

Community Integration: Much More Than “Being There”

**Bob Jackson
Edith Cowan University**

Dr Bob Jackson
Centre for Disability Research and Development
Edith Cowan University
JOONDALUP WA 6027

Phone: (08) 9400 5658
Fax: (08) 9400 5657
email: r.jackson@cowan.edu.au

**Paper delivered at the Annual Conference of the Australian Society for the Study of
Intellectual Disability, Brisbane, September 1997**

ABSTRACT

Despite overwhelming support from legislation and policy in the disability field for integration, much of the community involvement that is occurring owes more to a “place and pray” approach rather than a systematic attempt to investigate key variables involved. In this paper, an attempt is made to delineate some likely key variables with a view to providing a structure for considering community integration. This analysis indicates that community integration is complex and multifaceted and occurs within an environment of societal rejection that has persisted for centuries. In this context it is apparent that service agencies will need to rethink their integration practices if real community integration is to occur. It is concluded that the best strategies may be in the support of community members or providing a catalyst for bringing together those elements that seem to be central to community inclusion.

Introduction

Over the last three decades in Australia there has been a major move into community housing for people with an intellectual disability. It is now generally accepted that institutional living is harmful and a more community based residential option is required. While there has been some retreat to larger duplexes and cluster housing and even some retreat from institutional reform, there seems little argument in the field that community residence is to be preferred. Certainly the environmental quality and skills gained in small community houses has been found to be superior to institutional or hospital environments which bears out the move to the smaller community based accommodation (Felce, 1985; Felce, de-Kock, & Repp, 1986; Flynn, LaPointe, Wolfensberger, & Thomas, 1991; O'Neil, Brown, Gordon, & Schonhorn, 1985). Storey, (1987) argues that research studies show that people with handicaps can learn to interact appropriately in community settings. However, one of the hopes held for the move to the community was that people with an intellectual disability would develop relationships in their local community and go on to develop what could come close to an ordinary life.

The reality is that this is rare. People in group homes or units are often isolated and lonely with little other than superficial community contact through shopping or occasional recreation (Donegan & Potts, 1988). Even so, it appears that they do have a significantly higher rate of community interactions than those living in larger units (Ballinger, 1993), although this may be largely due to the administrative practices of the agency involved (Sinson, 1994). To try and encourage increased community participation numerous "integration programs" have been developed by service agencies. While there are some very encouraging stories to come out of these efforts, overall it would have to be said that the outcome has fallen far short of the vision.

The Literature

Surprisingly there is not a huge amount of literature on successful community integration although there is a considerable body of literature on the development of relationships in inclusive education. The literature is equivocal on presence in a social milieu being sufficient to promote relationships occurring. Baker & Salon, (1986) describe major behavioural changes resulting from even a short time in a community setting for people with significant intellectual and multiple disabilities. Condon, York, & Heal, (1986) surveyed over 500 students at two schools, one with several special classes. They found that older students and girls were more positive about interaction than boys, but this acceptance dissipated when contact between

handicapped and nonhandicapped students ceased. Similar results were reported by (Townsend, Wilton, & Vakilrad, 1993). Gilkey & Zetlin, (1987) noted differences in interaction patterns between handicapped and nonhandicapped children in a school setting depending on the formality of the situation, but overall reported very low levels of interaction. Guralnick, (1984) notes that mainstreaming by itself has minimal effects on social interaction between handicapped and non-handicapped children. Gottlieb, (1982) and Gresham, (1982) argue that there is little advantage in inclusive classrooms and that children with a mild disability continue to experience social rejection in such settings and do not model the appropriate social behaviours of their nonhandicapped peers. Sabornie, (1985) draws similar conclusions about the reality of school inclusion for many handicapped children and argues the need to consider social acceptance in their education.

Brinker and his colleagues (Brinker, 1983; Brinker, 1985; Brinker & Thorpe, 1983; Brinker & Thorpe, 1984; Brinker & Thorpe, 1986) found interactions to occur spontaneously in inclusive school settings to a greater degree than in segregated settings and the response to social bids from the more severely handicapped was greater than from students with lesser handicaps. They saw several factors in the administrative and social environment affecting the rate of interaction, but the largest factor was the social behaviour of the nonhandicapped children (Brinker & Thorpe, 1986). Cole and colleagues (Cole, 1986; Cole, Vandercook, & Rynders, 1987) found that the teacher intervention was important in establishing social play behaviours but that this impact decreased over time, leading them to conclude that the teacher intervention should be withdrawn over time to allow children to sort it out for themselves. Accepting or rejecting attitudes and the method of presentation of the children with disabilities to the class have been shown to markedly affect how they are perceived and reacted to (Bak & Siperstein, 1987; Forlin & Cole, 1994; Gilmore & Farina, 1989; Sasso, 1985). Slee & Cook (1994) argue that the very method of describing disability as a pathology is a very powerful means used by schools to control funding but at a considerable cost to the image of the children themselves. Organisation of the physical environment has also been proposed as an important factor in the inclusion of people with disabilities (Law, 1992; Law & Dunn, 1993; Peters, 1990).

Field (1984) showed that intellectually handicapped children did make friends with children of similar chronological age and that the characteristics of children who made friends were similar for handicapped and nonhandicapped children. However, matching children on mental age does not seem to have similar beneficial effects (Knapczyk & Peterson, 1976). On the other hand

Strain (1984a) found that nonhandicapped preschoolers tended to choose handicapped children who were older to play with.

