disorder.

**3.10** The Disability Equality Duty introduced within the Disability Discrimination Act (2005)<sup>2</sup> requires public sector employers to ensure that their workforces reflect the disability profiles of their local communities. As such employers have an additional duty to facilitate the employment and retention of disabled staff. Collaboration between vocational rehabilitation services and OH services for these employers should be considered, particularly as a way of facilitating the return of those with neurological conditions to the workplace after a period of joblessness.

### **Liaison with Occupational Health services**

**3.11** Where an employer sponsors the provision of occupational health advice the employer is likely to seek the advice and involvement of the OH service in any programme of vocational rehabilitation or prior to significant employment decisions, (such as decisions to recruit, implement capability procedures or in the assessment of ill health retirement benefits). When support is being provided to an individual, whose current or possible intended employer has access to an OH service, vocational practitioners should consider liaison with the service, subject to informed consent.

**3.12** The benefits of collaboration include more efficient use of resources and an opportunity for the vocational practitioner to gain an insight into economic considerations of pertinence to the employer in relation to the local sustainability of workplace adaptations. Identification of the latter helps potential obstacles to RTW to be considered early and within the specific context of the individual's work.

### **Access to Occupational Health services**

**3.13** When employers do not have in-house provision or access to OH services these can be obtained from commercial providers or through NHS Plus providers. NHS Plus is a source of OH advice provided by the NHS specifically for small and medium size enterprises, and can be accessed via the \*NHS Plus website.

## Jobcentre Plus services

### Jobcentre Plus

3.14 Jobcentre Plus is an executive agency of the Department for Work and Pensions, providing a service for people of working age who are looking for work or claiming benefits. The aim of the department is to 'promote opportunity and independence for all', through modern customer-focused services. Jobcentre Plus plays a major role in delivering this aim through helping people into work, helping employers fill their vacancies, and providing people of working age with the help and support to which they are entitled (see [Jobcentre Plus - DWP](#)).

### Jobcentre Plus Advisers

3.15 All Jobcentre Plus customer-facing staff receive disability awareness training. Advisers working in Pathways to Work (**Pathways Advisers**) are specialist advisers, whose role is to support people with health conditions or disabilities who are claiming Employment and Support Allowance (ESA) or incapacity benefits. Their training focuses on health issues in the context of work, and facilitating specific approaches to job search, which can lead to effective job outcomes together with improvements in individual well-being.

3.16 Specialist Jobcentre Plus services for people with disabilities can be accessed via the **Disability Employment Adviser (DEA)**. DEAs focus on individuals with more complex and substantial employment support needs, providing advice and support to disabled people who are either having difficulty in getting a job or who are in employment but concerned about losing their job because of issues relating to their disability.

3.17 DEA training enhances the training that is provided for other Jobcentre Plus advisers, giving them the skills to conduct effective interviews with people with a range of disabilities. DEAs can provide advice about the range of specialised support available for disabled people, such as WORKSTEP, Work Preparation, Residential Training Colleges and Access to Work (see below).

3.18 **Work Psychologists (WPs)** have (or are supported towards achieving) recognised post-graduate accreditation in occupational psychology. At present this involves gaining Chartership within the British Psychological Society (BPS) and full practitioner membership of the BPS Division of Occupational Psychology. In July 2009 regulation of occupational psychologists passed to the Health Professions Council (HPC).

3.19 WPs undertake additional in-service training programmes to enable them to deal effectively with 'harder to help' customer groups and those facing complex employment scenarios. This training includes a bespoke course on brain injury and is supported by an open-learning practice guide. A key aspect of WPs' work is to undertake employment assessments to enable individuals to identify an appropriate and realistic job goal - including training or development needs (eg work preparation) and work solutions which will enable them to progress towards and successfully perform in this job goal. WPs work closely with DEAs to identify appropriate work preparation provision that will meet the work-related needs of the individual. In partnership with DEAs, they undertake interventions with employers to help retain disabled/disadvantaged people in work. They also provide on-going coaching, mentoring and upskilling of DEAs.

### Government-funded programmes

3.20 Following customer assessment, Jobcentre Plus staff have access to a number of government-funded programmes which can be utilised to facilitate a person's RTW - including those listed below (see also [Directgov](#)).

### Pathways to Work

3.21 Pathways to Work is an initiative within Jobcentre Plus which has been designed specifically for people with health conditions or disabilities who are claiming Employment Support Allowance (ESA) or incapacity benefits, to help to improve their opportunities for employment. Externally commissioned research shows that Pathways to Work increases the chances of a person being in employment after 18 months by around 25%. This initiative is currently delivered via two routes: Jobcentre Plus-led Pathways to Work and Provider-led Pathways to Work (see [Directgov](#)).

**3.22 Jobcentre Plus-led Pathways to Work** is currently operating in 40% of the country. The process offers extra support through:

- mandatory work-focused interviews at regular fixed points during an individual's claim. Although primarily aimed at new customers, Pathways to Work is also available, on a voluntary basis, to existing customers and those not required to take part in Work Focused Interviews (WFIs), such as the [ESA Support Group](#)
- access to a range of programmes to support the individual in preparing for work. 'Choices' is the name by which the full range of employment, training and rehabilitation programmes is known in Jobcentre Plus-led Pathways to Work districts. The Choices package enables advisers to provide tailor-made support to ensure that people are neither written off, nor write themselves off, as being too ill to work
- the Condition Management Programme which is delivered on behalf of Jobcentre Plus by the NHS and the Department of Health (DoH), and aims to help the individual to manage their health condition or disability so that they can get back to work
- [financial incentives](#), particularly focused on supporting the initial steps back to work, such as the RTW Credit
- in-work support (in the form of coaching and mentoring), which is available to all customers who need it when they first RTW, in order to help them stay in employment.

**3.23 Provider-led Pathways to Work** are delivered in 60% of the country by external contractors. Under this initiative:

- Jobcentre Plus will conduct the first in the series of work-focused interviews and the provider will deliver the remainder
- people may have access to a Condition Management Programme which is either delivered in-house by qualified health practitioners or is sub-contracted to specialists
- providers have the flexibility to modify the range of programmes that is available to people in order to tailor provision to their needs. Therefore the support available in Provider-led Pathways areas may differ from that delivered in Jobcentre Plus-led Pathways to Work areas
- The RTW Credit is available to eligible people and is paid through Jobcentre Plus.

A summary of the provision currently available under both the Jobcentre Plus-led and provider-led Pathways to Work is provided in Table 3.1.

## Specialist Jobcentre Plus services for people with disabilities

### Access to Work

**3.24** Access to Work (AtW) provides advice and practical support to disabled people and their employers to help overcome work related obstacles resulting from a disability. As well as giving advice and information to disabled people and employers, AtW pays a grant through Jobcentre Plus towards any extra employment costs that result from a disability. This covers a percentage (up to 100%) of the total costs of approved support, depending on length of employment, what support is needed and whether the person is an employee or self-employed. AtW might help pay for:

- communicator support at interview, which meets the full cost of hiring an interpreter to remove obstacles to communication at interview
- a support worker, which allows the applicant to use the services of a helper; types of support might include reading to a visually impaired person, communicating for a hearing-impaired person via sign language, providing specialist coaching for a person with learning difficulties, or helping a person with care needs
- specialist aids and equipment to help a disabled person to function in the workplace
- adaptations to premises or to existing equipment
- help with the additional costs of travel to work, or in work for people who are unable to use public transport.

**3.25** AtW support may be accessed directly by an individual, by contacting their nearest regional Operational Support Unit (OSU) which deals with Access to Work first contact and enquiries or via Jobcentre Plus Advisers or Pathways Advisers. More information on your nearest AtW Operational Support Unit can be found at [Jobcentre Plus - Customers](#).

### Job Introduction Scheme

3.26 The **Job Introduction Scheme (JIS)** seeks to assist people with a disability in starting a new job - in situations where the disabled applicant is considered suitable, but the employer has genuine doubts about the individual's ability to cope with the proposed job or place of work. JIS provides a weekly grant, paid to the employer, to help towards wages or other employment costs. The job may be full time or part time but must be expected to last for at least six months. JIS is for use at the discretion of Jobcentre Plus staff, usually by Disability Employment Advisers (DEAs). It is paid for the first six weeks of employment but may, in exceptional circumstances (with the agreement of the DEA or nominated officer), be extended to 13 weeks. An application must be made before the job starts.

### Work Preparation

3.27 **Work Preparation** is an individually tailored programme designed to help people with a disability or health condition to RTW after a period of sickness or unemployment. Work Preparation can also be used to help people who are at risk of losing their job because of their disability by helping them to overcome difficulties that are affecting their work. The programme is run under contract by Work Preparation providers from the private, voluntary and public sectors.

3.28 Jobcentre Plus recognises brain injury as a specialist area and there is support available throughout the country, via both brain injury specific providers and those offering support across a range of impairments. Although each person has specific needs, the broad areas which are addressed during the Work Preparation programme include:

- occupational decision-making
- job-finding behaviours
- job-keeping behaviours.

3.29 It should be noted that Work Preparation programmes are provided for those individuals who are likely to be capable of entering work or training by the end of the programme.

### WORKSTEP

3.30 WORKSTEP is the current supported employment programme, introduced in April 2001 through which a provider offers support (eg placement monitoring, job coaching) and a development plan for progression in the workplace (and may also provide a grant of an agreed amount to the employer).

3.31 WORKSTEP seeks to provide supported job opportunities for people with disabilities who face more complex employment obstacles to getting and keeping a job, and who can work effectively with the right support. WORKSTEP providers also look to promote independence and personal development for individuals while on the programme. The programme seeks to empower eligible/suitable people to realise their full potential, by enabling them to work within a commercial environment, giving them, whenever possible, an opportunity to progress into open unsupported employment. WORKSTEP providers include large generic providers (eg Remploy, Shaw Trust), local providers and local authorities.

### Work Choice

3.32 In October 2010 an improved specialist disability employment programme will be introduced to replace the existing WORKSTEP and Work Preparation programmes and Job Introduction Scheme. Work Choice will be a single modular programme based on effective needs assessment and individual tailored packages of provision for disabled people with the most complex obstacles to gaining or retaining work.

3.33 Work Choice takes forward the government's commitment in the Green Paper 'No one written off: reforming welfare to reward responsibility'<sup>3</sup> and the subsequent White Paper; 'Raising expectations and increasing support: reforming welfare for the future'.<sup>4</sup>

3.34 A series of workshops for organisations currently delivering disability programmes and services, potential new providers and a range of specialist disability organisations, were held in December 2008. Views were sought on the high level design of the new specialist disability programme along with the proposed procurement and funding approach.

3.35 Work Choice will be introduced in October 2010.

### **New Deal for Disabled People (NDDP)**

3.36 NDDP seeks to help people with an incapacity, illness or disability RTW. It is delivered alongside other Jobcentre Plus initiatives in Jobcentre Plus-led Pathways to Work areas. A range of different organisations deliver the NDDP via 'job brokers' who are able to:

- give advice about how to get a job
- help with matching people's skills and abilities to employers' needs
- advise on training
- provide support when a person starts work.

3.37 The programme is voluntary and the help provided is free. Some people with a neurological condition may seek help through this route but need to be referred to one of the above programmes via the DEA. In Provider-led areas, the provider will offer a similar service.

3.38 **Permitted Work.** A proportion of people with neurological conditions will not be able to return to paid employment, even with the benefit of specialist vocational services. Whilst not therefore suitable for the above programmes, some may undertake 'Permitted Work'. This allows an individual on employment support allowance, incapacity benefit, severe disablement allowance, national insurance credits, income support (claimed on the grounds of incapacity), housing benefit or council tax benefit, to earn a modest additional income to help them ease their way back into employment. The current Permitted Work rules (as at October 2008) are summarised in Table 3.2 and more information can be found via [Permitted Work](#).

