ASSESSMENT AND SETTING STANDARDS

A Paper given by Dr. Nan Carle
At a BIMH Conference on 30 March 1983

'BEYOND INQUIRIES - IS THERE A BETTER WAY TO IMPROVE SERVICES FOR PEOPLE WHO ARE MENTALLY HANDICAPPED

Introduction

I come to you today as an outsider on two accounts. First because I have only lived in this country for four years, and second, because all my experience and energy has been directed to developing community services. However, I do not develop community services without concern for those people living in hospitals. Rather it is because of the hospital setting that I am concerned with creating alternatives.

In discussing enquiries, most people would say that they should have never happened; either because things should have never become that bad in the first place or because, even if they were that bad, the inquirie method is expensive and has minimal impact on the institution that has been investigated.

I had the opportunity to visit a hospital that had undergone an enquiry several years earlier. I was invited to give the Hospital Management Team advice on how well they were implementing some new ideas, especiallyas they compared to the principle of normalisation. I spent a full day and a half getting to know one woman. Among other things I found that the sum total of her possessions included:

1 large plastic chess piece
3 dirty combs
1 ceramic bird
1 skipping rope
3 colouring books

This woman was aged 36 years and had lived in the hospital for about 30 years. In comparison to the rest of us, no matter our financial situation, her belongings did not allow her much of a personal history.

A colleague of mine who has chaired two inquiries, talks about going back to one of the hospitals several years later. When he met the staff they were very excited that the residents now have their own locked wardrobes. However, when he was invited to look inside he found there was nothing in them! This is the same in many institutions. Sometimes there are no hangers and the clothes lie in a heap on the floor. Then we wonder why people are not neatly dressed. Or perhaps the ward sister keeps all the keys. She is the 'keeper of the Keys', the one with the power.

There does not appear to be as much noticeable physical force being used, but there are other more subtle ways of being cruel, such as over-protection and the lack of on-going human contact. Both are forms of making sure that a person does not have the opportunity to develop as a growing human being.

I am always surprised when driving through a hospital after dark and I meet no-one except a few other people in cars - who usually are not residents. It amazes me too that one can come to work in a hospital and rarely have direct eyeball to eyeball contact with a person who is mentally handicapped - this is true not only of psychologists, social workers, administrators and doctors who have offices away from the wards, but also of the ward staff themselves. The offices and the activities are often strategically placed so that the staff can see or hear everything from the office itself. Clearly there are a lot of people whose skills are lost or whose skills are just not developed, and people here include staff as well as residents.

THE BROADER CONTEXT

When we think about what the real impact inquiries have had on the lives of people in hospitals, the question might be posed "would NIMROD have happened if it had not been for the Ely Inquiry?". Or "would the multi-disciplinary approach and the community mental handicap team in Teddington have happened without the Normansfield Inquiry?".

Were these ideas not around at the time waiting to be implemented?

If we look at other things happening in the field of mental handicap, in 1970 just after the Ely Inquiry, the Education Act was passed, bringing all children, regardless of their handicap into the education system. In 1978, the same year as the Normansfield Inquiry hit the HMSO bookstand, so did the Warnock Report suggesting that local authorities think about bringing handicapped children into ordinary schools and not isolating them in special schools. Certainly these reports represent very conflicting ideas and practices. A clash seems inevitable.

I think it is important to look at the wider context of which inquiries are a part, and I would like to share with you some work I participated in last September in the North West. John O'Brien led us through a two and a half day planning session that was based on Eric Trist's concept of a Search Conference. The Search Conference idea was begun at the Tavistock in the early '70s. The ideas spread to Australia, developed there and then to North America. It is now once again being used in this country.

This two and a half day session was called 'The Future for People in Mental Handicap Hospitals in the NW Region'. 'People' was defined as including residents and staff and families. It was a small group with representatives from five hospitals, social services, psychology, voluntary organisations and one DMT member, the finance Officer. The agenda looked like this : (fig.1)

