

A new deal for welfare: Empowering people to work

The Genetic Interest Group (GIG) is a UK-wide alliance of organisations with a membership of over 130 charities which support children, families and individuals affected by genetic disorders. Its primary goal is to promote awareness and understanding of genetic disorders, and of the needs of those affected with or at risk, for appropriate advice and support.

The majority of our member organisations represent patients and families affected by or at risk from a condition or conditions that are uncommon, and which differ from other health issues in these ways:

- The conditions are generally neither curable, nor reversible.
- The conditions are often progressive, worsening at predictable or unpredictable rates.
- The conditions are not caused by environment, lifestyle, or workplace factors.
- Most are not common conditions, and many are poorly understood by the medical and research communities. Information regarding some of these conditions is as a result, often hard to obtain.
- Due to the complexity of many of these conditions the patient is sometimes not well placed to describe or explain the nature of the condition.

For the Department of Work and Pensions to be sure that their reforms benefit all those that are currently or potentially in receipt of incapacity benefit, GIG believes these factors will need to be taken into account, particularly in these areas:

Mental Health

The consultation document refers to rising incidence of mental health conditions as a contributory factor in the need for reform; and states that “we need to ensure that the mental health component of the new medical assessment reflects the type of conditions prevalent today.”

GIG asserts that the needs of the minority of mental health patients whose conditions are genetic in origin (although they may be influenced by environmental factors) should be not be marginalised or forgotten.

Genetic mental health conditions are usually incurable, often progressive, and intractable. Patients with these conditions do not respond to the same kind of initiatives or treatments that will help other patients with mental illness. We endorse the decision to convene a group of experts in this field, and would expect that the membership of this group should include expertise in genetics and mental health.

Gateway

We are pleased to see that the planned assessment process will be designed in consultation with health professionals and disability groups. **This Gateway will have to cope with all forms of incapacity, common and rare, with equal efficiency.** We would support the involvement of a wide range of expert healthcare organisations in the planning of this new assessment process.

GIG supports the new distinction between *eligibility for the benefit* and *capability for work*, but we are concerned by the implication in paragraph 65 of chapter 2 that “capability for work could be assessed by other health professionals as well” as the health professional that has made the original decision on the eligibility for benefit. This duplication of work could lead to frustration amongst patients, and unnecessary delays; particularly for patients with conditions that are little understood by the healthcare community, or require particularly specialised healthcare.

When an individual has a diagnosis of a rare genetic disorder a relevant expert with knowledge of the condition should be involved in assessing the current condition of the applicant and advising on his or her future prognosis.

The onus for corroborating diagnoses and obtaining information about the potential future progress of conditions should be fully upon the shoulders of the Personal Capability Assessment process, the patient should not be expected to advocate or defend their own status of disability.

For this process to be equitable to all applicants from common or rare conditions, proper and comprehensive education of the Personal Capability Assessment team is essential. Access to expertise in cases of uncertainty should be available quickly.

Workplace Health

GIG agrees that workplaces should be involved as much as possible in promoting and protecting employee health. A proper level of understanding between the employer, employee and colleagues will benefit the employee enormously when considering adaptations necessary to sustain the employment and protect the health (as far as possible) for those with genetic conditions.

This is another area in which education and information access is important. An employer should be fully informed (with the consent of the employee) of the specific healthcare needs of their employee, particularly when this condition is not common, or complicated. Active measures should be in place to prevent unfair discrimination against employees with progressive genetic conditions.

Conclusion

GIG broadly supports the aims and intentions of these reforms. For the reforms to be universally successful and appropriate to our members, two fundamental requirements must be satisfied.

Proper consideration of the individual is essential.


- Applicants should not be coerced into work.
- There should be an element of choice in what applicants are asked to do.

- Applicants should not be prejudged according to the condition they have but assessed as individuals in the context in which they operate.

Proper training of the new Personal Capability Assessment team is essential.

- This team should be able to deal with any health condition, however rare, and however well documented. This ability should be prepared for with good training, good consultation opportunities, and good information retrieval facilities.
- The team should be able to understand the complex situations that some conditions create – for example many of our member groups support patients with progressive conditions – patient’s ability to work may deteriorate continuously, with no recognisable steps or clear landmarks, or it may progress in fits and starts, with periods of stability in between.

The Genetic Interest Group and its members will be happy to be involved in any further consultation to ensure that this reform process meets the needs and circumstances of those with genetic conditions, and which recognises the impact that these may have, not only on the individual who has a diagnosis, but also on those in the family who may be at risk themselves, or who may be called on to provide care and support as the condition develops.



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