3.39 **Linking provisions.** In Incapacity Benefit (IB) there are linking rules that enable people who leave benefit to reclaim their previous rate of benefit if they become ill again within a given period (see Table 3.3). Linking rules are designed to help people who attempt a RTW which is not successful, from having to re-qualify for the higher rates of IB, which are paid after extended periods of incapacity. The linking provisions focus long-term IB on those who suffer prolonged periods of illness rather than people who only suffer occasional short bouts of sickness. There are similar linking rules for ESA customers who leave benefit for work or training.

3.40 The normal linking period between claims is eight weeks (12 weeks for ESA). However, as part of a commitment to help those with an illness or disability to move into work, a new 104 week linking rule was introduced in October 2006. This is aimed at people who leave ESA or IB to move into work or training schemes, such as Work Based Learning For Adults (WBLA), and helps reduce the risk and uncertainty faced by those who are considering a move into work. The new 104 week rule protects an individual's benefit position if they have to reclaim benefit during that period. (See Table 3.3 for more details or see [Employment Support Allowance](#) or [Permitted Work](#)).

## **Employment services in Northern Ireland**

3.41 In Northern Ireland the **Department for Employment and Learning (DEL)** has a network of 35 Job and Benefit Offices/Jobcentres, where individuals can access 'Jobpoints', which provide computerised information about job vacancies. Programmes are largely delivered by independent organisations. The main contacts, in particular for people with neurological conditions, are Pathways Personal Advisers.

3.42 The Disablement Advisory Service (DAS) is part of DEL and via a team of specialists including Pathways Personal Advisors, Disability Programme Managers and Occupational Psychologists, they provide vocational guidance, assessment, signposting and placing services for people with disabilities who wish to obtain or retain employment. These services are provided through the network of Jobcentres and Jobs and Benefits Offices.

3.43 DAS also provides a range of key programmes including the Job Introduction Scheme, Access to Work (NI), Workable (NI), and New Deal for Disabled People (NDDP), Work Preparation Programme (WPP), Condition Management Programme (CMP) and Vocational Training. Further information on the services provided by DAS can be found at [www.delni.co.uk](http://www.delni.co.uk).

**Table 3.1 Summary of current Pathways to Work provision**

| Pathways to Work (PtW) provision                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Jobcentre Plus-led PtW                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | Provider-led PtW                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| Key Features                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    | Key Features                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| <ul style="list-style-type: none"> <li>• A series of Work Focused Interviews for mandatory and voluntary customers</li> <li>• “Choices” Programme includes: <ul style="list-style-type: none"> <li>○ New Deal for Disabled People (NDDP)</li> <li>○ In Work Support</li> <li>○ Joint NHS/ DoH/ Jobcentre Plus Condition Management Programme</li> <li>○ Cities Strategy</li> <li>○ European Social Fund</li> <li>○ Learning and Skills Council funded provision</li> <li>○ Learn Direct</li> <li>○ Work-Based Learning for Adults (WBLA) <ul style="list-style-type: none"> <li>▪ Skills Build (Wales)</li> <li>▪ Training for Work (Scotland)</li> </ul> </li> <li>○ Programme Centres (up to 04/12/09 only)</li> <li>○ Local Employment Partnerships (LEP)</li> <li>○ LEP Pre-employment training (PET)</li> <li>○ Progress2Work</li> <li>○ Work Trials</li> <li>○ DEA Services</li> <li>○ Work Preparation</li> <li>○ Work Step</li> <li>○ Residential Training</li> </ul> </li> <li>• Financial Incentives <ul style="list-style-type: none"> <li>○ Adviser Discretion Fund</li> <li>○ Job Grant</li> <li>○ Travel to Interview Scheme</li> <li>○ Access to Work</li> <li>○ Job Introduction Scheme</li> <li>○ RTW Credit</li> </ul> </li> <li>• In Work Support <ul style="list-style-type: none"> <li>○ Coaching/ Mentoring</li> </ul> </li> </ul> <p><b>Note:</b><br/>Flexible New Deal (FND) replaces the existing New Deals for JSA customers. Pathways to Work customers will not be able to access FND after its phased rollout. Exceptionally, Advisers can procure other support not met by existing Jobcentre Plus provision.</p> | <ul style="list-style-type: none"> <li>• A series of Work Focused Interviews for mandatory and voluntary customers</li> <li>• Access to a Condition Management Programme</li> <li>• Range of provision tailored to meet the needs of individuals. Providers have flexibility to innovate when providing services. Customers may also access other existing provision which currently includes: <ul style="list-style-type: none"> <li>○ Access to Work</li> <li>○ Cities Strategy</li> <li>○ European Social Fund</li> <li>○ Learning and Skills Council</li> <li>○ Local Employment Partnerships (LEP)</li> <li>○ LEP Pre-employment Training (PET)</li> <li>○ Mentoring</li> <li>○ Progress2Work</li> <li>○ Work-Based Learning for Adults (WBLA)</li> <li>○ Skills Build (Wales)</li> <li>○ Training for Work (Scotland)</li> <li>○ Work Preparation (via Jobcentre Plus DEA)</li> <li>○ Work Step (via Jobcentre Plus DEA)</li> <li>○ Residential Training (via Jobcentre Plus DEA)</li> <li>○ Work Trials (via Jobcentre Plus)</li> </ul> </li> <li>• RTW Credit for eligible customers</li> <li>• Financial Incentives <ul style="list-style-type: none"> <li>○ Job Grant</li> <li>○ Travel to Interview Scheme</li> </ul> </li> </ul> <p><b>Note:</b><br/>Providers may choose to offer a service equivalent to other Jobcentre Plus provision</p> |

**Table 3.2 Summary of current Permitted Work Rules**

| Current Permitted Work Rules as at October 2008                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>These allow a person receiving Incapacity Benefit to:</p> <ul style="list-style-type: none"> <li>• work for earnings of up to and including £20.00 a week for an unlimited period. This is called Permitted Work Lower Limit (PWLL); or</li> <li>• work for less than 16 hours a week on average, and have earnings of up to and including £92.00 a week for a 52 week period. This is called Permitted Work Higher Limit (PWHL). Further periods of PWHL (up to 52 weeks) can be allowed once a 52-week gap period has been served. This is called Permitted Work Higher Limit Subsequent (PWHLS). There is no limit to the number of times you can do permitted work in this category whilst getting IB/Severe Disablement Allowance, but there must be a gap of at least 52 weeks between periods</li> <li>• do Supported Permitted Work whilst earning up to and including £92.00 a week for an unlimited period. Supported Permitted Work is work done with the ongoing support of a body or voluntary organisation whose job it is to find work for people with disabilities. This could be work done in the community or in a sheltered workshop. It could also include work done under medical supervision as part of a hospital treatment programme</li> <li>• do work for less than 16 hours a week on average and earn up to £92.00 a week for as long as a person's illness or disability is considered sufficiently severe that they are treated as meeting the threshold of incapacity without undergoing a medical assessment. This is called Permitted Work PCA Exempt (PWPCAEx).</li> </ul> |

**Table 3.3 Linking provisions**

| 104-Week and 2-Year Linking Rule                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>The <b>104 week linking</b> protection applies where the:</p> <ul style="list-style-type: none"> <li>• person has been continuously sick for 28 weeks</li> <li>• person has taken up work or training within a month of leaving benefit; and</li> <li>• benefit did not end as the result of a personal capability assessment or similar decision.</li> </ul> <p>The rules were designed in this way to encourage people with health conditions or disabilities to try work or undertake training without the fear of losing benefit if their efforts failed.</p> <p>In addition, a <b>special two-year linking rule</b> applies to people who leave the short-term higher or long-term rate of IB and claim Disabled Person's Tax Credit (DPTC, previously Disability Working Allowance (DWA)). In this case the previous rate of IB can be reclaimed within a two-year period. This special provision is designed to enable people with disabilities to take up employment without the fear of losing their accrued entitlement to the higher rates of IB if they are unable to continue working.</p> <p>The two year linking rule also applies to people who undertake training schemes, such as Work Based Learning for Adults (Training for Work in Scotland) administered by Employment Services, and training of 16 hours or more a week which is for the main purpose of learning occupational or vocational skills.</p> |

## Local Authority provision

3.44 Local authorities, mainly through their adult social services departments, have a number of key functions and commission or provide a range of services which are relevant to the vocational needs of people with a LTnC. The specific range of services will vary from council to council, but typically would include:

- advice and information
- social work services, often with specialist workers who deal with disabled adults including those with LTnCs, sometimes specialist workers for people with brain injury, and specialist support for people with sensory needs (ie hearing and/or visual impairment)
- practical assistance in the home – for example home care
- support to carers
- assistance with equipment and home adaptations
- visiting and sitting services
- day centre facilities or other resources for occupational, social, cultural and recreational activities outside the home
- transport concessions, including the 'blue badge' parking scheme.

3.45 Some local authorities have their own supported employment schemes and all should be working closely with other agencies to improve access to mainstream services for disabled people. Local authorities, like other public bodies, have specific duties under the DDA<sup>2</sup> to promote equality of opportunity, promote positive attitudes, encourage participation in public life and take steps to meet the needs of disabled people, even if this requires more favourable treatment.

3.46 Local authority adult social services departments have a duty to assess the needs of individuals who appear to be in need of community care services. At present they must do this using the Fair Access to Care Services (FACS) criteria, where each of an individual's social care needs are assessed as 'low', 'moderate', 'substantial' or 'critical' in nature. The FACS criteria require a wide range of needs to be considered including those related to work, education or learning. Depending on the priority of these needs and the level of needs that the Department has stated it will meet (for example all critical and substantial or all critical, substantial and moderate) it has a duty to address those needs which are eligible.

3.47 Some local authorities address vocational needs by referring people to agencies that specialise in vocational support, others have developed their own schemes to assist people towards employment through, for example, training in computer skills.

3.48 Adult social care provision is moving towards greater 'personalisation', meaning that increasingly people will have control over the money that the social services department spends on meeting their needs. This could take the form of a 'direct payment' (ie cash given to the service user) or an 'individual budget' (where the service user has control over the money but it is held as a budget for them by the social service department or by someone else). In time this could create more flexibility for disabled people who have eligible social care needs and help break down some of the obstacles to them in taking up vocational opportunities.

3.49 As a large local employer the local council should be setting a good example in terms of its policies for employing and supporting disabled staff. The local authority may also be able to provide help to find opportunities for voluntary work to enable people to gain experience and confidence before re-entering the job market.

## Further education

3.50 Further education courses may be of considerable benefit to people with a LTnC who are unable to RTW or training, in providing an opportunity to increase development of personal, social and work-related skills, language and communication, self confidence and self esteem.

**3.51** People may need an opportunity to identify new skills that then may lead to training or other vocational outlets, for example developing computer skills may then lead to training in a completely different area of occupation. Others may benefit from an access to learning time/programme that is not accredited prior to enrolling on an accredited course. This will give them the opportunity to try different and new areas of study, to re-learn how to study, to alleviate anxiety and to adjust to the changes in their abilities.

**3.52** Students with a neurological condition may need on-going support from an informed practitioner, as may the educational establishment. The support required and the length of time students need to attend courses should not be under-estimated. Whilst many colleges have an Integration or Diversity Officer for students with disabilities and/or a Learning Support Department, such staff need access to specialist advice to assist them in supporting students with complex needs.

**3.53** Provision of programmes that are specific to those making the transition from school to further education, and awareness of their particular needs, is crucial in providing these young adults with the opportunity to continue their education. On-going support from practitioners for both the students and the educational staff is essential.

**3.54** Students with more complex physical needs may benefit from referral to residential colleges to access the opportunity to develop independent living skills, but this may be provided by Further Education colleges in conjunction with other services (eg Connexions, Transition teams).

