

# **Review of the Disability Living Allowance Advisory Board**

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# Executive Summary

## Background

1. The Disability Living Allowance Advisory Board (DLAAB) is a Non-Departmental Public Body (NDPB) and was established in 1992. Its responsibilities are to: give advice to the Secretary of State for Department for Work and Pensions (DWP) on any matters he may refer to them for consideration; give advice to doctors working for the Department on any case or question they refer to the Board; and produce an annual report of the Board's activities.

## The Need for a Specialist Independent Disability Advisory Body

2. It is vital to the development of policy to have external input and challenge, no less so than in the area of disability. Whilst there are a variety of other independent bodies available to the Department, none bring together in one standing team those with direct experience of being disabled, alongside those with practical healthcare experience and those with medical knowledge of disabilities, and all focused on benefit issues.
3. This breadth of background and experience enables different perspectives to be considered and debated and for a single view to be provided to policy makers within a biopsychosocial model of disability. It also enables potential solutions outside of the social security system to be identified and thus potentially generate better cross Government working. This argues for the need to keep a body like DLAAB. This view was unanimously supported by the external organisations that offered an opinion.
4. DLAAB's focus is on Disability Living Allowance and Attendance Allowance (DLA/AA). However, nearly all AA customers and over 78% of DLA customers are paid another social security benefit. Each disabled customer then faces a variety of distinct and separate tests and assessments in order to have eligibility to benefit determined. The more the DWP continues to see policy development within benefit silos, the less likely it is to achieve its objective of delivering a truly customer focused welfare system. This demands that a refocused DLAAB should be able to be asked to offer advice across all benefits, other than Industrial Injuries Disablement Benefit (IIDB), which is outside the scope of this review.
5. There should be sufficient issues for a specialist advisory board to address. It will, however, need to support, complement and not duplicate the work of other advisory committees. This means that a refocused disability advisory board should collaborate more with other advisory committees and should be able, specifically, to give advice to the Social Security Advisory Committee (SSAC) and the Disability Employment Advisory Committee (DEAC).

6. **It is recommended that there should be an external advisory board, similar to DLAAB and distinct from SSAC and DEAC, and it should be able to provide advice to inform benefit policy and its delivery as it affects disabled people. This advice should integrate the perspectives of disabled people, frontline health care professionals and those with current medical knowledge. The Board should provide advice on disability issues across the full range of social security benefits (other than IIDB). It should work closely with SSAC and DEAC to ensure gaps and duplications are avoided. It should be able to provide advice directly to them.**

### **The Board's Remit and Purpose**

7. The opportunities offered by the DLAAB have not been fully seized. DWP has tended to ask the Board to focus on somewhat narrowly defined "medical" commissions. Whilst these commissions have been well executed, the Board's membership has significant knowledge and understanding of the needs of disabled people. It should be able to gauge well the impact of policy and operational proposals on them over a greater breadth of issues. Therefore, the refocused board should be more fully used to provide expert advice in the development of social security policy. It should not be seen as a replacement for appropriate external consultation or as an alternative to existing networks and relationships with outside organisations.
8. **It is recommended that the refocused board should provide advice on the needs of people with a disability and provide analysis of the effects on that group of customers. This advice should be sought at the earliest possible stages in policy thinking. It should also be able to offer feedback to DWP on the effects and adequacy of current policy and operational delivery.**
9. The Board should not exercise a scrutiny function, such as that provided by SSAC on regulations and leaflets. A refocused body would not have the capacity to do this and would probably duplicate the analysis provided by SSAC. Unlike the current DLAAB, a successor body should not provide educational seminars and newsletters to DLA/AA decision makers or other benefit staff since it will not have the capacity. Disability and Carers Service (DCS) may however wish to seek the Board's input in developing and improving its approach to developing its decision makers.
10. **It is recommended that DLAAB and its successor withdraw from providing seminars and newsletters. However, the Disability and Carers Service within DWP should bring to a conclusion, at the earliest opportunity, the work in hand to develop a strategy for educating DLA/AA decision makers on disability issues, and in doing so consider the value of involving a refocused Board in this.**

## The Basis, Form and Membership of a Refocused Board

11. The DLAAB's existence and scope are currently found in primary legislation. This provides a level of commitment by DWP to the Board, which helps give it the confidence to perform its duties and for the Department to support its activities. **It is recommended that, subject to consideration of the wider legal framework for advisory bodies, DWP takes the opportunity to change primary legislation to establish the scope of the newly focused board. It should give life to the new board through the means of a non-statutory mandate, pending legislation.**
12. The current DLAAB membership provides a good model for the breadth of knowledge and current, practical experience required and thus it should be able to perform the role of a refocused board. An area that continues to challenge policy makers and operational practitioners lies in mental disability and learning difficulties. Although the DLAAB currently has a mental health consultant and an occupational therapist in this field, a newly focused Board might benefit from the practical experience offered by, for example, a community psychiatric nurse and/or a community worker with experience in learning difficulties.
13. The social security system in Northern Ireland, and its context, is significantly different to the rest of GB to justify the appointment of a dedicated Northern Ireland representative to inform its deliberations, as works well on SSAC and Equality 2025. Subject to the approval of the Commissioners for Public Appointments, **it is recommended that the refocused board should have as its foundation the current DLAAB membership. It should however be widened to include, for example, a community psychiatric nurse and/or a community worker with experience of learning difficulties and the appointment of a dedicated Northern Ireland representative. DWP should continue to ensure that the Board's membership relies on those with current and practical experience of disability and that members have the skills and understanding to produce quality policy advice, as part of a diverse team.**
14. Currently DLAAB members are paid a differential rate, with medically qualified members earning £248 compared to £137 for others. It is unclear what rationale exists for this; how it ensures recruitment and retention of suitable members; or how such differences contribute to harmonious team working. Whilst conducting the review, it was also apparent that each advisory body had varying approaches to fees and expenses. Again, it was unclear why these differences existed. **It is recommended that DWP reviews the fees paid to members of DLAAB (and a successor body), taking account of the aims of equality; the need to recruit and retain suitably experienced and qualified members; and ensure effective team working. DWP may**

**wish to take this opportunity to look at its approach to remuneration across all of its advisory bodies.**

### **Ensuring Success**

15. The DLAAB is a valuable resource to DWP but its full potential has not been realised. Commissions tend to be piece-meal, with a limited forward look. This means that members' time cannot be effectively planned or used. The uncertainty also risks undermining the motivation of members. Moreover, it is not always evident how the decisions on commissions take account of the views of members and others, eg decision makers, on problematic DLA/AA issues. These problems, in large part, stem from a lack of clarity of purpose for the Board, and have been exacerbated by poor linkages between Board and policy-making and delivery communities. **It is recommended that the governance, accountability and support arrangements for DLAAB and its successor are significantly strengthened and improved. This should enable more effective evaluation, improved feedback between DWP and the Board, and the creation of a rich work programme for the Board.**
16. Vital to the Board's success is its ability to secure the confidence of Ministers and others that advice is well founded, authoritative and credible. In part, this relies on maintaining an up-to-date view on current issues and in being recognised by external organisations as expert and effective. The DLAAB currently has a low profile with organisations representing disabled people.
17. The DLAAB has developed a number of effective ways of working. Of particular note is the excellent leadership provided by the Chair. She has developed a highly effective team, which works well. DLAAB has however developed limited links with other related advisory boards, which lessens the opportunity to identify gaps and duplications. **It is recommended that the Board develops a clear stakeholder strategy and plan which, whilst taking account of the finite capacity of the Board, enables improved liaison with external representative groups.**

