



Fit for purpose?

Mental Health Services in Wales for young people with learning disabilities

Children and adolescents who have mental health problems receive services from Children and Adolescent Mental Health Service (CAMHS), while those who are older than 18 fall under the provision of Adult Mental Health Services (AMHS). How effectively both services link with each other varies widely across Wales. Axel Kaehne, explains how research by Cardiff University, School of Medicine charted the problems that occur as young people move from one service to another.

Imagine your daughter is turning 18 and about to leave special school to go to college. You managed to navigate the jungle of agencies and even found her a paid part time job on those days when she is not in college. But this suddenly does not matter anymore, since her behaviour during the last days in school becomes worse. Eventually it deteriorates to such an extent that you get a referral for a psychiatrist. What was supposed to be the beginning of the road to independence quickly turns out to be a long walk through services without ever getting the support she needed. After months of waiting, her behaviour thankfully improves before she has seen a psychiatrist at all.

According to mental health

professionals in Wales this is a typical story for young people with learning disabilities who experience mental health issues at times of transition from school to college. The system of mental health is built on hope: hope that things improve on their own before things get seriously out of hand.

Lack of research

In fact there is little research on what young people in transition experience in terms of their mental health and whether or not the current provision in Wales is sufficient. We do know that young people who are about to leave special school experience uncertainty and disruption which places them at a greater risk of mental health problems. The time

of transition is therefore a critical time for families and young people with learning disabilities.

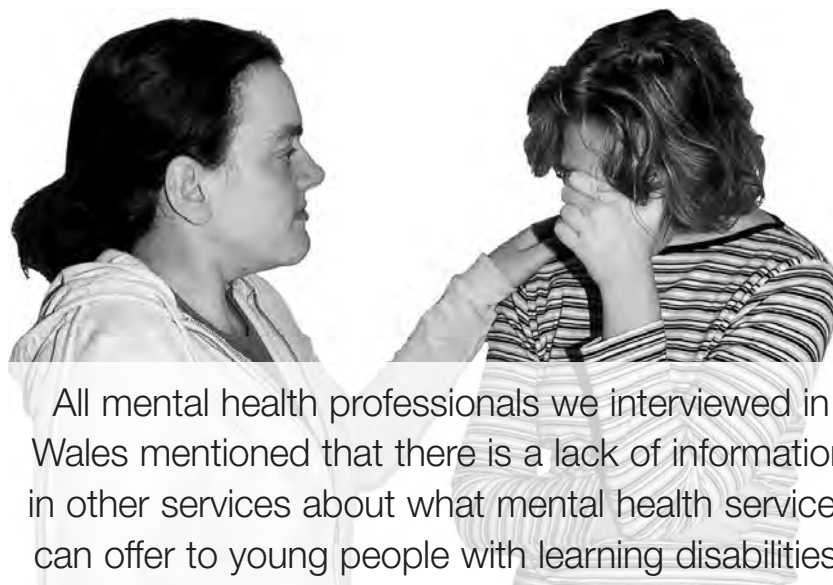
Not all young people leave special school at the same time. Some leave at 16 while others remain there until the age of 19, this means that 'one size fits all' approaches in mental health support may be misguided. Indeed flexible support structures are critical for good services. We also know that it may be difficult to identify mental health problems for those professionals who may not have experience in dealing with young people with learning disabilities. Communication problems and behavioural patterns may be different from the general population which may make reliable diagnosis of mental health issues difficult.

Change

Over the last decade all social and health services have undergone radical changes. Services are supposed to focus on the needs of the person with learning disabilities and they are urged to co-operate to eliminate service gaps. Children and adolescents who have mental health problems receive services from the so-called Children and Adolescent Mental Health Service (CAMHS), while those who are older than 18 fall under the provision of Adult Mental Health Services (AMHS).

How effectively both services link with each other varies widely across Wales and our research wanted to chart the problems that occur as young people move from one service to another. However, no service exists in a vacuum and so it is essential that mental health services, for adults and children, need to link up with other social and health services. Since all of these services are often equally divided between a children and adolescent and an adult side, young people with learning disabilities who happen to experience mental health problems are often caught between many different service structures and professionals. As they turn 18 they experience a hand-over to adult services in all service domains, social, primary health care and mental health.

