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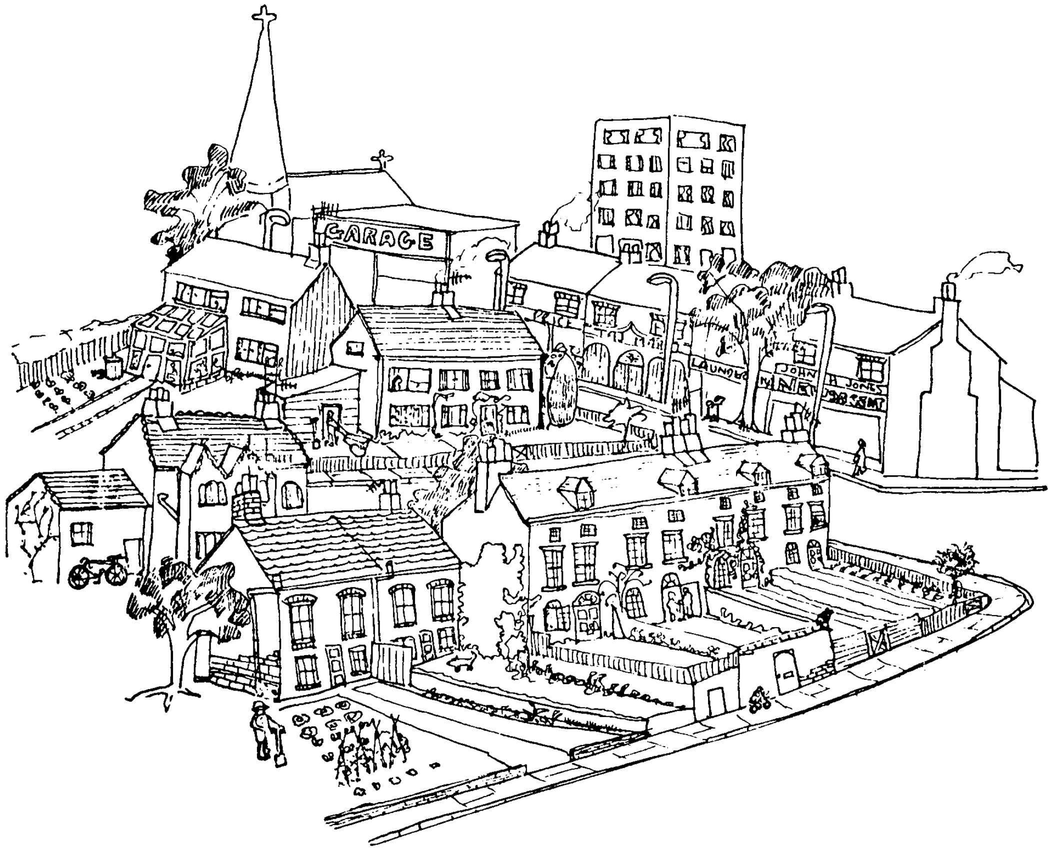
# BRINGING IT ALL BACK HOME



## Getting Mentally Handicapped People out of Hospital

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King Edward's Hospital Fund for London is an independent charity founded in 1897 and incorporated by Act of Parliament. It seeks to encourage good practice and innovation in health care through research, experiment, education and direct grants.

The King's Fund Centre was established in 1963 to provide an information service and a forum for discussion of hospital problems and for the advancement of inquiry, experiment and the formation of new ideas. The Centre now has a broader interest in problems of health and related social care and its permanent accommodation in Camden Town has excellent facilities for conferences and meetings. Allied to the Centre's work is the Fund's Project Committee which sponsors work of an experimental nature.

# BRINGING IT ALL BACK HOME

## Getting Mentally Handicapped People Out of Hospital

A report of the TASH 8th Annual Conference held at the New York Statler Hotel, 15-17 October 1981.

Written by Alison Wertheimer, Campaign for Mentally Handicapped People.

# FOREWORD

Whether we call it 'getting mentally handicapped people out of hospital', as in the recent government Green Paper, 'Care in the Community', or whether as in the United States it is called 'deinstitutionalisation', the challenge and the problems are the same. How do we ensure that community services which promote the fullest integration of handicapped people into local communities don't just remain the prerogative of less severely handicapped people? How do we ensure that comprehensive services are there to meet everyone's needs - no matter how severe their disabilities?

TASH, the Association of the Severely Handicapped in the United States, is a unique organisation which represents all severely handicapped people not matter what their handicaps are.

I learnt that their 8th Annual Conference was to take place in New York during October 1981 when I was to be in Massachusetts looking at community services for mentally handicapped people. Delegates would be looking at the progress of deinstitutionalisation over the last decade and coming together as a strong coalition to defend the rights of all people, no matter how severe their handicaps, to live in their own community.

I am extremely grateful to the King's Fund Centre for providing the funding which made it possible to attend the conference and to David Towell for his personal support. I hope this report will be one way in which I can share the experience of this conference with a wider audience.

Alison Wertheimer
January 1982

## INTRODUCTION

TASH is the Association for the Severely Handicapped. It was set up about ten years ago to campaign for people with severe handicaps who tend to receive the least good services and whose rights are the least respected. TASH has a membership across the whole of the USA, as well as abroad.