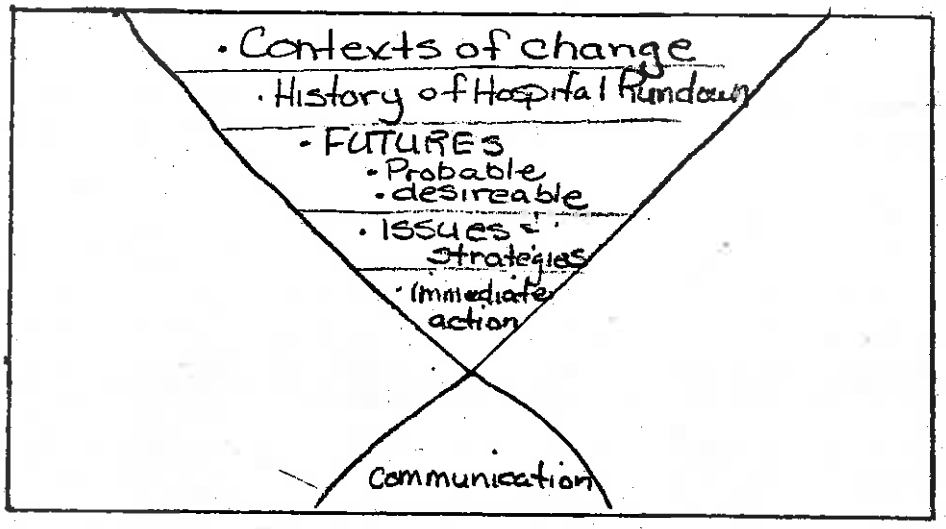
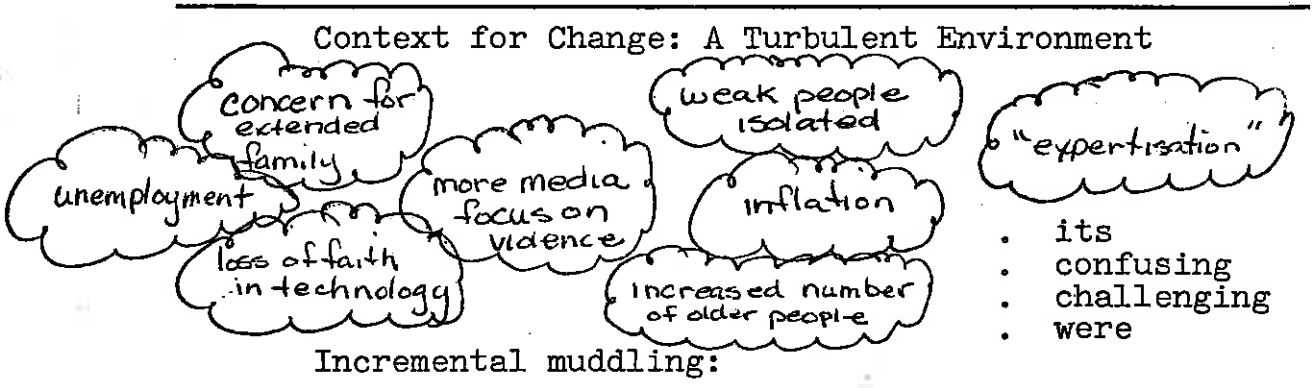


Fig.1. The Future of People in Mental Handicap Hospitals: 'People' means residents, staff and families.

We spent a great deal of time considering changes that had happened in the North West (Fig.2)



We spent a great deal of time considering changes that had happened in the North West. We considered dynamics such as the change in the extended family - more people are living on their own and growing older without help. Over the last 10 - 15 years the media has focussed more on violence, giving us a real picture of what war is like, war on a grand scale and on a street level as well. We see that weak people have become isolated, older people and handicapped people, vulnerable people in general, living apart from the rest of society. We hear words like 'abortion' and 'euthanasia' is 'all for the best'. We considered the importance of unemployment in the North West and the loss of faith in technology. Technology does not always help in the ways that we once hoped. Inflation was certainly a major theme, and it was not because the financial officer was present! We felt uncertainty in our own future, both financially and personally; not knowing quite what to predict and what to depend on in this age of rapid change.

We felt the turbulence that we are in when we discussed our response to these forces. We characterised it as a type of 'incremental muddling' - Muddling through as a way of coping with conflicting policies. It seemed an unhelpful way of finding real and adequate solutions to very real problems.

In some ways it felt like we were just blindly putting one foot in front of the other. To be sure this turbulence was a live, confusing, complex, challenging and we are in it!

The things that we did feel optimistic about were embryonic and included small things. small businesses, a re-discovery in craftmanship, a greater consciousness of trends, a sense of patterns in what was happening and individual relationships. I tended to take somewhat of a back seat in this discussion as I live in another part of the country and come from another part of the world. However, although the details were different about these concerns, there were common features in these basic dynamics whether one lives in London or the United States.