### **DWP Support to the Board**

18. More frequent reviews of the DLAAB might have enabled its potential to be realised sooner. During the review, concerns were raised about the plethora of advisory boards, their individual roles and their fit within an overarching landscape. It was also evident that best practice is not fully shared across DWP groups; learning is not routinely imported from outside of the Department; and collaboration between boards was patchy. This limits the effectiveness of each board and the totality of the advisory structure to improve the quality of DWP policy-making.

19. **It is recommended that accountability (but not necessarily direct line management) for advisory boards falls under one Director and that they are responsible for: ensuring the full framework of advisory bodies (and each of its constituent parts) remains relevant and value adding; providing assurance that adequate governance and support arrangements are in place for boards; enabling good practice to be shared within DWP and lessons learned from elsewhere; and helping DWP grow role model status.**
20. Each advisory Board has its own administrative arrangements eg for paying fees, arranging meetings and booking venues. This potentially adds to costs. **It is recommended that DWP actively considers the costs and benefits of centralisation of some, or all, of the administrative functions associated with advisory bodies, whilst leaving the pure secretariat functions with individual boards.**
21. Each board is also responsible for its own recruitment arrangements. This means expertise and best practice is not grown. It also risks lengthening recruitment exercises and adding to the overall DWP costs of advertising and recruitment. **It is recommended that DWP actively reviews the current recruitment arrangements to identify ways of improving processes to improve outcomes, increase speed and reduce costs.**
22. The DLAAB secretariat is currently located in London, even though membership and the issues being considered by the Board range across the country. Given the need to reduce the costs associated with a concentration of Government staff in London, **it is recommended that in setting up new secretariat and administrative functions, DWP takes the opportunity to actively consider moving this activity out of London.**

## The Review

23. As part of the Government's commitment to improving public services, all NDPBs should be subject to regular review. In particular, such reviews need to determine whether the function is still required and, if it is, whether the existing model is the best option for its delivery. This reflects the Government's policy of keeping the number of NDPBs to a minimum. If the NDPB is still required, the review then needs to look at how the services and functions could be provided more effectively.
24. The DLAAB has not been subject to any formal review since its introduction. In commissioning this review, the Minister for Disabled People asked that the review address a number of points. She has asked that it make recommendations on:
  - how the Secretary of State for DWP should be provided with benefit advice in respect of health and disability issues;

- whether these functions are best carried out by an advisory NDPB or whether there is a better way to execute these functions;
  - how the interests of Northern Ireland can be met; and
  - how any advisory body concerned with health and disability issues should work with SSAC and DEAC. (DWP officials have clarified that the intention was not to review the remit of either of these two bodies.)
25. This review began in April 2007. Between then and June 2007, interviews were conducted with the Chair and members of the DLAAB and a range of officials with an interest in DLAAB. In May, a letter was sent to over 100 organisations and individuals with an interest in disability related issues seeking their views on the DLAAB. 11 of these responded. Annex A contains details of those to whom the reviewer wrote and those who responded.
26. The reviewer attended meetings of the Board. She also reviewed Board publications and documentation. The findings of this review are based on consideration of these various forms of evidence.

## **The Disability Living Allowance Advisory Board**

### **Historical Background**

27. The DLAAB was established in 1992 as an NDPB. It replaced the Attendance Allowance Board, which was abolished with the introduction of DLA. Unlike its predecessor, the DLAAB cannot decide entitlement in individual cases. It is a purely advisory body. It draws together a wide range of people with experience of and/or expertise in disability related issues. They work as a Board to provide expert advice to the Secretary of State for DWP (or doctors acting on his behalf) to inform policy and the delivery of DLA/AA. The Board's work programme is set by DWP. It cannot instigate its own studies.
28. Much has changed within the Department and its surrounding landscape since 1992. The creation of DWP in 2001 brought together the employment responsibilities of the former DfEE with the former DSS pensions and benefits responsibilities. Increasingly, the agenda has moved from a benefit focus to a wider welfare agenda. This was further widened with the absorption of Health and Safety policy into the Department, which continued the shift towards a broader well-being agenda.
29. On the benefit front, the last decade has seen an increasing transfer of national insurance and benefit related activity to the HMRC, through the increasing use of Tax Credits. There have been many changes in those benefits still within DWP, with a move to a greater commonality of rules across benefits, particularly in the area of income replacement benefits. This has been coupled with a greater focus on the provision

of employment programmes alongside these benefits. Incapacity Benefit (IB), in particular, has been significantly changed and will be fundamentally reformed with the introduction of the Employment and Support Allowance in 2008.

## **DLA/AA Context**

30. Although other benefits have changed, DLA and AA have remained relatively similar in design to that originally introduced in the early 90s. There are about 10 million disabled people (including people with limiting long standing illnesses and infirmities) in the United Kingdom. Of these, about 2.8 million people receive DLA and approximately 1.5 million receive AA. These benefits are intended to provide a contribution to the extra costs associated with disability.
31. People claim DLA/AA by completing a form in which details of their disability and the needs associated with it are described. Claims can also be accompanied by additional information from the customer, a medical or healthcare professional and/or others. A decision maker, employed by the DCS uses this information, and any other additional information obtained, to assess entitlement.
32. There have however been changes in the way DLA/AA have been administered. A distinct agency, DCS, was set up to improve the focus on, and delivery of, DLA/AA. Much investment has been made to modernise its administration, including the development of a bespoke development programme for decision makers, leading to formal accreditation (Professionalism in Decision Making) and improved IT-enabled guidance in the form of the Customer Case Management system.
33. In terms of the future of DLA/AA, the European Commission is arguing in the European Court of Justice that the care component of DLA, AA and Carers Allowance should continue to be paid where recipients move to other EEA states. The European Court of Justice is currently considering this matter, with a judgment due in the autumn. More generally, the Department is looking to modernise the social security system and the way that it is organised and administered so that it better meets the needs of customers. In addition, the Independent Living Review, which will make recommendations to ensure independent living is a possibility for all disabled people is due to report this summer. It is difficult to see how DLA and AA will be unaffected by these changes.

## **Legal Basis**

34. The powers to establish the DLAAB were originally set out in section 3 of the Disability Living Allowance and Disability Working Allowance Act 1991 and subsequently confirmed by section 175 of the Social Security

Administration Act 1992. The Board's functions, ways of working, membership and members' terms of appointment are set out in the Disability Living Allowance Advisory Board regulations 1991 (SI 1991 No 1746).

