

A VISION OF TRANSITION

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INTRODUCTION

One of the joys of life for a parent is to see the child emerging as a capable, good and creative adult. However all parents will have experienced anxiety as the process of transition is complex and there are many difficulties on the way.

For those with disabilities there are more barriers to successful adulthood and both the young person and their parents may have many anxieties and sometimes find few professionals who can help.

So what is the process of Transition and how can we in Rehabilitation Medicine and the rehab professions help?

Transition is described by Hardoff and Chigier (1991) as a period of biological, social and emotional change in which the adolescent has 4 major developmental tasks: *to consolidate their identity, to achieve independence from their parents, to establish adult relationships outside the family and to find a vocation.*

This is an uncomfortable process.

It is thus not a single event but rather a process which may go on for a decade, usually from 16 to 25 years of age.

In addition, we have to consider the transition of the person between services whether these are from generic paediatric services or special to a diagnosis such as inflammatory arthritis or cystic fibrosis or sickle cell disease in which case there may be a linking adult service.

WHAT ARE THE PROBLEMS?

Many young people with mobility difficulties will not have been able to get to where they want to go independently. They will only have gone where their carers took them. They will have lost out on much normal experience and they will almost certainly not have earned a little money and gained a little independence by doing such things as baby-sitting, weekend jobs or a paper round. In some cases their immobility will have denied them access to schooling with able-bodied peers so limiting their experience and their possible careers (compounded, if the universities and further education establishments are not accessible or do not have support for disabled students).

Those with cognitive deficits may have struggled greatly with getting adequate schooling and may be several years behind their contemporaries in their abilities and their possession of diplomas and certificates. As well as this, they may continue to learn slowly.

Both groups may lack commonly needed skills, such as having passed their driving test (see below).

The health problems of disabled older children were documented fully 20 years ago in the UK by Thomas and Bax (1989). They were stark and included the following:

Problems of young people (Thomas and Bax, 1989)

Bladder	56%
Bowels	54%
Washing, bathing, menses	50%
Communication difficulties	20%
Major mobility problems	72%
Saw no physiotherapist	72%
Saw no occupational therapist	86%
Saw no dentist	50%

There is no reason to think that the problems are very different now in most parts of Europe. A recent publication from the Netherlands (Hilberink et al., 2007) enumerates those for the biggest group, that with cerebral palsy. They were pain, joint deformities and fatigue. Many young adults were deconditioned and some had spasticity. They had a variety of disorders of movement and posture which were major with difficulties of moving around and some had cognitive impairments.

All these impacted on function in a host of ways and on participation in society. Sadly, access to rehabilitation personnel (only 1/3 had been in contact with a RM physician) was only a little better than in the UK 20 years before.

The authors make the correct statement that we need a life-span perspective for managing the needs of these young people.

WHAT IS THE SIZE OF THE PROBLEM?

In the UK, which has a population of 60 million, there are some 340,000 disabled people under the age of 25. One

in 1000 of those aged 16-19 and 1 in 1000 of those aged 20 to 29 will be severely disabled. These numbers seem small but many will need contact with a team for at least a decade.

In Leeds (population 750,000), there are about 30 young people coming to the Young Adult Team each year and the active case load is over 120. This does not include those with learning disability; that is a much larger group.

What are the diagnoses of these young people?

As in Thomas and Bax's study most have neurological diagnoses; the predominant one is overwhelmingly cerebral palsy but acquired brain injury, spina bifida and neuromuscular disorders are also of the encountered.

However, many young people with muscular dystrophy are living into their 20s and so are those with treated childhood malignancies such as of the brain. There are a significant number of very small babies with disabilities and we do not yet know the size of their needs when they grow up.

Many will have a nearly full life expectancy so the aim must be to improve the quality of that life and reduce dependency where that is a wanted and feasible aim. Where that is not, we should seek to improve autonomy.

BARRIERS AND SKILLS REQUIRED

How is one to think about the barriers that confront the disabled young person? It is best to have some framework which itemises the skills required of the emerging adult? These can then be related to the service which needs to be put in place.

