

IMPROVING THE LIFE CHANCES OF DISABLED PEOPLE – interim analytical report

A response.

We are pleased to see Government acknowledging the inequalities in life chances afforded to disabled people and heartened that this work is collating evidence and formulating ideas to inform future policies and processes that will improve the lives of many people in the years to come.

We know from our own research amongst our members that discrimination and prejudice around ill health and disability is rife with 41% of survey respondents who said they had been bullied or harassed at work reporting health /disability to be the reason behind their unfair treatment. We agree that a cultural shift towards acceptance of difference is vital in achieving a more equitable society for disabled people and hope that this work will underpin such endeavours.

This response will consider each of the main sections in the analytical report and will consider the questions posed for consultation along the way. Additional issues will be raised where appropriate. We take as our focus, our members and the health problems and disabilities they experience rather than their clinical roles and the care they deliver to disabled patients and clients.

Definition of the problem

This paper provides a good evidence base on the life chances and experiences of living in UK for disabled people. This evidence review and collation of facts and figures is and will be helpful for making the case for change.

We agree with the way impairment and disability is defined and delineated and agree that commonality in language used by all of government is necessary and could lead way for attitude change in wider society

There is however, a clear need for joined up working – clearly stating who is doing what and to what end and how it ties in with other work on going to avoid duplication and confusion.

We whole heartedly agree that any changes or improvement of services must have disabled people at the very centre, so that relevant and appropriate choices and decisions can be made. It is also important that decision makers are held to account by disabled people too. There may at this stage be a reality gap between what disabled people feel sufficiently empowered to do or capable of doing, but it is an important commitment for the future nonetheless.

A vision for the future

We whole heartedly agree that a shift to the social model of disability should be made and that this model should inform future legislation and service delivery. However, we are under no illusions that this transition will not be an easy one and fear that opportunities for change may be lost if this is not properly grappled with. For example, it is clear to see that the medical model of disability pervades the health service and its attitude towards its staff with health problems and disabilities. There are pockets of good practice, but these are undermined by the overriding ethos of disability as being an illness or condition that is necessary to treat or ameliorate by medical interventions. We would like to see the extension of Expert patient

programmes and condition management programmes but also see a greater user involvement in both packages.

We agree with three main components listed: removing barriers, meeting individualised requirements and empowering disabled people to fulfil their potential. However, we feel it necessary here to reiterate the need for sensible, clear joined up working and suggest that this could be done by way of a logo or phrase that is attached to all relevant pieces of work whether their impact on disabled people is direct or indirect, to give surety that the impact on disabled people has been assessed.. This would have the benefit of showing commitment throughout the system, not just in isolated pockets.

We agree that a balance needs to be found between empowerment and improvement and the resultant costs, but hope that cost will not ever be used as a sole limiting factor.

We feel that all civil service and public sector bodies should be exemplars of good practice, but recognise that this is rarely the case now as public service is often found lagging behind the voluntary / not for profit sector and some commercial businesses. Important lessons can be learnt from multi-agency working and public service should be initiating this agenda wherever possible.

It is also important to learn lessons from other disadvantaged groups and to recognise that disability is often not the sole limiting factor people may experience. We are sure that the experience of the CRE and EOC and the work they do with Government will be of use here.

Analysis of the issues

We have focussed our response to this section on matters relating to employment and consequently are not addressing issues relating to early years and the transition from childhood to adulthood.

We would however like to draw your attention to the problems students can encounter when trying to access support in the higher education system. It is our experience that the support available to disabled nursing students varies considerably from institution to institution. Some are excellent and offer good, appropriate support to our student members including learning support and flexibility within the course requirements. Others however are found to be extremely lacking and such inconsistencies are a significant barrier to disabled students achieving their full potential.

In other instances, students are let down by the inconsistencies of support provided by the HEI and the provider of their clinical placements. We look forward to the time, later this year, when clinical placements in nurse education start to fall under the Disability Discrimination Act (DDA) and believe that this will go a long way to reducing some of the barriers our student members face in their training. Coupled with the coverage of qualifying bodies, we are hopeful that many more disabled people will be encouraged and supported into professions such as nursing.