Hill & Whiteley (1985) found that while on-task behaviour of handicapped and non-handicapped preschool and school-aged children was not significantly different, there were less peer interactions and more teacher interactions with the handicapped children than nonhandicapped students. They concluded that intervention is necessary to facilitate social contact. A similar conclusion was reached by Hoben & Lindstrom (1979) for blind children in regular classes. An experimental study by Jenkins, Odom, & Speltz (1989) showed different levels of interaction and social competence depending on the experimental condition, with children in the integrated/social interaction receiving significantly higher outcomes in social performance. These data suggested that structuring social interaction between high and low performing children on social competence can significantly improve the competence of the lower performing children. Structuring goal directed activity in cooperative conditions was found to have a more positive effect on interactions in a school situation than in individualistic or free condition (Johnson, Rynders, Johnson, Schmidt, & Haider 1979). Rynders, Johnson, Johnson, & Schmidt (1980) found similar advantages for a cooperatively structured bowling session with handicapped and nonhandicapped teenagers.

In an extensive review of the research literature on integration, Schutz, Williams, Iverson, & Duncan (1984) concluded that students with and without handicaps will only interact if they spend time together and systematic intervention is necessary to remedy interaction deficits of students who are severely handicapped. Strain (1983., 1984b) showed that generalisation of social skills is greater in integrated than segregated settings but that children with handicaps only tended to approach nonhandicapped children when asked to interact, indicating the need for structured peer interactions. In a beautiful article that stands out in providing practical advice on how this might be achieved, Stainback & Stainback (1987) argue that gaining friends is a skill that is learned and can be taught.

Peer interventions

Brady, Shores, Gunter, McEvoy, Foxx, & White (1984) found that spontaneous interactions with an autistic child increased when a second and subsequent training peers were utilised which generalised to other children and continued after the training ceased. Strain et al (1983) demonstrated equivalent treatment gains for handicapped and nonhandicapped children in terms

of positive peer interactions using a peer tutoring approach. Haring, Breen, Pitts-Conway, Lee, & Gaylord-Ross (1987) found that both a peer tutoring and special friend program had beneficial effects on interactions between handicapped and nonhandicapped children, with some slight advantages for the 'special friend' approach. Both approaches produced much longer interactions than a control group. Sasso, Mitchell, & Struthers (1986) found structured interaction activities to be superior to straight peer tutoring and Sasso & Rude (1987) found that structuring interactions with high status nonhandicapped peers resulted in generalisation of interaction to other nonhandicapped children who were not trained. The social status of the nonhandicapped children who participated in the interaction programs was also found to increase Sasso & Rude (1988).

In summary, the research literature indicates:

- Social interaction is more likely to occur in physically integrated settings.
- Small community housing provides a higher quality of physical and social environment than larger housing or institutions.
- The rate of community relationships in community housing situations is low on the basis of published data. Many people are lonely and isolated.
- Administrative and attitudinal factors can dramatically affect the likelihood of interaction with nonhandicapped people occurring.
- While some interaction between handicapped and nonhandicapped people will occur in shared physical environments, this is not guaranteed and may not be long lasting.
- Structuring interactions can dramatically increase the interactions between handicapped and non-handicapped people.
- The impact of such structured interactions can generalise across people, environments and time.
- Structured interactions based on cooperative or shared endeavours of people with shared characteristics or interests tend to be most effective.

Definition of Integration or 'Community Inclusion'

While the literature is extensive on both integration and inclusion, little attempt is made to define what is meant. Integration can mean everything from the sharing of a physical environment such as a suburban street by handicapped and nonhandicapped people, through to the complex range of relationships and experiences that we experience in our own lives. Probably the clearest

definition of integration has been developed by Professor Wolf Wolfensberger who uses the following definition in public workshops of “Personal Social Integration and Valued Social and Societal Participation”:

Adaptive participation by a (devalued) person in a culturally normative quantity of contacts, interactions and relationships with ordinary and valued citizens, in normative activities, and in valued (or at least ordinary) physical and social settings.

While the title is complex it is descriptive, and the definition itself clearly sets out a goal to be achieved. It is clearly a very difficult goal, but it is a close approximation to what we all experience as a natural part of being valued citizens. It does not set out how to achieve the goal although Wolfensberger has written extensively on the subject, and the influence of these writings on this paper is acknowledged (Wolfensberger, 1972; Wolfensberger, 1980; Wolfensberger, 1987; Wolfensberger & Thomas, 1983). The rejection of the word ‘inclusion’ by Wolfensberger is based on the perversion of the term in the US over the 20 years of school integration. However in Australia the word ‘inclusion’ still retains the dictionary meaning and it is suggested that an appropriate term is ‘community inclusion’ rather than ‘integration’ to describe the involvement of people with their communities in a varied and deep way.

Who are the people?

The first question to ask when looking at integration is who are the people we are trying to integrate? Many services do look at this issue, but the information is primarily of the demographic variety -- the sort of information normally held in personal files. For example they will take into account gender, age, level of disability, behaviour, social skills and similar information. While all of this information is important, perhaps critical, it only provides a part of the picture. If we think of how we describe ourselves, we might start off by demographics (job, where we live, marital status, how many children) but we would not consider that anyone who held just this information would have any real understanding of us. In particular we would be careful to conceal any negative information about ourselves in the earlier stages of getting to know someone - the sort of information held on personal files. For someone to really know us we would consider it essential that they knew of our existential environment. Where we grew up, significant issues in childhood, school experiences, current interests and so on. All through our life we are shaped at critical points ... a particular teacher, parent, mentor, peer or environment steers our life in one direction when a different experience at that point might have

produced a quite different life outcome and personality. Second, a key characteristic in understanding us as individuals is to look at the roles that we fulfill in society. If you take away the roles that we have, then we are left with little more than a past and an empty shell to describe.

