

Camphill Families and Friends

Response to PIP consultation documents, 27th April 2012

Camphill Families and Friends is a charity which supports the seven hundred plus people with learning disabilities who live in Camphill intentional communities in England and Wales. We comprise about three hundred families of Camphill residents. The Camphill movement is the largest provider of such communities for people with learning disabilities in this country.

Many Camphill residents have severe autism; learning disabilities and autism; autism, LD, and additional comorbid conditions such as epilepsy, chromosomal/genetic disorders, physical disabilities and sensory impairments - including those who are deaf-blind; speech and language difficulties; some have additional mental health difficulties. There are profound, multiple, complex and high levels of need, many of which are invisible or not immediately obvious.

Our main concern

As the families of people with serious learning disabilities, we are deeply concerned by several elements of the proposals contained in the consultation document. Our main concern is that, while the document covers several types of vulnerable people, it does not apply well to our learning disabled relatives. The actual descriptions, references and case studies mostly apply to other vulnerable groups and not to learning disability. They describe people and situations which we do not recognise. They do not seem to have been written by people familiar with learning disabilities and they are not imbued with a true grasp of what we regard as the essential aspects of learning disability.

Particular concerns

We refer particularly to the PIP second draft assessment criteria document. We also welcome the inclusion of three new activities but we feel that, throughout the questions, there are several serious faults.

- We feel that the community care Single Assessment process for vulnerable people (Unified Assessment in Wales) has developed in recent years in its ability to produce a valid assessment of people with learning disability by being capable of holistic interpretation, sensitive treatment and thoughtful, balanced consideration. This in turn enables decision-makers to put people with learning disabilities into four eligibility criteria. We despair that the proposed PIP criteria, thresholds etc would not achieve a valid assessment of individuals with learning disabilities. We fear that people who are correctly put into the higher (critical and substantial) category of the Single Assessment eligibility criteria, could well score at a low level for their benefits by being poorly assessed according to the proposed PIP criteria. Indeed, we have actually tried using your criteria to assess some of our relatives – real people - and have failed to reach any real grasp of their disabilities and dependence.
- The criteria are much too blunt and rigid to cater for the complexity and variety of learning disability. We feel that this bluntness applies to all the activities described, but

especially to the newly added ones, which are particularly in need of reconsideration using the expertise of MIND, Mencap and the NAS.

- The criteria concentrate much too closely on particular functions of daily activity, especially on physical activities, and fail to recognise emotional and psychological dependence and risk. Our relatives have LEARNING disabilities, which affect not only the functional aspects of tasks but the confidence and independence that are also required to carry them out. Risk also constantly comes into any situation. For instance the act of walking 200 yards might be possible but having the confidence to walk 200 yards on one's own and to complete the 200 yards along a busy street without risking life and limb is another – and much more important - matter altogether.
- The over-simplicity of the criteria, such as measuring times taken, distances walked and days affected, fails cruelly to deal with the variability and complexity of learning disability.
- Dependence is not recognised in the criteria. We constantly encourage our relatives to become independent individuals and we rejoice in their achievements, but we are acutely aware that they are actually and realistically dependent on others for most/all aspects of their lives. There is no panacea for learning disability. In some cases there will be no progress at all, in others progress will be slow, gradual and limited. Dependent people need supporters not just in the performance of particular tasks but also to provide the emotional support needed by just being there. It is so sad that the criteria simply do not recognise this.
- Learning disability is a holistic condition that needs to be assessed and treated holistically. The mere adding up of points is an ineffective and deeply unfair way of dealing with learning disabled citizens. The splitting of life into domains and functions goes counter to all modern trends, as well as not reflecting reality.
- Making distinctions between and allocating different points for “prompting” and “assisting” is not a realistic reflection of what really happens when learning disabled people perform activities. Of course there is a difference in performance but effectively both require the same time, attention and cost and both should come into the highest category.
- The involvement of people with learning disabilities in the process of their ongoing assessment is not easy to achieve. We are aware that:
 - The assessor needs considerable training in learning disability and its associated conditions, which are often hidden or extremely difficult to identify. Also to be taken into account in face-to-face contacts are the vulnerability, gullibility, incomprehensibility and challenging nature of many people with learning disabilities. Such necessary training and expertise, we feel, will not be forthcoming in the constant and sensitive way that is needed. Great experience is needed to get anywhere near the truth.
 - Others will need to be involved to help the individual, such as carers and advocates.
 - The sheer anticipation and participation in assessment will be truly stressful for many people with learning disabilities.

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