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**Abstract**

Graham Harper, a County Development Officer, writes about Clywd's Community Living Services, which are being reconstructed to help all people with disability live in their own homes and communities. The support needs of all individuals must be identified and met, irrespective of the degree or nature of disability. The paper describes how the establishment of the service has been achieved- not without problems- and the need for recognising the importance of families and neighbourhoods. **Keywords: Individualisation, Accommodation**

# A BETTER LIFE ON THE OUTSIDE

**Graham Harper writes about Clwyd's Community Living Services, which are being structured to help all people with learning difficulties live in their own homes and communities, in the area of an authority where 'there are no exclusion clauses'.**

How do we organise and deliver a service which is capable of supporting all people with learning difficulties to live in their own homes and local communities, and which is sufficiently adaptive to cope with so many and varied needs?

Clwyd's intention to close all the hostels and hospitals for people labelled mentally handicapped and the requirements of implementing the All Wales Strategy initiative have focused our minds on the search for a possible solution. The article 'Making each day matter' in the July 1989 issue of Community Living outlined the thinking behind the new patterns of service in Clwyd.

One main element is the Community Living Service. Eventually this will replace traditional residential hostels and hospitals as well as those parts of day services which seek to meet people's social and home related needs such as domestic skills or personal hygiene training and leisure activities etc.

The 'mission' of the Community Living Service is to identify and respond to individuals with learning difficulties, who require help in obtaining or keeping a home and home life of their own, in a way which leaves communities stronger, or more competent at supporting people with disabilities. Although many will be familiar with services where the stated aim is to provide support for achieving a home and home life, few mention any intentions in relation to the communities in which the people will live. In Clwyd we feel this is very important. History suggests that services and professionals damage people and communities, albeit unintentionally and with the highest of motives. As soon as the social worker arrives, often, the neighbours, having done their bit, stand back to make way for the 'professionals'. The relatives, probably

already worn out through lack of earlier support, may resign themselves to their own assumed inability to cope or just feel a great sense of relief that help in some form may be at hand.

'Service' solutions are mostly not about helping communities to become or stay involved and thereby share responsibility for supporting people who are fellow members; they are generally about providing supports from within their own formal structures. This is usually in settings which gather users together in large numbers thereby segregating them from ordinary citizens. It is almost as though there is a collaboration in which 'services' encourage communities to abdicate an active responsibility.

This is nothing new. It is the history of services as far back as the first work-house. The very best of intentions may do more harm than good. Professionals move in, relatives and neighbours move out. Our thinking about these matters was particularly influenced by some of the work of John McKnight in the US and the usefulness of this is now in evidence in the recent King's Fund publication, Ties and Connections.

To pursue the above 'mission' we needed to think carefully about the different communities in Clwyd and how we could best organise ourselves to respond to them and the individuals with learning difficulties who belong there. This includes those who got moved out to institutions because local supports were not available and who now may wish to return to their home area. The most useful notion of community was that of 'neighbourhood'.

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Clwyd has six district council areas and from last April, each of these had a local Community Living Service. This comprises a Community Living Manager with several 'neighbourhood' Community Living Organisers (currently called Team Leaders for local administrative reasons). Neighbourhoods are determined by the size and geographic nature of the area. We can already see that our initial assessment of what constitutes a manageable neighbourhood will need to be modified. In one area which has a mixture of urban and rural patterns of living and a general population of 110,000 people, there are six neighbourhoods; another area, which is geographically large and very rural but only has a general population of 35,000 people, has three neighbourhoods; yet another area, which is fairly compact and predominantly urban with a general population of 70,000 has four neighbourhoods. Even if it is possible and desirable, it may be some years before we can identify the characteristics of an 'optimal' neighbourhood.

Community Living Managers have responsibility for a local budget which comprises funds made available by the Social Services Department (partly from the closure of hostels), the Welsh Office, through the All Wales Strategy, from the Health Authority, through the Hospital Closure Programme. These funds are used to provide direct support to service users.