To understand a person with a disability then, these same principles would apply. We need to know “demographic” information, but we also need to know about existential experience and roles.

Demographics, Factual Information

Age, gender, address, skills, limitations, time available, and support needed are all of course essential to know. However, the most important single factor determining success from the point of view of the individual may be choice and interest. If a person is highly motivated and interested, then skill deficits and behaviour tend to be issues that are more easily overcome.

Existential Information

Life experience

John was born some thirty years ago. At the time of his birth his mother sensed that something was wrong by the behaviour of the medical staff. They did not say anything to her but whisked him away immediately after the delivery with worried expressions on their faces. Some time later the doctor came back and informed the mother that the child had significant disabilities and it might be best if they didn't treat the child and let nature take its course -- in other words, John was to be starved to death. Even in her emotional state at that time the mother would not agree so John was given to her to feed. During her time in the hospital she was counseled to put John into an institution as soon as possible and have another child.

In the days following the birth John's mother felt devastated by the shattered dream of the perfect child, but this turned out to be a minor part of her emotional turmoil. Her husband wished to follow the advice of the doctor. Her own parents refused to visit and totally rejected John. Some of her friends of many years either did not visit because they did not know what to say, or did visit but did not congratulate her on the birth but instead pitied her.

When she took John home she found that she received few visitors as people were embarrassed or uncomfortable. Her husband could not come to accept John and withdrew support from them both, leaving her with a very tiring schedule as well as considerable emotional turmoil. Her

parents continued to reject John, refusing to touch him and clearly preferred that he not be visible when they visited.

Over the next year or so the life of John and his mother was a succession of visits to specialists, many of whom gave similar advice to when John was born -- put him away and have another child. John was prodded, poked and assessed interminably, but little constructive help was forthcoming. Over time John's sister was born, which increased the workload on John's mother considerably. For this child however, the reaction was totally different -- John's mother was congratulated, visited, and generally supported, which put her experiences with John into even greater relief. The extent of rejection of John by her family became apparent when she was trying to load both children into the car with the attendant nappies, car seats and paraphernalia that come with young children. She needed to strap her daughter into the car and handed John to her father to hold while she did this. Her father pulled his hands away and John fell to the ground, luckily without serious injury.

Over time the marriage broke down and John's mother was left to look after both children on her own. John and his mother received few services and most of them were either in medical clinics or in a segregated day care centre. She did receive some visits from a range of social workers and other professionals, most of whom only seemed to last a few months before they were replaced by a new person who wanted her to go through her family history and other intimate details again as well as reassess John. Eventually she refused to let this happen, but became aware of a considerable coolness from service workers -- clearly she was a problem parent. While John's sister had friends around to visit and even stay over, no-one came for John. His mother and sister were the only people in the world who responded to him as an individual human being. Even neighbours and family friends would avoid meeting with the family --- one neighbour even asked if John could be kept inside that day as the neighbour was having friends around and would hate to have them upset if they saw John.

Eventually the pressure became too much for John's mother and when he was five he was placed in an institution with thirty other people. He did not receive any education until he was 15 when the Education Department policy changed and he went on a 90 minute bus ride to a segregated school.

His mother used to visit him but found it too distressing, and eventually would just visit at Christmas for a short period. He did not receive any other visitors, and his life was a succession of faces that changed with the shifts, promotions and moving on to other jobs.

John is now thirty and has moved into a group home with four other people from the institution. He did not choose who he lives with or where he lives and in fact he has almost no choices in his life at all. He has few academic skills due to the lack of schooling and his social skills have mainly been learnt from his fellow inmates, many of whom have had a similar life experience.

There is now a new policy in the Department that John and the others should be integrated into the community. This means that they go on bus trips to the local supermarket or bowling alley as a group of five with two staff. While the staff at these places do talk to them, they are clearly uncomfortable. At the bowling alley they always get the lane right down at the end and the lane next door is almost always left empty.

Current relationships

Effectively all of the relationships in John's life are paid relationships. Many of the staff are very kind to John and clearly like him, but a quarter of a century of experience has taught John that they will all move out of his life, even when they have promised that they will "always be there for him". Even the few staff who have been there for a long time could not be considered anything like a friend -- there is always the question of whether they would be here if they were not being paid.

Image/stereotypes/roles

John has no positive roles in his life at all. Even when he was younger, the roles of 'son', 'brother', 'family member' were tentative and certainly not as clearly established as other children. Now even these roles are present in name only -- they are not a reality of his life. However, he has taken on a range of other roles. He is an "inmate" "retarded person", "eternal child" "object of pity" and so on. All of these roles are reinforced on a regular basis by the buildings, staff, activities, grouping and other characteristics of the service. The very fact of being grouped with other people with a disability means that this characteristic is considered to be more important than any other characteristic he might have such as his personality, skills, background, gender...

Impact

We need to reflect on just what this life experience would do to someone. If our lives are shaped by the range of positive and negative experiences, what would be the impact of *these* experiences? What would it be like to be rejected consistently from the moment of birth? Most of us can remember vividly the few times that we have been rejected. What would be the impact of having spent most of your life congregated with people similarly rejected and devalued by society? What would be the impact of having no person in your life who is there for you alone?