After we had considered these patterns of change those present at the discussion split into groups, where people considered the history as it related specifically to their own hospitals or geographic area. Although many of the hospitals are quite isolated it was interesting to see how certain reports and pieces of legislation had affected them. The Inquiries, the Warnock Report, An Ordinary Life, the Jay Report, the Salmon Report; all had their impact, either because of the fear that people felt or because they felt the ideas expressed were useful, and in their own ways according to their own situations they had tried to implement some of these ideas or some of these fears. It was also interesting to see how their history affected each other. When in the late 50s one hospital decided they wanted to open up the institution to the outside world, to let people in and to let people out, they took down the railings surrounding the hospital grounds. They took down the railings and sold them to the mental handicap hospital just down the road.

THE FUTURES WE ARE IN

When we sat back to look at the pattern of events and to discuss the future, we talked first of probable futures, what was likely to happen if things went on as they are. We looked at the resources available, the plans being made, and the relationships between agencies, particularly health and social services. The one comment that struck me most was that of developing -

'Five Star Asylums'

The group that discussed this had a member who had been through an official GNC visit, which had its own set of ramifications. The cycle predicted looked like this (fig.3).

'Five Star Asylums'

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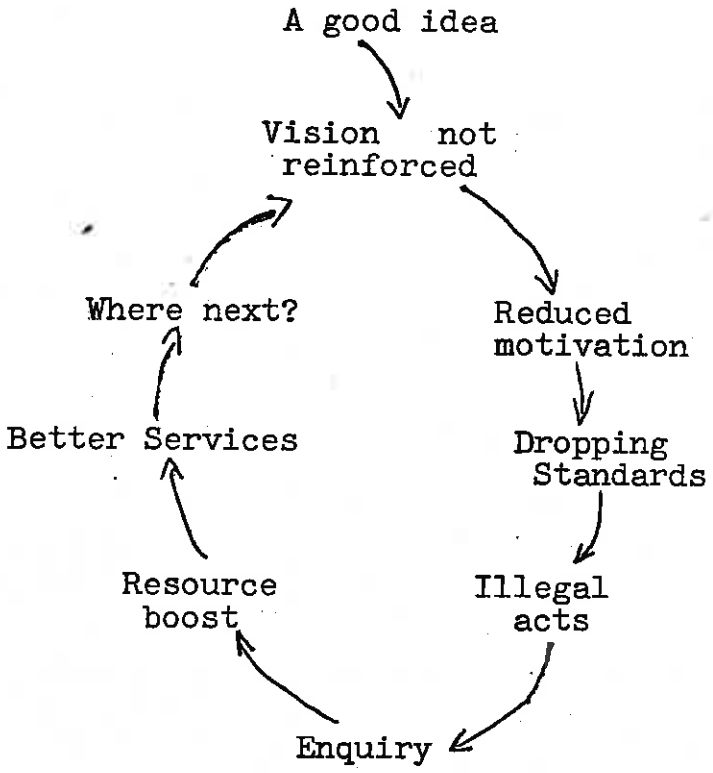


Figure 3. The probable future

It was felt that the people involved had a good idea - to teach somebody a new skill, or to bring in more volunteers or to spend more time with one of the residents, or to move a few people out into the community. For one reason or another this good idea or this vision was not reinforced. Either the length of time between thinking about an idea and actually being able to implement it was so long that it changed drastically, so that they were not even sure what the idea had been in the first place; or because they just met with too many obstacles.

When staff did have a good idea, often it was not used and they became dispirited - motivation dropped. I think that psychologists would bear this one out that we are not helped to feel positive about what we plan or do when we are not encouraged to try new things or to improve the situation. Sometimes this leads to a dropping of standards. People do just exactly what is expected of them - no more and sometimes less. When we feel less motivation it does not really matter if we spend more time talking to other staff in the office or if we do not spend time actively engaged with the residents. It is felt that we have no control over events.

Sometimes this leads to illegal acts; illegal acts would at one time be defined as physical cruelty. Perhaps now we should think about some of the more subtle ways of being cruel. The use of illegal treatment often led to enquiries where there was big public exposure of what was going on. These enquiries all led to a resource boost, which in, and of, themselves led to better services of a sort. New buildings were built, walls were painted, new people were employed. However they had not hit the structural difficulties of the situation, and over time they began to wonder where do we go next. Often the resources they got to make the services better were difficult to keep. They had to fight very hard not to be left out - "you already had enough!" Where next? The vision is not reinforced.