The theme of this, their 8th Annual Conference, was 'Bringing it all back home'. The aim of the conference was to think about how everyone, including those with the most severe handicaps, can be fully involved in life in the community. This was seen as the natural sequence to what has started to happen over the last decade in the United States, where opportunities for education and rehabilitation for all handicapped individuals have started to be developed more widely.

Subsumed under this main theme there were three subsidiary themes:

* Going to the Country: the process of establishing basic rights through legislative process and through the courts.

* Exploration: the transition as we move from services based on institutions, to community-based models of care which integrate severely handicapped people into their communities.

* Coming Home: the directions we want to take in the future.

TASH felt that although considerable progress has been made in providing for the educational and rehabilitation needs of severely handicapped people, 'integration' remained a major challenge. To quote from the conference programme:

> 'The idea of "community" is an inherently powerful concept which engenders the association of friends and neighbours, an implicit acceptance of handicapped individuals as friends and neighbours. Friendship and a feeling of neighbourhood demand the substantial personal investment of time and energy. We must make that investment'.

### The Conference format

The term 'conference' was really something of an understatement'. Fifteen hundred people came to what was in fact a series of conferences under one roof:

> The Community Imperative: presentations which were addressing themselves to the critical issues confronting the deinstitutionalisation movement. Sessions looked at community service models; current methods of service provision; self-advocacy; the changing role of the courts; and the professional and community backlash hindering efforts to move people out of institutions.

Growing Powerful and Political: this was organised by METRO-TASH, who wanted to challenge the perception that there are two sorts of people in society: 'handicapped people', who are dependent, have special needs and who need things done for them, and 'normal people' who are independent, have no special needs and who can 'help the needy'. Sessions in this conference looked at such aspects as: 'determining our own lifestyles' (led by mentally handicapped people); organising consumer leadership; communication for survival - how can we be powerful without speech; and partnership with the media.

Working with Families: The Parents Room: this was not only a room where parents could meet and talk with other parents but was the base for a series of sessions relating to families such as in-home training and models of family training .

Individual Presentations: Simultaneously with these three conferences there were individual presentations being made on a number of broad themes. These included: service models; behaviour management; curricular design, language and communication; and staff training.

The wealth of choice then was quite amazing; some sessions were very practical disseminating specific areas of knowledge; others were more generally 'consciousness-raising' as in many of the 'making it powerful and political' sessions. The 'Community Imperative' conference, as well as providing the chance for those fighting the deinstitutionalisation backlash to establish some solidarity with one another, adopted a broad policy perspective. I chose to attend this part of the gathering because it related closely to the sort of policies and developments I was observing during the rest of my stay in Western Massachusetts; it also gave me many opportunities to meet with and listen to people who are grappling with the same issues that we are facing in England; namely - how can we move from a hospital-based service to service to services in the community, and ensure that we provide a better quality of life for mentally handicapped people?

If my notes are occasionally brief, for example, on Burton Blatt's presentation, it is because the sheer enthusiasm and commitment of the speaker captured my attention completely and diverted me away from my pen and notebook'.

I have taken the opportunity at the end of this report to share some of my general impressions of the conference. I felt that there were lessons for us in England - both in our role as conference provider, and as attenders of conferences.

## THE COMMUNITY IMPERATIVE

### 'Fighting the Deinstitutionalisation Backlash'

Burton Blatt, School of Education, Syracuse University.

Burton Blatt knows as well as anyone in the United States what institutions are like and what they do to the people we choose to place in them. With a photographer, Fred Kaplan, Burton Blatt spent Christmas 1965 visiting some of the long-stay mental handicap hospitals following some whirlwind visits by Senator Robert Kennedy. The result - a horrifying but moving photographic record entitled 'Christmas in Purgatory'. As Burton Blatt wrote in his introduction, the reasons for the state of long-stay hospitals were complex but 'we know that what Senator Kennedy claimed to have seen he did see'.

Blatts presentation, which opened the conference, was an unashamed rallying call to the delegates, delivered in a style which is rarely heard at these sort of conferences. He was there to defend the rights of mentally handicapped people to live in the community at a time in the United States when there is a considerable backlash emerging, intent on reversing the programmes of large-scale deinstitutionalisation.

Some of the criticisms of programmes to discharge people from long-stay hospitals could be justified. In the late 1960s and early 1970s what can only be described as dumping occured in many States when patients were simply turned out of hospital and left to fend for themselves; many former residents of Willowbrook State School on Staten Island were left to roam the New York streets. But this wave of dumping has been followed by some much more succesful programmes which have placed former hospital residents in ordinary houses in the community and which have to a large measure succeeded in integrating formerly institutionalised people into local communities.

But, 'dumping' isn't the only reason why some people are fighting to keep the long-stay hospitals in existence. A new wave of critics maintains that the ability to learn should govern whether you live in the community or in an institution, Burton Blatt said. "But as we all know, the quality of life is likely to be inferior in any institutional setting"so, as he went on the say "should a person's quality of life be determined by their ability to learn? Should people have to 'learn' their way out of institutions?"

Arguments about whether people should leave hospital seem to revolve around two standpoints - values and attitudes versus empirical data. In terms of developing policies and laws relating to mentally handicapped people it would appear that values are responsible for change and innovation yet there are still those who want to insist that empirical data should be the determinants of how we meet the needs of handicapped people. As Burton Blatt put it so succinctly: "Nobody dies for (lack of) a reading score but people can die for a lack of freedom'."