We can only guess at some of the possible impacts. They might be withdrawal; acceptance of your lot or the opposite -- anger at the world; almost certainly low motivation to try anything new due to the life experience of regular failure ... Whatever the impacts are, it is clear that they are likely to be profound.

The Johns of the world are known to all of us, but we rarely get the time or opportunity to reflect on their life. However, if we work towards “integrating” John, we should not be surprised that a failure to think through these issues results in another rejection by the society.

The social milieu

Apart from the knowledge of John, we also need to be acutely aware of the prevailing attitudes in society towards people with a disability. In the 1920's and 30's in Germany, over a quarter of a million people with a disability were murdered (Gallagher, 1990). Policies of sterilisation and abortion of people with a disability are still prevailing and generally accepted in society. The general public has little direct experience of people with a disability, particularly people with severe disabilities, because they have been excluded from schools and communities for generations. This is the milieu that we are looking to accept the people with a disability and to take them into their lives. This is not to say that it is impossible, clearly there are examples that show that it is. However, we are placing very vulnerable people at risk of further rejection and it will not help if we are rosy eyed and unaccepting of the level of rejection and devaluation of people with a disability.

Some hard truths

From the above analysis, it should be clear that much of the damage done to people with a disability -- particularly to their image and reputation -- comes from association with services. Services have a tendency to break community helping responses. The aura of expertise means that ordinary people are afraid that they are incompetent; in a community that needs to struggle

with an issue such as the role of a person with a disability, a service can be seen as a solution and the community may well be unaccepting of a move to give them back that responsibility. By congregating people with a disability and conducting media campaigns highlighting their characteristics and deficiencies, the differences to others is highlighted. All of which indicates that service workers are highly unlikely to be very effective at integrating people. While they may have an essential role in bringing others into the lives of people with a disability (who after all is going to go into an institution seeking a friend?) as long as they are around as a paid support the integration is likely to be limited and superficial.

Second, we have the absurd situation where paid service workers encourage members of the public to become intimately involved in the lives of people with a disability, but they themselves have no informal unpaid contact with any devalued person outside of their work role. If modeling is as important as the literature indicates, then this area of modeling needs to be addressed by us all.

Community Inclusion: Technical Considerations

To even consider the issue of personal social integration, one must start with a detailed and deep understanding of the individual. What are the person's life experiences that made them who they are; what are their interests; what are their strengths; what are their weaknesses; what are their natural supports; who will stand by them; what relationships do they currently have; what effect would a failure have? If we do not do this, we are almost asking for failure for a group who do not need further experiences of rejection.

However, even if we do have this level of understanding of a person, there is still the technical issue of how to bring about community inclusion. To describe this in detail is beyond the scope of this paper, but it is suggested that community inclusion can be considered to be composed of eight different elements, each of which interact with each other. This is set out in Figure 1.

Inclusion Issues

1 Physical Presence

To be personally socially integrated one needs to be present in the regular environment. If you're not in the regular environment it is effectively impossible to become personally socially integrated. However, just "being there" is only the first (critically important) step.

Some key issues to be considered when thinking about physical presence are:

- **Where/when/how often** it occurs:

Some places are more conducive to personal social integration than others. Members of the public tend to avoid segregated centres, or may come for the wrong type of reasons (e.g. charity). If we think about the types of areas that are more conducive to relationships forming, they tend to be in work sites, clubs, sporting fields etc. As a result, the idea of “reverse integration” has been found to be unsuccessful world-wide as a means of establishing real relationships. Reverse integration is the idea of “bringing the public to us” rather than going out to the public. People are generally uncertain, even fearful, about devalued groups and this uncertainty is magnified if they are also on unfamiliar territory with large numbers of such people present. In short, members of the public generally don’t want to come and when they do come, they tend to be overwhelmed by the numbers of non-typical people present.

- The amount of time one spends in that environment is directly related to the probability of personal social integration occurring, and it may be that a minimum level of presence is essential for personal social integration to occur. For example, if the only community presence is a weekly outing to the local bowling alley, it may be that this level of presence is insufficient to allow natural relationships with community members to be established. Similarly, if the ‘community presence’ is a trip to the bowling alley this week, MacDonalds next week, something else the week after ... then it is unlikely to lead to much. It is essential to be strategic and plan where, what time is available and what time is needed. This includes duration -- it may be that there is a minimum time necessary to stay at a venue before it is possible to meet people in a natural way. Other considerations might be the capacity to absorb people and environmental restrictions. A large club might be more anonymous but easily absorb one or even two people whereas a small club might be welcoming but easily overwhelmed. Clearly if the environment is not accessible to the people going there, it is not going to work easily.

2. Social inclusion

Social inclusion relates to a massive number of variables, some of which are listed below. A good guideline is to think of how you would involve your long lost cousin who has just stepped

off the plane from New Zealand and wants your help to become included in the local scene.

How would you go about it?

- *Models* - which models are present, are they good models, could they be 'primed'?
- *Receptivity* -- how receptive is the environment? Should you go very gently and slowly?
- *Mentor*- Is there a mentor available? Best to be unpaid, a guiding hand that can steer the person in the right direction and oil the social networks.
- *Support* The reality is that many if not most of the people require support. If this support is not present, it can be very damaging to the person and future inclusion attempts. However, support does not need to be paid support, -- in fact it is better if it is not.

