

Guide to Services for Young People with Learning Difficulties/Disabilities and Mental Health Problems/ Challenging Behaviour:

Technical Document -

Chapter 5.3 Findings from Fieldwork – Other Interviews

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A small number of interviews have also been conducted during the course of the year. A summary of findings is presented below.

Professor Barry Carpenter, Principal of Sunfield School, a large independent school for children with severe learning disabilities in the West Midlands chaired research that led to the publication of *Count Us In*, (FPLD 2002). *Count Us In* emerged from a widespread concern amongst many professionals that mental health needs were prevalent in the LD population but that this was not widely recognised. Schools, for example, tend to give mental health a low priority. Service barriers may prevent recognition and effective referral on to other services, before and during transition. In many cases, the learning disability of a child is seen to subsume any mental health need, a tendency known as ‘diagnostic overshadow’.

Recognition of the problem is increasing. The Department of Health, for example, has revised its estimate of the prevalence of ASD in the general population from 1/1000 to 1/800.

The prevalence of mental illness within the population of people with learning disability is high. In his estimation: 40% of children with learning disabilities have a mental health problem; 50% of children with ASD have a mental health problem; and 65% of children with profound ASD have a mental health problem.

Sunfield School is taking a pioneering role in research and service development for young people with learning disabilities and mental health problems. It is working with the Home Farm Trust to create a special post-19 provision for their students, who have very complex needs. Its transition review system has been highly praised.

Nevertheless, approximately half of all placements from Sunfield fail within the first year. The main cause is inadequate planning and poor understanding of the student’s needs. The worst-case scenario, which he claims happens too often (no figures given), is that the young person is detained under the Mental Health Act 1983 because there are not appropriate services available to them.

The Community Care Assessment is the key to many services, of which Direct Payment can be one of the most effective. But there is a very low take-up of Direct Payments. In fact some local authorities seem to actively conspire against its usage. Some local authorities (example cited) do not have any forms to apply for it. Others are much better.

Reviewing Officer and Family Services Coordinator, Sunfield School, West Midlands noted a significant shortfall in support from social services and from Connexions. In their experience, though social services have a formal duty to prepare a transition plan, often they do not do so. Almost all students at Sunfield need

intensive social care and support on leaving the school. Most go to residential care with day service attached.

The presence of a plan alone is not enough to activate services. It requires the participation of key agencies and staff, who often do not take part, even in crucial plans such as Community Care Assessments (CCA). Ideally, the whole process should revolve around a single plan, but in practice it tends to involve a number of separate plans. CCAs are often not done until the young person is 18 and about to leave. Local authorities and health trusts vary considerably in their procedures.

Good transition planning involves more than simply finding a placement. Preparation for leaving can take many years for young people with ASD. It requires time and commitment on the part of the receiving agencies to help the young person accommodate to the change. Sunfield is able to provide a very carefully planned and structured environment, which can be hard to replicate elsewhere. This includes its own clinical psychology service. The school makes every effort to support receiving institutions in the transition process, but few agencies accept this help, possibly due to lack of staff or institutional culture.

Each student's home Social Services Department has the responsibility for preparing and coordinating a care plan, which shall include any input from health services and from education services. An agency such as Sunfield is a service provider, contracted by the young person's local authority to provide a service, and has no authority over any other agency in the process. When it comes to the commissioning of further services it is the responsibility of the young person's social worker to make recommendations, which are assessed by a panel. The respondents in this interview noted that such a panel can only act on the evidence it has before it. They felt that many aspects of their students' characters and needs are not evident in reports, and that many social workers are unaware of service providers outside their own county. It is therefore often only the parents that drive the transition process away from a means by which individuals are 'slotted' into pre-existing and often inadequate services. Such factors can contribute to breakdown of placements.

The various service sectors involved at transition have different cultures and procedures. Put crudely, they felt that social services have a general responsibility to all people with learning disabilities and are likely to try to "fit people into boxes." By contrast, health services tend to see people in terms of their pathologies and to see their responsibilities as the elimination of certain problems. Such distinctions can result in a failure to perceive the individual's needs as a whole.

To a large extent it is up to families to drive the transition process. But many SSDs have little information on providers outside their county. Families are often unaware of the range of benefits they can get, and are not always told.