## **Remit**

35. The DLAAB's remit is confined to DLA and AA matters and not to other disability related benefits. It has three functions:
  - to give advice to the Secretary of State for DWP on such matters he may refer to it;
  - to give advice to doctors, acting for the Secretary of State, on any case or question; and
  - to present an annual report on its activities over the year to the SofS.
36. When the Board was first established, it was mainly asked to provide advice on the accuracy and relevance of the contents of the Disability Handbook. This was the primary form of advice to DLA/AA decision makers on disability and their effects. Over the years, the Board's role has tended to fall into three areas:
  - providing advice on specific areas of difficulty for decision makers, usually in terms of updating and refining advice in the Disability Handbook;
  - producing regular newsletters to decision makers and running seminars to widen decision makers understanding of disability issues; and
  - meeting with external customer representative groups to hear concerns about DLA/AA and to feed back as necessary to DWP where guidance may need amending.
37. There has only been one occasion, in 2001, where an individual case was been referred to the Board.

## **Membership**

38. The Board comprises a Chair and not less than 11 and not more than 20 members. It is required to have members with professional knowledge or experience of: physiotherapy; occupational therapy; social work; nursing people with disabilities; and medical practice. In addition, the Board must have 6 or more members who are, themselves, disabled and at least one who cares for a disabled person.
39. The current Board has one Chair and 15 members. It has professional expertise in: the care of the elderly; general practice; general medicine; malignant diseases; neurology; nursing disabled people; occupational therapy; paediatrics; physiotherapy; psychiatry; rehabilitation;

rheumatology; and social work. 5 members are disabled people. DWP is currently in the process of recruiting a carer and disabled person. (Annex B shows the areas of expertise of the existing board).

### **Other Related Advisory Bodies**

40. There are a number of standing independent organisations available to advise DWP, specifically. These include the:
  - SSAC which offers advice on all social security matters, including scrutinising regulations and leaflets;
  - DEAC which provides advice on improving the employment opportunities of disabled people;
  - Industrial Injuries Advisory Council (IIAC) which gives advice on the Industrial Injuries Disablement Scheme; and
  - National Employment Panel (NEP) which advises on welfare reform and labour market issues
41. There are consultative groups such as the DWP Disability Forum and the DCS Forum. There are also ad hoc groups set up to advise on specific areas of policy development, such as those set up to help on the development of a new Personal Capability Assessment (PCA) within the IB regime.
42. In addition, there are a range of bodies that provide advice on disability issues across Government, such as: the Disability Rights Commission (DRC), whose aim is to stop discrimination and promote equality of opportunity for disabled people; the Disabled Persons Transport Advisory Committee (DiPTAC) which advises on improving access to transport for disabled people; and the more recently formed Equality 2025 Committee which provides a direct voice for disabled people into Government.

### **DLAAB Resources**

43. The cost of the Board, excluding secretariat costs, was approximately £43,000 in 2005/06 and £56,000 in 2006/07.
44. A total of 2.4 full time equivalents provide secretariat support to the Board. In addition, senior managers in the Disability Benefits and the Health, Work and Well-being Directorates within DWP provide sponsorship to it.

## **Current DLAAB Performance**

### **Fulfilling Its Role**

45. It is clear from talking to Board members and officials, that whilst the Board has offered valuable advice to the Department, both have

struggled to create a fulfilling work programme which makes full use of the Board's expertise and knowledge. This appears in large part due to a lack of a clearly articulated and understood role for it. The Board and officials are to be commended for finding ways around this by creating 3 broad streams of activity:

- providing advice in response to specific commissions from DWP;
- providing educational services to DLA/AA decision makers; and
- meeting with external customer representative groups to hear their concerns.

### **Acting on Commissions**

46. The commissions to the Board have mainly been generated from the medical advisory function within DWP. Studies completed in the last two years include: the operation of the "special rules" arrangements for people who are terminally ill; improving guidance for claims from people with malignant diseases; handling claims from children and adults with learning difficulties; and determining claims from people with multiple sclerosis. Though these commissions are discussed with the Board, there is limited evidence that it is able to play as full a part, as it might, in setting its work programme. This means that activity does not necessarily capitalise on the knowledge Board members have of current issues and concerns around DLA/AA.
47. The commissions completed have resulted in changes to guidance to decision makers, though they appear to have less direct impact on policy or operational processes or services. The exception to this has been the special rules commission. A particular focus of this study was how best to handle those awards that had lasted for a considerable number of years beyond the initial prognosis. This is a delicate and complex issue. The Board's advice enabled guidance to decision makers on special rules to be clarified and for a process for reconsidering current cases to be put in place. Thus, the study led to a significant change in approach.
48. There has been no formal evaluation of the studies, though DWP officials may give informal feedback to the Board. Wider awareness of the Board is low, thus assessments about the value of its work are limited. The special rules study is notable in that it had much higher visibility amongst officials and Ministers. Feedback from both is that the Board's advice provided valuable input in the tackling of a difficult and sensitive policy issue.
49. Board members also cited this as a study that played very well to their strengths. There is, amongst Board members, a disappointment that they do not receive more formal feedback on their studies and that they are not updated regularly on the progress of actions resulting from them.

## **Education of DLA/AA Decision Makers**

50. DLAAB provides regular newsletters and face-to-face seminars. They are intended to improve understanding of disability issues. Newsletters are produced three times a year. They are sent to all decision makers and members of Appeal Tribunals and their content is determined on the basis of feedback from decision makers. There has been limited formal evaluation of the value of these newsletters but anecdotal feedback from decision makers is that they are extremely useful and are able to offer a real insight into the experience of disabled people. This, in turn, helps decision makers better understand the likely effects of particular disabilities on customers to help inform decision making.
51. Seminars are run twice a year, with Board members, and others, giving presentations and facilitating plenary discussion on areas suggested by decision makers. On average, about 30 decision makers attend, out of a total population of around 1300. Feedback from attendees is extremely positive.

## **Meeting with Customer Representative Groups**

52. The Board has met 5 groups in the last two years, namely the British Limbless Ex-Servicemen's Association, MIND, the Scottish Association for Mental Health, Afasic; and the Royal National Institute for the Blind. The discussions mainly focus on concerns over DLA/AA policy and/or operations. There is limited evidence that these encounters have led to significant changes in guidance, policy or operations, though they have helped widen members' knowledge and understanding of some disabilities.

## **The Future**

### **Is There a Need for Specialist Advice?**

53. Best practice in policy making presumes the value of external, expert input and challenge. The questions are whether the features of the disabled segment of the DWP customer base justify more focused advice and whether other external advisory bodies could provide this? There is strong argument that each customer has their own set of unique needs and issues and that segmenting into clusters undermines a focus on the customer as an individual.
54. That said, much of the current social security system targets provision on the basis of assumptions about and tests of disability. For example, DLA/AA are solely intended to contribute towards the extra costs arising from certain effects of disability; IB relies on the degree to which a person is unable to carry out work related activities because of illness

and/or disability; Income Support is increased to take account of the additional costs of disability; and there are specialist work programmes and accompanying financial support available to disabled people, eg New Deal for Disabled People and Pathways to Work. Secondly, the help, support and treatments available to disabled people continue to evolve and change. DWP needs to take account of these in maintaining a relevant and effective social security system.