Support issues:

- Who?
- How much?
- How long?
- *Group size*-- Any more than one person with a disability tends to highlight the disability as the key issue. Better to concentrate on including one individual with natural supports and then move to the next person rather than try to include a group of three or four at a time.
- *Group composition* - Modeling benefits are maximised when the large majority of people in the group are nonhandicapped.
- *Personal presentation*- this issue is well accepted now as an important issue, but even so fine attention to detail is essential. Dressing slightly on the more formal end of the acceptable range is advised to maximise positive images. If 'Nike' is the generally accepted footwear, Dunlops will be noticed negatively. Presentation also includes details such as nails, breath, teeth, polished (or unpolished) shoes etc. If a staff member is involved in the initial phases, these issues are also directly relevant. Staff uniforms, or a staff member who ensures that everyone knows that he or she is the staff and not the client tend to be absolutely destructive of community inclusion.
- *Manners* - Most of us were brought up with a huge emphasis on manners (say please, thankyou, etc etc) as our parents knew how central they were to acceptance. Most of us also probably drive our own children mad with the same rantings, or we will when we have children. In fact manners may be a much much more important skill to learn than skills directly related to community inclusion. If a person is unfailingly polite,

deficiencies in skills are likely to be overlooked or supported in the natural environment. However a skilled person with appalling manners may well not last long.

- *Personality* - Consider the personality of the person carefully in terms of the type of activity being considered. For example, some activities blend better with introverted or extroverted personalities.
- *Stereotypes* - All of us can run off the common prevailing stereotypes of people with a disability such as menace, dirty, dangerous, childlike and so on. This means that these stereotypes are deeply embedded in society and are easily attached to the person with a disability. Avoid situations that pose a risk of attachment to such stereotypes or even better, look for situations and activities that counteract them.

Skill considerations

3. Skill Relevance

- *What are the most important skills for the person to learn?* They might be manners! That is, the critical skills might not be the most obvious.
- *What skills are needed here?* To join in most community activities, some skills are required. However, there may be ways of overcoming a skill lack if the person does not have the skills and might have great difficulty acquiring them. A mentor or helper could fill the gap, The person could do part of the task in combination with someone else. The research indicates that cooperative ventures have the most positive impact on interaction so this might be a strategy to look out for.
- *What skills are present?* Clearly you need to know the person well enough to have a good idea of the skills that they possess.
- *What skills can be taught there?* In almost all cases it is better to teach the skills in the actual environment where they are to be practiced. Our history has been to have people with a disability spending their lifetime in segregated environments forever learning the skills to earn a real life. In most cases this is unnecessary and inefficient. Skills tend to be learned faster and generalise better if taught in the real environment.
- *What skills need to be established before starting?* While it is almost always better to learn the skill on site, there may be occasions where a minimal level of competence is required prior to attempting the activity or where the person might suffer ridicule due to their level of incompetence. Generally however it is better to provide the necessary support for the person to learn the skill on site.

4. Skill Potency

A reality of people with an intellectual disability is that they tend to learn a given skill more slowly (require more learning trials) than a nonhandicapped person. Hence there is a great responsibility on us to use all possible learning opportunities and the most potent teaching methods available.

- *What is the most potent way to teach these skills?* The literature is full of methods to teach skills rapidly. They normally include breaking the skill down into understandable ‘chunks’, use of reward and encouragement, mastery before progress to the next step, repetition of the skill to the point of overlearning and building in generalisation. Of course this has to be done sensitively to ensure that undue attention is not brought on the person through the teaching.
- *Intensity of time use* With the extra teaching needed to mastery, intensity of time use is critical. However the life experience of people with a disability is long periods of waiting and generally non-intense environments. We need to stop wasting people’s lives. It does not mean that a person has to be intensely programmed every minute but that when teaching is occurring it is intense, stimulating and effective.
- *Developmental sequence* Teaching in a development sequence does not mean going back to the sand box if a person has missed those skills. It does mean that in many cases skills build on other skills and if the initial skills are missing, learning may become very difficult or impossible. It is critical to have thought through this issue and worked out the appropriate sequence. However, care needs to be taken as many people have spent a lifetime learning skills that while perhaps developmental in a broad sense, are nonetheless irrelevant to the person’s current learning. For example, a person may have spent years sorting colours as part of therapy but have no social or work skills.
- *Comfort of the learner* We all learn best in a comfortable environment. Learning in a smelly, cold, noisy institution is not likely to be efficient.
- *Materials needed* Often material supports can dramatically simplify the learning of a task. Similarly, the carrying out of many tasks is dependent on the appropriate material being available.

Image issues

5. Self image

While most of us spend a large proportion of our time concentrating on our image (the clothes we wear, the car we buy, the house we buy and decorate, showering, washing clothes etc etc) we

spend little time concerned about the image of the people we are supporting. While the personal presentation of handicapped people has progressed enormously over the last decade or more, images are carried by the buildings, activities, language used, grouping of people and in many other ways. If our image is poor (for example we are dirty, unkempt, don't have the right equipment) our self esteem and motivation tends to be effected.

