

Making the transition: addressing barriers in services for disabled people

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This qualitative study was commissioned in response to the Disability Rights Task Force's recommendations¹ regarding the need to tackle barriers to joint working in the provision of services and support to disabled people. Based on in-depth interviews and focus groups with service users and local service providers in six local authority areas, and with central government policy officials, the research explored how and why disabled people can experience discontinuity in the provision of equipment and services at points of **transition** in their lives. It also explored how barriers to making a smooth transition might be addressed. The main types of transition covered in the research were: movement into, within and out of different educational settings; from child to adult services; into, within and out of employment; from one local authority to another, and between different living situations, including hospital, home, and different types of accommodation. The project was conducted by the National Centre for Social Research, with Disability Alliance.

Key findings

- Disabled people experienced a range of difficulties when making transitions in their lives, with the main negative impacts being delays to the service they needed, or not receiving the service at all.

- Service providers identified a range of barriers which may disrupt a smooth transition. These may originate at the central government level, local service delivery level, or both. Barriers can be grouped into **organisational/structural** issues (the way a particular service is structured can have implications for service delivery), **budgetary** issues (in particular, the way that budgetary boundaries and procedures operate between and within organisations in different sectors) and **procedural** issues (such as procedures being incompatible between organisations, procedures not being followed, or not existing in the first place).
- From the service user perspective, the factors that were felt to contribute to a smooth transition were the approach of the service provider, resourcefulness of the service user, availability and flexibility of the service, and availability of information about appropriate services.
- The research identified a number of national and local initiatives in different sectors which are seeking to facilitate smoother transitions for disabled people. However, a number of possible areas for policy development, common across all sectors, were suggested to improve the process of transition. These include raising awareness of services amongst both service users and providers, increasing joint working between providers, investigating the possibility of a 'key worker' role for service users, widening already existing initiatives and policies, and ensuring new initiatives are evidence-based.

¹ Disability Rights Task Force (1999) From Exclusion to Inclusion A Report of the Disability Rights Task Force on Civil Rights for Disabled People, (see recommendations 10.17 and 10.18 p.195-196).

Summary of research

Background

The aim of the research was to explore how and why structural transitions in disabled people's lives can lead to discontinuity in the provision of equipment and services, and how this might be addressed.

Difficulties faced by disabled people making a transition

The two main negative impacts experienced by disabled people when making a transition in their life were not getting the service they needed (including a new need not being met, or losing an existing service), and delays in getting the service they needed. Examples of the former included a child moving to a new school who lost on-site provision of specialist therapy, and an adult moving home to a new local authority who had to give up equipment provided as an adaptation to their former home. Examples of delays in receipt of service included someone starting a new job, but not having the necessary IT equipment in place when required, and structural changes not being ready in time for the start of term, thus delaying the transition from nursery to infants' school for a child.

Alongside these negative impacts, disabled people could also find the transition process stressful. This could be caused by a lack of awareness about available support and services, uncertainty about their eligibility, and anxiety about the impact of making the transition on current and future service provision. From the user point of view, the following factors were identified as making a difference to how smooth a transition was:

- approach of service provider: their capacity to refer, co-ordination of the process including of assessments, and the level of transition planning;
- resourcefulness of the service user;
- availability of appropriate service, flexibility and transferability of service; and
- availability of information about appropriate services.

Barriers that impede the delivery of services during transitions

Interviews with a wide variety of service providers enabled the research to identify a range of barriers to smooth transitions across different service areas. Barriers were grouped by whether they had an **organisational/structural**, **budgetary** or **procedural** basis.

Organisational/structural: the way that some services were organised or structured could lead to discontinuity at points of transition. Key barriers identified in this area were:

- the division of a service between sectors or organisations (for example, housing adaptations provided by both housing and social services) can lead to a lack of understanding between organisations about their role and purpose, as well as a lack of information-sharing about users. In turn this can lead to delays for a user and confusion over the process of accessing a service;
- demarcation of service delivery according to team structures: the division of professional staff into different delivery teams (for example, 'child' teams, or 'mental health' teams) could have a variable impact for the service user, depending on how the team 'boundary' fitted with their particular needs. On the one hand, it could bring greater co-ordination for the service user; however, if the service user's needs cut across team boundaries, there could be a risk of poorer co-ordination of service delivery;
- flexibility of staff roles and responsibilities: there was a perception in some sectors that roles of professional staff were perhaps too fixed and that a more flexible approach towards carrying out assessments, or other aspects of service delivery would lead to fewer delays and discontinuities for the service user. Related to this, there was a debate around the extent to which the roles of professional staff should be designed to be based around specialist skills or more generalist skills. A specialist approach might give a more focused service, but perhaps involve a longer delay

for the user if there were limited numbers of specialist staff. A more generalist approach might involve a quicker contact for the user, but perhaps would be more simplistic in its view.