The Team Leaders manage the direct service operations and have responsibility for ensuring that the needs of all individuals with learning difficulties who live in their neighbourhood are identified and met. There are no exclusion clauses. Irrespective of the nature or degree of disability, we expect all people labelled mentally handicapped to be supported in their own homes in their own localities and have included this in the job description for Community Living Managers and Team Leaders.

There have already been some notable successes in supporting individuals presenting substantial 'challenges' in behaviour which other people find unacceptable to live in homes of their own.

To develop this aspect of our responsibilities we have established an Intensive Support Team operating for the whole County to provide specialist guidance and help to direct support providers. This supplements the support already available through inter-agency agreement about the role of community nurses and clinical psychologists. In time this should prove effective but at present it would be wrong to assume that

everything is working as we would wish. In the absence of a complete Intensive Support Team the past year saw three people admitted to hospital albeit for short periods.

Alongside each neighbourhood team leader there will eventually be a community nurse. Whilst we had much debate about the relevance of the title 'Nurse', the fact remains that many people with learning difficulties (particularly those we find difficult to understand) have many health care needs which go unnoticed and unattended. The community nurse has a positive role to play in meeting these needs. This arrangement seems to accommodate the requirements of the Government's White Paper, *Caring for People*, in facilitating a proper assessment of people's health care needs.

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Service staff employed directly in neighbourhoods are currently known as Project Workers. These are mostly people who live near to service users and are recruited to provide local support responsive to individual needs. However, we are increasingly developing a range of options which seem to fit comfortably with our interpretation of the White Paper. These include 'Lifesharing' and 'Good Neighbours'.

Lifesharing was described in *Community Living* (April, 1989). This is where someone goes to live with a person with learning difficulty, an arrangement which may involve paying a fee to the lifesharer. Our thinking on this has developed substantially as a result of an external evaluation carried out by Alan Tyne and Sheila Morris. One of the lessons learned is the importance of recruiting local people who already have good local networks and contacts. Another is the need to build adequate circles of support around service users which include people besides the 'lifesharers'. The evaluation report, describing the successes and failures should be available during 1990 (publication will be announced in *Community Living*).

## Good neighbour

A 'Good Neighbour' is a person who lives local to people with learning difficulties, has good local ties and connections and is recruited to provide direct support. This can range from simply keeping in touch to providing direct help. Often, the 'good neighbour' may be the first point of contact at a time of difficulty. In some instances they may even provide temporary accommodation. The people who receive the service may either still live with their families or in homes of their own. Our expectations of 'good neighbours' are specified in a contract related to the needs of the people for whom support is provided.

One intention is that people will have positive introductions to other citizens in the wider local community with a view to the development of valued friendships. 'Good neighbours' are paid a fee in the same way as foster parents although where support is provided to a maximum of eight people, this can amount to more than the equivalent salary of a service worker. The current maximum is £11,000 but the cost of supporting people in this way using traditional staff, even if it were possible, would be much more. It would be impossible to achieve the desired results because of the constraints of local authority staffing contracts and conditions of service.

In designing this service, the job titles 'Community Living Manager' and 'Team Leader', were chosen as they did not assume or prescribe a particular qualification or range of experiences. This meant that we could take or leave 'the professionals' as appropriate. We believe that if we can appoint people with the right personal attitude and values, the rest can be learned. As a result we hope all the managers and team leaders will become familiar with the Framework for Accomplishment developed by John O'Brien and Connie Lyle O'Brien as well as become involved in our own in-service management development programme.

The establishment of the Community Living Service has mostly been achieved through managing change in traditional day and residential services. Following agreement with the Union we transferred all existing monthly paid staff to new job descriptions which equated with the new services. This, combined with the setting up of objectives for each of the new service components, enabled us to focus clearly on the tasks in hand. This has not been without costs. Some people for whom we have not yet been able

to provide work through the Work Opportunities Service have lost activities which they previously valued.

By summer 1990 we should have enabled nearly sixty people with learning difficulties to move out of Clwyd's three hostels to homes of their own in local communities. Two hostels have already closed. Although most people seem settled in their new homes, it would be wrong to give the impression that all has gone well for everyone. Five people have had their lives more disrupted than improved. Three of these ended up in hospital and two are still waiting to move to homes of their own.