## References

1. Data Protection Act (1998). London: HMSO.
2. Disability Discrimination Act (1995; 2005). London: HMSO.
3. DWP (2008) No one written off: reforming welfare to reward responsibility. Department for Work and Pensions. (Green Paper, July 2008).
4. DWP (2008) Raising expectations and increasing support: reforming welfare for the future. Department for Work and Pensions. (White Paper, December 2008).

## \*Websites

|                              |                                                                                                                                                            |
|------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------|
| NHS Plus                     | <a href="http://www.nhsplus.nhs.uk">www.nhsplus.nhs.uk</a>                                                                                                 |
| Jobcentre Plus – DWP         | <a href="http://www.dwp.gov.uk/about-dwp/customer-delivery/jobcentre-plus/">www.dwp.gov.uk/about-dwp/customer-delivery/jobcentre-plus/</a>                 |
| Directgov                    | <a href="http://www.direct.gov.uk/en/index.htm">www.direct.gov.uk/en/index.htm</a>                                                                         |
| ESA support group            | <a href="http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/esa/DG_171894">www.direct.gov.uk/en/DisabledPeople/FinancialSupport/esa/DG_171894</a> |
| Permitted work link          | <a href="http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/esa/DG_171909">www.direct.gov.uk/en/DisabledPeople/FinancialSupport/esa/DG_171909</a> |
| Employment Support Allowance | <a href="http://www.dwp.gov.uk/employment-and-support/">www.dwp.gov.uk/employment-and-support/</a>                                                         |

## 4 How to use the Recommendations for Best Practice

**4.1** People with a long-term neurological condition (LTnC) may need support from a variety of agencies for a range of vocational issues across their working life. Whilst current rates of employment for people with a LTnC are low, with the right help many more can work or find alternative occupation. Figure 4.1 displays the range of needs of the individual and the complexity of relationships between services. Consequently a wide range of staff from statutory services and other government agencies (ie health, employment, educational and social services) and the independent/voluntary sectors may be involved in assisting people with a LTnC with their vocational needs and career advice. Such staff are referred to collectively as 'practitioners', or as 'vocational practitioners' when a role is specific to vocational rehabilitation. Whilst practitioners will be subject to their own particular professional code of practice, there are also generic Vocational Rehabilitation Standards of Practice.<sup>1</sup>

**4.2** The availability of specialist services to assist people with vocational needs varies markedly across the UK and the required flexibility in provision is reflected in the Recommendations for Best Practice. The availability of occupational health advice also varies markedly between employers. However when an employer sponsors the provision of occupational health advice they are likely to seek their involvement in any programme of vocational rehabilitation and, as such, joint working with occupational health (when involved) is essential (see 3.11-3.12).

**4.3** It is noted that Department for Work and Pensions (DWP) funded disability employment provision is changing with new integrated provision due to replace the current Work Preparation, Workstep and Job Introduction Scheme from 2010 (see 3.14-3.43), along with increased funding for Access to Work. This was outlined in the Green Paper, 'No-one written off: reforming welfare to reward responsibility'<sup>2</sup> and confirmed in the White Paper, 'Raising expectations and increasing support: reforming welfare for the future'.<sup>3</sup> Whilst the nature of the new provision has yet to be specified in detail, the principles of joint working across all relevant agencies, as set out in these recommendations, will remain essential to the effectiveness of future provision in meeting the vocational needs of people with a neurological condition.

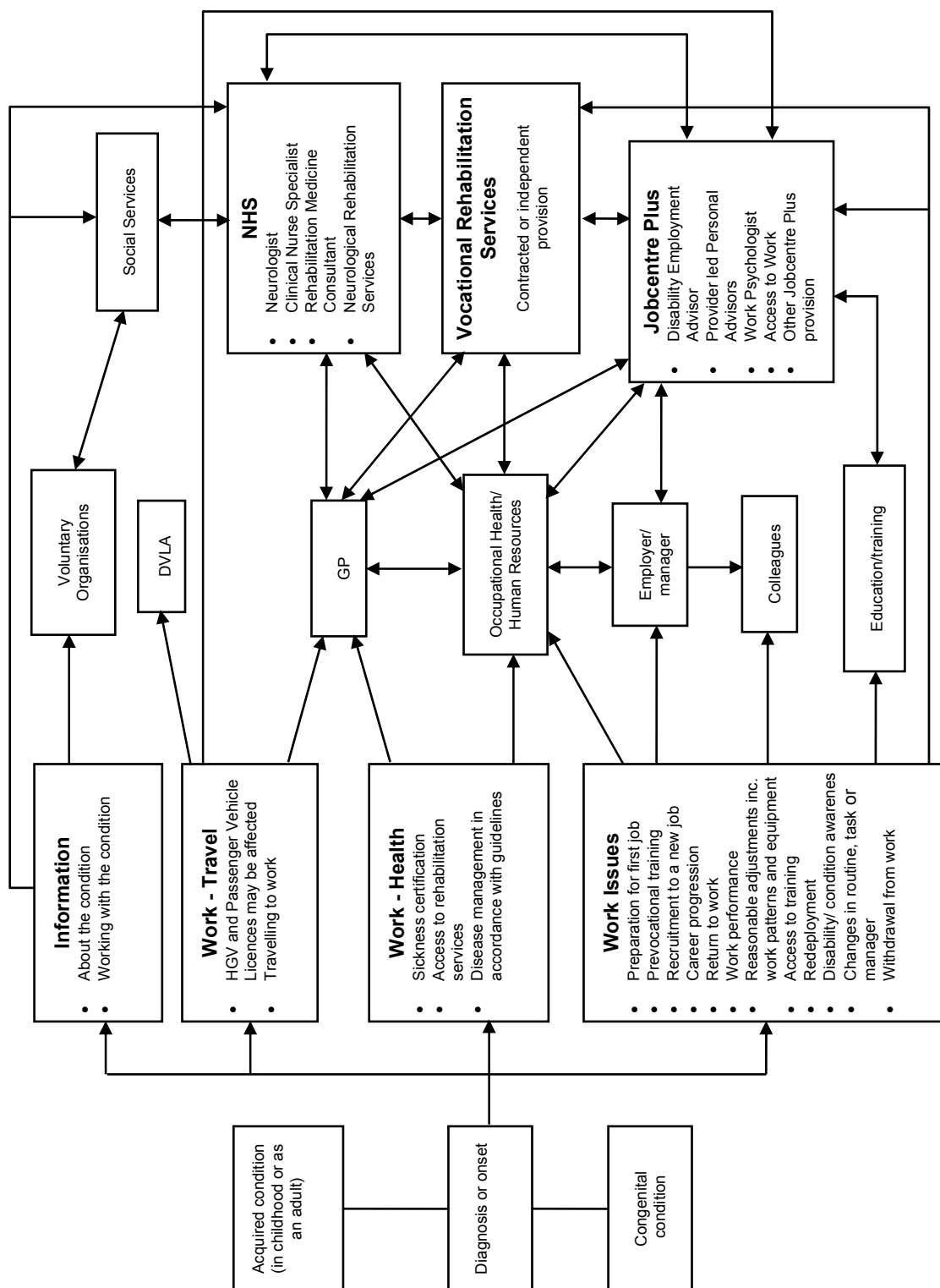
**4.4** Building on the previous inter-agency guidelines on 'Vocational assessment and rehabilitation after acquired brain injury',<sup>4</sup> these Recommendations for Best Practice cover specific vocational needs experienced by people with a LTnC. These are divided into nine subsections:

- general issues (disclosure; consent and capacity; open access/re-access)
- identification of vocational need/provision of information
- vocational/employment assessment
- job retention interventions
- return to occupation
- withdrawal from work on health grounds
- preparation for alternative occupation
- transition from education to employment or other occupation
- occupational/educational provision.

**4.5** To reduce repetition the terms 'vocational' and 'work' are used to denote all forms of occupation including paid or self-employment, vocational training, permitted work, voluntary work and adult education.

**4.6** While it is possible to read a single subsection of the Recommendations for Best Practice related to a specific area of need or practice, it is important to note that there is substantial cross referencing (eg with respect to consent, assessment and occupational health). As such, it is recommended that all sections of the recommendations are read, particularly the first three sections which are relevant to all subsequent sections.

Fig 4.1 Links between needs and services



## References

1. VRA (2009) Vocational Rehabilitation Standards of Practice. London: Vocational Rehabilitation Association. (see [www.vocationalrehabilitationassociation.org.uk](http://www.vocationalrehabilitationassociation.org.uk))
2. DWP (2008a). No-one written off: reforming welfare to reward responsibility. Department for Work and Pensions. London: The Stationary Office
3. DWP (2008b). Raising expectations and increasing support: reforming welfare for the future. Department for Work and Pensions. London: The Stationary Office
4. BSRM/Jobcentre Plus/RCP (2004). Vocational Assessment and Rehabilitation After Acquired Brain Injury: Inter Agency Guidelines. London: Royal College of Physicians/Jobcentre Plus/British Society of Rehabilitation Medicine.



## 5 Recommendations for Best Practice

These recommendations for best practice should be read in conjunction with the previous section on 'How to use the Recommendations for Best Practice'.

### General issues

#### Disclosure of a long-term neurological condition

5.1 Disclosure of a long-term neurological condition (LTnC) and associated difficulties at work provides an opportunity for an employer to work with the person, taking specialist advice as appropriate, to develop reasonable work adjustments to support the person at work, as required by the Disability Discrimination Act (DDA).<sup>1</sup> If a condition is not disclosed, the employer is under no obligation to make such adjustments. However it is important to note that the person is not obliged to disclose the condition under the DDA.

5.2 Concerns about the disclosure of a LTnC and its effects to an employer or educational establishment may arise at various stages, for example:

- on applying for a new job or training course
- on seeking progression within the same organisation
- in work or training following onset or change in a condition
- in response to a change of manager or work colleagues
- when seeking to negotiate a change or reduction in work duties
- when considering a withdrawal from work on health grounds.

5.3 Some people may disclose their condition early at a time when they are still coming to terms with the diagnosis or are having difficulty in acknowledging its implications for work. They may lack the knowledge to answer all their employer's questions, particularly if they are newly diagnosed or have limited insight into their difficulties as a function of their condition. Others with symptoms that are not visible may choose not to disclose, for example those with subtle effects of brain injury, those in remission or in the early stages of a condition (such as Multiple Sclerosis) or those with a fully controlled condition (such as fully controlled epilepsy).

5.4 Disclosure may also be a concern for people seeking employment for the first time or those seeking a new job. If the person is not asked by a potential employer to declare any medical history on application, then there is no need to do so but the person may choose to do so after they have been successful in obtaining a job or at a later stage, as and when a need arises. If a person is asked to declare relevant medical history on applying for a job there is no statutory duty to do so, but this could represent a breach of contract if satisfactory pre-employment clearance is a condition of employment. Where medical information is required it constitutes 'sensitive data' and must be processed in accordance with the Data Protection Act (1998).<sup>2</sup> An employer has no right to know an applicant's medical diagnosis and must not demand to see any declaration of diagnoses/clinical investigations. This information should only be sent to a qualified medical practitioner or nurse (usually the Occupational Health Service), who can then advise on any necessary workplace adjustments arising from the functional impact of the person's condition. However, an employer without access to occupational health advice may legitimately ask general questions about function, for example asking an applicant if they fall within the legal definition of the DDA<sup>1</sup> and, if so, whether they would need any adjustments at work.

5.5 There may however be unforeseen consequences of non-disclosure if work performance is affected or if there is significant risk to the person or others. For example an undisclosed condition (such as epilepsy) may compromise safety, particularly when the person's job involves driving, working at heights or operating dangerous machinery. Whilst, as noted above, a person is not obliged to disclose their condition under the DDA,<sup>1</sup> this does not over-ride any requirement to do so under other legislation, such as the Health and Safety at Work Act.<sup>3</sup> Under the latter it is a duty of every employee to take reasonable care for the health and safety of self and others at work and to

cooperate with the employer or any other person in fulfilling their related obligations (for relevant sources of advice see 5.48).