Whilst we don't want to deny to handicapped people the chance to develop and acquire skills and abilities. Blatt was saying "don't let's make that the yardstick of whether we allow people to leave institutional care". Handicapped people who have been living in long-stay hospitals must not be made to 'earn' their right to discharge. If we believe that everyone has the right to a normal life in the community, whatever their level of handicap, then the learning theory and empirical evidence of skills acquisition aren't relevant to this debate.

## 'The Politics and Economics of Deinstitutionalisation'

Doug Bicklen, Centre on Human Policy, Syracuse Universiry.
Gunnar Dybwad, Brandeis University (and currently President of the International League of Societies for Persons with Mental Handicap).

Like Burton Blatt's opening talk this was a scene-setting presentation from two people acquainted with a new and exciting developments in community services in the United States. Both Gunnar Dybwad and Doug Bicklen are in touch with both the positive moves to provide good high-quality services in the community and the moves of those who wish to strengthen the institutional base for service provision by rehabilitation and renewal of the existing long-stay institutions.

As Gunnar Dybwad said, "we in the USA are in a combative situation at present". Political support for community services is not always forthcoming. In a small town called Ware in Massachusetts there were recently plans to open a group home residence for mentally handicapped adults. Members of the local community opposed this plan and appealed to the State Governor, Ed King. The outcome? The Governor supported the residents, the home will not now open; and indeed the residents received a personal letter from the governor thanking them for their support. That's the sort of opposition that is around at the moment.

Attackers of community services are constantly demanding that research be undertaken to see if community services are 'more economical and effective'. They want to place the burden of proof on the natural setting of the community. Gunnar Dybwad asked why? "If we believe that the community is the natural setting where everyone has the right to live then we should rather ask the institutions to prove that they can provide a better quality of life and a better service to mentally handicapped people. We should shift the burden of proof".

However, as Gunner Dybwad pointed out, those working in long-stay hospitals can be the allies of deinstitutionalisation. David Rosen, who had been largely responsible for setting up and directing the Macomb Oakland Centre ( a base for comprehensive community services) had a long career in institutions where his work with mentally handicapped people gave him the experience and knowledge to set up MORC.

Despite some clear evidence of hasty discharges from long-stay hospitals resulting in people being dumped in the community, by 1979 there were only 139,000 mentally handicapped people living in institutions in the USA compared with about 45,000 in England. (This is not a bad effort considering that the American population as a whole is about 4½ times larger than that of England!)

It was important to understand that the man wandering the streets, homeless and with no daytime activities, after a lifetime in institutions was not a casualty of the community system but a casualty of institutional life which had rendered him unable to function in the community. As Gunnar Dybwad said "dumping and incarceration are integrally related - the man living on the street is the casualty of the institution not of deinstitutionalisation".

As Doug Bicklen pointed out, inevitably there will be times when one is tempted to do a trade-off to accept the second best, to achieve a short-term gain because to hold out for the best can mean to keep people living longer in institutions. He urged everyone to 'hold fast for what you know to be true - don't trade-off for short-term gains'; these may possibly sound just like fine words, rhetoric. But when you aren't emptying out the hospitals as fast as you thought and less than ideal community services are offered (large old buildings for residences, for example, rather than domestic housing) it's difficult to resist the pressures, particularly when you are told that if you don't accept that then people are going to start rehabilitating the institution, or even building new institutions.

## Launch of 'Operation Real Rights'

Tim Nerney, Connecticut Association for Retarded Citizens
Frank Laski, Public Interest Law Center, Philadelphia

This organisation was being launched at the conference with a single purpose: to work until Congress enables a Bill of Rights for people with disabilities which will be respected by all branches of government and which will guarantee community living for all disabled people and redirect funds to effect services which will make this possible.

It is useful to look at the background to show why this pressure group has been set up. In the years 1968-1978 various laws were enacted, notably the Developmentally Disabled Assistance and Bill of Rights Act 1975, which established the rights of all disabled people to an integrated life in the community.

However, these laws have been successively challenged by the courts, and those with the funds have not always made the upholding of the rights these laws established a reality for individual handicapped people. (If anyone in England still thinks that a handicapped person in the USA can always successfully up hold in the courts his rights to services then they had better think again. Would that this was so. It may happen sometimes but it can be as elusive as the sort of law we know that says 'local authorities may provide care and after-care in the community for mentally handicapped people.....)

A steering group has been set up whose members include Gunnar Dybwad (see page 5), Bob Perske, Burton Blatt and Professor Lou Brown (President of TASH). Broadly, this new initiative is the political arm of TASH. It is also seen as a move to broaden TASH's membership.

Underpinning Operation Real Rights' single aim of getting a new Bill of Rights with teeth through Congress are the following beliefs:

* severely handicapped people should not be the recipients of handouts from a 'welfare system'. Funding for services should encourage independent living schemes;
* employment opportunities should be available to give people real opportunities to achieve maximum economic dependence;
* services should be geared towards consumer control;
* there should be a national moratorium on costly new buildings, resulting in new institutional forms of care.

The steering group has already begun a series of meetings in Washington with Congress members. It is hoped that all who join ORR will involve themselves in local lobbying and together will form a network of people with a common aim.

## The Impact of the Pennhurst Case

Frank Laski, Public Interest Law Center, Philadelphia

This session was based on the case of Halderman et al v Pennhurst State School and Hospital which was bought before the courts in 1977. The case against the hospital, known in the USA as a "state school" was filed in the mid-1970s after attempts in the late 60s and early 70s to transfer residents from the hospital into the community.