We believe that there should be better monitoring and enforcement of clear entitlement to Disabled Students Allowances and that work should be undertaken to ensure clarity and consistency throughout the system in this regard.

The process of promoting work and career structures for disabled young people is a slow one and one often left to the charitable sector. It is essential that positive role models exist but they should not only be token gestures or isolated instances. There needs to be a focus on inclusion and ownership across the whole of society, with leadership from government through legislation and solid enforcement. An essential part of this process is the establishment of a system that truly considers capability and resources over symptoms and medication. We believe that a crucial part of this process could be improving access to appropriate employment support, be that from Occupational health Services (OHS), Disability Employment Adviser (DEAs) or others.

Prevention and preparation

We are concerned that existing services to support disabled workers, in or returning to work, remain fragmented. There is still limited communication and joint working between occupational health services (OHS) and the primary health care team (PHCT). More joint working and case management between GPs & OH physicians, and Practice Nurses (PN), Community Psychiatric Nurses (CPN) and OH Nurses (OHN) would improve the situation. Whilst there is some joint teaching in the specialist practitioner programmes of community nurses (including PN, CPNs & OHN), the evidence suggests that these groups of nurses still work in isolation of one another.

We consider that GP's may in part be compounding the problem of the recruitment of, or early return to work of disabled workers. This is because most GPs still do not understand the nature and scope of work (and potential support and reasonable adjustments) that a disabled person may be employed in. More OH in the training programmes of GPs would be beneficial, as currently this is limited.

Barriers to work also arise from the fear and ignorance of prospective employers. We are concerned that there remains a great lack of understanding about the capability and capacity of disabled workers, and the unfounded fear that disabled workers will have greater sickness absence and less reliability than other workers. Employers need support and education to reverse this.

It is our contention that OH professionals, who have completed appropriate education and training should be competent to advise employees on prospective and returning employee health capability and capacity; on reasonable adjustments; on special equipment; on potential flexibility requirements (such as attendance for health related support and medication etc); on potential adjustment to safety features (such as alarms and access etc). However, many employers still have little or no access to OHS; and we are also extremely concerned that many nurse and Drs providing advice have no specific qualification in OH, leading to variable degrees and quality of OHS support and information. We feel this must be addressed as part of the overall strategy to improve disabled people's chances of entering or returning to work, and would like to point out the difficulties many nurses face when trying to secure funding for OH training. Whilst there is money available from NHS Confederations, this does not assist the private sector and is an issue we would like to see addressed.

There is also a need to consider support and education of co-workers who play a significant part in the successful integration and support of disabled workers. Fear and stigma arise through ignorance, and can be damaging to the health of the organisation. Paper policy, in the absence of active and sensitive education of co-workers will only partially meet the objectives

and we believe that the services offered by the Occupational psychologists who work alongside the DEAs may be invaluable in this respect.

In our experience OHS and HR departments have hitherto concentrated on sickness-absence management rather than vocational rehabilitation, generally relying on the GP sick note and not actively supporting employees whilst they are on sick leave. GPs (as noted earlier) often extend a persons sick time because of lack of understanding of the reasonable adjustments that can be made to enable a partial and or phased return to work (with appropriate support). Barriers to phased and partial return to work also include the impact on “sick pay” and “benefits” and we believe that the issue of remuneration must be solved, alongside active sickness management which aims for earlier return to work without un-due pressure on the ill or disabled person. The HSE consultation on supporting ill and disabled persons back into work should assist with this, but we must stress that there is a need for sensitive and non-judgemental approaches, and care that all employees are treated with equality. We feel that clear policy guidelines should be put in place, and the process should be open, transparent and aim to support and benefit the ill or injured worker, not used as a tool to reduce sickness-absence at any cost.

We agree that NHSPlus has in part helped to increase the availability of OHS. However, there is lack of data to confirm how far they, and the private sector, are managing to cover the majority of workplaces and we fear that the many of which are still not accessing OHS. In addition, anecdotal evidence suggests that many NHSPlus sites have not actually expanded their “selling out” of OHS, but have just branded what they were doing formerly under a new name. We are therefore concerned that hopes rested on NHSPlus to overturn OH provision may be misplaced.