**5.6** People with a LTnC may therefore need support to:

- seek further information to increase their understanding of the condition and its implications for work
- explore the likely consequences of disclosure and non-disclosure of the condition, both when a person is in work and also when applying for a new job
- explain their condition, its effects on work and how these might be managed to their employer and colleagues, as and when they decide to disclose the condition.

## Driving

**5.7** Diagnosis of a LTnC also commonly requires the person to notify the Driver and Vehicle Licensing Authority (DVLA), which may result in a temporary or permanent withdrawal of their driving licence. This commonly affects the ability to get to work but may also affect the ability to carry out a job, particularly for people who hold HGV licences or those who drive passenger vehicles who may face additional restrictions to their licence.

**5.8** People should be informed of their duty to declare the condition to DVLA (see [www.dvla.gov.uk](http://www.dvla.gov.uk) - medical rules: 'Advice on how to tell DVLA about a medical condition'<sup>4</sup>) and/or be referred, as appropriate, to a relevant medical practitioner or a specialist driving assessment centre. People with transport needs should be directed to relevant publications/websites (eg 'in work support'/relevant voluntary group). Access to Work (AtW) support may be able to assist people with transport to and from the workplace (see 5.51).

## Choice, Confidentiality, Consent and Capacity

**5.9** In addressing vocational needs all agencies and practitioners need to be mindful of the complex issues of confidentiality, consent and capacity that may arise.

**5.10** Occupation is central to a person's self-esteem and quality of life. People with a neurological disability often face complex and difficult decisions about their current and future occupational options. In offering vocational advice and support, the individual's values, wishes and choices should be respected.

**5.11** All verbal and written communication about a LTnC and its vocational implications must conform to the requirements of the Data Protection Act (see [www.opsi.gov.uk](http://www.opsi.gov.uk)) and both professional and local organisational guidelines. It is essential that all practitioners are aware of when informed consent is required prior to any disclosure. Informed consent requires that the person understands the information to be disclosed, the recipient, the purpose of disclosure and its potential consequences.

**5.12** It is good practice to offer the person the opportunity to comment on draft written submissions prior to disclosure of information to other agencies especially employers.

**5.13** All actions of practitioners should be undertaken with appropriate informed consent in accordance with the requirements of both professional and local organisational guidelines. It is essential that the consentor understands the implications of their consent and the purpose and boundaries of any proposed action. It is important to recognise both that the person may later withdraw their consent and that consent will often need to be revisited as an intervention develops - consent for initial action does not constitute informed consent for all subsequent actions.

**5.14** When a condition has a major effect on cognitive function and/or emotional/behavioural control, practitioners need to consider whether the person has the capacity to reach a decision and/or consent to proposed action in accordance with the requirements of the Mental Capacity Act<sup>5</sup> (see [www.justice.gov.uk/guidance/mental-capacity](http://www.justice.gov.uk/guidance/mental-capacity)) and both professional and local guidelines. When an individual is considered to lack capacity this should be clearly documented by the practitioner and action based on a 'best interests' decision, or when a designated advocate has been appointed on that individual's consent.

## Open access/re-access

5.15 It is common for people with a LTnC not to appreciate fully the extent and implications of their vocational difficulties. This may be a feature of their condition due to reduced awareness or marked cognitive-behavioural difficulties. As such, they may not be ready to accept recommendations about vocational assessment, rehabilitation or other support at the time that these are first offered.

5.16 It is essential both to provide ongoing review of the occupational situation and open access to people with a LTnC to act on vocational advice and to access support, as and when they choose, during the course of their condition.

## Identification of vocational need/provision of information

5.17 Health and social care practitioners should identify occupational status and, when appropriate, vocational needs routinely in all assessments, care plans and reviews for people with an identified or suspected LTnC. This should include young people during their secondary education (see 5.100-5.110).

5.18 Health and social care practitioners involved routinely with people with a LTnC (eg GPs, Neurologists, Clinical Nurse Specialists, Care Managers) should be aware of the services available locally to help with vocational needs and be provided with clear guidance about when and how to refer to them (see Section 6 - Implementation).

5.19 When questions or concerns about vocational issues are raised by a person, relative or employer (or identified by a health practitioner) these should either be addressed directly, if this falls within the practitioner's area of expertise, or referred on to relevant staff. This may include other health professionals (eg medical consultant, clinical nurse specialist, clinical neuropsychologist, occupational therapist etc) or other agencies (eg Occupational Health, Jobcentre Plus, vocational practitioner, relevant voluntary group), appropriate to the condition and identified need.

5.20 Requests for information, clarification or advice from the person, employer or other agencies should be met with a timely response (with appropriate consent) to ensure that decisions about work, vocational rehabilitation or benefit entitlements are based on full and accurate information.

5.21 Health practitioners should avoid making premature and/or independent judgments about fitness for work without understanding the effects (including any variability) of the condition for the individual, the requirements of the occupation and the available support that may enable the person to continue in that occupation. Rather they should seek additional information, defer to expert opinion and/or consider referring the person to relevant specialist services (eg NHS rehabilitation service, Occupational Health, Jobcentre Plus, and/or independent vocational service/ practitioner). However such services should recognise the value of the longstanding and overall health knowledge of the person that may be provided by the GP.

5.22 When a vocational need is identified the person should be provided with, or made aware of, sources of information (eg websites of relevant agencies and voluntary groups) and/or specialist advice (eg Occupational Health, Disability Employment Advisor (DEA), benefits advice etc.). The person should be referred, as appropriate, to vocational assessment, rehabilitation and support services to give every possible opportunity to remain in work. Early intervention may be critical to success.

## Vocational/employment assessment

5.23 The terms 'vocational assessment' and 'employment assessment' are both used due to the specific meaning attached to 'employment assessment' within Jobcentre Plus.

5.24 **Vocational assessment** has been defined as a 'global appraisal of an individual's work/training background, general functional capacities and social/behavioural characteristics. Vocational assessment can include an evaluation of medical factors, psychological makeup, educational background, social behaviours, attitudes, values, work skills and abilities.<sup>6</sup> As such,

vocational assessment is a broad term encompassing all forms of assessment of vocational strengths, weaknesses, needs and prospects.

**5.25 Employment assessment (EA)** addresses the **job-person interaction** and seeks to enable individuals to predict their performance and needs in job opportunities. EA is described as assisting individuals to make an informed decision about an appropriate and specific job.<sup>7</sup> This involves helping the individual to acquire information about the job (eg roles, responsibilities, competences, interpersonal skills etc) and assessing their potential to perform successfully in that job. The process of EA may involve a number of stages (eg interview, measurement, feedback, action planning) and tools (aptitude tests, work samples, job trials etc), each of which can differ in their predictive ability or quality of information obtained.<sup>7</sup> Employment Assessment is not just concerned with whether an individual can perform the tasks required by the job, but also explores whether the individual is able to sustain employment and, when appropriate, develop in the job.

**5.26** For all people with a LTnC with a vocational need consideration should be given to the need for and timing of referral for specialist assessment by a suitably qualified practitioner experienced in the vocational effects of LTnCs.

**5.27** Vocational/employment assessment should take into account the following:

- the person's personal and family circumstances
- an evaluation of motor, sensory, communication and cognitive function
- behavioural control and emotional status
- the effects of current medication and other interventions
- the demands of the current or desired occupation
- the current skills and employment assets of the individual
- the practical obstacles to accessing and undertaking that occupation, and
- potential work solutions to facilitate successful job performance.

**5.28** When a person is in employment the assessment should also take into account the support available at work (see 5.43-67).

**5.29** On planning such an assessment practitioners should consider whether they have the expertise to deal with the issues that may arise.

- If there is any doubt as to the appropriateness of a practitioner continuing with an intervention, the advice of the relevant supervisor or manager and/or other expert should be sought
- When it is considered that the practitioner does not have the required expertise the intervention should be referred on to an appropriate practitioner or agency.

**5.30** A specialist assessment for people with a LTnC will normally draw on a combination of the components in Table 5.1, depending on the specific condition, individual circumstances and the specific vocational needs identified.

**5.31** It is usually in the person's best interests for relevant background clinical information to be shared and assessment results pooled across agencies to avoid duplication and to facilitate full assessment and appropriate recommendations. However this is subject to informed consent (see 5.11). If health professionals have concerns about the risk of misunderstanding of clinical information they should liaise directly with the agency undertaking the assessment, supply additional information by way of clarification and/or attend the initial assessment of that agency.

**Table 5.1 Components of specialist VR assessment for people with a long-term neurological condition****Components of VR assessment**

- Interview with the person including educational history, vocational qualifications, employment history, medical history (including neurological and other relevant conditions), past and current rehabilitation, current effects (eg physical, sensory, communication, cognitive, behavioural, emotional and family/social), experience of employment post-onset, leisure activities and current vocational interests and aspirations.
- Interview, whenever appropriate, with a close relative (with informed consent - see 5.13-14), to assist the person in providing a full history, in describing their needs and in identifying any personal or family circumstances that need to be taken into consideration. (An interview with a close relative should be considered routinely for those with cognitive and/or behavioural difficulties). Relatives should, whenever possible, be provided with the opportunity of a separate interview so that they may speak freely about the needs of the person and family without risk of embarrassing or upsetting the person. (When concerns are raised about carers, they should be made aware of the availability of a carer's assessment through their local Council).
- Review of past clinical information including previous assessment or rehabilitation reports and/or consultation with health or other practitioners with knowledge both of the person's current difficulties and of their overall health status (eg from the GP).
- Formal interview, testing and/or examination of work-related skills (eg motor, sensory, cognitive, communication, educational and social), work capacity (eg strength, endurance, fatigue etc) and related management/coping strategies.
- Psychological adjustment (ie emotional state/behaviour), as expressed, whenever possible, either in the workplace or on work-related activities.
- Structured evaluation and/or ratings of work attitude, performance and behaviour based on direct observation and/or feedback/reports from employers of current or recent employment or work placements.
- Assessment of obstacles that might prevent a person from getting to work (see 5.8), accessing all relevant facilities at a worksite including staff room, toilets etc and/or undertaking a specific work role (eg transport, access, environment, equipment etc).
- Assessment of home facilities to support home working for an existing job or setting up a new job or business.
- Review of the requirements of a job (eg job description/person specification).
- Worksite assessment to evaluate the actual requirements of a work role, performance in the role and/or work adjustments to enable a person to undertake the work role.
- Consideration of training programmes to up-date current skills and/or develop new skills, including how such training would need to be adapted to meet the needs of the individual (eg shorter sessions and other learning support – see 5.61).
- Careers guidance and/or job matching to identify alternative occupation/specific job goal (both for those seeking to start out in employment or training and for those unable to return to or continue with their existing occupation).
- Assessment of the financial consequences of a proposed decision to reduce or withdraw from work (eg 'better off calculation' by a Jobcentre Plus DEA or other adviser and/or independent benefit/pensions advice).

5.32 When a vocational assessment is undertaken by NHS or other health rehabilitation services it will commonly involve an occupational therapy assessment plus liaison with and/or assessment by other relevant practitioners (eg neurologist, clinical nurse specialist, Rehabilitation Medicine physician, clinical neuropsychologist, physiotherapist, and/or speech and language therapist), as appropriate to the needs of the individual. It is essential that health practitioners consider the need to obtain, undertake or refer the person for a practical assessment of specific work skills relevant to the occupation (see 5.30), alongside standard clinical assessment. When the person is in employment it is also essential to liaise with occupational health, when involved (see 5.47).

5.33 When an assessment is undertaken by other agencies (eg by a Jobcentre Plus DEA or work psychologist, Occupational Health or other suitably experienced vocational practitioner) they should seek and be provided with copies of relevant clinical reports and/or liaise directly with relevant health professionals to gain an understanding of the effects of the condition and its prognosis.