If one reflects on the aims of transition it becomes clear that many competences are required of adults. These can be divided into those which pertain to health and the management of ongoing disease or disability and those which are called life-skills.

It is not useful to produce services which respond to a single diagnosis for many of the needs of those with different diagnoses related to task deficits and desired role are similar. Those with life-threatening disorders may need rather a different approach and the literature is sparse about how best to help.

The skills include:

Skills needed related to health and disability

Health	Self care	Mobility
Nutrition	Feeding	Indoors
Exercise	Washing	Thresholds
Joint maintenance	Bath/shower	Outdoors
Skin care	Toilet and bowels	On foot
Medication	Menstruation	Transport private
Disease management	Sexual health	Transport public
Disability management		
Use of health services		

Social and life-skills needed

Work	Home	Learning	Self-development	Relationships	Leisure
Vocational	Food acquisition	Information	Assertiveness	Sexual	Hobbies
Related elements (transport)	Food preparation, cleaning, storage	Experiential	Negotiation	Family/children/parents/sibs	Sports and fitness
Movement in the workplace	Household cleaning	Vocational education	Decision-making Planning	Social	
Seating	Maintenance	Recreational	Budgeting	Workplace	
Adaptations		Reading, writing, number	Risk-taking	Other friends	

EVIDENCE FOR THE VALUE OF A SERVICE

In the Lancet of 2002, we reported on the use made of 2 multidisciplinary rehabilitation teams in 2 cities and compared the results with 2 other cities where there was, as yet, no such team specific to the young adults in transition (YATs). We were able to show that the young people who had access to the YATs participated in society over twice as well as those who had no such service and had to make their own way as best they could through the many services which they needed to use in the health system.

Importantly, there was no additional cost to the health service in having a team. This should not surprise us - it is a question of organisation.

Although there is a growing literature on transition there is little other hard evidence for the value of transition services - it is urgently needed.

THE VISION

What vision do you have for a service to your young people?

I believe one of the best responses to their needs is to establish an interdisciplinary rehabilitation team along the lines of the one I founded in Leeds and which has run and evolved for 20 years.

THE AIM OF A YOUNG ADULT TEAM

Our team describes this as **To help young physically disabled people between the ages of 16 and 25 years achieve the lifestyle they want.**

This definition establishes that practice is driven by the (interpreted) goals of the person and that the biopsychosocial model is more appropriate than the medical model.

The age range can be adjusted to link with paediatric and school services and some would see the age at which the person leaves the service as being too low but this depends on what rehabilitation services the person can access afterwards.

WHO SHOULD BE IN THE TEAM?

The core team needs to relate to the core functions.

Thus there will be a **consultant in Rehabilitation Medicine**, who can lead in such things as the management of spasticity, with drugs, Botulinum Toxin and using the skills of the therapists. He/she will increasingly need to be knowledgeable about rarer medical conditions of those who survive their deleterious effects in childhood. Many links and referrals will be out to such areas as renal medicine (for renal function review), neurology and orthopaedics and in from a wide range of specialties. Close links have to be built up with Paediatrics.

We also had input from a **GP** who specialised in family planning and was instrumental in ensuring that the needs of this group for the routine screening that the general population has are accessible to the young disabled person. There is frequently no appreciation of their needs and no access or variable height couch or knowledge of how to examine in the presence of spasticity.

Although we do not have a **nurse**, the team believes that this would be a good appointment and might be an alternative to the GP. She would link with district nurses and advise on the protection of vulnerable skin against pressure sores. There is much health education to be done with the clients (sex education in the presence of disability, contraception and awareness of how to look after the body).

A **psychologist** has much work to do with helping the young person come to terms with their disability and maximise their ability. Where there are behavioural problems or cognitive deficits, the psychologist will assess and manage these and advise the teaching establishments the person will use.

The **occupational therapist** also has a great deal of work to do with the young person over a long period as one of their goals will often be about achieving independence and living away from parents. He/she will address many ADL areas,

both personal and domestic and is frequently asked to help with the acquisition of life-skills of increasing complexity over the years.