The judges ruling was based on existing legal and constitutional rights, including the Developmentally Disabled Assistance and Bill of Rights Act which gave mentally handicapped people the right to receive services in the least restrictive setting. A Court Master was appointed to oversee the ruling that 1200 mentally handicapped people living in Pennhurst, 75% of whom were severely/profoundly handicapped, should be placed in 'alternative living units' in the community.

Although the ruling involved some community placements, the position taken by the courts was that the DDA and Bill of Rights Act 1975 was not strictly enforceable and that whilst the courts generally favoured community programmes no individual or group of people had the automatic right to receive services in the community.

The ruling provides a good example of some of the tensions which exist between the legislature which passes laws (as in the British Parliament) and the courts which hear cases like Pennhurst. The court may order certain provisions to be made but the State must ultimately provide the funding for these provisions to come into being and the relationship between courts orders and state funding of programmes continues to be a cause for tension in many parts of the United States.

Since 1978 when the Court order was made there have been no further admissions to Pennhurst and 220 people have left there. Of these:

157 have moved into community-based services
7 people have returned to their families
10 have transfered to other hospital-type settings
57 have died (54 of them at Pennhurst)

No one who was discharged from Pennhurst has returned and there are no longer any children living there.

The placement of people into the community raised the following issues:

Everyone involved in the case as a class member* must have an individual plan.

Those being discharged into the community often go out from the hospital for a trial period when the Court Master (see above) monitors the placement independently. Parents too are involved in monitoring the suitability of the placement. Although this is cumbersome it does provide an independent forum for satisfactory placement. All community placements must be seen to provide a better quality of life than the hospital offers.

A longitudinal study of people who left Pennhurst to live in the community has shown that they developed more skills and made marked progress in acquiring adaptive behaviour in comparison to their time in hospital.

Interviews undertaken with families of people discharged from Pennhurst showed that family contact increased five-fold after discharge.

A study has been undertaken to see whether community attitudes change over time and whether 'opponents' of community placements become advocates after people move into the community. There is some evidence (mainly anecdotal) that this is happening.

*Class action lawsuits are legal procedures that permit one or more persons to seek relief through the courts on behalf of themselves and all others similarly situated in the perceived unfairness. If this small group of individuals succeeds in persuading the court, a much larger number of individuals benefits from the action.

Some of the positive aspects have been:

> The appointment of a Court Master has provided a safeguard against 'dumping' in the community. The Master's office has been cautious and firm about appropriate community placements.
>
> The Court placed a clear responsibility on the State to carry out their orders and this provided a clear focus for accountability (backed up by monitoring of the Court Master's office).
>
> There have been some well-documented gains for mentally handicapped people leaving Pennhurst (see above).

Like any major undertaking of this kind the situation has not been without its difficulties:

> Parents of some Pennhurst residents, together with some staff, have banded together to fight the discharge of residents. $100,000 has been raised to fight their case in the courts.
>
> Transfer of staff into community services has been hampered by low rates of pay in the community and the non-unionisation by workers outside the hospital. With the help of the Court Master's office a base was established in the hospital where individual employees could discuss future plans and options for leaving the hospitals employ. However, the unions' acceptance of this has been questionable.

In conclusion - Pennhurst became a national symbol in the wider debate about deinstitutionalisation. To the opponents of the case it became a real opportunity to provide better alternatives in the community for institutionalised hospital residents, with the added bonus of having built-in accountability through the Master's office.

Using the Courts is not the <u>sole</u> answer to quickly establishing satisfactory alternatives to long stay institutions in the community. But when progress is slow and there are general financial restrictions, using the courts may be a useful back-up in an overall strategy of moving people out of institutions. (Because the State has been impeding the funding of the Court Master's office they are currently being fined $10,000 day).

## 'Deinstitutionalisation in Michigan: Homecomings for Persons with Severe and Profound Mental Retardation'

Gerald Leismer, Office of the Special Master for the Plymouth Court Order.

In this session Gerald Leismer described how in the state of Michigan there had been moves towards establishing community-based services for mentally handicapped people who were formally living in hospital:

| | |
|---|---|
| 1969; | 12,600 mentally handicapped people living in long-stay institutions in Michigan. |
| 1960s; | Some alternatives were being developed but these were largely 30 beds or larger. This would now be considered far too large but at the time it seemed a lot better than the thousands of beds in long-stay institutions. Former TB hospitals were being used, for example. Two decades later this sort of building is being brought into use in the name of "community care" in England. |
| 1970s; | In the early 70s nursing homes proliferated; these were thought to provide a suitable alternative to the large hospital. |
| 1972; | David Rosen becomes the first Director of MORC - the Macomb-Oakland Regional Centre - a 'de-institutionalising institution' which aims to establish comprehensive community-based services for all mentally handicapped people in its catchment area (2 million population) including those now in long-stay institutions. |
| 1977; | Training programmes were held in all twelve mental handicap hospitals in the State on the use of day and residential services in the community. |
| 1981; | 3,800 people remain in hospitals, but this represents a decrease of nearly 9,000 over 12 years.<br>650 people are living in specialised 'foster care' settings;<br>1300 people are living in small community residences (maximum of 6 people per house). |
| 1981-3; | Three hospitals are due to close during this period. |

Gerald Leismer described some components of the community services in Michigan:

Foster Care: presently serving over 640 people. Foster 'parents' for both adults and children are recruited through an aggressive assertive publicity drive. There is intensive screening and families are expected not only to provide care but also to have the ability to carry out training programmes in the home. About 35 families are recruited each year and although they will initally have one mentally handicapped person living with them, many go on to provide a home for a second (and sometimes third) person.