We can say with some certainty that hospitals havenot set out to hire bad staff, nor do people set out to do a job with the intention of hurting other people, or with the intention of doing less than their very best. The group of people looking at the pattems of hospital service worried very much that the cycle could continue forever. Unless

some very fundamental changes took place, throwing money at the problem or hiring new people would not make a permanent break in the cycle that we are in.

In the inquiries that I have read, or heard discussed, there are a number of common themes. It is not any one thing that sets up an institution for inquiry, it seems to be a combination of the following ingredients : (fig. 4)

COMMON THEMES :

* There is a lack of policy for treatment
* There is a lack of leadership - a good deal of 'buck passing' — demoralised staff
* Doctors are unwilling to work in a multi-disciplinary approach
* There is an unacceptable standard of care for many patients — care is custodial in nature
* Mistreatment and malpractice occur
* There is an inadequate level of health care and medication is not regularly reviewed

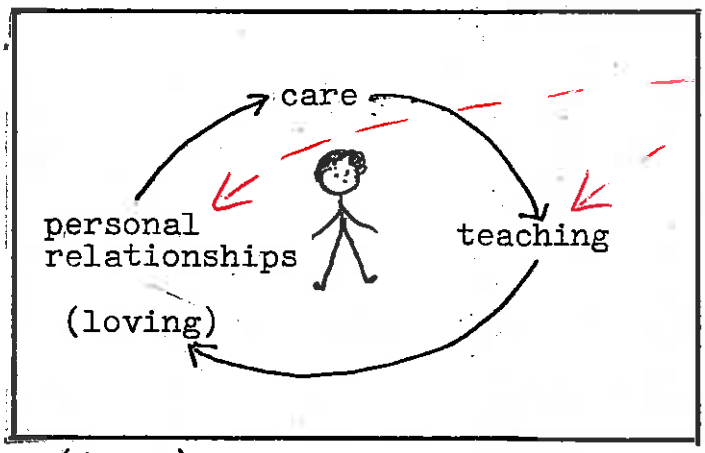
(Fig.4)

It is considered that there is a lack of clearly defined policy and purpose for treatment. No one is quite sure what they are working towards, or how do they know when they have done a good job. There seems to be no standard againstwhich they can judge their own performance as well as the performance of the hospital as a whole. There seem to be conflicting opinions about what they are training people for - institutional life or for life in the community.

Certainly one major theme in the enquiries is lack of leadership. There is a great deal of 'buck passing' with no one person or no one group taking responsibility. There are often times when no one seems to be in charge, no one seems to be leading and things just happen. It is always someone elses fault. It is often said that staff do not feel that they have any control over the situation, nor do they feel that they have the ability to make any difference in peoples lives. They do not want to get too close to any of the residents because others will suffer.

Another theme certainly is that of the doctor's role in the administration of the service. It is often said that doctors are unwilling to work in a multi-disciplinary approach. They frequently make decisions on their own, without consulting or informing other people involved. It might be fair to say that the doctors are trained for split second decision making; they have to respond to immediate situations, in surgery or in the mending of bones, or the mending of hearts. Their very training does not lend itself to working as a member of a team or in a management position. They often have been placed in these roles because of their titles without regard to their skills in management and administration.

It is also said that there is an unacceptable standard of care for many patients. The care is most often custodial in nature. The triad of good nursing, that of caring, teaching and loving, seems to break down at the "care" position. (Figure 5) So much time is spent on the daily routine of helping people to eat, to dress, to bathe, to get into bed, to get out of bed, and so forth, that there is little time and energy left to encourage an individual to develop new skills.



without these two ingredients simultaneously occuring with 'care', enquiries are likely to continue .....

(Fig 5)

There is very little time for real affection as it becomes easier to do things for the person. The three components of the nursing triad tend not to happen at once. In order that individual bodily functions can be taken care of, they lose out on learning to do things for themselves, and on physical contact - that human contact that is so necessary for personal growth. Without the attention to skill acquisition and personal contact it becomes easier to mistreat an individual, or to treat the resident as a 'charge' as opposed to a person or a friend. Thus in the reports we read of mistreatment and malpractice in hospital situations.