The main characteristic which the five have in common is that, for a long time, services and society failed them. Being resident in a hostel simply hid their substantial unmet needs and provided a more structured environment in which particular forms of behaviour could be supervised or contained. Most had no friends, no meaningful social relationships, no interested family and seemingly few good experiences in life. One man had experienced a period in a secure hospital and still requires full time supervision to prevent some particularly unacceptable behaviour.

Clearly, there are lessons to be learned. After considerable planning, we have started on a programme to enable all those Clwyd people who live in hospitals for people labelled mentally handicapped, to move to their own homes. The dilemmas and challenges are likely to be with us always. We have probably learned more from the experience and making some mistakes than anything else. Such is the human condition.

## Fulfilling

On the positive side many people now have a much more fulfilling way of life. Christopher, for example, finds it difficult to communicate with us but has now moved to live in his own home with a couple of friends. We knew he liked music because he always took people up to his room to see his varied record collection. He met Paul, the son of one of the project workers, who is in a rock band. Paul invited Christopher to go to a band practice night. He greatly enjoyed having a go on various instruments and now he goes on 'gigs' and helps as a 'roadie'. Christopher also goes to other rock concerts with the group and seems to have a good time with friends he never previously had the opportunity to meet.

Ted's life has also changed. He is 59 and after living in a hostel for many years moved out to share a flat with his friend Alan. After 18 months Ted wanted to move to his own flat. We helped

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*The five people whose lives were disrupted by the move to their own homes had one main characteristic in common - services and society had failed them for a long time.*

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arrange this and he is now well settled. Ted used to attend a day centre which was visited one day by the local mayoress. He invited her to tea in his new flat and she accepted. They subsequently became good friends - he visits her home and now has a full social life including political party coffee mornings! He tells the staff of the Community Living Service which influential people they should meet! This all seems a long way from the hostel where Ted felt so inhibited he rarely spoke and seemed almost to apologise for his existence.

Susan also lived in a hostel. She is 22 and in addition to having substantial learning difficulties has a life limiting skin disease. Rachael, a divorced woman who works in a local solicitor's office and who is a bit older than Susan, became her friend. When Susan was to move out of the hostel we helped her to compile an advert for the local press to recruit a 'lifesharer'. Rachael applied saying she would not want any payment except enough to keep her own flat on for a while until they were sure whether things would work out. Rachael felt she and Susan got on well together and she would like to try sharing a home. She had lived alone since her marriage had ended and sharing for a while would give both herself and Susan an opportunity to look at what the future might hold.

### **Culture change**

There are many other stories - of success and failure. There have been occasions where people were unfriendly. One of the most interesting out comes has been in relation to the different staff culture. Many staff who have been associated with traditional services seem to have different expectations and values. Whilst they value people

with learning difficulties, their views are still characterised by 'conditions of service' issues and trade union activities. This culture change is well illustrated by Brenda and Mary, twin sisters aged 45 years. Each has substantial learning difficulties and lived with their elderly father until his death on Boxing Day. Their mother died a few years ago and we had recruited two local part-time project workers to help them maintain the only home they had known. As he became older and increasingly infirm more help was given to him than to his daughters. On Boxing Day, when Dad would not respond, one of the project workers was the first to be called. She involved Brenda and Mary in making the usual arrangements. Brenda and Mary spent the rest of the day at the home of one of the project workers and although invited to stay for the night wished to return home. The project worker returned with them and stayed overnight. Brenda and Mary arranged the funeral with the assistance of the project workers, including the refreshments. This was very important to them. The project workers only claimed the usual hours during this period and were offended when this was taken up with them, feeling that Brenda and Mary needed them as friends during this difficult time.

The lessons we are learning from these experiences and stories reinforce our commitment to developing stronger ties and connections for people within communities. The notion of 'the good which is in everyone' so far seems well founded. The major role of our Community Living Service is to act as a catalyst in the process.

### **Background reading**

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