

The challenges of long term care – A Service Provider perspective

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EASPD (the European Association of Service Providers for People with Disabilities), represents over 8,000 service provider organisations in Europe. These observations reflect their experience.

1. EASPD very much welcomes the opportunity to participate. The actual services people receive are delivered by service provider organisations- NGO's, private organisations, or specific parts of authorities. They need to be engaged to ensure we produce the best solutions.
2. EASPD is disability focussed, but the same essential issues apply to all long term care/support, and indeed ageing is intertwined with disability, since disabled people are, thankfully, living longer, and also because ageing itself brings disability.
3. The future of long term care should first be considered from a values perspective. We need to articulate a clear understanding of what is DESIRABLE long term care.
4. Part of this articulation should be the use of the word "support" rather than "caring"-it is more active and participative, and in line with the social rather than medical model.
5. The aims should be to provide
 - individual, person centred services which clearly reflect the wishes of the person being supported, and, within that,
 - the maintenance of maximum independence-so that people can "age in place", and not have to be uprooted.
6. Assessment
 - 6.1 It is vital that needs assessment is participative, with open participation by the person concerned.
 - 6.2 The assessment should also take into account cultural, ethnic and religious needs without becoming stereotypical.
 - 6.3 The assessment must also be informed by best practice relating to particular types of need.
 - 6.4 The assessment must involve "key others" - ESPECIALLY the family-since in reality it is families who provide most support, and who themselves need support.
7. Eligibility

Eligibility criteria should be clear, transparent and equitable. There is still too much variation between and within different countries. Services should be provided according to needs rather than personal resources. It can also be the case that false solutions can be found by tightening eligibility criteria - but the needs themselves do not go away. Poorer and less articulate people in particular can be put off from applying if services are made difficult to obtain. In addition, means tested services can often be hugely disadvantageous to those of middle income. We need to develop a consensus of expectations and fairness.

8. Continuum of support

People frequently do not need “care” or medical support –they need both. The false distinction can lead to over complex, costly and fragmented systems, where it is often the family or the person who de facto “manages” the system.

9. Models of support

There is no one size fits all solution. Personalised budgets are welcomed by many people, but not everyone. Also personalised budgets do not remove the challenge of needing to find the personnel. There is as yet no long term evidence of the pros and cons. At the same time EASPD’s position is that we should be moving away from institutionalised support. There is a real opportunity to make best use of Assistive Technology, and at the same time making sure it does not replace human contact. We need a clear ethical code for its use.

10. Personnel

This will continue to be a major issue. Staff, especially front line support staff, need proper salary, training and conditions, and public respect .Much needs to be done to improve status and conditions if we are to attract and keep them. Without such measures the quality of services will suffer.

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