5.34 When a person has not been seen previously by relevant health practitioners, consideration should be given to the need to refer the person for assessment, either directly or via the GP prior to, or in parallel with, the vocational assessment.

5.35 When a vocational practitioner identifies outstanding care or rehabilitation needs, the person should be referred, either via the GP or direct to the relevant health and/or social care service.

5.36 Vocational/employment assessment should also be available to young adults with a LTnC prior to leaving education to assist them in making informed career choices and to identify vocational rehabilitation and support needs (see 5.100-110).

5.37 Assessment findings and recommendations should be discussed first with the person and then with other relevant parties. Whilst it may be appropriate to arrange a meeting with all relevant parties, some people with a LTnC have difficulty in coping with large meetings and separate meetings are sometimes more appropriate.

5.38 The findings and recommendations should then be confirmed in writing and copied to all relevant parties, subject to informed consent. When assessments are undertaken by health practitioners the GP and other key health practitioners should be copied in.

5.39 The findings of a vocational/employment assessment may be critical in ensuring that people receive the correct State benefits and are not subject to any inappropriate sanctions (eg due to a failure to attend appointments or pursue specified action due to memory or executive difficulties). As such, the practitioner should be proactive in discussing with the person whether a summary of the findings and recommendations should be made available to the benefits assessor.

5.40 Practitioners need to be aware that most people applying for (or transferring to) Employment Support Allowance (ESA) will be referred for a Work Capability Assessment (WCA) and that those considered to be able to undertake work-related activity will also take part in a Work Focussed Health Related Assessment and a series of Work-Focussed Interviews with a Personal Adviser.

5.41 It is good practice for practitioners to provide people with an up-to-date summary of their work-related health needs to assist them in their application for ESA and to assist benefit assessors and personal advisers in making informed judgments and recommendations, particularly with respect to any identified health risk.

5.42 Vocational/employment review and/or re-assessment may be required when there has been a significant change in need eg

- fluctuation/progression of symptoms
- change in job role
- change in supervisor, manager or employer
- completion of training
- career progression, and/or
- recognition of need for support.

## Job retention interventions

**5.43** When a person with a LTnC is experiencing vocational difficulties (including repeated episodes of sick leave), consideration should be given to the need for a referral to a vocational practitioner with experience of LTnCs to assess the nature of the difficulties and identify any required work adjustments and other support needs (see 5.23-5.42).

**5.44** When vocational difficulties have been identified a rapid response is often required to prevent difficulties from escalating and the long-term viability of the position being put at risk.

**5.45** The need for a rapid response may be clear, for example when disciplinary action or a capability assessment has been initiated. However in other circumstances this need may only become apparent on making contact with the employer (ie manager or Human Resources). As such, routine early action to evaluate urgency is required.

**5.46** The initial assessment should establish the nature of concerns to determine the appropriate form of the assessment and obtain consent to proceed. When undertaken by a health professional the initial assessment is likely to be with the person with the condition. However, when a referral is received from an employer, the Jobcentre Plus DEA or Work Psychologist (or other agency) may undertake an initial 'scoping' meeting with the employer, as well as the person (see 5.48 below).

**5.47** It is important to establish whether the person has access to an Occupational Health service through their employer.

- if the person has been seen it is important to make contact with Occupational Health, with the person's consent, to seek a coordinated response
- if there is such a service but contact has not yet been made it is important to discuss with the person and the employer the likely benefit of Occupational Health advice
- if there is no access to an Occupational Health service the employer should be advised that they can access such services via NHS Plus (see 3.13).

**5.48** Prior to proceeding with the assessment it is vital to:

- Check that all parties are clear about on whose behalf the assessment is taking place: health practitioners may be acting on behalf of the person; Jobcentre Plus staff (ie DEA, Work Psychologist) on behalf of either the person or the employer; Occupational Health on behalf of the employer but also the employee (except for pre-employment health assessments); and independent vocational case managers on behalf of insurance companies.
- Explain to all parties the role (including the limitations) of the assessment and any subsequent recommendations and discuss any issues that arise with respect to rights and responsibilities of the person, the employer (or educational establishment), the vocational practitioner and any other agency involved (eg Occupational Health or Jobcentre Plus). When another agency is involved the vocational practitioners concerned should liaise to agree their respective roles and responsibilities.
- Make it clear that, whilst the assessment is likely to lead to recommendations, the employer remains responsible for implementation of 'reasonable work adjustments' under the DDA. The vocational practitioner should direct the person and employer, as appropriate, to sources of further information on the DDA (eg Equality and Human Rights Commission, [direct.gov.uk](http://direct.gov.uk), Employers' Forum on Disability, Occupational Health).
- Check that the person is aware of sources of independent advice, advocacy and support (eg Trade Union, Citizen's Advice Bureau, legal advice, voluntary group).
- If capability or disciplinary procedures have been initiated check that the person is aware of the implications and relevant sources of advice and advocacy (see above).
- Discuss issues of confidentiality (see 5.11-14). As noted, it is normally in the person's best interests for summary information to be shared openly across agencies, subject to informed consent. However, the employer has only limited legal rights for information and does not need to know full detailed information of the person's condition, all the associated symptoms, assessment results or other personal details (see 3.4-10).

**5.49** For a person in work a vocational/employment assessment is likely to include a combination of the following elements, depending on the specific circumstances:

**Table 5.2 Components of vocational/employment assessment for a person in work**

| Components of vocational/employment assessment                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
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| <ul style="list-style-type: none"> <li>• Job profiling – reviewing the job description/person specification</li> <li>• Undertaking a worksite visit with the person and supervisor/manager</li> <li>• Direct observation of the specific job/training role</li> <li>• Consulting with other employers/training colleges about the requirements of specific jobs</li> <li>• Interviewing the person (and a relative, when appropriate) – this should cover the person's job satisfaction and any work-related stress, as well as job performance</li> <li>• Reviewing the person's performance against duties in job description</li> <li>• Obtaining feedback from work supervisor/manager and colleagues</li> <li>• Direct observation of work performance/behaviour/use of coping strategies etc</li> <li>• Reviewing clinical information including previous assessments</li> <li>• Consulting health or other practitioners with knowledge of the person's difficulties</li> <li>• Undertaking or referring on for assessment of motor, sensory, communication and/or cognitive skills and behavioural/emotional control (see 5.59)</li> <li>• Setting up practical assessments to evaluate specific work skills/behaviours</li> </ul> |

**5.50** If there is concern about a person's fitness to fulfil a job role and/or the management of the condition at work, practitioners should consider whether referral to an Occupational Health Physician is indicated (see 5.47).

**5.51** If it becomes apparent that ongoing adjustments to the job and/or additional support are required health practitioners should consult the Jobcentre Plus DEA/Work Psychologist (and Occupational Health, if involved) to discuss the appropriate action:

- when physical adaptations to the workplace, specialist equipment or aids, assistance with travel to work are required, a person may benefit from support through Access to Work (AtW) direct from an AtW Support Unit, local AtW Adviser or DEA, as appropriate
- when a person requires significant changes to work duties, an alternative job role and/or ongoing advice or support in the workplace, a referral should normally be made to the DEA (or to a specialist vocational rehabilitation provider/practitioner), in liaison with Occupational Health, if involved
- when such interventions are undertaken through Jobcentre Plus they should be undertaken or overseen by a suitably trained work psychologist experienced in assessing the effects of a LTnC or one who is supervised by an experienced practitioner.

**5.52** When health practitioners refer a person to the DEA, Work Psychologist or other vocational rehabilitation agency/practitioner, they should:

- provide summary information and explanation about the LTnC and its effects, the rehabilitation input received to date and likely future needs
- whenever possible attend the initial interview to assist the person in explaining about their work related difficulties and to contribute to the development of an agreed joint plan of action.

**5.53** The assessment findings and recommendations should be discussed first with the person and then with the employer (ie including the manager and Human Resources), Occupational Health (when involved) and a Health and Safety representative when appropriate (see 5.37).

**5.54** Whilst the employer is responsible under the DDA for 'reasonable work adjustments', the practitioner should seek to facilitate a meeting between the person and the manager, Human Resources, Occupational Health (when involved) and a Health and Safety representative (when appropriate) to outline the identified vocational needs and promote consensus on the primary issues, suggested work adjustments and how these might be implemented and monitored.

**5.55** It is important for practitioners to recognise that the employer is not obliged to implement their recommendations and that the judgment about what constitutes 'reasonable' adjustments is likely to be based on the capacity of the organisation to respond, as well as on the needs of the individual.

**5.56** Assessment findings and recommendations should then be confirmed in writing and copied to all relevant parties. This may form the basis for a job retention plan/agreement between the person and the employer. This might include the needs of the person, the agreed action on the part of the person, the employer and the support agency and arrangements for progress monitoring and review. (The employer or practitioner may wish to seek advice and practical examples on the format of job retention agreements from the Employers' Forum on Disability or other specialist sources – see 5.59).

## Recommendations for work adjustments

**5.57** Recommendations for work adjustments may include one or more of the following:

**Table 5.3 Recommendations for work adjustments**

| Recommendations for work adjustments                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
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| <ul style="list-style-type: none"> <li>• Flexibility in hours and/or duties eg:             <ul style="list-style-type: none"> <li>○ changes to working hours or days</li> <li>○ time off to attend health-related appointments</li> <li>○ provision of additional breaks during the working day</li> <li>○ changes to start/finish times to reduce travel during the busiest times</li> <li>○ review/adjustment to the overall level of responsibility of a job role</li> <li>○ changes to specific work duties (eg redistribution of duties to/from colleagues)</li> <li>○ consideration of an alternative job role</li> </ul> </li> <li>• Adaptations, equipment and coping strategies, eg:             <ul style="list-style-type: none"> <li>○ help with travel (eg designated parking space or taxi through Access to Work)</li> <li>○ provision of home working to reduce travel demands</li> <li>○ physical adaptations or re-organisation of the working environment (eg to allow wheelchair accessibility)</li> <li>○ additional equipment, aids and adaptations (eg communication aids/software, specialist seating)</li> <li>○ advice on specific symptom management (eg fatigue management)</li> <li>○ advice/support on the use of coping strategies (eg for cognitive impairment)</li> </ul> </li> <li>• Additional training, supervision and support, eg:             <ul style="list-style-type: none"> <li>○ job coaching/support worker in the workplace</li> <li>○ ongoing support from a co-worker</li> <li>○ a 'buddy' trained to respond to specific needs (eg seizure) in the workplace</li> <li>○ additional training, supervision and/or support (eg mentoring, advocacy etc)</li> <li>○ education for supervisor, manager and colleagues about the condition and its effects</li> <li>○ advice/support for supervisor, manager and colleagues</li> <li>○ regular reviews with supervisor/manager (eg to assist work planning/ prioritising)</li> <li>○ additional support from colleagues in the workplace</li> <li>○ off-site support (eg from a rehabilitation service or vocational practitioner)</li> </ul> </li> </ul> |

**5.58** In discussing and reviewing work adjustments it is important to be sensitive to the potential emotional impact for the person, particularly when they involve a reduced work role, and to provide the time and support to consider fully the recommended adjustments.

