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'Caught in the Competence Trap': the challenge for rehabilitation services for people with mental health difficulties in addition to moderate learning difficulties

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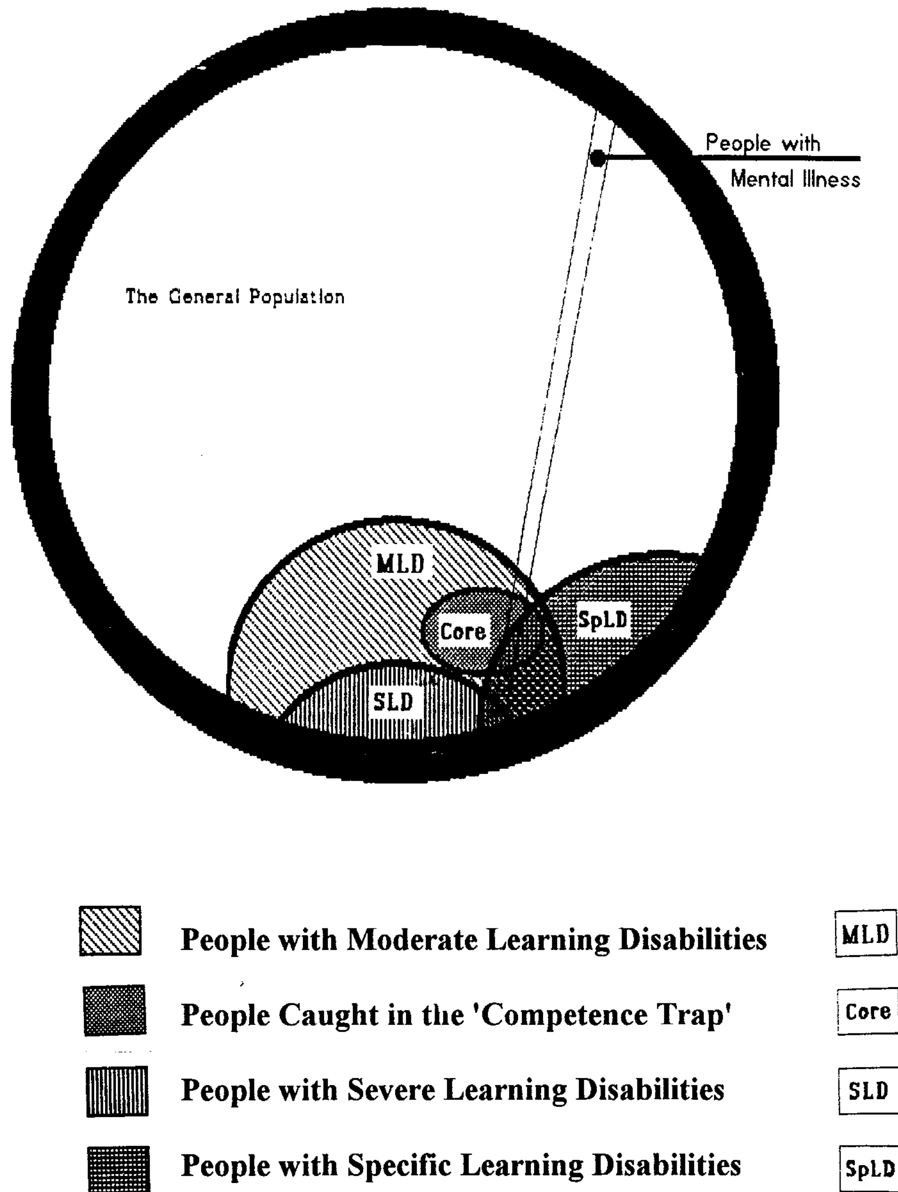
ABSTRACT

A survey and case-study evaluations were made of people with mental health problems and moderate learning difficulties living in the North West of England (Burton, 1992). A core group of people were found to have areas of competence, but insufficient to enable them to live independently. However, their needs for supports were hidden by their limited competencies, and they repeatedly fell into the 'competence trap'. Once in this trap, service providers made assumptions about their abilities to live independently, and they themselves experienced abandonment and failure. Instead of planning for individuals proactively, services were driven by a succession of crises, and people themselves often ended up unemployed, homeless, in prison or abused by others. In some areas, no particular service took direct responsibility for these people and they were passed from one service to another. As a result of the study, recommendations for the identification, assessment and support of people caught in the 'competence trap' were made.

People with moderate learning disabilities are those who find it difficult to acquire and retain knowledge and skills, which may lead to further problems in learning the personal and social skills necessary for independent living. They should be distinguished from both those with severe learning difficulties (severe learning disabilities) and those with specific learning disabilities but no generalised learning disability (such as dyslexia). Only some people with moderate learning difficulties have mental health problems (Hamilton, 1989). Figure 1 illustrates the relationships of this population to these others.