Whilst we agree that the role of a qualified OH Dr and Nurse in rehabilitation is clearly important, we believe there is a great need to increase the knowledge and understanding of OH issues in all health care professionals’ preparations. The aim should be to provide a “scaffold” of care decisions and support relating to work place ill health and disability. We would like to see all workplaces with a system than embraces good OH principles with access to appropriately qualified OH personnel to advise and support on the more complex issues. In addition, care must be taken to ensure the confidentiality of health related data. Developing the wider workforce for greater participation in OH and rehabilitation strategies, should not be at the cost of diminishing professional leadership from qualified health care personnel.

Routes into employment

It is clear to us that matters relating to recruitment and retention are of equal importance. Disabled people need to feel secure in work and employers also need to have confidence in the support systems available to them to make this work for all.

In the NHS all employing authorities are supposed to have met the criteria for the “Two Ticks” award. It is our experience that this is often little more than a paper exercise that doesn’t travel much further than the Human Resources department and is not widely known about or understood by recruiting line managers or the staff they manage. We therefore hold that there has to be better enforcement and monitoring of Two Ticks and that it should be made mandatory for all public sector bodies, as a way of leading by example and fulfilling positive duties.

We agree with the analysis of the current situation and would like to see resources and emphasis placed on further encouragement of flexible approaches to working – joining

initiatives for family friendly policies with support for disabled people. This may also include incentivising part time work, and improving access to transport

We are concerned however at the emphasis being placed on the Pathways to Work pilots and would like to see a full evaluation of these projects before any decisions are made as to their future roll out. It is apparent that they are currently focussing on those already most willing to be helped into employment and we are therefore uncertain of their benefit for helping harder to manage groups.

Voluntary and part time employment has been and continues to be an important route into fuller employment for our members. However there are a number of anomalies that have hindered their progress over the years. The change from Therapeutic work to Permitted work, whilst welcome in many areas has actually lead to a number of our members losing work and becoming solely reliant on benefits once again. It is also of concern that there are inconsistencies in earnings disregards that adversely affect permitted workers claiming other means tested benefits and we would therefore like to see harmony in these figures.

We also believe that it is important for voluntary work to be covered by DDA. Many of our members have built up the confidence to return to work by undertaking voluntary work and have been lucky that they have been supported in this journey. Not all volunteers are this fortunate and we believe that including voluntary work in this way would send out a message to disabled people about the perceived value of taking on voluntary work and would also ensure their support and protection if they do so.

We wish to be optimistic that changes elsewhere in the lives of disabled people will have a positive knock on effect in their working lives. Better educational opportunities will hopefully lead to people feeling more confident about the world of work and will empower them to feel they can take advantage of a wider range of opportunities. However, the whole system will need to be clear and consistent and easily navigated by the service user. It is also worth saying here that, whilst it is clear that work has to pay more than welfare, that shouldn't mean that welfare should be cut or made harder to claim.

Other issues –

We agree that there is a need to streamline support systems and ensure systems are in place for easy, timely access. From our members we know that the first six to twelve months after injury or acquiring a disability are the most important, as this is the time when support systems are most needed and people are coping with many transitional issues (including finances, benefits, pensions, accessing appropriate care services etc....). The complexity of existing support systems affects people most during this time as they are perhaps least equipped to deal with bureaucracy along side everything else. For this reason we feel it is imperative that these systems be simplified and that greater availability and use of advice and advocates be facilitated.

Whilst we strive to ensure that all our members have the information they need in such circumstances, we appreciate that there are many people who do not have such support and many who are baffled by the multifarious agencies and processes they have to engage with. We would like to see priority given to education and information relating to rights, responsibilities and entitlements and for disabled people themselves to be consulted about what their support and information requirement are and how and when they would like support to be accessed.

Improving access and availability to transport is the key to many issues and to opening up opportunities and life chances. Anyone denied the ability to move from their immediate environment would find life difficult and limiting. We are pleased to see the measures relating to transport amongst other things, included in the new Disability Bill and hope that suitable and appropriate education and enforcement measures will be drawn up too.