55. The Department has considerable expertise in policy making; extensive knowledge of disability benefit issues and in-house medical expertise. More recently the formation of the Health, Work and Well-being Directorate has enabled increased integration of medical and health related advice into the policy making process. Nevertheless, DWP still has limited current and direct practical knowledge and understanding of the real experiences faced by disabled people, day-to-day.
56. The DLAAB provides a unique demonstration of the power of bringing together those who are, themselves, disabled, alongside those with practical, front-line healthcare experience and those with medical knowledge of disabilities. This enables different perspectives to be considered and a single biopsychosocial model view on disability issues to be generated. This was particularly evident in the recent advice provided on special rules. Most respondents agree that this challenging issue would have proved difficult to resolve without DLAAB.
57. This provides a strong presumption that, since disabled people form a significant proportion of the customer base, value is added by having external advice, integrating varied perspectives, within a single model of disability. Moreover, that this advice is important in guiding thinking on policy formulation, at its earliest stages, to avoid investing time and resources on inappropriate issues and/or assumptions.
58. It is vital that this advice is available easily and quickly, and in collaborative partnership with DWP, as it continues to shift its focus towards improving the social security system for disabled people, through, for example, ESA and a modernised service delivery model which puts customers at the heart of its design and operation.

### **Scope of View**

59. Given the logic of the arguments above, it is extremely difficult to see why such advice should be confined to DLA/AA, especially given that nearly all AA customers and over 78% of DLA customers are in receipt of other benefits. Moreover, to continue to compartmentalise policy thinking along benefit chimneys, reinforces the current barriers to truly customer-focused services to which the Department aspires.
60. There are many aspects of the social security policy which would benefit from a breadth of knowledge and experience about disability issues. The setting up of ad hoc groups to advise on the development

of a new IB PCA and the involvement of customer representative groups on ESA demonstrates this need. Whilst there may still be a need to have further expert opinion and wider consultation as policy develops, a DLAAB-like body could advise on issues before design is entrenched and without placing more consultation burdens on external groups.

### **Another Board?**

61. There are many bodies available to provide advice on disability issues. So it is questionable whether a distinct body is needed or whether existing bodies (or ad hoc groups or specific consultation exercises) could provide the advice needed. In considering this, it is first useful to draw out a distinction between an expert and consultative body. The distinctions are usefully set out by Anthony Ogus in his article "*SSAC as an advisory body: its role and influence in policymaking*". In the former, the body must make its own mind up upon an issue, balancing competing views. The latter will summarise the range of views provided to it. A consultative body, by simply articulating others' (often anti-Government) views, might risk its neutrality. On the other hand, the former may, on occasion, fall from favour with some lobbyists for taking a different, independent view.
62. It is helpful to policy makers, especially at the early stage of policy making, to have authoritative help in guiding them through a maze of different views. This is particularly the case when policy is sensitive and public debate and/or major consultations may prove nugatory, unhelpful or unnecessarily burdensome on representative groups. This calls for an expert, rather than a purely consultative group, in the early stages of policy making. However, that should not obviate the need for proposals, and the advice on which they are based, to be exposed to challenge through external discussion and consultation, at an appropriate time.
63. Bringing together ad hoc groups, as needed, could provide the necessary advice and avoid the overhead of a standing group. However, it is difficult, when bringing people together only occasionally, to develop effective ways of working necessary to ensure a single view, taking full account of the diversity of opinions. There is also a risk of a lack of continuity. A standing body, which continues to learn and grow, avoids such risks.
64. There are, however, other expert standing groups available to provide advice to DWP on disability issues. It has been suggested that SSAC and DEAC might, with some reshaping, be able to provide such advice. Whilst any suggestions to change the remit of either SSAC and DEAC are out of the scope of this review, observations are offered to help guide future thinking.

65. SSAC provides valuable advice to DWP on the full range of social security issues. However, it does not have a membership that would enable it to provide specialist advice on the practical implications of policy on, and the needs of, disabled people. To change the membership of SSAC to do this would undermine its intended role and skew attention to one customer group and away from the cross customer view so ably provided by SSAC.
66. The last review of SSAC contained a suggestion that DLAAB might act as a sub-group of SSAC. This would certainly ensure that SSAC had close first-hand knowledge on which to call. However, this would mean that any refocused board's agenda would be determined by SSAC, potentially to the exclusion of the demands of DWP policy makers. Close linkage with a proactive body such as SSAC might also create a nervousness (not necessarily justified) amongst some officials. This might limit their eagerness to involve the disability board in early policy making. The advisory body should therefore be a distinct body, working closely alongside the Department, in a manner similar to DEAC.
67. There is also an argument about whether both DEAC and a benefit focused disability advisory board are needed. The DLAAB's membership has extensive frontline medical and healthcare experience, whilst DEAC has a membership which covers disability employment experience. Widening DEAC's membership, as well as its remit, is likely to jeopardise its focus on advising DWP on improving employment opportunities for disabled people.
68. This confirms that the membership and focus of a DLAAB-like board is unique and vital. Moreover, that it has a role distinct from DEAC and SSAC. It should not, however, operate in isolation from them. First, it should be able to offer advice directly to each. The Board and the Department, would need to consider the feasibility and priority of this alongside the board's existing work programme and role. Second, it should seek opportunities to share knowledge and understanding between the groups, for example, by regular meetings between the Chairs, the use of "twinned" members from each and joint subgroups to explore areas of mutual interest.
69. The reviewer has taken the view that there is a strong case for a distinct advisory body but recognises that, unless properly used and supported, it will not represent value for money. The recommendations made in paras 104 et seq. are intended to improve accountability and evaluation to ensure that this risk is properly managed.
70. IIDB and the Industrial Injuries Advisory Council were excluded from the scope of this review. Depending on decisions on the future in this area, DWP may wish to consider whether there is any scope for a refocused Board to offer advice in this area.