5.59 Sources of information on relevant equipment, aids, adaptations, symptoms management and coping strategies and other work adjustments include:

**Table 5.4 Sources of information**

| Sources of information                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
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| <ul style="list-style-type: none"> <li>• <b>Health practitioners</b> with an identified role in managing work-related difficulties (eg Occupational Therapist) or with expertise related to specific areas of difficulty eg:             <ul style="list-style-type: none"> <li>○ Medical consultant (<i>re diagnosis, prognosis, management of seizures, spasticity etc</i>)</li> <li>○ Neuropsychologist (<i>re cognitive, behavioural and emotional difficulties</i>)</li> <li>○ Nurse Specialist (<i>re continence, self-management of drugs, health education etc</i>)</li> <li>○ Occupational Therapist (<i>re motor skills, fatigue, cognitive skills, activity analysis etc</i>)</li> <li>○ Physiotherapist (<i>re posture, mobility, balance, etc</i>)</li> <li>○ Speech and Language Therapist (<i>re communication and swallowing</i>)</li> </ul> </li> <li>• <b>Jobcentre Plus services eg:</b> <ul style="list-style-type: none"> <li>○ Disability Employment Adviser</li> <li>○ Work Psychologist</li> <li>○ Access to Work Support Unit/Adviser</li> </ul> </li> <li>• <b>Occupational Health Practitioner</b> (when involved)</li> <li>• <b>Health and Safety representative</b></li> <li>• <b>Vocational rehabilitation services specialising in supporting people with a LTnC</b></li> <li>• <b>Related websites and other publications</b> <ul style="list-style-type: none"> <li>○ Disability Discrimination Act (<i>eg Equality and Human Rights Commission</i>)</li> <li>○ Employers' Forum on Disability (<i>including booklets on specific conditions</i>)</li> <li>○ Health and Safety Executive</li> <li>○ Chartered Institute of Personnel and Development</li> </ul> </li> <li>• <b>Job Accommodation Network</b> (including booklets on specific conditions)</li> <li>• <b>Voluntary groups</b> supporting people with a LTnC or with employment issues, some of which have a helpline facility as well as publications</li> </ul> |

5.60 When a practitioner considers that obstacles to employment/training are not being addressed by an employer, they should discuss this with the person and, as agreed, raise their concerns with the employer and other relevant parties (eg Occupational Health, DEA).

5.61 When a person is in education or training, contact should be made with the relevant Academic/Course Tutor and, as appropriate, with the Learning Support Department and/or Personal Tutor, to discuss the identified difficulties and support needs. The agreed support might include one or more of the following:

- adjustments to/flexibility in specific assignments/deadlines
- adjustments to overall course (eg deferral/repetition of modules etc)
- learning support equipment (eg computer, tape recorder etc)
- individual learning support (signing, note-taking, reading services etc)
- personal assistance
- examination support (eg additional time, prompt notes, separate room)
- additional general support from personal tutor.

**5.62** Ongoing monitoring, advice and support from a specialist vocational practitioner may be required for those in education or training, especially when the person has limited awareness of their own difficulties.

**5.63** Progress should be reviewed regularly and proactively (without waiting for reports of difficulties) by an appropriate vocational practitioner and any recommended modifications to the job retention plan communicated to the person and employer.

**5.64** When an Occupational Health service is involved it will often be appropriate for ongoing reviews to pass to this service once the need for specialist input is no longer required. However this should include an agreement about when to seek further specialist input should the need arise.

**5.65** Reviews should consider feedback from the person and employer (ie supervisor, manager and/or work colleague, as appropriate) about how the person is managing the job and the support provided. They should also consider how coping with the job is impacting on the person's health and quality of life outside work.

**5.66** When appropriate (eg when there are significant cognitive and/or behavioural difficulties, particularly those of an executive nature), feedback should also be sought from a relative or close friend about how coping with the job is impacting on the person's quality of life and that of the family.

**5.67** When a job retention intervention has been undertaken at the request of an employer they should be advised about the need for ongoing review of progress and support needs and how to obtain further specialist advice and support, when required.

## Return to occupation

**5.68** People with a LTnC may experience single or multiple episodes of extended sick leave lasting for a period of weeks, months or years.

**5.69** People seeking to return to previous occupation following an extended period off sick should routinely be offered an assessment of vocational skills and support needs by a suitably qualified practitioner (see 5.23-42 above).

**5.70** When core rehabilitation or care needs are identified people should be referred, either direct or via the GP, to relevant rehabilitation or social care services.

**5.71** People with identified vocational rehabilitation needs prior to a return to occupation should be provided with interventions to promote optimal management of difficulties likely to limit the prospects of a successful RTW. This is likely to include one or more of the following:

- inclusion of specific vocational goals in the overall rehabilitation plan
- education about difficulties likely to affect work or study
- development of skills/behaviours necessary for work or study
- restoring work-related routines (time-keeping, travel, money management etc)
- building up of attention, work/study tolerance and stamina
- confidence building
- assessment, training and support in travelling to the workplace, college etc
- advice about aids and assistive technology to support the person in their work
- developing cognitive and other coping strategies for use in the workplace or in study
- work on material drawn from, or relevant to, the person's work or study
- graded re-orientation to the workplace (eg in voluntary capacity) or college etc
- general encouragement and support
- psychological support
- advice on balancing the demands of work, home and family life.

**5.72** Recommendations for a RTW should take into account the person's personal and family circumstances (as well as evaluation of the required motor, sensory and cognitive skills, behavioural control and emotional state) and be discussed, when appropriate, with a close relative as well as the person (eg for those with significant cognitive and/or behavioural difficulties).

**5.73** When there is doubt as to the ability of a person to cope with a RTW, the relevant health practitioners should consult the relevant Occupational Health service, DEA/work psychologist or specialist vocational service/practitioner to discuss the appropriate action such as referral for specialist vocational/employment assessment (see 5.23-42).

**5.74** The relevant health practitioner should seek the agreement of the person to make contact with the employer, education or training provider to discuss needs prior to a RTW. This should include close liaison with the relevant Occupational Health service, when involved (and Health and Safety, when appropriate).

**5.75** Information to be disclosed to an employer or Occupational Health should be discussed and agreed in advance with the person. It is good practice to offer the person the opportunity to comment on draft written submissions prior to disclosure.

**5.76** Recommendations for a RTW will normally include a gradual build up of duties/hours and other specific work adjustments/learning support, as discussed for job retention interventions (see 5.57-61). However, as previously noted, the employer is not obliged to implement these recommendations (see 5.55).

**5.77** Whenever appropriate and agreed with the person, it is good practice to recommend a worksite meeting to discuss plans for a RTW (or study) with the employer (or college) and Occupational Health (when involved) (see 5.37 and 5.53-6).

**5.78** Prior to a return to previous occupation the person should be given explicit verbal and written advice about the appropriate timing and gradual build up of hours and responsibilities at work by the relevant practitioner. Such advice may be provided by a health or vocational practitioner or by Occupational Health, when involved. This advice should be communicated routinely to the GP and other key health practitioners to reduce the risk that decisions about RTW are made without reference to specialist advice.

**5.79** Following intervention to assist a person in returning to work progress should be reviewed by the practitioner, as discussed for job retention interventions (see 5.63-7), providing further advice and support, as required.

**5.80** If it becomes apparent to a healthcare practitioner that long-term adjustments or support are required to enable a person to remain in work the DEA, Work Psychologist, Access to Work Adviser (and/or Occupational Health, if involved) should be consulted, as well as the employer, to discuss the appropriate action (see 5.51-2).

## **Withdrawal from work on health grounds**

**5.81** It is imperative that agencies work together to support people with a LTnC in remaining in work for as long as they wish and are able to do so. However, for many there will come a time when they make the decision to stop working, either because their condition has made work too difficult to sustain or because they wish to have the time to pursue other activities while still able. People need access to expert advice and support when considering a withdrawal from work. This is essential for people facing increased restrictions arising from a progressive condition but also for people with other conditions unable to return or sustain work. Decisions about withdrawal from work need to be managed sensitively; financial advice needs to be accurate, balanced and comprehensible. People may have put so much energy into maintaining work that they may have let other interests and social contacts lapse and, as such, may also need support to take up these activities again.

**5.82** People considering withdrawal from work should be encouraged to seek expert advice before doing so and not to make a hasty decision. People with a rapidly progressing condition need prompt access to appropriate advice both about leaving work and about pension and benefit entitlements.

**5.83** Practitioners advising people who are considering withdrawal from work on health grounds should ensure that the person is aware of and referred, as appropriate, for:

- assessment by an Occupational Health Physician (see 5.47), particularly when ill health retirement pension benefits may be an issue
- expert advice about symptom management, work adjustments and/or alternative job roles from relevant practitioners (see 5.57 and 5.59)
- information about the financial consequences (eg pension and benefits entitlement) from the employer, government agency (DWP/Jobcentre Plus) or independent/voluntary organisations (eg benefit advisory services, Citizens' Advice Bureau etc).

**5.84** Practitioners supporting people in making a decision to withdraw from work should be alert to the emotional impact of the decision and either respond to this need themselves or offer to refer the person on to appropriate counselling.

**5.85** When there is concern about emotional state (eg depression) the person should be referred back to their GP, medical consultant, clinical neuropsychologist/mental health services (if involved) for assessment/intervention. If a practitioner has serious concerns about suicide intent this should be brought to the immediate attention of the person's GP.

**5.86** Following a decision to withdraw from work, people should be offered support in finding suitable alternative occupation to help structure their time and to enable them to participate in valued activities and roles (see 5.111-116). Consideration should also be given, when appropriate, to a referral for a care needs assessment (see 3.44-3.49).

## Preparation for alternative occupation

**5.87** People considered to be capable of employment but who have been unable to return to or retain work should be referred for a vocational or employment assessment by a specialist service or suitably qualified practitioner (see 5.23-42).

**5.88** When a need for vocational rehabilitation prior to RTW is identified people with a LTnC should be referred to a vocational programme appropriate to their needs. People with complex vocational needs should be referred (whenever possible) to a specialist programme for people with a LTnC in accordance with Quality Requirement 6 of the National Service Framework for Long-term (Neurological) Conditions.<sup>8</sup>

**5.89** When a person with a LTnC is seen on a vocational programme, background clinical information should be obtained (ie from GP, neurologist, clinical nurse specialist, Rehabilitation Medicine physician, occupational therapist or other rehabilitation practitioner, as appropriate) and specialist advice sought about whether the programme is able to meet the needs, with referral (as appropriate) to the DEA and/or to a specialist neurological vocational service.

**5.90** When a practitioner is aware that a person with substantial or complex needs has been referred to a pan-disability programme (eg Pathways to Work, current Work Preparation, future DWP funded disability employment provision, or independent programme), consent should be sought from the person to contact the relevant adviser or provider to explain the vocational needs of the individual and to discuss the most appropriate provision.

**5.91** When a practitioner is concerned that a course of action poses a risk to the health or well-being of the person or any third party, this should be brought to the immediate attention of the adviser or provider and confirmed in writing.

**5.92** When a person with a LTnC with substantial or complex needs is seen on a pan disability programme (see 5.90 above), their neurological needs should be clearly stated. The agreed

objectives, programme and progress should be monitored and evaluated by a provider/practitioner with relevant expertise.

**5.93** Specialist vocational rehabilitation programmes for people with a LTnC should include access to the components listed in relation to a preparation for a return to previous occupation (see 5.71), plus additional components to assist in preparation for and support in pursuing alternative occupation ie:

- graded progression of work related activities
- careers guidance and vocational counselling to identify a suitable job
- links with any local Employers' Partnership or Employers' Forum
- 'work tasters' to sample alternative avenues of occupation
- assisted job selection, search, application, interviews etc
- voluntary work trials
- permitted work options
- supported work placements.

**5.94** In setting up a voluntary work trial or supported placement, arrangements with providers need to ensure that:

- the requirements of the job match the skills of the person
- the needs of the person are communicated clearly to the employer
- health and safety training and insurance cover is provided by the employer
- there is provision for on-site job coaching, when required
- the person is guided and supported in adapting strategies to the workplace
- the trial/placement is monitored closely through contact with the person and employer
- the trial/placement does not impact negatively on either the person or their relatives.

**5.95** In setting up a long-term work placement the provider should also make provision for ongoing monitoring for at least six months to respond to any emergent difficulties to establish long-term viability of the placement. This should include feedback from the person and employer and, when appropriate, feedback from a relative or close friend about any negative impact on the quality of life of the person or their family.

**5.96** When ongoing support needs are identified in maintaining alternative employment, consideration should be given to the work adjustments outlined for job retention interventions (see 5.56-61) and/or referral to current Workstep supported employment or future DWP or other specialist disability employment provision.