Community living facility: this usually provides a home for up to six people. General criteria are that it must look 'normal' within its neighbourhood and must be a home that anyone would want to live in. Each house normally has about 260 staff-hours per week with residents out during the day, evenings and weekends have a 1:3 staff:resident ratio.

Alternative intermediate service: usually a purpose-built facility, these residences cater for up to 8 people, including 2 who are non-ambulant. Staff:resident ratio is higher - usually 1:2.

Home training programme: This is an integral part of the foster programme described above. Each mentally handicapped person has an individual programme and foster families are expected, with appropriate help from social workers and other professionals to implement it.

## Comparative costings

Plymouth Center (the large hospital which still serves some mentally handicapped people in Michigan) has daily per capita costs of $194 (approximately £98).

Community Living Facilities cost $40-60 per head (£25-30 per day). To this must be added $25 for day programmes and $5-10 for administrative costs.

However, as Gerald Leismer pointed out, costings must be looked at in 'human terms' as well and although community programmes do appear to be a lot more economical this should not be the sole reason for moving people out of long-stay institutions. As he said 'we mustn't base our morality on economics'.

## Who gets placed in community services?

We tend to 'cream off', to take the most able people from our hospitals first and think about the others later - if at all - when planning community based services. Attempts have been made in Michigan to avoid this approach and about 80% of the people discharged from Plymouth hospital into the community are profoundly or severely mentally or multiply handicapped. In the area served by MORC, in and around Detroit, this rises to 90%.

MORC adopts the general stance that people should not be returned to hospital and only three people have returned to Plymouth in the last few years. To make this possible careful attention is paid to making the right sort of initial placement but if people are not settling into the initial home in the community then MORC will look for a suitable alternative.

Parents have the right of appeal against a proposed community placement for their son or daughter. This may be on the grounds that the community placement either is more restrictive than the hospital or does not offer adequate opportunities for training, only one parent has used this procedure so far.

Some general aspects:

A pro-active approach to public relations has been central to the overall strategy of moving people into the community. At MORC, for example, at least four press releases a month go out, dealing with 'success stories', asking for new foster families etc. In one year they made over 120 presentations about their work to community groups. They do numerous radio and TV interviews as well as using the whole range of publicity gimmicks like car stickers.

In 1977 a study was carried out to measure newly acquired skills in group home residents. On average each person acquired 77 new skills during one year. Unfortunately no parallel study has been carried out in a hospital setting.

Placing mentally handicapped people in small residential settings is likely to mean that those involved with them will feel a greater share of responsibility for them. It is a well known (and tested) theory that the more people are around and witnessing something, the less any individual is likely to feel responsible. (This diffusion of responsibility operates to a large extent in our hospitals and in a horrifying example was played out in a New York street when large crowds watched a murder and made no move to intervene - everyone waiting for the next person to act).

A general looking-forward approach is needed so that, for example, there are plenty of opportunities to scan a large number of possible houses, this means that the impetus to place people in the community is not held up for lack of places for people to move into.

Community involvement will enhance the community's sense of responsibility towards its handicapped fellow-citizens. It is important to build up a strong coalition of people in the community who support moves to provide mentally handicapped people with integrated living. To some extent this happens when a large number of people are having mentally handicapped people coming to live in their homes (through the foster care programme). Volunteers are used to visit all the community residences in turn and ask 'Would I like to live here'.

Community programmes in Michigan have been able to demonstrate that you don't need huge numbers of highly trained staff to provide services to mentally handicapped people - people who Gerry Leismer described as 'John the Baptists with PhDs'. It works as long as you gove your foster parents and others adequate back-up from appropriate professionals.

What services in the community in Michigan have done, in particular around the Macomb-Oakland Regional Centre, is to demonstrate that mentally handicapped people with severe handicaps can live in ordinary settings in the community. It is fulfilling a vital role in providing models which demonstrate an ideology.

## 'Serving the Severely Handicapped in the Community: Emerging Models'

William Jones, Belchertown State School, Massachusetts.
Irene Powell, Residential Services Inc., Nashville Tenessee.
Edward Skarnulis, Division for Community Services, Kentucky.

William Jones is the Superintendent of Belchertown State School, a mental handicap hospital which a decade ago had over 1200 patients. By adopting an active discharge programme in collaboration with a concerted effort in the community to build up locally based services they have been able to reduce the beds at the hospital by almost two-thirds.

As Belchertown and the surrounding area was the focus of my visit to the States there is a separate report (to be published by CMH in 1982), which will describe this service in detail. I will just mention here some of the points of general interest which William Jones made:

> Moves towards a community-based network of services involve not only a re-structuring of service systems but profound social changes as well. Positive community attitudes are as important as systems.
>
> A policy of serving mentally handicapped people on the basis of Individual Service Plans and the use of 'key workers' will provide the most effective means of meeting individual needs in the most appropriate fashion.
>
> Services in the community are being developed on the basis of the normalisation principle so that mentally handicapped people are living in the most normative settings possible; residential services concentrate on the use of ordinary domestic housing.
>
> The hospital has stopped admissions (except for short-term admissions through the courts). This may not always result in 'zero reject' by community services (some people may 'buy into the private system') but it does provide an impetus to community service providers.
>
> The community is seen as the 'client' as well as the handicapped person and strenuous efforts are made to work with local communities in overcoming resistance to new residential services and generally in engendering a sense of acceptance by the community.
>
> Strong leadership skills are needed at the local level to ensure that services are properly developed, well managed and that the needs of the community are met too.