71. **Recommendation 1: there should be an external advisory board, distinct from SSAC and DEAC, able to provide advice to inform benefit policy and its delivery. It would supplement the in-house expertise provided by healthcare professionals in the Department's Health, Work and Wellbeing Directorate. The advice should integrate the perspectives of disabled people, frontline healthcare professionals and those with current medical knowledge. The Board should provide advice on disability issues across the full range of social security benefits. It should work closely with SSAC and DEAC to ensure gaps and duplications are avoided. It should be able to provide advice directly to them.**

### **The Role and Purpose of the Board**

72. The decision to have a distinct external advisory body is intended to ensure that the needs of disabled people and the context in which they live are understood at the earliest stages in policy thinking. This insight should also help to identify and solve problems on current policy delivery. The Board would also enable identification of solutions that may lie outside of the benefit system. This would help encourage greater collaborative and imaginative cross-Government working, as well as the creation of more innovative thinking and partnerships with others.
73. In performing this role, a board might usefully set its own agenda, as well as requiring DWP to consult it on issues, as SSAC does. However, a strong research role, combined with a heavy scrutiny role, might jeopardise its ability to do this. SSAC already provides such a role, which should be enhanced by enabling it to seek advice from a disability board, if it wishes. Consequently, a refocused DLAAB should provide advice at the behest of the DWP, in a similar way as appears to operate successfully for DEAC. However, the work programme should be developed with the input of the Board to ensure that it takes account of current issues and concerns and balances short and longer-term issues.
74. The value of the current DLAAB has not been fully achieved. It has tended to focus on somewhat narrowly defined "medical" commissions. Yet its membership has significant knowledge and understanding of the needs of disabled people and should be able to gauge well the impact of policy and operational proposals on them.
75. Thus, the Board's purpose should be to provide the Secretary of State with authoritative, independent expert advice on:
- the benefit needs of people with a disability and/or illness; and
  - the impacts on those customers of emerging social security policy and operational design as well as its ongoing delivery.
- An outline of the role and suggestions for ways of working are at Annex C.

76. Short of analysing all the current disability issues facing the DWP, it is difficult, at this point, to provide an immediate work programme for the Board. But in doing so, both the DWP and the Board will need to ensure it makes best use of the board. The more generic the questions asked of it, the greater the risk that it will duplicate SSAC activity or not properly utilise members' specialist skills and knowledge.
77. So, for example, whilst the DWP's channel strategy might have specific implications for disabled people, so it will for other groups eg elderly people and those from ethnic minorities. Thus, it is less likely that a specialist disability advisory board would add value to considerations in this area, though it might contribute say to a SSAC contribution to, or study of, it. However, in developing a new benefit largely for disabled people, such as ESA, the board could usefully play an active part in its policy and operational design. Whilst the design of ESA may be too far advanced for DLAAB to add value to that, it could potentially offer input to its implementation and ongoing delivery. A refocused Board could also help DWP develop its thinking on the newly created customer insight role as it relates to disabled people. Alongside this, it could also advise on more specific policy questions, such as, assessing the issues raised by the Royal National Institute for the Blind in its recent campaign for the higher mobility component of DLA to be automatically awarded to blind people.
78. Initially, given the Board's low profile within the Department, it will need to actively engage with policy units for opportunities to provide advice. There is a huge change agenda facing DWP, along with continual external challenge to current policy and its delivery. It is difficult to conceive that the Department is not rich with opportunities where a DLAAB-style body could add real value. Over time, as that value is seen and appreciated, it is anticipated that potential areas of input will exceed the Board's capacity. With the benefit of growing experience, it should be possible to develop criteria to prioritise such candidates so that the Board's work programme is focused on those areas where it can provide most impact.
79. Whatever question the Board is invited to consider, its advice should, in line with the principles of good government, be available openly. However, in the interests of informing early policy making it should be able to provide such advice confidentially, subject to Data Protection and Freedom of Information policies.
80. **Recommendation 2: the refocused board should provide independent external advice on the benefit needs of people with a disability and/or illness and provide analysis of the effects of social security on this group. This advice should be sought at the earliest possible stages in policy thinking. It should also give feedback to DWP on the effects and adequacy of current benefit policy and operational delivery.**

81. The thrust of the recommendations in this report is to move the Board's role firmly into the policy making sphere. This goes alongside it needing to withdraw from some activities. Unlike DLAAB, the refocused board should not provide newsletters and seminars to decision makers, since it will not have the capacity to provide such services across the whole of the decision making community. However, given the very positive feedback from decision makers about the value of such learning opportunities, it is clear that DCS needs to consider how best to fill the gap the withdrawal of the DLAAB from this area creates. It is understood that DCS are currently developing such a strategy and it may well prove helpful for DCS to have DLAAB input into the development of this agenda. The Board will, however, need to work with DCS to create opportunities for Board members to keep in touch with decision makers to understand the challenges facing them and the context in which they are operating.
82. **Recommendation 3: the DLAAB and its refocused successor should not provide seminars or newsletters to DLA/AA or other benefit staff and find other opportunities to keep in touch with the issues facing decision makers and other front-line staff. DCS should bring to a conclusion, at the earliest opportunity, the work in hand to develop a strategy for educating DLA/AA decision makers on disability issues and actively consider how the DLAAB might to contribute to its creation and delivery.**

### The Legislative Foundation

83. Currently the DLAAB's existence and scope are found in primary legislation. A commitment to the use of expert opinion in policy making is given more force by elaborating it in primary legislation. Similarly, it helps give the Board the message that its role is seen as important and long standing. This in turn should give the membership the confidence and motivation to provide quality, value-adding advice. However, relying on primary legislation to widen the DLAAB's remit, will delay improvements.
84. A way forward would be to consider changing legislation, when a suitable opportunity arises. This would enable the scope and purpose of a widened disability board as described in primary legislation and for details of the membership and the relationship to other groups to be revised and continue within the scope of regulations. Until such legislative changes can be effected, a non-statutory mandate (akin to that used for DEAC) should be used to give life to a refocused board.
85. Setting out the Board's role in primary legislation does, however, mean that it makes it more difficult to vary it so that it can change within a wider landscape of advisory bodies. It also means that the legal basis for this disability advisory board is different from both SSAC and DEAC, and from other DWP/government advisory bodies. This will militate

against improving the cohesion and relevance of expert input and risk inefficiency. Whilst this review is unable to offer views on the legislative provisions for other bodies, paragraph 104 et seq. make recommendations to improve the way in which the all DWP advisory bodies are stewarded, since without these changes a DLAAB- style body cannot operate at an optimum level.

86. **Recommendation 4: subject to wider considerations on the overall legislative framework for advisory bodies, the DWP should, when a suitable occasion arises, take the opportunity to change primary legislation to establish the newly focused Board and pending legislation, it should give life to the new Board through the means of a non-statutory mandate.**

### **Membership**

87. The current DLAAB membership provides a good model of the breadth of knowledge and experience necessary to inform policy on benefits for disabled people. Thus, it could be used to deliver a widened remit. There will be, however, be occasions when the Board needs additional expertise. The Board should therefore also be able to co-opt additional members to it.
88. Any such board needs to ensure that members have direct practical and current knowledge and experience of disability issues; can work effectively in a diverse team; and are able to operate effectively in a policy-making context. Critical to the Board's success is a chair of the calibre currently on the DLAAB. She exemplifies the leadership skills necessary to build inclusive behaviours within and beyond the Board and to develop focused and credible advice. DWP will need to ensure that any refocused Board continues to have this style of leadership.
89. An area that continues to challenge policy makers and operational practitioners lies in mental disability and learning difficulties. Although the DLAAB currently has a mental health consultant and an occupational therapist in this field, a newly focused Board might benefit from the practical experience offered by, for example, a community psychiatric nurse and/or a community worker with experience of learning difficulties.
90. Membership should continue to ensure that the interests of Scotland and Wales and other parts of the country are adequately understood. In the case of Northern Ireland, there is sufficient difference in context and service for disabled people that the advisory board would benefit from a dedicated Northern Ireland representative, as works well in SSAC and Equality 2025.
91. **Recommendation 5: subject to the approval of the Commissioner for Public Affairs, the refocused board should have as its foundation the current DLAAB membership and widened to**