The inadequate level of health care and medication is a theme that continues to concern me. When one goes into a hospital the very least one would expect is that they would have good physical, medical and dental care. People often sit in wheelchairs in uncomfortable positions or their teeth either rot or are all taken out making speech even more difficult. When we take people out of hospital in our Region we will find that we will regularly be using the general practitioner's skills - not to mention the skills of the dentist.

A Case for Ideal Standards

When we begin to consider what a more desirable future would look like for mentally handicapped people, their families and the people who serve them, we must find ways of breaking into the cycle of hospital care. We must break into the structure, the very foundation of the way our services are provided. It is helpful to remember this quote by Eric Trist.

> "Only when what ought to be done has been considered and a general direction set can questions of what will be done (strategies) and what can be done (operations) be usefully addressed."

I should like to propose that we establish what our ideal standards should be. We must get away from merely establishing minimal standards as a way of thinking about what we are trying to accomplish and where we are going. If we know what we are trying to achieve, then we are much more likely to find ourselves on the right course. There is an old Alice in Wonderland proverb: "If you don't know where you are going it doesn't matter which way you go." Minimal standards give us nothing to brag about and no information about the whole of the service. Ideal standards on the other hand can assist us in two ways:

1. To help us maintain continuity in direction and a cohesiveness in our actions. They help when we want to choose another objective after we have achieved the first, or if we have failed it helps us establish another objective.

2. To help us in times of compromise to know what we can sacrifice in a manner that is consistent with what we are trying to do.

I find this particularly important in the development of community services, to understand the implications of the compromise that we have to make, and we certainly have to make compromises! It is helpful to me to be able to determine the difference between compromising and just plain selling out. It also helps me determine who my allies are.

Thriving for ideal standards give us something to always look forward to. They give us information that is developmental in nature in that we are helped to know what the next step should be. They also give us assistance in steering a course in the environment that is so turbulent. If we think about the ideal of fairness; fairness is something we can never truly achieve, but is somthing that we strive for, something that guides our responses and our actions. Fairness is a very helpful gauge against which we can judge our actions.

The set of ideal accomplishments that I should like to put forth as guides for developing services for people with mental handicap have been developed by John O'Brien and include:

Personal continuity
Community presence
Community participation
Promotion of individual interests
Continuous growth and development
A positive reputation

Personal Continuity Personal continuity includes allowing people to maintain their history and to experience continuity across time. This means making sure that people get to stay near their family and friends. It also includes acknowledging a person's past, and not to deny it. For example, when they took some children out of one hospital they did not allow any of the individual records to go with that person into the community. This meant for all practical purposes their lives did not exist before that time. Staff and friends had no way of knowing anything about them before they met. For people who could not speak very well it meant there was no way to know who they might miss. It is important that we allow an individual to have their past as well as their future.

Community Presence Community presence means making sure that we bring back into the community people who have been sent away - all people regardless of the severity or nature of their handicap. There is a place for everyone and not just for some people whose needs are not as complex. We should locate our services in natural ordinary settings, not in specialised large group homes nor large group day services.

It means that we should use those services used by the general public. We also need to make sure that services are local and are dispersed across a given area. We must not congregate services in specific settings or with all other groups of people receiving special services and then wonder why the public at large does not accept people with mental handicaps.

Community Participation

Being present in the community is only half the battle. It is, however, the pre-condition for participating in community life. We as professionals should enable mentally handicapped people to have relationships with people who are not handicapped and are not paid to be in their lives. For example, volunteers may volunteer to be with just one person. It is only in this way that each individual has the opportunity to receive the human contact that develops our humaness and our uniqueness. We also want to make sure that we remember that the general public is more likely to become involved with specific individuals or with small groups, than they are with large groups. When we go on holidays and go into a pub, how many people have we taken in and how have the staff interacted with the people they are with? We cannot expect, to gain acceptance without realising our own roles in setting and reinforcing the attitude of the community.

Promotion of Individual Interests

We must also learn how to promote the interest of each individual and this includes those people who are very seriously handicapped, and who may currently be spending most of their time on bean bags. By sitting down and spending time with people we can find out a great deal more than we may have thought possible. A woman I met in an institution not long ago was said to have no skills and no interests whatsoever. However, as I sat with her, when Coronation Street came on TV I found that she hummed to the theme song; which meant that she did enjoy things that were familiar to her, and there was something here to build on. She could imitate sounds and actions. We must also find ways of resolving conflict. The very notion of conflict means that there are two voices speaking, and not just one. Although that may cause us grief it certainly is more healthy in the long run. People with handicaps have rights too. We must find ways of including the consumer and their families in what is happening to them.