Irene Powell, Residential Services Inc., Nashville, Tennessee. This is a community-based residential alternative for children who are unable to remain with their own families. The sort of children this agency serves have either been institutionalised or would be destined for an institution unless alternatives like this were available.

In the first 6½ months after RSI opened 7 homes were found for a total of 28 children. They now have 49 children in the scheme, 56% of whom are multiply handicapped.

After initial screening and selection, foster families are given training as well as some practical experience prior to having a child placed in their home.

Homes are now smaller than the original 4 children per home. Foster parents found that they were beginning to take the children round in a group - eg to medical or dental appointments - because it was easier.

Some of the reasons for the success of the project can be attributed to the following:

> Each family has a social worker and caseloads of workers are kept deliberately low so that they can make quick responses as individual needs arise.
>
> Families get funding to enable them to purchase respite care; they make their own arrangements for this.
>
> There is on-going training as well as the initial orientation and families are evaluated annually.
>
> Foster parents are given professional assistance in handling their relationships with the child's natural parents where there is still contact.

Edward Skarnulis, Division for Community Services, Kentucky. Ed Skarnulis is known to some people in England for the work he did with the ENCOR service in Nebraska*. He left 18 months ago to work in Kentucky.

Kentucky is a predominantly rural state with a population of 3.5 million. This is divided into 15 regions.

Kentucky has three major mental handicap hospitals and at present:

> 1,000 mentally handicapped people are living in hospital;
>
> 622 people are living in private homes in the community (some as large as 180 people in one setting);
>
> over 2,000 people are living in nursing homes.

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* ENCOR: A Way Ahead, CMH Publications, 1978.

Because many of these facilities such as private homes or nursing homes have a bad reputation, community services in general are not well thought of and there have been many accusations of 'dumping' people from the hospitals.

In response to this situation the New Neighbours programme has been set up to provide a range of services supporting people in natural and appropriate settings in the community and to prevent institutionalisation.

In the New Neighbours programme residential services will be based on the ENCOR model, using a core and cluster system of housing. As in ENCOR, people will not be moved from house to house as they become more independent and acquire greater living skills. Levels of staffing support will be varied as the needs change. This avoids the 'continuum concept' where people become locked into a system and each stage has its 'entry' and 'exit' criteria. It tends too to militate against the individual service approach as if one place becomes available in a community residence as someone passes the 'exit criteria' it is likely that the place will have to be filled - possibly by someone who has (or nearly has) the 'entrance criteria' or just filled anyway 'to keep the numbers up' (and the fixed costs of such services down).

Residential units will be small - a maximum of three people in each - they will be near the persons natural home as possible and will be in the least restrictive setting.

Costing issues: institutions will have a high proportion of fixed costs and the per capita figures may be a poor indicator of what the individual resident is actually receiving. It is easier to cost services to individuals living in the community and these costs may of course decrease as people become less dependent and require fewer supports.

There have been some problems in setting up the New Neighbours programme:

> There is still a complete split in the funding between the hospitals and the community systems. The resources of the institutions are not available to community programmes.
>
> Coordination of community placements needs to be carried out in one place with one clear focus of responsibility. At present responsibilities are diffused.
>
> The organisation and management of community services for mentally handicapped people is banded together systematically with responsibility for services to people with mental illness. This leads to confusion - and to the continued domination of the medical model.
>
> The parent movement has lost impetus and there is polarisation in the community where some people are feeling that money spent on bringing people out of institutions should have been spent on services for people already living in the community.

> Changes in the governorship of the State could place community programmes in a vulnerable position as a new Governor may not necessarily support deinstitutionalisation moves.

Despite these problems, Ed Skarnulis is obviously determined to initiate the same sort of community programmes that he helped to develop with ENCOR in Nebraska. He is hiring a training coordinator who will act as a 'normalisation proseltyser' and will educate staff and the wider community in a real understanding of normalisation and the implications for services.

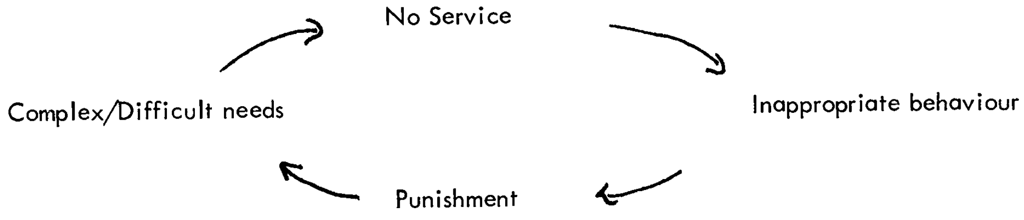
One of the future problems may be lack of funding and to forestall possible difficulties, a consultant has also been hired who will be examining the different ways that community services can be funded. This is an important move at a time when budgets are seriously threatened in many parts of the United States.