**include a community psychiatric nurse and/or community worker with experience of learning difficulties and a dedicated Northern Ireland representative. DWP should ensure that the Board's membership continues to rely heavily on those with current and practical experience of disability and have the skills and understanding to produce quality policy advice as part of a diverse team.**

## **Remuneration**

92. The remuneration and terms and condition must attract and retain the right membership and ensure effective ways of working. Currently, medically qualified board members are paid £248 per day, whilst others are paid £137. The rationale for this is unclear. The current approach appears to reward people for expertise outside of the Board, rather than members' contribution to it. The differential payment may lead to perceptions of a second-class tier within the Board, and may harm effective team working.
93. **Recommendation 6: DWP should review the fees paid to members of DLAAB (and a successor body), taking account of the aims of equality; the need to recruit and retain suitably experienced members; and the value of encouraging effective team working.**
94. In undertaking this review it was also apparent that a wide range of approaches operates in relation to remuneration across advisory boards. Again, the rationale is unclear, as is the contribution of the policy to an effective framework for securing quality, expert advice and in a cost-effective way.
95. **Recommendation 7: DWP should consider reviewing the remuneration arrangements across advisory boards so that they have a clear rationale and that any differences in approach are soundly based.**

## **Ensuring Success**

96. The full potential of the current DLAAB has not been fully utilised. There are a variety of reasons for this. DWP and the Board have suffered from a lack of clarity about its purpose. This has also led to an absence of success criteria and performance measures against which to judge the success and value of the DLAAB.
97. On the advice and services provided by the Board, there has been limited, systematic feedback to the Board on its performance or regular updates on how its advice has been used. Similarly, there are no formal mechanisms for the Board to give feedback to the Department on its use and support of it.

98. Given that the DLAAB relies upon the Department for its agenda, it is incumbent on DWP to ensure that this is done. Until recently, limited resources, competing priorities and loose accountability arrangements have meant that there has been limited senior management focus on the Board and little proactive support of it, of the sort so ably demonstrated by the SSAC and DEAC secretariats. This would have allowed policy horizons to be scanned and opportunities for the Board to add value identified and optimised. Moreover, this has also meant that the Board has limited profile within DWP, which further limits the use made of it.
99. **Recommendation 8: the sponsorship and support arrangements of the DLAAB and its successor should be immediately reviewed and strengthened:**
- so that it has a clearly articulated purpose, success criteria and performance measures. These should be used as the basis for regular, formal reviews leading to improvement action;
  - there should be regular two way feedback between the DWP and the Board so that issues can be quickly identified and resolved and the board is kept regularly appraised of its impact and value of its advice;
  - the sponsorship/secretariat functions should be suitably resourced and staffed to enable a proactive approach to generating the Board's work programme;
  - an annual rolling work programme should be developed with the active input of the Board, which is regularly reviewed and prioritised;
  - secretariat and sponsorship accountabilities should be clearly articulated within the Performance and Development Process through clear key work objectives and effective appraisal, relying on feedback from the board on DWP officials' performance;
  - annual appraisals for members should continue and performance issues and development needs should be addressed; and
  - the sponsorship/secretariat should work closely with the Board chair to raise the profile of the Board within DWP, both within policy and in operations.
100. The DLAAB has developed a number of effective ways of working. Of particular note, is the excellent leadership provided by the Chair in terms of developing a highly effective team, which demonstrates very strong inclusive and respectful behaviours. She has also introduced effective processes, which enable commissions to be taken forward in a focused and well-managed way and for lessons to be learned.
101. However, the DLAAB has been less strong in developing a systematic approach to managing its relationships with other groups and boards. The Board needs to ensure that its knowledge and understanding

remain current and relevant, and are seen as credible. The DLAAB and its successor need to develop a clear strategy and underpinning plan for working, meeting with a range of external organisations and front line benefit staff and other practitioners. This will help it maintain the relevance of its knowledge and its ability to keep a finger on the pulse of issues.

102. Similarly, the Board need to consider how best it meets with and understands the agendas of groups such as the DRC, DiPTAC, Equality 2025, the DWP Disability Forum and the DWP Standards Committee so that opportunities and knowledge can be shared and optimised.
103. **Recommendation 9: DWP and the Board should develop a clear stakeholder strategy and plan (which takes account of capacity constraints) for ensuring the continued quality and credibility of its advice.**

### **The Departmental Context**

104. It is regrettable that no formal review has been undertaken of the DLAAB since its inception in 1992. More frequent reviews might have enabled its potential to be realised sooner. However, as this review illustrates, it is peculiarly difficult to assess the value of one board, without seeing its place within the wider landscape of policy advice groups, their intended use and their interrelationship.
105. A wide range of different practices, and staffing and skills levels, exist around the different advisory boards. Despite the good intention of individual secretariats, it is clear that best practice within DWP is not being shared easily and value assured. Moreover, there is little evidence of DWP learning from others across or beyond Government.
106. The Department has a unit responsible for overseeing the governance of all NDPBs, which might facilitate cohesion and sharing of best practice. However, NDPBs range widely in size, shape and role, and include large operational units. This unit may not, therefore, be able to address the specific questions about the relevance and value of the framework of advisory bodies. There are sufficient advisory bodies in the policy making sphere to justify a more coherent oversight of them to ensure that they fit and add value.
107. It would be helpful to bring oversight of policy type advisory bodies under one Director. That does not, however, mean full accountability for each board sitting under that person. The board sponsors need to ensure close connection between the boards and the relevant policy areas. It is therefore sensible to keep individual secretariats within the relevant policy directorates.

