Valuing People
The White Paper and People with Profound Learning Disabilities

SUMMARY

For the first time in 30 years the government has published a White Paper, Valuing People outlining a strategy for learning disability services. It has been seen as a positive document and widely welcomed. There are nonetheless concerns about limited resources and whether some people's lives will benefit substantially.

People with profound learning disabilities are not identified as a priority group in the White Paper. However, with determination in implementing the principles underlying the strategy, the lives of people with profound learning disabilities should improve.

The findings and recommendations in the Foundation for People with Learning Disabilities' report Everyday Lives, Everyday Choices for people with learning disabilities and high support needs (2000) indicate how policies could have been further developed in some areas to meet the specific needs of people with profound learning disabilities.

BACKGROUND

Between 1997 and 2000 the Foundation examined the needs of people with severe and profound learning disabilities, through five projects which explored daytime opportunities, employment, friendship, transition from full time education and citizen advocacy. The findings were incorporated in the report Everyday Lives, Everyday Choices.

The purpose of this update is to explore issues in these reports relevant to the White Paper and to ask to what extent the strategy is likely to meet the needs of people with profound learning disabilities.

THE WHITE PAPER

Its principles

The White Paper encompassed the needs of all people with learning disabilities. Its principles, rights, independence, choice and inclusion, are seen as universally applicable. Choice includes “people with severe and profound disabilities who with the right help and support can make important choices and express preferences about their daily lives.” This is reflected in the findings of the projects.
Definitions

References to people with profound learning disabilities are limited in the White Paper. There is a lack of clarity about who is included. For example there are references to “children with severe disabilities and complex needs”, “people with additional or complex needs” and “children with complex medical problems.” Definitions were also an issue in recruiting participants for the projects. They were people who needed support in communication, and in developing an understanding of choice. It was recognised that some participants could be described as having severe rather than profound learning disabilities.

Communication

Communication should have been further addressed in the White Paper. It is crucial if there is to be genuine person-centred planning. Communication plans are mentioned in connection with care management. Organisations working with people with learning disabilities are expected to develop communication policies. Although the importance of technological support is recognised, communication needs are not fully explored.

Advocacy

Citizen advocates have an important role to play in supporting communication and choice. A National Citizen Advocacy network led by a consortium of leading voluntary organisations will aim to work towards one citizen advocacy group in each local authority area. This is not expected to replace existing funding sources for citizen advocacy. However the more radical option of implementing clauses 1 & 2 of the Disabled Persons Act (1986) to ensure the right to advocacy and independent funding was not taken.

Transition to adult services

Young people with profound learning disabilities, like other young people, will be supported by the Connexions service until the age of 25 if necessary. Person-centred planning, which runs as a thread through the White Paper will be crucial at this stage. It is recognised that inadequate health care plans may prevent young people with complex health needs from participating in education training, or employment.

Day time provision

People with the most severe learning disabilities have been identified as a group often poorly served by day centres. In the five-year modernisation programme, the needs of “people with profound or complex disabilities” will be carefully considered. How people with profound learning disabilities can access education and employment is not specifically addressed.

Housing

The final closure of long-stay hospitals, and person-centred planning as a priority for those in NHS residential campuses is likely to have an impact on many people with profound learning disabilities. The principle of choice in housing, between supported living, small-scale ordinary housing and village and intentional communities, has the potential to revolutionise provision for people with profound learning disabilities. Traditionally choice in the form of the provision has often depended on 'the assistance and discretion of professionals' (Foundation for People with Learning Disabilities 2000).
Friendship

Helping people to sustain friendships is seen as one the greatest challenges for learning disability services. There is an issue to be addressed regarding enabling people to make, as well as retain friends and indeed even have the importance of relationships recognised.

Healthcare

People with profound learning disabilities are particularly likely to benefit from the provision in relation to health. Health facilitators are to be in place by the Spring 2003 and the development of Health Action Plans by the Learning Disability Partnership Boards is expected by June 2005. As Barbara McIntosh argued, ‘people’s ability to access community activities may be enhanced or alternatively jeopardised depending on whether their health care needs are receiving attention.’ (Foundation for People with Learning Disabilities 2000)

IMPLICATIONS

- It will be difficult to plan services effectively for people with profound learning disabilities without greater clarity about definition and numbers.
- Further attention is needed to identify the principles underlying a sound communication policy if people’s needs are to be fully met. Everyday Lives Everyday Choices highlights the shortage and inequity across the country in the provision of Speech and Language Therapists.
- Citizen advocacy will be more widely recognised but the resources from the Implementation Support Fund for the development of a Citizen Advocacy Network will be inadequate to provide citizen advocacy for all who wish to use it.
- The health plans should bring substantial improvement to meeting the health needs of people with profound learning disabilities. Detailed monitoring of Primary Care Trusts will be needed to ensure they meet the needs of those with profound learning disabilities.
- Careful thought needs to be given to the modernisation of day services in relation to people with profound learning disabilities if they are to be supported to lead more interesting lives of their choice.
- Imaginative ways need to be developed to listen to people’s preferences about where they live if they are to have genuine choice in housing.
- If attention is genuinely paid to making and sustaining friends, this could enrich the quality of life of people with profound learning disabilities.
- Risk policies that encompass empowerment as well as protection will be crucial for choice and independence.
- Since people with profound learning disabilities have not been identified as a priority group, there will need to be real determination and vigilance to ensure that they are not marginalised and the principles of independence and rights, choice and inclusion underpin the planning of individual services. If this can happen their lives will be revolutionised.
FURTHER READING


This Update was written by Hazel Morgan, Head of the Foundation for People with Learning Disabilities.