## 'Who's Left in the Institutions and Why They Shouldn't Be - the Behaviourally Challenging'

John McGee, University of Nebraska Medical Center.

These two sessions on the final day of the conference were concentrating less on broad policy issues and systemic changes involved in deinstitutionalisation, and more on the practical aspects of how we enable people with severe behaviour disorders or major physical handicaps to exercise their right to live in non-institutional forms of care. It is true to say that these two 'groups' of people have probably suffered more than others at the hands of institutional systems of care.

John McGee opened his presentation by reminding the conference that people with severe behaviour difficulties tend to receive some of the poorest services and can be the most vulnerable to abuse. He described the 'cycle of despair' which commonly operates and heavily reduces people's chances or receiving the help they need:



There is currently a great deal of controversy in the United States as to how people with severe behaviour problems should be served. There is a strong lobby which challenges the assumption that all mentally handicapped people, no matter what their problems are, should have the chance to live in non-institutionalised settings with appropriate help and support. They:

> Would disagree with the view that everyone is capable of some development, no matter how severe their handicap;
>
> assume that 'community care' means fewer services and less protection for the handicapped person;
>
> assume that difficult behaviour and other problems must be the 'fault' of the handicapped person rather than perhaps being(in part) due to the inappropratseness of the services they are receiving - or the absence of services;
>
> deny the rights of handicapped people to receive services on an individual basis to meet their individual needs;
>
> assume that people with severe behaviour difficulties must be happier living in institutions than in the community;

As a result there are some moves back to the provision of services in the institutional settings with an 'enriched environment'. Those who support these moves contend that the costs of providing services in community settings for people with special needs are too high and that institutions can be the least restrictive setting for people with disturbed behaviour.

In the state of Nebraska where John McGee works there are 830 people living in long-stay mental handicap hospitals of whom 50 are labelled as having 'severe behaviour problems'. They may display one or more of the following behaviours: self-abusive, aggresive towards others, bizarre, repetitive or avoidant. Many have severe problems in communicating with those around them.

John McGee went on to describe his method of working with these very severely disturbed individuals. His work had, he said, three main goals: to help people achieve control over the undesirable behaviours, to increase self-control and to enable them to enjoy increased participation in community life. His approach was a two-fold one which tried to combine a broadly behaviourist line (for example, positively reinforcing desired behaviours) with a 'humanistic'line where respect and acceptance of the handicapped person.

For those working directly with disturbed mentally handicapped people, John McGee had the following points to make, arising from his own work:

> If someone is displaying unwanted behaviour avoid eye contact with them; (but if someone goes to hit you it's a good idea to just put your hands up to ward off unwanted blows).
>
> Reinforce even the most mildly appropriate behaviour and wait in silence if someone displays inappropriate behaviour.
>
> Give plenty of cues: if someone you are trying to work with won't come near you - go over and touch them or give them some other physical cue.
>
> Provide plenty of physical and verbal assistance which will aid communication and lessen the handicapped person's dysfunction and 'disconnectedness'.
>
> Key in on 'precursor' behaviour most people will give some sort of cues before an outburst; remove your demands on them if you see an outburst coming on; wait; return to the tasks later.

In his experience, John McGee said, people will tend to show some changes after about two to four months; they will begin to show some contact with those around them and their behaviour and general appearance will be less bizarre.

For those involved in setting up services and programmes which are for disturbed handicapped people John McGee had some advice:

> There is a need for structure in this sort of work even if the work itself - two people spending time daily in a room together - is perceived as very informal.
>
> There must be scheduling so that this sort of work is not done on an ad hoc basis.
>
> Consistency of staffing is very important to minimise the 'disconnectednes' that these people are experiencing.
>
> Staffing intensity should ideally be 1 to 1 and whilst this may be needed for the first few months it should be possible to adjust this ratio later.
>
> It is important for back-up to be provided for residential staff working with very disturbed people.
>
> There should be as much parental involvement as possible

NOTE: Obviously in the time made available to him John McGee was only able to sketch in very broadly his approach to this work. I have a copy of a paper he wrote on this subject: Persons with severe mental retardation and behavioural challenges; from disconnectedness to human engagement. I will be glad to make photocopies available for a small charge. (The paper is 24 pages long and was written in 1981).

## 'Who's Left in the Institutions and Why they Shouldn't Be: the Medically Fragile'

Karen Green, Boston, Massachusetts

Karen Green opened her presentation by showing two slides - a 'before' and an 'after' of a young woman with severe physical and mental handicaps. It illustrates very clearly how with appropriate help a person can change from looking twisted, bizarre and probably feeling very uncomfortable to being a very presentable and comfortable young lady.

Multiply handicapped people in institutional care are subject to a great deal of physical, if unintentional, 'abuse', for example with inappropriate use of the floor. Instead of providing people with proper chairs and good support we have often moved them from bed to beanbag on the floor or onto cushions.

Karen Green described how sometimes inappropriate handling of physically handicapped people can not only be uncomfortable or even painful for them, but can actually disable them further. In order to combat this and to provide help for staff working in remote or dispersed settings she has prepared a booklet which will help those caring for physically handicapped people to handle them correctly and minimise their discomfort.

People who have physical as well as mental handicaps or are medically fragile are often the subject of a great deal of pity from those around them. This may seem quite reasonable but the 'pity' image can deflect attention from the notion that people with these difficulties have to *work* to acquire skills and abilities. Pity can end up supporting people where they are at - not where they might be - and it excuses the handicapped person from working to become more able.