Since many young people with learning disabilities are lifelong and frequent users of social and health services, the disruption to their lives at the time of transition can be immense. The many changes in their lives as they leave school may make mental health support critical for some young people at



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exactly the time when one service ceases to be responsible for their care and another one is just taking over.

Research

In our research we wanted to know how mental health professionals who work with adults as well as adolescents view the problems at this time of transition for young people with learning disabilities. We selected 3 local authorities in Wales and contacted professionals who worked in the adult as well as the adolescent side of mental health. All of them were involved in working with young people with learning disabilities so they were well aware of the additional difficulties and risks that learning disabilities bring to the issue of transition. We also contacted managers of mental health services in all three local authorities since we wanted to know what the barriers are to linking mental health provision effectively with other services.

Some young people with learning disabilities who are seen by a mental health professional also receive social service input but we do not know much about the way in which services liaise with each other. In our interviews with professionals we asked what

professionals thought the main challenges are during transition for young people with learning disabilities, how mental health provision can be improved, and how partnership working with other agencies and services can be organised better?

Lack of information

All mental health professionals we interviewed in Wales mentioned that there is a lack of information in other services about what mental health services can offer to young people with learning disabilities. Interestingly, this lack of information sometimes also applied to some mental health professionals. In other words, psychiatrists in children's services are often unsure whether or not a young person they work with will receive services from the adult team in the same local authority if they turn 18. The issue is one of eligibility criteria which differ dramatically between children and adolescent services and adult teams. As people leave school and experience disruption and change in their lives, they may get input from an adolescent mental health service but this may end abruptly as they come to be handed over to an adult team which applies different eligibility criteria.

There is also a lack of information about the young people across all services who may be involved with a particular family. A young person with learning disability may have a social worker but mental health professionals often feel that there is little exchange of information between them and the social worker. In addition, none of the three mental health services in the local authorities we examined were effectively integrated into the so-called transition partnerships that organised transition for young people with learning disabilities between schools, social services and voluntary agencies as they leave school.

This is odd since it is often the increasing difficulty of navigating the various children's and adult services that may contribute to the mental health risks for young people at the time of transition. As long as mental health services are not effectively part of the transition partnership it is hard to see how behavioural problems of young people with learning disabilities at these difficult times can be dealt with quickly and proper referrals can be made.

Service gaps

The professionals we interviewed also indicated that there are significant service gaps for some young people where psychiatrists do not get involved with the family or young person simply because either they do not meet the requirements for service or because there are doubts over which service should provide support at what time. One group that is often turned away are young people with learning

disabilities who are on the high functioning end of the scale.

Adult mental health services in particular rarely engage with that group unless they suffer from acute and ongoing mental health problems. In some local authorities there are also inconsistencies about which service should engage with

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patients who are not yet 18 but have left school at 16. Whilst, technically, adult mental health services will offer psychiatric support only to those 18 and older, in some cases their counterpart in children and adolescent services stop working with youngsters who have left school at 16. It is highly likely that in those cases some young people with learning disabilities and their families find themselves in a situation where no mental health professional will in fact offer any support until the young person turns 18.

Different models

In addition, many of the problems of transition occur because children and adolescent services often use a different service model. In our interviews one aspect was raised again and again. While psychiatrists in children and adolescent mental health services tried to look at problems in a holistic way which included the young person and the family, adult services often work with a fire fighting, quick throughput model which requires any patient to show an acute need of psychiatric input. Preventative work is rare amongst adult mental health professionals if only because the services are often stretched to breaking point and under-resourced.

Young people with learning disabilities who need mental health support, therefore, may experience very disruptive times during transition. As they leave school, move from family social services to adult services, embarked on their first work experiences, and explore new opportunities in social and cultural life, they are often also at higher risk of developing mental health issues. Without further integrating mental health professionals into the wider transition partnership framework, chances are that mental health support for young people with learning disabilities will remain patchy across Wales and marked by frustrated expectations for young people and their families.

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