- *Countering stereotypes* As mentioned above, stereotypes are deeply ingrained in us and the society. The person themselves may have even taken on some of the stereotypes due to the expectations of others -- they may actually act in a child-like manner. By countering stereotypes we can minimise image damage as well as build an alternative image for the person in their own eyes as competent, well dressed and so on.
- *Self esteem* A lot of our self esteem comes form the feedback of others. If we think of a person with a disability, much, probably most, of this feedback has been negative. This means that it is critical to establish a positive environment with lot of encouragement. A good rule might be to surround the person with four positive statements to every negative one.

6 *Image in others' eyes*

How the person is seen by others will affect the probability of acceptance as well as indirectly impact on the person's self esteem.

- *Obvious competencies* Quite often one or more obvious competencies can compensate for a range of skill deficits. This is known as the competency/deviancy hypothesis where the presence of a major competency can overcome deviancies. For example, Richard Hawkins, the nuclear physicist, is massively handicapped but his obvious competency in physics means that he is universally known and positively regarded.
- *Image issues to minimise* Sometimes the person has some image problem that can have a very detrimental impact in the eyes of others. Drooling is one example, where teaching the skill of using a handkerchief or even corrective surgery may be alternatives.

7. *Valued Roles*

Our life and image are defined by the roles that we fulfill. The fact that we are a driver, houseowner, spouse, parent etc all mean that we gain automatic entry into the benefits of society. Hence the more and powerful the roles that a person has, the more likely that they will be accepted, and the more opportunities will occur for real relationships to develop. On the diagram this is the heart of community inclusion. Without valued roles, inclusion is likely to be superficial and tentative.

One trend that seems to be occurring is to view community inclusion as equivalent to recreation. While some of our valued roles and community inclusion come from this area, it is one small part of our lives and generally one of the less powerful. We clearly need to think outside of just recreation and look to other areas such as work (not necessarily employment), home ownership, community helping roles and so on. Taking a neighbour's dog for a walk each morning may be a more powerful means of developing real roles and relationships than attending a dog show each week.

- *What roles does the person now have?* In most cases many if not most of these roles will be negative.
- *What roles is the person going to play?* To be present in an environment without a clear role makes everyone feel awkward. Clearly delineate the role and the role expectations so that the person can immediately fit in and be seen to fit in.
- *Can the person fulfil these roles?* Very few of us can settle immediately into a new untried role - it takes some adjustment (learning) and support. The same applies for the person with a disability, although they may need more support. This support can be given in a variety of ways -- direct support; relaxing the role expectations initially; short periods in the role and gradually building up time; starting off in an adjacent role that is easier to hold down; jointly fulfilling the role with some more competent person.
- *What do they need to fulfil these roles?* There may be some essential pre-requisite skills to hold a role that have to be learned beforehand. This however is rare if some of the strategies outlined above are utilised.
- *What other roles might become accessible?* One role by itself can be very beneficial, but our lives incorporate hundreds of roles of varying power. It is necessary to look developmentally at roles so that the person can increase both the number and power of roles undertaken over time.

8. Expectations

For people with an intellectual disability in particular, expectations tend to be life defining. Challenges tend to be limited, supervision is extensive. Consider your own life if people said you had reached your potential (or even implied it). Our reaction might range from anger to depression. The history of people with an intellectual disability has been one of appalling expectations and lifetimes of wasted opportunity.

- *What are your expectations for the person?*

- *Are they too low? They usually are.*
- *What are the expectations of others?*
- *How can negative expectations be countered?*
- *How can positive achievements be communicated?*

Remember it is better to set a positive expectation and fail to meet it than to set and meet a negative expectation.

Safeguarding issues

An overriding issue for people who have the life experience similar to John is their heightened vulnerability. All of us are vulnerable but for people with a disability who have suffered rejection and other wounds through their life, their capacity to cope with further wounding is diminished. Hence there is an essential need to safeguard what we are doing. We do make mistakes, and people with a disability live them out.

- *What safeguards are in place to cope with?*
 - *Staff changes*
 - *Rejection*
 - *Failure*
 - *Loss of key people*
- *What would be the impact of failure?* For us one failure might be a setback, but for a person with the heightened vulnerability of John, it might be devastating and define the rest of his life. Most of us know of people who are still rotting in institutions because of the failure of one poorly thought-out and supported community experience.
- *Could the person cope with failure?* For some people with an intellectual disability, failure or rejection can be overcome. It is indeed amazing for some of us to see people who have had a lifetime of ill-treatment still showing a positive, friendly personality. However, for others this is not the case. We need to know each individual in great depth before experimenting with potentially life-defining issues.
- *Is planning sufficient?* All eventualities need to be thought through. A “what if” analysis can be helpful in doing this. One tantrum that could have been predicted or one community person thrown too quickly into a situation where they feel out of their depth can have long term impacts on not only the person with a disability but others who follow.
- *What back-up supports are in place?* ‘Murphy’ is real and alive in Australia. Staff can’t always be relied on; community members will default; transport systems break down. We

need to predict these events and have back-ups ready or alternative strategies to cope with such problems.

Interactions

All of the above eight points interact with each other. A person who is taught relevant skills by powerful methods is more likely to gain social acceptance and valued roles. If a person's personal presentation and image are enhanced it is likely that their motivation will increase and their image in the eyes of others will improve. On the other hand, if expectations are low then teaching outcomes are likely to be poor, self image will suffer and rejection is more likely.