**5.97** Within a vocational programme it may be necessary to revisit the management of specific difficulties likely to obstruct RTW. When interventions are work focussed they may fall within the scope of a DWP/Jobcentre Plus or other vocational contract. However, when a need for core rehabilitation is identified, consideration should be given to a referral to an NHS or other health rehabilitation service (either direct or via GP) for further assessment/intervention. The vocational programme may need to be put on hold until this work has been completed.

**5.98** All providers of vocational rehabilitation for people with a LTnC need effective working links with local neurological and rehabilitation services and include relevant expertise, eg:

- where a programme is provided by an NHS or other health rehabilitation service there will be a need to add vocational rehabilitation expertise
- where a programme is provided by an independent vocational provider there will be a need to add rehabilitation expertise in managing LTnCs
- where programmes are provided by social services there will be a need to include both specialist health and vocational rehabilitation expertise.

**5.99** Both condition specific and pan disability vocational providers who accept people with a LTnC should ensure that staff are provided with specialist training in the nature and effects of LTnCs and their management.

## **Transition from education to employment or other occupation**

**5.100** For young people with a LTnC vocational needs should be considered in the context of overall development of the individual towards adulthood and independence and the full range of their health, support, educational and social needs. Parents and young people need to begin to think about the development of independence when secondary school education commences, when their peers are beginning to become more independent. In addition to the development of independence and social skills, self-confidence and maturity (eg in accepting feedback) can be developed from extra curricular activities such as sport, outdoor activities etc. It is crucial to encourage exploration of the individual's potential and to discuss their vocational aspirations. Exposure to appropriate role models who have achieved in spite of childhood disabilities is often beneficial.

**5.101** A minority of young people with disabilities will have the dual issues of rapid maturation during the teenage years with a progressive condition. This may be testing for specialist services, as well as for individuals and families. In spite of such difficulties, given support from family, the voluntary sector and statutory services these young people can often progress into work. Young people with life-limiting illness also need access to vocational opportunities including work experience.

**5.102** Young people who are likely to depend on assistive technology for their future employment should be exposed to appropriate powered wheelchairs, communication support and environmental equipment services early in their teenage years in order to optimise personal independence, minimise dependence on parents and enhance their future employment prospects.

**5.103** Young people with a LTnC nearing the end of secondary or further education should have their current vocational needs and aspirations identified in all health or social care assessments, care plans and reviews.

**5.104** Practitioners working with young people with a LTnC should anticipate likely vocational needs and obstacles to progress towards vocational goals on leaving education. They should inform the person (and parents, as appropriate) of the availability of local sources of vocational assessment, advice and support.

**5.105** When unmet vocational needs are identified consideration should be given to a referral to Connexions, Social Service Transitions Team or vocational rehabilitation services experienced in addressing the needs of such young adults. This advice needs to be provided in liaison with the case manager, key worker or other specialist, overseeing the overall care plan for that individual.

**5.106** Some young people may have vocational needs that are not readily apparent on leaving education. When a young person experiences difficulty in coping with vocational training or in establishing themselves in employment, consideration should be given to a referral to Connexions, the DEA and/or specialist vocational services.

**5.107** Young people with complex vocational needs should be referred to a specialist vocational programme appropriate to their needs in line with the requirements of the National Service Framework for Long-term Conditions - Quality Requirement 6.<sup>8</sup> When such programmes have been designed for adults they will need to consider and take advice, as appropriate, about how best to meet outstanding development needs.

**5.108** When young people are referred to an educational course or vocational service that does not specialise in addressing vocational needs related to LTnCs, contact should be made with appropriate specialist services to obtain background information relating to the person's health needs and/or advice on the management of symptoms likely to impede progress. Ongoing support

from a specialist service may be required for both the individual and the educational establishment or employer.

**5.109** In progressing towards their vocational goals young people with a LTnC may benefit from referral for a wide range of vocational interventions. This may include one or more of the following:

- help with independent living skills
- help with community living skills (eg transport, social skills)
- vocational assessment (see 5.23-42)
- pre-vocational (or other) adult education course
- work experience and/or work tasters
- voluntary work
- vocational rehabilitation programmes (see 5.87-99)
- vocational training course (residential or non-residential)
- work trials (see 5.87-99)
- supported work provision
- guidance in identifying and securing a suitable job (see 5.87-99)
- consideration for working from home, either as an employee or self-employed
- support in maintaining employment including assistive technology (see 5.43-5.67).

**5.110** Practitioners should recognise that the needs of young people with a LTnC (eg people with cerebral palsy) may change over time, which may complicate or jeopardise their vocational position. Such changes may require further work adjustments (see para 5.43-5.67) and/or re-referral to relevant health and social care practitioners including help with broader adjustment to the effects of their disability.

## Occupational/educational provision

**5.111** People with a LTnC who are unable to work should be offered guidance and support from specialist health rehabilitation services, Local Council or vocational practitioner in finding alternative occupational or educational opportunities (eg voluntary work, permitted work, sheltered workshop, further education or other occupational provision), in liaison with local voluntary groups, as appropriate.

**5.112** All relevant statutory, independent and voluntary services should share information about occupational and educational opportunities suitable for people with a LTnC and develop local referral pathways/protocols.

**5.113** When health practitioners refer a person to alternative occupational/educational provision they should share information as for job retention interventions (see 5.31 and 5.52).

**5.114** Providers of occupational and educational opportunities require training on the effects of LTnCs and ongoing guidance and support from specialist services (eg rehabilitation teams, clinical nurse specialists) regarding the needs of individuals. This should include provision for joint assessment and reviews, as appropriate.

**5.115** People with a LTnC attending occupational or educational provision will require access to ongoing monitoring and review as much of the provision (eg further education) is time limited and peoples' interests and needs often change over time.

**5.116** Rehabilitation services and local Councils should work with Colleges of Further Education, voluntary agencies and multi-agency bodies (such as Welfare to Work groups) to review and develop occupational and educational opportunities appropriate to the needs of people with a LTnC. Agencies will need to work together to address transport restrictions in accessing such opportunities.

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## 6 Implementation

### Inter agency implementation

**6.1** Under-developed health rehabilitation services, shortage of specialist vocational rehabilitation and suitable occupational/educational provision and a lack of joint working across agencies mean that many people with a long-term neurological condition (LTnC) do not currently have the opportunity to achieve their optimal occupational outcome. These recommendations are intended to facilitate liaison between agencies and access to available vocational rehabilitation suitable for people with a LTnC.

**6.2** Whilst there are various national Department for Work and Pensions (DWP) initiatives (eg Pathways to Work and the new planned specialist disability employment provision), these have to date focused on the needs of people with other conditions (eg musculo-skeletal, mental health and cardio-vascular). The research reviews for the four exemplar LTnCs highlighted the need for specialist provision to address the needs of people with a LTnC. Given the complex nature of these needs it is essential that specific vocational rehabilitation is developed for this group; this is a vital component of the network of services required to achieve optimal occupational outcome.

### Recommendations

**6.3** Local specialist rehabilitation services, Jobcentre Plus, local councils, vocational rehabilitation, occupational health services, further education and other occupational providers undertake a joint review of services available to people with a LTnC to identify existing resources and current gaps in provision. This should be undertaken in the context of the National Service Framework for Long-term (Neurological) Conditions Quality Requirement 6 on Vocational Rehabilitation (NSF-LTnC-QR6) and it's evidence-based markers of good practice (EBMGP).<sup>1</sup>

**6.4** The above services develop local referral criteria and protocols, drawing on these recommendations, to ensure timely access to appropriate vocational services and provision.

**6.5** Key staff from relevant agencies establish ongoing service links (eg between the clinical nurse specialist, neuropsychologist, and/or occupational therapist with the Jobcentre Plus DEA and/or work psychologist and Pathways to Work and other relevant vocational providers) to discuss and review the complex vocational needs of individuals with a LTnC.

**6.6** All relevant professional groups within statutory and government agencies (ie NHS, Jobcentre Plus, Social Services and Education) and the independent/voluntary sector review the training provided to enable staff to identify and address the vocational needs of people with a LTnC, as identified in these recommendations.

**6.7** An inter-agency approach is adopted to increasing awareness of vocational needs and the development of specialist skills training for all providers of vocational assessment, rehabilitation and support for people with a LTnC.

**6.8** Research is commissioned to identify new and the most effective current strategies to respond to the vocational needs of people with a LTnC.

**6.9** Existing provision of employment opportunities and support for people with a LTnC are regularly audited against the following criteria:

- Compliance with the Disability Discrimination Act (2005)<sup>2</sup> and in particular with the requirement that the proportion of employees with a neurological disability in larger workplaces reflects that of the local population.
- Appropriate access to occupational health, local rehabilitation and employment services and vocational rehabilitation services suitable for people with a LTnC including those with complex needs<sup>1,2</sup> (see 1.4) .

- Locally agreed job retention targets for employees with neurological disabilities are met including monitoring of the reasons for failure to remain in employment<sup>1</sup> (see 1.4 and 3.10).

## Key messages for professional groups

6.10 There is widespread agreement that effective vocational rehabilitation involves four key players: the employee (or person seeking employment), the (potential) employer, health professionals, and the State-provided specialist employment services (from the DWP in the UK) or other vocational rehabilitation services. As such, it is expected that specific agencies and professional groups will identify different key messages from the recommendations. This is illustrated below by and for three professional groups represented in the Recommendations for Best Practice Development Group (ie medical practitioners, community therapy staff and Jobcentre Plus work psychologists).

## Key messages for medical practitioners

6.11 Whenever changes in the health of people with LTnCs jeopardise their ability to work, they should be assessed urgently by a Rehabilitation Medicine Service and given high priority for treatment and vocational rehabilitation.

### *Vocational rehabilitation (VR) – when is it needed and how should it be accessed?*

6.12 VR is relevant for those with LTnCs who are:

- seeking work
- in work but experiencing problems
- trying to RTW.

6.13 Health professionals should seek expert VR advice before making fitness to work judgements in people with LTnCs. People with disabilities should also be directed to relevant voluntary sector organisations and web-based resources for information, advice and support.

### *Sharing information*

6.14 A person with a LTnCs applying for a job should carefully consider disclosure of their health condition. Discrimination is frequently a worry, but disclosure does allow and place a responsibility on employers to make reasonable workplace adjustments. An undisclosed condition such as epilepsy may compromise safety for the affected individual or others at work, particularly where a job involves driving, working at heights or operating potentially dangerous machinery.

6.15 Unless safety is an overriding issue, disclosure by others such as health professionals should be with informed consent. Reports should respond specifically to information regarding the demands of the job and the employer's concerns.

6.16 Those advising the person with a LTnCs about disclosure need to be aware of relevant legislation:

- Disability Discrimination Act<sup>2</sup>
- Health and Safety at Work Act<sup>3</sup>
- DVLA regulations<sup>4</sup>
- Mental Capacity Act<sup>5</sup>
- Data Protection Act<sup>6</sup>

### *Assessment*

6.17 Motor, sensory, communication, cognitive and emotional/behaviour problems should be assessed and treated or alleviated where possible. The assessment should also consider issues such as job satisfaction and work-related stress and identify benefits and obstacles to employment including financial implications. Work-related skills, capacity and coping strategies should be assessed under the guidance/supervision of occupational therapy services.

### *Job retention strategies*

6.18 When a person requires significant changes to work duties, an alternative job role and/or ongoing advice or support in the workplace, a referral should be made to the Disability Employment

Adviser (DEA) and, where available to a specialist vocational rehabilitation provider/practitioner, in liaison with Occupational Health services where available. A summary of information concerning the health condition, its outlook and implications for a particular job should be made available.

**6.19** Physical adaptations to the workplace, provision of specialist equipment or aids, and/or assistance with travel to work should be facilitated by Access to Work (AtW) from an AtW Support Unit or via a Jobcentre Plus Adviser.