Continuing the theme of images, it was important, Karen Green said, to do everything possible to ensure that physically handicapped people presented in as positive a way as possible to minimise their deficits. This meant paying attention to clothes so that people are attractively and appropriately dressed, making sure that chairs and other aids are doing a good job for the particular individual, and above all, avoiding congregate settings so that the non-handicapped person is not confronted with a large number of people who look *very* different when viewed as a whole but who viewed as individuals would seem less *so.*

The fact that people acquire such as 'fragile' is highly dangerous. Many people who have multiple handicaps and lived for years in long-stay institutions like Willowbrook must be reasonably tough to have survived the appalling conditions in many of these places.

Minimising turnover of direct care staff is as important for physically handicapped people as it is for behaviourally disturbed mentally handicapped people. Frequent staff changes can result in the same 'disconnectedness' described by John McGee in the previous presentation.

Good access to adaptive services is extremely important in providing services to multiply handicapped people. Many people will require special custom-built work to their wheelchairs and other aids. Massachusetts is still one of the only states that has a proper individualised service for adaptive equipment.

Finally - a general point. Professionals must be aware of the importance of advocating for the people they work with and for. They must help parents to become more skilled advocates too. Professionals should not only be involved in the strictly 'professional' aspects of their work (as psychologists, social workers, etc) but should be aware of the political and economic dimensions too.

## Some General Thoughts on the Conference

The conference provided an outstanding opportunity to gather together in one place for a few days with people from a very wide area to hear about many of the very exciting things which are happening in different parts of the United States. The presentations I have described in this report give some flavour of this - and I was only attending a small part of the whole event'.

Although TASH could be criticised for trying to pack too much into three days it did give people choices to listen to what interested them, to avoid things they weren't interested in and not just to sit there feeling uptight that the conference wasn't doing what they wanted.

The success of many of the good services I heard about was due in part to one common factor. The people who had set up and were running these services had done so with an explicit and coherent ideology. They weren't doing it 'because services have to be provided' or 'because mentally handicapped people need to be cared for'. In many cases they were trying to realise what normalisation is saying about the way we meet the needs of people with handicaps.

I don't think it's just a cultural difference but it was good to hear so many people stand up and speak unashamedly about their values, about their beliefs that mentally handicapped people are valued citizens too, that they shouldn't have to win their way out of institutions by proving they have acquired certain skills.

As a get-together the TASH conference provided an opportunity for people who shared the same beliefs and values to be together and to get strength from that solidarity. Initiatives like Operation Real Rights were building on that solidarity by asking people to take the next step and become active as a political coalition in the community - to fight to ensure that mentally handicapped people got a better deal.

Many of the people I spoke to were grateful to have the time away from their offices or services (as I was!) and I felt that the conference was a real renewal opportunity when they could meet people from other areas and stand back and take a more distanced look at their own work.

I often sense that conferences in England are seen by participants as a renewal which is equivalent to a rest. TASH worked people hard and although no sessions were 'compulsory' going at 8am for those who wished and there were no scheduled meal breaks - just brief gaps for a dash to the coffee shop for a bagel....!

On a show of hands, the majority of people had come to TASH under their own steam and at their own expense. Few people had been sent by their authorities. It was good to see so many people motivated to attend but perhaps that was because they got as much out of it as I did.

Alison Wertheimer
Campaign for Mentally Handicapped People

# APPENDIX

## Names and Addresses of conference speakers:

Doug Bicklen,
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Syracuse University,
New York, NY 13210

Burton Blatt,
106 Cedar Heights Drive,
Jamesville, NY 13078

Gunnar Dybwad,
Heller Graduate School for Social Welfare,
Brandeis University,
Waltham, Mass. 02154.

Karen Green,
c/o Camie Allen,
4th Floor, 160 N. Washington,
Boston, Mass 02114

William Jones,
Belchertown State School,
Belchertown, Mass.

Frank Laski,
Public Interest Law Center,
1315 Walnut Street 16th Pl.,
Philadelphia, Pa.19107.

Gerald Leismer,
Deputy Master Office,
15480 Sheldon Road,
Northville, Mi 48167.

John McGee,
Meyer Children's Rehabilitation Institute,
University of Nebraska Medical Center,
444 South 44th Street,
Omaha Ne.68131.

Tom Nerney,
Connecticut ARC,
15 High Street, Hartford, Ct 06103.

Irene Powell,
Residential Services Inc.,
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Ed Skarnulis,
Director,
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for Mental Retardation,
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## APPENDIX

### Conference Programme

#### 15 October 1981

'Fighting the Deinstitutionalisation Backlash', Burton Blatt.

'The Politics and Economics of Deinstitutionalisation', Doug Bicklen and Gunnar Dybwad.

'Launch of Operation Real Rights', Tom Nerney and Frank Laski.

#### 16 October 1981

'The Impact of the Pennhurst Case', Frank Laski

'Deinstitutionalisation in Michigan: Homecomings for Persons with Severe and Profound Mental Retardation', Geral Leismer.

'Serving the Severely Handicapped in the Community: Emerging Models', William Jones, Irene Powell and Edward Skarnulis.

#### 17 October 1981

'Who's Left in the Institutions and Why they shouldn't be there: the Behaviourally Challenging'. John McGee.

'Who's Left in the Institutions and Why they shouldn't be there: the medically fragile', Karen Green.