Less time may be needed from the **physiotherapist**, but it is very important that she is a part of the team, and motivates the individual to continue exercise or start sports. He/she will also be needed to advise on lifting and handling and equipment just as the OT will facilitate getting equipment for personal and domestic tasks. There are many things the young person has to learn so both therapists are needed to teach many skills.

These will include learning to use private and public transport and undertaking education and training which will in some cases lead to employment and in all cases to a more rewarding life style.

There needs to be input from a **speech and language therapist** for the same reasons in relation to communication and communication aids.

It is not efficient for professionals to do the many administrative tasks of the team and make appointments for patients and meetings. This work and the collection of routine data (an important function) need a **secretary**.

Clients of the team get a much better deal from the social services and from Local Authority departments such as housing and careers if a **social worker** is seconded to the team and based with it. Otherwise their particular needs will not be understood and will not be a priority.

The young person

To ensure the engagement of the person and the team making decisions about goals which are correct all goals will be negotiated with client; increasingly more of the responsibility should rest on them for achieving those goals.

The parents will not be the main players and will rarely be involved in the consultations. But their needs should not be forgotten. They have battled for their child, often against uncomprehending authorities, for many years and they will need help to let go of the controlling reins. Yet they will be relieved that their son or daughter may be able to run their own life when the parents die.

This is the core team but many others will be called on regularly; to have a lead person in each of these disciplines is helpful.

The wider team

This frequently includes a careers advisor who will link with the careers service and with the occupational therapist of the

team. It will include professionals in Housing, Education, Employment and various voluntary organisations. Within the Health Service the team makes frequent use of orthoses and wheel chairs, communication aids and the advisory Disabled Living Centre.

The Education Department may have someone designated to produce a transition policy for the schools which describes what is required after the young person leaves school; this is not the same as providing for that need for 10 years during which the person is maturing.

The team will thus build up many other links. They will need to be aware of policy changes which may affect them, either negatively or positively and should have a route into policy making. This means that for the immediate benefit of disabled young people and for their future benefit, the team must input into the policy-making bodies of the city. It is important that they publicise their work for both these reasons.

TRANSITION BETWEEN SIMILAR SERVICES FOR CHILDREN AND ADULTS

Those with conditions such as Cystic Fibrosis, cancer and various cardiac conditions may have designated adult service into which they can slot. In this case some support during transition between services will be needed not only for them but also for the paediatric and adult doctors and nurses. This will help to ensure that the general problems of transition are addressed as well those related to the transition between services.

WHERE SHOULD THIS TEAM BE BASED? WHAT RESOURCES DOES IT NEED?

A young adult team is essentially a community team but its location should not be isolated from other rehabilitation facilities nor should its staff. The team need to be exposed to new ideas both in rehabilitation and paediatrics. There are many children with obscure diagnoses who need ongoing but knowledgeable treatment which requires a high level of medical input.

The team needs a physical base and a budget. They need champions and a link with rehabilitation researchers for there is research to be done in this area.

Does this give enough information to help your vision to become reality? To re-iterate, I think it is about giving these young people the tools to support them in their growth to maturity. It may be about independence; it is certainly about giving them as much autonomy as can be managed and as they want. It is also about helping them gain the ability to form good adult relationships which will go much of the way

to ensuring a good quality of life for many years, perhaps for half a century.

AN EXAMPLE

Laura, who has CP, was in mainstream schooling before coming, some months later, to YAT. She had spasticity and some joint deformities. She could walk with difficulty, was of normal intelligence but difficult to understand. Her posture had deteriorated since leaving school and she took no exercise. She was able to manage most of her personal ADL but no domestic tasks and so would be unable to live alone. She had no formal qualifications and no aspirations of work. She had no boy friend and since leaving school had remained at home, did not go out of the house alone, and had no social activities.

She said she wished to go out of the house, to shop at the local shops using her speech, to swim weekly and be able to make a simple meal.

All of these goals were achieved in the first six months of contact with the team.

Long term goals were then set. These included joining a social club, a placement doing voluntary work in a shop and living alone.

These were achieved in the next year. At the same time she had begun a general skills course at the local Further Education college with a view to gaining vocational skills. These took several years to acquire.

Further reading

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