Summary

In this analysis it is argued that many current attempts at community inclusion are not successful due to an insufficient knowledge of the individuals and failing to appreciate the extent of community rejection of people with a disability. It is argued that services are fundamentally incompatible with community, so the possibility of services being able to undertake community building and inclusion is remote. Service workers may have a role as a catalyst for bridging the gap between the totally segregated lives of many people and community members, but they should not see themselves as the ongoing supports. Finally, a technical analysis of community inclusion is presented where it is argued that 8 separate areas have to be addressed and followed with safeguards if successful community inclusion is to occur.

References

- Bak, J. J., & Siperstein, G. N. (1987). Similarity as a factor effecting change in children's attitude towards mentally retarded peers. American Journal on Mental Deficiency. 91, 524-531.
- Baker, M. J., & Salon, R. S. (1986). The power of community integration in liberating institutionalized adults from the bonds of their past. Journal of the Association for Persons with Severe Handicaps. 11, 176-181.
- Ballinger, C. (1993). Do smaller homes result in increased integration? Mental Handicap Research. 6(4), 303-311.
- Brady, M. P., Shores, R. E., Gunter, P., McEvoy, M. A., Foxx, J. J., & White, C. (1984). Generalization of an adolescent's social interaction behaviour via multiple peers in a classroom setting. Journal of the Association for Persons with Severe Handicaps. 9, 278-286.
- Brinker, R. P. (1983). The rate and quality of social behavior of severely handicapped students in integrated and non-integrated settings (ERIC Document Reproduction Service No. ED 232 337). Educational Testing Service, Education Policy Research Institute.
- Brinker, R. P. (1985). Interactions between severely mentally retarded students and other students in integrated and segregated settings. American Journal of Mental Deficiency. 89, 587-594.
- Brinker, R. P., & Thorpe, M. E. (1983). Evaluation of the integration of severely handicapped students in regular education and community settings . Educational Testing Service, Education Policy Research Institute.
- Brinker, R. P., & Thorpe, M. E. (1984). Integration of severely handicapped students and the proportion of IEP objectives achieved. Exceptional Children. 51(168-175).
- Brinker, R. P., & Thorpe, M. E. (1986). Features of integrated educational ecologies that predict social behavior among severely mentally retarded and nonretarded students. American Journal of Mental Deficiency. 91(150-159).
- Cole, D. A. (1986). Facilitating play in children's peer relationships: Are we having fun yet? American Educational Research Journal. 23, 201-215.
- Cole, D. A., Vandercook, T., & Rynders, J. (1987). Dyadic interactions between children with and without mental retardation: Effects of age discrepancy. American Journal of Mental Deficiency. 92, 194-202.
- Condon, M. E., York, R., & Heal, L. W. (1986). Acceptance of severely handicapped students by nonhandicapped peers. Journal of the Association for Persons with Severe Handicaps. 11, 216-219.
- Donegan, C., & Potts, M. (1988). People with mental handicap living alone in the community: A pilot study of their quality of life. British Journal of Mental Subnormality. 34(1)(66), 10-22.

- Felce, D. (1985). An ecological comparison of small community based houses and traditional institutions: II. Physical setting and the use of opportunities. Behavior Research and Therapy. 23, 337-348.
- Felce, D., de-Kock, U., & Repp, A. C. (1986). An eco-behavioral analysis of small community-based houses and traditional large hospitals for severely and profoundly mentally handicapped adults. Applied Research in Mental Retardation. 7, 393-408.
- Field, T. (1984). Play behaviors of handicapped children who have friends. In T. Field, J. Roopnarine, & M. Segal (Eds.), Friendships in normal and handicapped children (pp. 153-162). Norwood NJ: Ablex.
- Flynn, R. J., LaPointe, N., Wolfensberger, W., & Thomas, S. (1991). Quality of institutional and community human service programs in Canada and the United States. Journal of Psychiatry and Neuroscience. 16(3), 146-153.
- Forlin, C., & Cole, P. (1994). Attributions of the social acceptance and integration of children with mild intellectual disability. Australia and New Zealand Journal of Developmental Disabilities. 19(1), 11-23.
- Gallagher, H. G. (1990). By trust betrayed. Patients, physicians and the license to kill in the Third Reich. New York: Henry Holt & Company.
- Gilkey, G. L., & Zetlin, A. G. (1987). Peer relationships of mentally handicapped adolescent pupils at an ordinary school. British Journal of Mental Subnormality. 33, 50-56.
- Gilmore, J. L., & Farina, A. (1989). The social reception of mainstreamed children in the regular classroom. Journal of Mental Deficiency Research. 33, 301-311.
- Gottlieb, J. (1982). Mainstreaming: Fulfilling the promise? American Journal of Mental Deficiency. 86, 115-126.
- Gresham, F. M. (1982). Misguided mainstreaming: The case for social skills training with handicapped children. Exceptional Children. 48, 422-435.
- Guralnick, M. J. (1984). The peer interactions of young developmentally delayed children in specialized and integrated settings. In T. Field, J. Roopnarine, & M. Segal (Eds.), Friendships in normal and handicapped children (pp. 139-152). Norwood NJ: Ablex.
- Haring, T. G., Breen, C., Pitts-Conway, V., Lee, M., & Gaylord-Ross, R. (1987). An adolescent peer tutoring and special friends experience. Journal of the Association for Persons with Severe Handicaps. 12, 280-286.
- Hill, C. A., & Whiteley, J. H. (1985). Social interactions and on-task behavior of severely multihandicapped children and nonhandicapped children in mainstreamed classrooms. Canadian Journal for Exceptional Children. 1, 136-140.
- Hoben, M., & Lindstrom, V. (1979). Evidence of isolation in the mainstream. Journal of Visual Impairment and Blindness. 74, 289-296.