108. However, it would be helpful for a single Director to have clear accountability for the suitability and effectiveness of the structure of advisory boards. This would involve addressing questions such as: why do we need them at all; how do we judge their value; which individual boards are needed; what is their specific purpose; and how should they interrelate?
109. The Director would also be able to provide assurance to the Permanent Secretary, and others, that: each board's performance is being regularly monitored; they are adequately staffed and supported; and best practice is grown and shared. This assurance might then enable fundamental, periodic, reviews to focus on the landscape of boards, with specific reviews of individual boards only undertaken on an exception basis, that is, when ongoing monitoring suggests that the Board's role needs rethinking. This would save costs, offer greater learning opportunities and help improve the overall quality of policy-making.
110. **Recommendation 10: accountability (but not necessarily direct line management) for advisory boards should fall to one Director who is responsible for ensuring that :**
- **the full framework of advisory bodies is regularly reviewed and evaluated so that it remains relevant and value adding;**
  - **each board is adequately resourced and supported and the board's performance is routinely monitored, evaluated and improved; and**
  - **good practice is shared within DWP, lessons learned from elsewhere and it grows role model status.**
111. Each advisory Board has its own administrative arrangements, for example, for paying fees, arranging meetings and booking venues. This potentially adds to costs. By centralising the functions, efficiencies could be made. It has not been possible within this review to undertake the detailed analysis of likely benefits but similar such centralisations suggest savings in the order of at least 10%. In addition, greater flexibility to cover absence, peaks and troughs can be introduced. Against that, there are concerns that centralisation might cut across and undermine the relationship that individual secretariats have with members, and will cause confusion.
112. **Recommendation 11: DWP actively considers the costs and benefits of centralising advisory support functions, whilst leaving the "pure" secretariat functions dedicated to serving the individual boards.**
113. Each board is responsible for its own recruitment arrangements. Since recruitment is not constant, it means that expertise and best practice is not grown, recruitment times may be longer as the secretariat "gets up to speed" with what is required, and it is difficult for forthcoming opportunities to be brigaded together and co-ordinated advertising and

recruitment exercises undertaken, thus saving costs and potential increasing the number and quality of applications. A recommendation to set up a dedicated central appointments unit within Departments to support the recruitment of NDPBs, especially when only one or two members were recruited a year was made in the Tenth Report of the Committee on Standards in Public Life. Whilst this was accepted by Government, DWP decided that it was not appropriate for its organisation. However, there still appears scope to improve the way in which members of advisory boards are identified and recruited.

114. **Recommendation 12: the Department should review the current arrangements for recruiting members of advisory boards to identify ways of improving the recruitment processes to improve outcome, increase speed and reduce costs.**
115. The DLAAB secretariat is currently located in London, even though membership and the issues being considered by the Board range across the country. Given the need to reduce the costs associated with a concentration of Government staff in London, there appears no fundamental obstacle to moving the secretariat out of London, so long as they operate in a way which ensures the horizon scanning function and networking activities are properly undertaken.
116. **Recommendation 13: in setting up new secretariat and administrative functions, DWP should take the opportunity to actively consider moving this activity out of London.**

## Annexes

### Annex A – Information gathering exercise, organisations consulted

Leonard Cheshire Foundation  
MENCAP  
MIND  
RADAR  
RNIB  
RNID  
Department of Health  
Inclusion Scotland  
National Federation of the Blind  
Age Concern Cymru  
Carers UK  
Carers Wales  
Princess Royal Spinal Injuries Unit  
**Princess Royal Trust for Carers**  
Independent Living  
Disability Awareness in Action  
Joseph Rowntree Foundation  
**Multiple Sclerosis Society**  
Disability Rights Commission  
Scottish Deaf Association  
UKAN  
NCIL  
The British Council of Disabled People  
Social Exclusion Task Force  
DEMOS  
SCOPE  
Policy Studies Institute  
National Centre for Social Research  
Kings Fund  
Employers Forum on Disability  
Trade Union Congress  
Disabled Parents Network  
Turning Point  
Commission for Social Care Inspection  
Age Concern  
British Deaf Association  
British Institute of Learning  
Deaf Association Wales  
National Assembly for Wales  
Mental Health Employment and Training  
Local Government Association  
Carers Scotland  
SSPLD, Department for Social Development  
National Forum for People with Learning Difficulties  
Scottish Executive  
Age Concern England  
Kings College  
Disability Alliance  
**Help the Aged**

National Autistic Society  
People First  
Equalities National Council  
**Spinal Injuries Association**  
British Council of Disabled People  
Association of Directors of Social Services  
**Royal College of General Practitioners**  
Royal College of Psychiatrists  
Royal College of Physicians  
Royal College of Physicians  
Royal College of Surgeons  
British Medical Association  
Royal College of Nursing  
Industrial Injuries Advisory Council  
Social Security Advisory Council  
Royal College of Speech and Language Therapists  
British Association of Social Workers  
Disability Employment Advisory Committee  
Work and Pensions Committee  
DWP Decision-Making Standards Committee  
Royal College of Occupational Therapy  
Chartered Society of Physiotherapy  
Disability Matters Ltd  
Hoffman Foundation for Autism  
Charity Commission  
Prime Minister's Strategy Unit  
Capability Scotland  
Scottish Disability Equality  
**Disability Agenda Scotland**  
ENABLE Scotland  
SENSE Scotland  
Queen Elizabeth Foundation for Disabled People  
**Wales Council for Deaf People**  
Cystic Fibrosis Trust  
**BLESMA**  
British Polio Fellowship  
**Down Syndrome Association**  
Trade Union Disability Alliance  
Citizen's Advice  
Citizen's Advice Scotland  
Equality 2025  
DPTAC  
Macmillan Cancer Support  
RETHINK  
Paul Treloar

*Those organisations which responded are shown in bold*

## **Annex B – DLAAB Board Members**

### **Chairman**

**Mrs Anne Spaight, MBE, MA, MCSP** is a physiotherapist and health management professional with over 30 years experiences of NHS therapy services across the country. She is currently Associate Director of Clinical Governance for Lincolnshire Ambulance Service NHS Trust. Her special interest is in rheumatology and she has lectured widely both in the UK and overseas. Mrs Spaight is a lay member, appointed Chairman in May 2003.

### **Vice Chairman**

**Dr Ian McGill, MA, BM BCh, FRCP** was formerly Consultant Physician at Torbay Hospital and Director of Cancer Services. He has a wide medical background and was responsible for care of AIDS patients as well as a range of malignant diseases. He is an assessor for the Professional Performance Review Panel of the GMC and was appointed assessor by the Commission for Health Improvement. He has a special interest in support services for patients with cancer. Dr McGill is a medical member, appointed to the Board in 1998.

### **Members**

**Dr Amit Arora, MD, MRCP, MSc** is a consultant physician in Stroke Medicine at the North Staffordshire Combined Healthcare NHS Trust. His special interests are in management of acute stroke, risk factor modification and community participation in disease prevention. He is a module leader for the MSc course in Geriatric Medicine at Keele University and a member of BMA Medical Speciality Sub-committee. Dr Arora is a medical member, appointed to the Board in 2006.

**Mrs Simone Baker** works in a number of organisations in the voluntary sector. She is Vice Chair of the Disabled Parents Network, member of the West Berkshire Maternity Services Liaison Committee and the SE Regional Committee for the Big Lottery Fund (formerly Community Fund). She has worked with the Thalidomide Society and served on the Thalidomide Trust's National Advisory Council. She is a member of the Restricted Growth Association and serves on the DLA Appeals Tribunal. Mrs Baker has congenital malformations of all four limbs caused by the Thalidomide drug. She is a lay member, appointed to the Board in 2000.