Figure 1: Relationship of populations of people with moderate learning disabilities to other populations (not to scale) (Burton, 1992)



It is difficult to estimate numbers of people with moderate learning disabilities, as many are not known to services. However, those with additional mental health needs form part of a small 'core group' of people in need of active service provision. All too often this core group of people are assumed to be more capable than they are: competence in one or two areas is assumed to extend to all areas of independent living. They fall into a 'competence trap' as a result of which service providers underestimate their needs for supports and they, themselves, experience repeated failure in independent living.

In 1969 Edgerton coined the term 'cloak of competence' to describe the attempts that people with moderate or mild learning disabilities went to in order to avoid stigma and discrimination. In the face of public disapproval and reluctance to accept diversity in fellow citizens, people made attempts to 'pass' as more competent than they really were (see for example, Goffman (1963)). In some respects, public attitudes have not changed, although social policy in Britain has led to a wider diversity of people living in local communities, rather than hidden away in long stay hospitals. People with moderate learning disabilities still learn to disguise their difficulties by avoiding demands that reveal them as different from others.

One of the consequences of 'passing' in this way has been that some people have not always been able to cope as well as they might, and service providers, neighbours and acquaintances, assume they have greater competence to live independently than they do. This means that they are left to fend for themselves and only come to the attention of service providers once things have broken down considerably. They may fall out with their neighbours, lose their home, commit some petty offence or be exploited by others. Crises occur which necessitate some involvement from the statutory agencies, whether this be social services, health services, housing services or the criminal justice system. Each time a crisis occurs, services are mobilised, and sometimes it is different services that are involved on different occasions. The people come to be seen to be a nuisance and acquire greater negative reputations.

What kinds of lives do people have?

Some illustrative case studies were constructed from the lives of real people known to the research team. Two case examples will be used, here, to illustrate the kinds of lives people in the core group have. Names and details have been altered to protect identities: where events have been substituted to preserve anonymity, the replacement incident is one that has happened to someone else known to the team.

Peter is 33. His parents both have a history of mental health problems. At the age of 7 he was taken into the care of the local authority, and his childhood was spent in a succession of foster homes and residential schools. With little in the way of preparation for an independent life, Peter left care to live in a bedsit. Desperately lonely, he made contact with people who themselves were finding life a struggle, and who frequently exploited him. His lack of money would lead to outbursts aimed at gaining a response from those in authority. The police were often called and on more than one occasion Peter was charged with breach of the peace, wilful damage and with threatening behaviour. He has appeared in court several times.

Sometimes stresses would accumulate so that Peter became acutely disturbed, leading to periods of hospitalisation. These psychotic states subside once the stress is removed, but in the past they have occasioned contact with all the main caring agencies as well as the police.

Over the course of his adult life, Peter has also spent some years in a mental handicap hospital and he exhibits some institutional behaviours in public places (for example, cadging for cigarettes).

Peter has benefited from frequent and regular support from the local social services office in helping him deal with every day problems, but the lack of out-of-office-hours support makes it difficult for him to gain the help he needs when everyday practical

problems of living arise. He can solve many problems, but will sometimes choose an unorthodox solution that can create further problems for him.

Ann is 27. She lives in a flat to which she moved from a private sector hostel. She was sexually abused whilst living there and suffered a mental breakdown shortly afterwards. Ann's stay in psychiatric hospital was unnecessarily extended while mental health and mental handicap teams debated about whose responsibility she should be, and therefore who should provide support for her on discharge from hospital.

Ann is gradually regaining her sense of self confidence and is also making progress in speech therapy sessions where she is working to remove some childish sounding pronunciations.

Ann has little with which to occupy herself during the daytime. She stays in at night and says she is lonely at weekends.

What support services are available?

A survey of 30 organisations in one large northern city was undertaken to assess the community services available. These organisations covered health services, social services, education, employment, housing agencies, probation services and various voluntary organisations. Whilst people in our core group were at times in contact with a wide range of different service providers, no one agency took primary responsibility for meeting the needs of people with moderate learning disabilities, or for seeing that their needs were met. This was summed up by the following comments

> *most agencies feel that it is not their role and they (people with moderate learning disabilities) fall between different services.*

Similarly

> *people with moderate learning disabilities do not have any specific organisation that is responsive to them on the basis of their learning disabilities*

The absence of a lead authority with clearly defined statutory responsibilities (despite legislation that enabled these to be undertaken (Burton, 1992)) was continually noted, and there often seemed to be a large element of chance in deciding which service (or part of service) a person might become involved with, or whether a service is received at all. Within social services, people with moderate learning disabilities and mental health difficulties might be contact with teams specialising in mental health, alcohol abuse, homelessness or learning disability. Mental health services drew our attention to their belief that people with learning disabilities and mental health problems with whom they had contact were likely also to be known to the criminal justice system, which suggests they may be even more vulnerable than most people had supposed. Some learning disability services did not provide resources for people with mental health problems, and some mental health services did not provide resources for those with learning disabilities. In these cases, people will not have got a service form either one of the agencies. One community based project that caters for young people under stress said:

> *we have many telephone referrals from other organisations trying to find a place for those with moderate learning disabilities, and because of this we have some idea of the lack of organisations in the area.*