Budgetary: Budget boundaries and regulations governing the delivery of services had implications for making transitions. The key barriers identified in this area were:

- existence and management of budget boundaries: having to fund related services from separate organisational budgets could lead to delays in provision of service or equipment;
- consequences of financial year planning: if an application for a service (for example adaptations to a home) came at a point when the annual budget was virtually accounted for, then this could cause a delay while waiting for the new financial year;
- inconsistency in scope or application of budget criteria: there could be differences in the way that criteria to determine service provision were applied i) between local authorities and ii) between different staff administering the same budget. This could lead to variability of experience for service users, but also might lead to changes in receipt of service, for example following a move across a local authority boundary;
- requirement for prioritisation due to limited budgets: a user who ends up being lower priority would be likely to have to wait longer for a service, or perhaps not get the service they would have liked;
- limited funds available for joint working: joint working arrangements were said to involve considerable time and resources, especially in getting them established;
- shortages of resource (for example qualified staff or suitable housing stock) were felt to hinder the ability to provide speedy and smooth transitions for service users.

Procedural issues creating barriers to smooth transitions included:

- difficulties for users and other providers in finding out about a service: where users or service providers were not aware of the relevant services or did not know how to go about applying for it, it created an obvious barrier to accessing the most suitable service;
- the effects of multiple assessments or duplication of assessments: where a service or similar service was delivered by two different organisations or two teams, this could result in more than one assessment, meaning a likely delay and probable confusion for the user;
- missing information or missing professional staff at assessments: not getting an appropriate service following a transition could come about because the full information was not provided at an assessment. Insufficient sharing of information came about through lack of liaison between service providers, and lack of knowledge of each other's roles;
- insufficient liaison between organisations (and between local authorities) to manage and co-ordinate changes in user needs: ongoing changes in user needs could result in lack of appropriate service response when there was not enough pro-active contact and liaison between service providers;
- lack of planning and preparation for predictable transitions, such as moves between schools.

What is being done to address barriers

A range of national policies and initiatives are designed specifically to help facilitate transitions and overcome some of the barriers identified in this report. Examples of these include Connexions, which aims to assist in making smooth and effective transitions from childhood through to adult activities, the Integrating Community Equipment Services initiative, which aims to bring together key agencies in the delivery of equipment by pooling of health and social

services equipment stocks and budgets, and Access to Work, providing advice and practical support to enable a disabled person to make a transition into work, or to stay in work.

There were also numerous examples of work being done locally to address some of the barriers to smooth transitions. These included the design of joint procedures to reduce duplication of assessments by health and social services, and creation of multi-disciplinary teams involving social services and housing to improve co-ordination of services.

Issues to consider for policy development

The report identified sector-specific issues for policy development that may ease the process of transition, but also broader areas for development which are common across all policy areas and sectors. The latter include:

- **raise awareness of services** among service providers so they can make appropriate referrals, and also among service users so that they know what to apply for. Alongside this, increased user choice and control over the process is likely to result in more successful (or at least less frustrating) transitions;
- **increase 'joint working'**: although procedures and structures appear to be beginning to reflect moves towards joint working, there is scope for improvement here. Working collaboratively, carrying out joint assessments, setting up joint procedures, or joint teams that can pool budgets – all these should help to smooth a transition process for a service user. However, joint working can entail a financial cost, and this needs to be considered when developing ideas;
- **'key worker' role**: allocating someone to manage and co-ordinate the process (a 'key worker') can ease the process for the user and appears to help create a more positive outcome;

- **widen existing initiatives and policies**: there is scope among some programmes to widen their remit in order to assist more people with transitions, for example broadening employment programmes to include help with routes to self-employment, or ensuring that disabled young people who do not have a Statement nonetheless receive the additional support they need during a transition;
- **focus on evidence-based initiatives and policies**: a concern voiced among respondents was that the need to be seen to be innovative in new initiatives could mean that insufficient attention was given to existing good practice. There is greater scope for new initiatives to demonstrate how they are building on existing effective approaches.

The full report of these research findings is published for the Department for Work and Pensions by Corporate Document Services (ISBN 1 84123 651 9. Price £44.00. Research Report 204. February 2004).

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