**6.20** Greater flexibility with hours of work and provision of more frequent short breaks should be considered; this is often a key factor enabling someone with a LTnC to remain in employment.

**6.21** If provision of specific training and support is needed for those with complex problems, eg cognitive problems, this should take place at work under the guidance of a vocational rehabilitation service and be regularly reviewed.

### **Return to work after a neurological illness or injury**

**6.22** Employee's and employer's uncertainties about work potential should be addressed. An initial assessment will generally need to take place off-site (see 6.17) followed by clinical and vocational rehabilitation to overcome potential obstacles.

**6.23** A trial of limited duties in the work environment followed by a gradual build up of working hours and responsibilities is usually the best approach. The speed of this graded RTW should be adjusted according to progress.

### **Retirement on health grounds**

**6.24** People considering a decision to retire on health grounds should first be offered advice regarding the health condition itself, the potential to alleviate difficulties via clinical interventions, rehabilitation and work adjustments, and also be referred for financial advice. Occupational Health, where available, may take the lead in this process.

**6.25** Since people with progressive LTnCs in particular may have been struggling on with work whilst neglecting outside interests as their health and stamina have deteriorated, the decision to retire needs sensitive handling. Advice and support regarding alternative occupations and other activities should be provided as well.

### **Preparation for alternative work**

**6.26** Where assessment has identified a need, referral to a vocational rehabilitation programme for work preparation should be offered. This programme must take account of the underlying LTnC and the particular difficulties that individual is experiencing.

**6.27** People with complex needs, for example cognitive impairments related to a LTnC, should be referred to a specialist programme of vocational rehabilitation with relevant expertise.

### **Transition from education to employment**

**6.28** Teenagers with LTnCs should be referred for careers advice and work experience opportunities comparable with that available to their able-bodied peers. This should include contact with relevant role models.

**6.29** Specific advice should be offered to those considering further education and, for those who opt for this, on-going specialist support should be available both to the individual and to the educational provider.

**6.30** Clear lines of communication should be established between education, employment, social services and health.

**6.31** If there is uncertainty about how a young person with a LTnC will gain and cope with paid employment, the person should be offered referral to a Young Adult or Transition Team. Such teams are usually NHS or Social Services based.

### **Alternative occupational or educational opportunities**

**6.32** Alternative educational and/or voluntary or supported occupational opportunities should be considered for those precluded from work by the severity of problems associated with their LTnC.

6.33 These individuals should be offered a review of their employment potential (including voluntary work), particularly if

- their needs have changed or they are still recovering from a sudden-onset LTnC
- new employment opportunities have become available.

### **Key messages for community therapy staff**

6.34 Therapists assisting people with vocational needs due to a LTnC should recognise the complexity and variability of such needs, develop their expertise in vocational rehabilitation and establish close working links with the local Jobcentre Plus Disability Employment Advisers/work psychologists and vocational providers.

6.35 After initial disclosure of a LTnC to an employer people may need ongoing advice and support from the therapists working with them in explaining the implications for work and how best to manage their difficulties, both at the time and later as a condition changes (see 5.1-6).

6.36 Therapists need to adopt a flexible, multifaceted approach to vocational assessment, combining interviews and formal assessments with practical assessment or feedback of work skills, performance and behaviour, appropriate to the specific circumstances (see 5.30).

6.37 Job retention interventions for those in work should be tailored to the specific needs of the individual. This may include off-site advice, support and review (for those able to manage their own situation) or a worksite assessment followed by implementation and monitoring of specific work adjustments. This often requires information-sharing (with informed consent) and joint working with the employer and vocational services (eg Occupational Health, Disability Employment Adviser, Work Psychologist (WP), Access to Work Adviser; vocational rehabilitation provider/practitioner - see 5.43-67).

6.38 When referring to vocational services therapists should, whenever appropriate, attend the initial appointment to assist the person in explaining their neurological needs (see 5.51-5.52).

6.39 For those seeking a return to previous occupation, rehabilitation interventions need to focus on the specific skills or behaviours required for work, drawing as appropriate on material directly relevant to that occupation. An individually-tailored RTW plan (including ongoing support and review) will often need to be developed jointly with the person and employer (or tutor), drawing on expert advice as required. Therapists play an important role in identifying adaptations, equipment and coping strategies for the workplace (see 5.68-80).

6.40 Therapists need to be alert to the psychological and social impact of decisions to withdraw from work and provide, or refer the person on for, advice and support about alternative occupational and leisure activities (see 5.81-86 and 5.111-116).

6.41 Most vocational rehabilitation programmes are not geared to the complex needs of people with a LTnC. As such, therapists need to be proactive in discussing with the person the benefits of making direct contact with vocational providers to assist in explaining their neurological needs (especially any identified risks) and to advise on and contribute to appropriate interventions (see 5.90-92).

### **Key messages for Jobcentre Plus Work Psychologists (WP)**

6.42 When an individual with a LTnC is referred for employment assessment, WPs should, with the individual's informed consent, establish contact with other relevant professionals (eg clinical neuropsychologists, occupational therapists, occupational health advisers, GPs, etc) who may have prior knowledge of the individual, to ensure that the conduct and focus of the employment assessment is informed appropriately.

6.43 WPs should seek to develop local links with specialist rehabilitation services: to facilitate awareness of the range of Jobcentre Plus services and help which are available to people with LTnCs who wish to work or remain in work; and to establish mutually agreed referral procedures.

**6.44** WPs should strive to develop mutually beneficial 'joint working' arrangements with other professionals (occupational therapists, neuropsychologists, etc), to inform the employment progression of people with LTnCs. Examples could include, establishing effective information-sharing protocols (with appropriate consents), joint case conferences, and training workshops.

**6.45** WPs should continue to seek opportunities to develop their knowledge and skills in the employment assessment of people with LTnCs. In addition, WPs should aim to establish and disseminate best practice and research in employment assessment for these individuals, to Jobcentre Plus colleagues and the wider rehabilitation community.

**6.46** With input from relevant professionals where appropriate, WPs should devise and deliver upskilling and awareness resources, aimed at helping Jobcentre Plus advisers and those working for partner organisations, to meet the employment-related needs of people with LTnCs.

### **Key messages for other practitioners**

**6.47** The Recommendations for Best Practice Development Group encourages other staff groups to identify the key messages from the recommendations for their respective practitioners. This would include other health professionals (eg clinical nurse specialists, physiotherapists), occupational health practitioners, disability employment advisors, vocational rehabilitation providers, vocational case managers/practitioners, care managers, further education tutors and voluntary groups.

**6.48** It is hoped that the recommendations will act as a catalyst for agencies and practitioners to join together to review current local provision and improve joint working in addressing vocational needs, as suggested in the inter-agency implementation recommendations above.

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5. Mental Capacity Act (2005). London: HMSO.
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## Appendix 1 – Recommendations Development Group

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For details of the wider consultation group - please see Appendix 2

*\* The views expressed in this document are those of the authors and do not necessarily represent those of Jobcentre Plus or the Department for Work and Pensions*



**Appendix 2 - Recommendations for Best Practice Consultation Process****Initial consultation**

The initial consultation exercise comprised four elements:

- an approach to individual practitioners and organisations involved in vocational rehabilitation for people with a LTnC including: NHS staff (general practice, neurology, Rehabilitation Medicine, neuropsychology, nursing, occupational therapy); Employers' Forum on Disability; Occupational Medicine; Primary Care Neurology Society; vocational providers; Vocational Rehabilitation Association
- a small number of interviews with specialist practitioners/vocational services
- a consultation meeting with invited Department for Work and Pensions/Jobcentre Plus staff (including disability employment and other personal advisors and Work Psychologists)
- a consultation meeting with representatives of voluntary groups supporting people with a LTnC.

A series of consultation questions were developed by members of the Recommendations Development Group. Participants were sent a copy of the existing acquired brain injury (ABI) guidelines (Vocational assessment and rehabilitation after acquired brain injury: inter-agency guidelines) and asked how these might be modified to address the needs of people with other neurological conditions, with the opportunity to make additional comments and suggestions. The initial consultation questions were as follows:

**Consultation Questions**

1. How would you suggest that the inter-agency operating framework developed for ABI (see Section 7 of ABI guidelines) is broadened to address the needs of people with other neurological conditions?
2. What broad areas of vocational need should be covered in the recommendations for best practice? (The ABI guidelines (Section 8) cover the following: return to previous employment, education or training; vocational/employment assessment; vocational rehabilitation/work preparation; Workstep-supported employment and occupational/educational provision.)
3. Where the areas of vocational need that you have identified (in response to Q2 above) are addressed in the ABI guidelines how should they be broadened/adapted to address the needs of people with other neurological conditions?
4. Where the areas of vocational need that you have identified (in response to Q2 above) are not addressed in the ABI guidelines what specific recommendations do you suggest?
5. Any other comments about the structure or content of the new recommendations?
6. Any examples of good practice in vocational rehabilitation for people with a neurological condition that you wish to draw to our attention.
7. Are there any existing guidelines on vocational rehabilitation relevant to people with a neurological condition that you would recommend that we consider. If so, please specify.

## Consultation on draft recommendations

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Drawing on the responses to the initial consultation, a new draft recommendations section was developed. This was modified in response to ongoing dialogue with specific stakeholders, recommendations from the literature reviews, discussions with members of the Recommendations Development Group and a meeting of the group with the Department for Work and Pensions regarding future specialist disability employment provision.

The fifth draft of the Recommendations for Best Practice section was circulated for comment to a wide range of agencies and practitioners across the care pathway including all the individuals who participated in the initial consultation (see above), specific additional practitioners (eg from further education, neurosurgery, social services) and the following organisations/groups:

- Care Services Improvement Partnership
- Department of Health Neurology Advisory Group
- Employers' Forum on Disability
- Research Project Steering Group (RTW following Traumatic Brain Injury)
- Stakeholders Group, National Service Framework for Long-term Conditions
- Vocational Rehabilitation Association
- Vocational Rehabilitation Practice Development Group, Bucks. (an inter-agency group with NHS, Jobcentre Plus, Adult Social Care, client and family representation)
- Vocational rehabilitation providers - brain injury (identified in previous guidelines)
- Voluntary groups representing people with a neurological condition.

Based on the above responses suggested additions and modifications were included in a sixth draft which was discussed and agreed at a meeting of the Recommendations Development Group in May 2009. A further draft was then completed and finalised.

## Contributors

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The Recommendations Development group would like to thank the following for their contribution to the development of the Recommendations for Best Practice

### Organisations/groups:

British Polio Fellowship  
Different Strokes  
Encephalitis Society  
Headway, the brain injury association  
Multiple Sclerosis Society  
Multiple Sclerosis Trust  
National Society for Epilepsy  
Parkinson's Disease Society  
Scope  
Spinal Injuries Association  
Stroke Association  
Vocational Rehabilitation Association

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## **A Selection of Other BSRM Publications**

### **Vocational assessment and rehabilitation after acquired brain injury**

ISBN 1-86016-231-2 pub 2004

### **Use of antidepressant medication in adults undergoing recovery and rehabilitation following ABI**

ISBN 1-86016-243-6 pub 2005

### **Guide to best practice at the interface between rehabilitation and the medico-legal process**

ISBN 0-9540879-6-8 pub 2006

### **Undergraduate medical education in Rehabilitation Medicine**

isbn 0-9540879-5-X pub 2006

### **Chronic spinal cord injury: management of patients in acute hospital settings National Guidelines**

ISBN 978-1-86016-324-1 pub 2008

### **Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care**

ISBN 978-1-86016-330-2 pub 2008

### **Spasticity in adults: management using botulinum toxin**

ISBN 978-1-86016-350-0 pub 2009

### **BSRM Standards for rehabilitation services mapped on to the National Service Framework for Long-Term Conditions**

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