- Jenkins, J. R., Odom, S. L., & Speltz, M. L. (1989). Effects of social integration on preschool children with handicaps. Exceptional Children. 55, 420-428.
- Johnson, R. T., Rynders, J., Johnson, D. W., Schmidt, B., & Haider, S. (1979). Interaction between handicapped and nonhandicapped teenagers as a function of social goal structuring. American Educational Research Journal. 16, 161-167.
- Knapczyk, D. R., & Peterson, N. L. (1976). Social play interaction of retarded children in an integrated classroom environment. Research and the Retarded. 3, 104-112.
- Law, M. (1992). Michel Foucault's historical perspective on normality and restrictive environments. Canadian Journal of Rehabilitation. 5(4), 193-203.
- Law, M., & Dunn, W. (1993). Perspectives on understanding and changing the environments of children with disabilities. Physical and Occupational Therapy in Pediatrics. 13(3), 1-17.
- O'Neil, J., Brown, M., Gordon, W., & Schonhorn, R. (1985). The impact of deinstitutionalization on activities and skills of severely/profoundly mentally retarded multiply-handicapped adults. Applied Research in Mental Retardation. 6, 361-371.
- Peters, S.J. (1990). Integration and socialization of exceptional children. Anthropology and Education Quarterly. 21(4), 319-339.
- Rynders, J., Johnson, R. T., Johnson, D. W., & Schmidt, B. (1980). Producing positive interaction among Down Syndrome and nonhandicapped teenagers through cooperative goal structuring. American Journal of Mental Deficiency. 85, 268-273.
- Sabornie, E. J. (1985). Social mainstreaming of handicapped students: Facing an unpleasant reality. Remedial and Special Education. 6(2), 12-16.
- Sasso, G. M. (1985). Procedures for facilitating integration of autistic children in public school settings. Analysis and Intervention in Developmental Disabilities. 5, 233-246.
- Sasso, G. M., Mitchell, V. M., & Struthers, E. M. (1986). Peer tutoring versus structured interaction activities: Effects on the frequency and topography of peer initiations. Behavioral Disorders. 11, 249-259.
- Sasso, G. M., & Rude, H. A. (1987). Unprogrammed effects of training high status peers to interact with severely handicapped children. Journal of Applied Behavior Analysis. 20, 35-44.
- Sasso, G. M., & Rude, H. A. (1988). The social effects of integration on non-handicapped children. Education and Training in Mental Retardation. 23(1), 18-25.
- Schutz, R. P., Williams, W., Iverson, G. s., & Duncan, D. (1984). Social integration of severely handicapped students. In N. Certo, N. Haring, & R. York (Eds.), Public school integration of severely handicapped students: Rational issues and progressive alternatives (pp. 15-42). Baltimore: Paul H Brooks.

- Sinson, J. C. (1994). Normalization and community integration of adults with severe mental handicap relocated to group homes. Journal of Developmental and Physical Disabilities. 6(3), 255-270.
- Slee, R., & Cook, S. (1994). Creating cultures of disability to control young people in Australian schools. Urban Review. 26(1), 15-23.
- Stainback, W. C., & Stainback, S. B. (1987). Facilitating friendships. Mental Retardation. 22, 18-25.
- Storey, K. (1987). Teaching social skills to persons with severe handicaps in community settings: A review. Australia and New Zealand Journal of Developmental Disabilities. 13(143-150).
- Strain, P. S. (1983). Generalization of autistic children's social behavior change: Effects of developmentally integrated and segregated settings. Analysis and Intervention in Developmental Disabilities. 3, 23-34.
- Strain, P. S. (1984a). Social behavior patterns of nonhandicapped and developmentally disabled friend pairs in mainstream schools. Analysis and Intervention in Developmental Disabilities. 4, 15-28.
- Strain, P. S. (1984b). Social interactions of handicapped preschoolers in developmentally integrated and segregated settings. In T. Field, J. Roopnarine, & M. Segal (Eds.), Friendships in normal and handicapped children (pp. 188-207). Norwood, NJ: Ablex.
- Strain, P. S., & etal (1983). Normally developing preschoolers as intervention agents for autistic-like children: Effects on class deportment and social interaction. Journal of the Division for Early Childhood. 9, 105-115.
- Townsend, M. A., Wilton, K. M., & Vakilirad, T. (1993). Children's attitudes toward peers with intellectual disability. 9th World Conference of the International Association for the Scientific Study of Mental Deficiency (1992, Broadbeach, Australia). Journal of Intellectual Disability Research. 37(4), 405-411.
- Wills, D., & Jackson, R. (1996). Inclusion: Much more than being there. Interaction, 10(2), 19-24.
- Wolfensberger, W. (1972). The principle of normalization in human services . Toronto: National Institute on Mental Retardation.
- Wolfensberger, W. (1980). A brief overview of the principle of normalization. In R. J. Flynn & K. E. Nitsch (Eds.), Normalization, social integration, and community services (pp. 7-30). Baltimore, MD: University Park Press.
- Wolfensberger, W. (1987). The ideal human service. Interaction. 1(2), 5-7.
- Wolfensberger, W., & Thomas, S. (1983). PASSING: Program Analysis of Service Systems' Implementation of Normalization Goals . Ontario: National Institute on Mental Retardation.

Figure 1: A model of issues involved in community inclusion. Based on Wills and Jackson (1996).