Even if agencies were involved with people in our core group, they frequently only dealt with some small part of the person's overall needs. For instance, education agencies may include people in courses but do little to enhance peoples life and social

skills or their accommodation needs, and so on. Lack of comprehensive service, and lack of inter-agency collaboration is highlighted in the following comment

> *the main problem seems to be that if someone's problems cannot easily be categorised and they have a housing problem, then the housing department will meet their housing needs but cannot guarantee that this will provide the appropriate level or type of support in other ways for that individual*

Even when agencies are involved, they sometimes are so, reluctantly. We received comments such as:

> *we do not see people with moderate learning disabilities as strictly eligible for our service*

> *our mental health services are often inappropriately involved in the absence of other services*

When asked to comment upon gaps in their own services, agencies excused their limited response by drawing attention to their limited resources: this was particularly so for respondents from social services, who also mentioned the difficulties of providing for those who "don't fit the boxes". Some health service replies pointed to specific gaps, but it was also strongly argued that

> *the responsibility for major provision for this group should not be according to a health model*

Education professionals also identified internal gaps whilst indicating the wider context in which these problems arose,. Thus in one college it was reported that staff were not able

to persuade mainstream lecturers to identify such students and then refer them for additional support

Two comments from voluntary agencies have potentially important implications as pressure is made for greater involvement of volunteers in support services.. A local Neighbourhood Care Group identified its principal weakness as

not having volunteers who are willing to give plenty of time and commitment to this particular group: volunteers feel 'unconfident' about their ability and skill to deal with these people

The organiser for a social club for people with disabilities also focused on the demands made by young people with moderate learning disabilities. He said the club receives insufficient carer support: much of my time - even with the other students' support - is spent with these students with learning disabilities.

People who have no direct contact with families or carers are more likely not to receive any service and thus to be more vulnerable. This did not seem to be because they were more independent and better able to support themselves. Indeed, another study of people living independently suggested that they were particularly vulnerable to abuse from others if they had no family involvement (Flynn, 1989).

The survey of local organisations, then, revealed a picture of gaps in service provision, lack of co-ordination between services, along with widespread concern at the consequences for individual people who fell into the competence trap. No person or agency within the locality had responsibility for the core group of people with moderate learning disabilities and mental health difficulties. If any agency is involved, this may give grounds for other agencies not to make a response. There would seem to be a clear demand and necessity to formulate policy, determine priorities and set

objectives to ensure the availability and comprehensiveness as well as the co-ordination of services.

Agencies who have some involvement with people in our core group outlined the main difficulties faced by people as poverty, accommodation, employment, isolation, social relationships and independent living skills (including budgeting skills). less often mentioned were crime and offending, exploitation by others, difficulties in coping with stress and controlling emotions and problems relating to sex.

What should be done?

There is no reason, in principle, why services should not be provided for people with moderate learning disabilities and mental health needs. The community care legislation (DoH 1991) provides a framework in which the individual needs of people with these difficulties and needs could be assessed and met. It should be sufficient to define eligibility in terms of need rather than in terms of membership of a specific group on the basis of impairment, age etc. For example, *evidence of persistent difficulties in practical and/or social problem solving in everyday life*, or *risk of exploitation, institutionalisation or homelessness without help from others.* However, for this to happen in a systematic way a number of things will have to happen.

Firstly, senior managers from health, social services, education, housing and the independent sector will have to realise the need is there, and take measures to estimate the number of people who have such unmet needs (including those currently in prison, hospital, residential institutions and in the community).

Secondly, specific mention of people with these needs will have to be made in Community Care Plans, as the eligibility criteria established for both learning disability and mental health services excludes people with moderate learning disabilities and mental health needs.

Thirdly, those charged with commissioning services (from health, social services, education, housing and from preventative forensic services) will have to get to know people with moderate learning disabilities and mental health problems, in order to ascertain their needs for supports.

Fourthly, imaginative contract specifications will need to be established, which includes the requirements for agencies to establish clear responsibilities for the coordination of services for people with moderate learning disabilities and mental health difficulties.

Fifthly, potential provider services will need to be stimulated and nurtured so that they are able to offer supports that are relevant and targeted at the core group of people with whom we are concerned. This will be particularly difficult as there is little existing knowledge about practice issues in this field, and if developments are left entirely to market forces, value-based, individually tailored services will be difficult to ensure. New models of service provision that incorporate positive strategies for inclusion of people in their local communities (see, for example, Burton and Kagan, 1995) will be required.

Lastly, if people are to be supported by relevant services to live meaningful and good quality lives, efforts will have to be made at all stages to involve them discussions about the types of services that will make a positive difference to their lives, about the delivery of the supports and in evaluating the effectiveness of any services that are established. Perhaps the greatest need of all of people with moderate learning disabilities is to be autonomous and in control of stimulating lives in communion with others.

All of this will require tremendous efforts of inter-agency and intra-authority collaboration as well as different models of working that lead to social inclusion not

exclusion. If it is successful, it will challenge the boundaries around service organisation as well as professional practice.

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