Continuous Growth and Development

Continuous growth and development includes making sure that we realise that it is not just an increase in skills that we are after, but also a greater number of experiences and relationships for each person. When we think about what has contributed to our own personal and professional development it is these three areas that assist us. It is not just our

skills but our relationships which support us or encourage us to move ahead and it is our experiences that help to increase our awareness and understanding of the world about us. Thatcher, as Secretary of State for Education and Science said in 1971 that all stages of development should be considered temporary and that everyone has the potential to learn new skills and develop new characteristics.

A Positive Reputation

A positive reputation is an important issue especially when considering inquiries. Because inquiries have so much impact on public attitudes, we must realise our own roles in assistanting mentally handicapped people to be viewed in a positive way. It is important that we create ways in which adults who are mentally handicaps can have skills, experiences and relationships that are appropriate to their age. We cannot let the concept of "mental age" become an excuse to stop a persons progression into adulthood. The environment and behaviours that surround people with mental handicap says to me much more about the staff than about the individual with the handicap.

Evaluating Ideal Standards

In some work that I have done for Lewisham and North Southwark Health Authority I have taken these six accomplishments, discussed each one and broken it down into a series of questions. For each question I have suggested ways in which it relates to the performance of staff, and to the service as a whole. There is no point in evaluating staff performance without looking at the situations in which they operate that allows them to take risks or not. An example of the accomplishment, "promotion of individual interest and protection of rights" includes working toward:

- Including consumers and their families in decision making
- Assisting people to define their own personal interests
- Creating procedures for resolving conflicts
- Ensuring people have needed personal representation
- Guaranteeing access to education, medical care or other entitlements

The questions about this accomplishment include:

- What happens differently for each person?
- In what ways are individual preferences reflected?
- What are the options for consumers to change what is happening to them?

. How can the interactions between consumers and staff be described?

. How are all individuals helped to advocate for their own rights and interests, including those people who are the most substantially handicapped?

When we come to assessing the situation there are four components which needs to be considered (Figure 6.) Whether we are talking about individuals or groups we must consider <u>who</u> it is, what the strength and needs are, <u>what the goals</u> are that we have chosen to work on, how we intend to accomplish those goals, and <u>who</u> is going to do it? Each of those components is directly related to these six accomplishments, When we are talking about assessing the person's strengths and needs we must indicate what their experiences have been with regard to developing their own interests, with regard to living and participating in the community, acquisition of skills and opportunity for experiences, the status and reputation and with regard to continuity of life experiences.