Once again we feel it is necessary to reiterate our desire to see better joined up working, not just within public service but across all stakeholder agencies, facilitated by Government. A key aspect of this is communication, both internally within stakeholder groupings but also externally to the wider society. There sometimes seems to be so many different initiatives, often very localised, that disabled people feel disempowered by the inequalities they perceive between themselves and their peers, even if these are being created solely for the purpose of testing out new support mechanisms. We think it is also necessary for Government to be aware of and acknowledge the possible suspicion any move to change support systems and services may be met with. Trust needs to be established very slowly and champions and role models used to best effect wherever possible.

Over 50s

Our main concern here regards the emphasis placed on programmes and initiatives that have yet to be fully evaluated and assessed, such as Pathways to Work and New Deal programmes. We feel that the impact of these programmes may be skewed by their targeting so far of groups of claimants acknowledged as being the easiest to help, and we are concerned that inappropriate assumptions and recommendations may be made about this group of disabled people with very different support needs and expectations.

Work has to be attractive on many different fronts, not just financially. Flexible working patterns are essential in this age group, as they are in many others, but especially so for retention of skills and expertise within the workforce. For example, nursing is an ageing work force and we are concerned that the impact of inflexible working practices and retirement policies has a detrimental effect on the skill bank of the health care workforce as a whole. Nurses feel they must retire and leave nursing completely because the advantages and opportunities of flexible and “reasonably adjusted” working are not made available to them.

Moves to rename Incapacity Benefit will not in themselves be sufficient to change the perception of the benefit. Eligibility criteria and assessment processes will also need to be changed but we would like to see care taken to ensure that those claimants who are truly unable to work are still properly supported. We would also like to see clear information about benefit entitlement especially those that can be claimed whilst a person is off sick from their place of work, as we find that many of our members are very confused by this.

We agree that it is important to reduce the “cliff edge” of retirement but believe that raising retirement age isn’t the only option that needs to be considered. We feel strongly that work must be more flexible to be attractive for older people and that their continuation in work should be encouraged by a package of incentives.

UP TO HERE

Common Themes

We agree with many of the issues raised in this section and are pleased to see the acknowledgement of some of the failings of the present support systems. A big cultural shift is necessary to replace a medical model of disability with a social model. Work to address this may involve building on existing work for citizenship programmes in schools, and

evaluating successful programmes of work in other countries. We feel that resources need to be targeted at early intervention and rehabilitation programmes, but do not wish to see this happen at the expense of other vital services.

We also agree that disabled people undergo far too many medical assessments for support services, not to mention the medical interventions they experience when accessing health care

Conclusion

Overall, we are in broad agreement with the analysis of issues in this report, but we feel that it is important not to raise hopes unfairly or create divisions amongst other civil rights matters. There are many obstacles to life chances that people may experience and it is going to take a long-time to make the necessary cultural changes involved in this work. We feel it is imperative that this important work is viewed in as wide a context as possible, as disability doesn't affect people in isolation to other factors, e.g. age, ethnicity, geography etc...

We are concerned about the potential for over reliance on programmes of work that have yet to be fully evaluated and analysed, or on programmes not yet available nationwide or easily accessible to all.

We would like to see resources targeted at employment opportunities and the support of both employers and employees.

Employers might be encouraged to care more for their workers health if:

- a) the fiscal benefits are more overt
- b) there is statutory requirement to have *access* to qualified OH personnel, who would in turn increase knowledge and understanding of the benefits of employee support schemes
- c) there is more education and information on the positive benefits of employing disabled workers
- d) commitment and effort of employees
- e) tax relief
- f) access to *ring fenced pots of money* for education and training of employees
- g) reduced insurance costs
- h) better support services (*for employers*) – i.e. if they have had one poor experience of employing some one through “Connexions” – and feel un-supported or have experience problems with co-workers, they are less likely to take another disabled person.

Disabled people will feel better supported regarding their employment options if:

- a) the financial benefits are clear and the fear of being worse off by working is removed
- b) more flexible work options are available
- c) Flexible pension options are also available to those wishing to step down or reduce their working commitments
- d) Good, trustworthy occupational health services are available for all.
- e) They receive support managing their condition from an occupational not just domestic perspective.

But finally we hope that Government will continue its commitment to improving the lives of disabled people, though legislative and other changes, and we look forward to a day when all citizens have the ability to engage in society unhindered by unnecessary barriers or obstacles.