**Mrs Jean Cooper, BSc Econ, HOLRCC, RSW** is a qualified social worker. She currently assesses the needs of children with disabilities for the Family Fund and the care needs of severely disabled adults for the Independent Living Funds. She is a member of the Appeals Tribunal and a part-time social work tutor for Nottingham Trent University. Mrs Cooper is a lay member, appointed to the Board in 1999.

**Mrs Judith Holt, DipCOT, MBAOT, SROT** is an occupational therapist working with people with both physical and mental disabilities. She has served with the Mental Health Review Tribunal Service reviewing the detention of patients treated under the Mental Health Act. She has been a member of the Appeals Tribunal since 2005. Mrs Holt is a lay member, appointed to the Board in 2001.

**Mohammed Zubair Khan** is a Crime Scene Manager, Diversity Champion and Chair of Diversity Forum with West Midlands Police. He is a lay member of Employment Tribunals and Public Governor at Heart of England NHS Foundation Trust. He is an authorised assessor for new police recruits and a member of Solihull Police Development Board, and a visiting lecturer in Crime Scene investigations at Sutton Coldfield College. Mr Khan has experience of caring for a disabled person and has helped people within the community with applications for benefits and other provisions. He is a lay member, newly appointed to the Board in September 2007.

**Dr Ben Ko, MB, ChB, MRCP, FRCPCH** is a consultant community paediatrician, specialising in childhood neurodisability and pervasive developmental disorders. He is a council member and trustee of the Royal College of Paediatrics and Child Health, and contributes to setting national standards for paediatric practice and training. He was formerly a member of the Appeals Service. Dr Ko is a medical member, appointed to the Board in 2003.

**Dr Mohammad Obaidullah, MB, BS, FRCOG, FRCGP** is a GP with special interest in obstetrics and gynaecology, dermatology and palliative care. He is a member of the Multi Research Ethics Committee for Wales, the Appeals Service and associate member of the GMC. He is a GP appraiser for the University of Wales College of Medicine and a volunteer on the Doctors' Support Line. Dr Obaidullah is a medical member, appointed to the Board in 2004.

**Dr Ronald Pearce, MD, PhD, FRCPC, FRCP** is a consultant neurologist at Charing Cross and West Middlesex University Hospitals, with special interest in Parkinson's Disease and movement disorders. He runs specialist clinics in Epilepsy, Parkinson's disease and other movement disorders and is Clinical Director of the UK Parkinson's Disease Society Tissue bank at Imperial College. He is involved in clinical and laboratory-based research into Parkinson's and chronic psychiatric disorders. Dr Pearce is a medical member, appointed to the Board in 2005.

**Ms Sarah Playforth, MCLIP, DipPSM, DipITEC** was formerly chief librarian in a new unitary authority and currently runs her own business providing access and equalities consultancy and training. She is a lay member on Employment Tribunals and has served as volunteer, Trustee, middle and senior manager in both the statutory and independent sectors managing and developing public library services and equal access. She has researched, planned and campaigned for equality of access and inclusion for deaf and

disabled people; Sarah herself is D/deaf. She is a lay member, appointed to the Board in 2003.

**Mrs Clair Poole** is a landscape artist. She has experience of committee work relating to health and welfare issues, provisions for sport and play, and education through play for the under 5s. She has Multiple Sclerosis and firmly believes access is essential to equality. Mrs Poole is a lay member, re-appointed to the Board in 2003.

**Mr Douglas Ross** has worked in the disability sector for 17 years, mainly in the field of employment relating to disabled people. He currently works for the Leonard Cheshire Foundation on their 'Workability' project, and was previously with the RNIB and the Government's Employment (Disability) Service. He is a former member of the British Computer Society Disability Group Committee and the Greater London Network on Disability Working Group. He has been disabled since birth due to spina bifida. Mr Ross is a lay member, appointed to the Board in 2003.

**Professor David L Scott, BSc, MD, FRCP** is a rheumatologist leading a team delivering specialist care at King's College Hospital. He also heads a research team focusing primarily on improving outcome and reducing disability in arthritis through optimal medical care. He was previously editor of '*Rheumatology*' and is closely involved in patient groups including Arthritis Care and the Myositis Support Group. He is a member of the executive of the Arthritis and Musculoskeletal Alliance. Professor Scott is a lay member, appointed to the Board in 2003.

**Professor Tom Sensky, PhD MB BS, FRCPsych** is Professor of Psychological Medicine at Imperial College and Honorary Consultant Psychiatrist at West London Mental Health NHS Trust. Most of his clinical work relates to psychiatric and psychological problems in employment, or the psychological aspects of chronic illness – physical as well as mental. His research has focused on understanding and management of psychological problems related to long-term illnesses, ranging from rheumatoid arthritis to schizophrenia. Professor Sensky is a lay member, appointed to the Board in 2004.

**Mrs Sarah Vines** is a qualified physiotherapist, working in the acute, community and voluntary sectors for Croydon Primary Care Trust wheelchair service with adults and children with disabilities. She is a freelance assessor for Access to Work and physiotherapist for NE Surrey MS Society. Her main area of interest is adults with acquired neuro-disability. Mrs Vines is a lay member, appointed to the Board in 2004.

**Mrs Christine Whitehead, RGN, RSCN, BA(Hons)** is an HIV nurse consultant at a teaching hospital coordinating care of individuals with HIV and AIDS. She has wide experience in the NHS including discharge planning, care of the elderly and general medicine. She has personal experience of caring for a disabled person and is a member of the Appeals Service. Mrs Whitehead is a lay member, appointed to the Board in 1998.

## **Annex C – Suggested role and ways of working for an advisory board on benefit related disability issues**

### **Role**

The Board's purpose should provide the Secretary of State with authoritative, independent, external advice on the:

- benefit needs of people with a disability and/or illness; and
- impacts on those customers of emerging social security policy and operational design, and its ongoing delivery.

It should be able to offer advice across the full range of benefits with the exception of Industrial Injuries Disablement Benefit.

The Board should complement and contribute to the roles being performed by SSAC and DEAC but not duplicate their activity. Subject to DWP and Board agreement it should be able to provide direct advice to them.

Its role is to enhance the policy making process and not be used in place of appropriate external consultation.

### **Ways of Working**

DWP and the Board will work together to:

- establish clear success criteria and performance measures for the Board;
- generate effective links with the strategy, policy and operational parts of the Department to ensure its potential is maximised;
- create a do-able, value-adding, prioritised, rolling 1 year programme for the Board;
- implement effective communications to enable the performance of both parties to improve and for best practice to be shared with other advisory bodies;
- run effective administrative and financial management arrangements to enable the Board to deliver its role effectively; and
- ensure its advice is open and transparent, though on occasions offered on a confidential basis to DWP.

The Board will collaborate with SSAC and DEAC to ensure that they each complement and enhance advice to the Department and do not duplicate activities.

The Board will develop effective links with key external organisations and boards to:

- support the effective delivery of its work programme;
- the identification of emerging issues;
- maintain the relevance of the Board's knowledge and understanding.