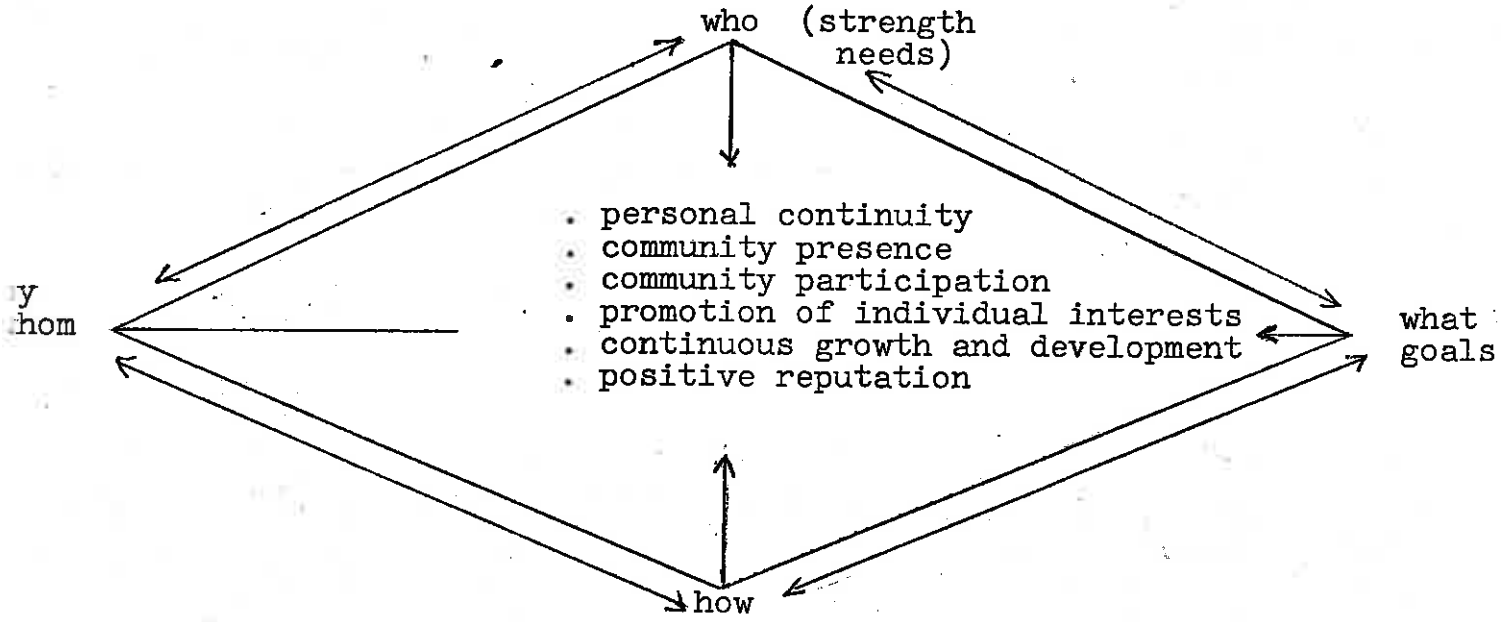


Fig. 6 <u>Components of assessment</u>

The same ideas must be included when we are talking about the goals, the strategy and who is going to do it.

When I was teaching teachers, I had one student who was working with a group of six women who were labelled severely mentally handicapped. Her goal plan for the six week period was to teach these women the four basic food groups. I asked her how the four basic food groups were relevant to their daily lives. I suggested that it might be more to their advantage to think about ways of helping them prepare more of their own food, whether that included spreading butter on bread, making a sandwich, and so forth. She and I had many battles over that six weeks and she ended up not being a teacher. Not because of anything that I said or did, but because she was not interested in what was best for the women she was teaching. She was more interested in what kind of things she enjoyed doing, and not what these women were interested in. Fair enough, but I am pleased that she left education.

If we are going to enable ideal standards to break into the futility that is often felt by members of staff and by handicapped people themselves, then we must make sure that setting standards and assessing them is something that is seen to be done by everyone and not just by other people. Standards must be stated in ways that are relevant to each person concerned. If we are going to seriously consider continuous and adaptive planning according to ideal standards, then we must be aware that we must be engaged in:

1) frequent modification

2) participation of all stakeholders

3) input from all levels

4) co-ordination and interdependence.

In one area of the country the director of social services and his senior managers put out a paper saying what their values are, and what the standards should be in services for people who are handicapped. They sent them to all groups in the organisation and asked them to re-state them in ways that were relevant to their own situations. This gave them room for negotiation, it gave all the groups a way to plan and judge their soundness and feasibility and gave everybody a part in planning and assessing the quality of the service.

The first instance then, is to establish who the stake holders are; some of these people will include the handicapped persons themselves, their families, the direct service staff, psychologists, social workers, doctors, remedial professions, and so forth. They must define how standards apply to their own situations and how they can be used.

A second way is to set up review teams, both internal and external, to look at the function of services and/or to look at the performance of staff in enabling mentally handicapped people to participate in their local neighbourhoods.

A third way is to use PASS: an instrument called Programme Analysis of Service Systems (Wolfensburgh and Glenn 1975). This is a system that is used by trained people and is an excellent tool for measuring the quality of service that is being provided. Also it is an extremely useful tool for both staff development and for planning.

There are 50 ratings which give 50 different views of the service. One rating, model coherency, takes an overall view of how well the service is meeting the needs of its consumers. These 50 ratings and the six accomplishments briefly discussed here show many common elements. Some of you may already be familiar with PASS Workshops which are held several times a year sponsored by Community and Mental Handicap Education and Research Association (CMHERA).

Each of these ways of looking at ideal standards and accomplishments can help us achieve a more effective service; a service that does not include poor treatment, poor leadership, demoralised staff, misuse of finances and a lack of a clear vision that what we are involved in is the creation of a lifestyle for 1,000's of people.

Here's to no more enquiries.

NC/PF