Community Integration or Community Exposure? A Review and Discussion in Relation to People with an Intellectual Disability

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Background This paper reviews the issue of integration as it applies to people with an intellectual disability. A compelling finding is the almost exclusive orientation of the literature to physical integration within the general community of non-disabled people. Moreover, it seems to be generally assumed that the more frequently people experience such integration the better their lives will be.

Methods We question the validity of this assumption on several grounds. It is social, not physical integration, that has a reliable positive influence on well-being. This is an important conclusion as some disabled people find effective social integration with the general community extremely difficult to achieve. Because of this, the consequences of an overly enthusiastic program of integration for such people has more potential to be more stressful than beneficial.

Results We further argue that, as integration is being pursued to benefit the individual, the essential goal of service provision should be to achieve a sense of community connectedness, rather than being concerned with physical integration within the general community.

Conclusion It is proposed that such connectedness is more likely to be achieved within the community of people with an intellectual disability.

Keywords: community integration, intellectual disability, quality of life, subjective well-being

Introduction

The issue of community integration has been seen as a critical aspect of successful service provision ever since the issue of Normalization (Wolfensberger 1970, 1972) and Social Role Valorization (Wolfensberger 1992, 1995, 2000) started to impact on service delivery for people with an intellectual disability. Institutions, with their exclusive enclaves of social interaction, are the antithesis of what became, and is now seen, as desirable. Contemporary service policy is steadfast in its commitment to accommodating people with disabilities in the general community and facilitating their integration with non-disabled people.

But what, exactly, is meant by 'integration'? It is clear that the geographical location of people in the general community, as opposed to an institution, causes them to be physically more integrated. They are far more likely under such living conditions to engage in community living activities such as to go shopping, use general recreation facilities, medical services, etc. (e.g. Campbell 1968; Willer & Intagliata 1981; DeKock *et al.* 1988). Does such use, however, constitute 'integration'? Or, does it simply mean that people with an intellectual disability are more exposed to the general community without being socially integrated? The difference between these concepts needs to be understood if policy makers and service providers are to be clear about the nature of their responsibilities in this area.

An additional issue, highly relevant to this discussion, is whether the people being integrated actually benefit from such an enterprise. It is clear that other people benefit. Policy makers can obtain satisfaction from knowing that they are successfully implementing the dominant philosophy. Service providers benefit by having a clear goal of

physical integration which they can demonstrably meet. Even the abstract 'society' may benefit from regular encounters between disabled and non-disabled people, in the sense that this raises awareness of difference and, perhaps, engenders understanding and compassion (Saxby *et al*. 1986). But do the people with an intellectual disability directly benefit from actively encouraged social integration? As has been argued previously (e.g. Landesman-Dwyer 1981; Goldberg & Connolly 1982) this issue is crucial to judgements concerning service delivery effectiveness. Unless a direct personal benefit can be clearly demonstrated, benefits to others cannot be easily justified.

This paper will review these issues in an effort to understand not only the meaning of integration for the parties involved, but also the consequences of this policy on the service recipients. The papers that are cited represent all of those available to the authors from the collection maintained by the Australian Centre on Quality of Life (http://acqol.deakin.edu.au) supplemented by other articles, acquired as a result of their apparent relevance. No article has been excluded on the grounds that it offered data or argument against the thesis development in this review.

What is integration and why is it such a concern?

Judging by the measurement instruments that are most commonly used (see later), most researchers and service providers define integration as being physically present in locations that are frequented by the general public. Consequently, the more often people are present in such locations, the more 'integrated' they are, and the more desirable is their lifestyle as a consequence. Thus people are not integrated if they remain at home with their family, if they attend segregated schools or engage in sheltered employment, or live in circumstances where they are mainly in the presence of other people with a similar disability. This is considered to be undesirable for the person in question.

In these terms, service providers view integration as an area of concern as many people with an intellectual disability evidence such low levels. These people tend to have small social networks in which staff or family members are often the only non-disabled members (e.g. Robertson *et al*. 2001). If they live in group homes they have less contact than non-disabled people normally have with their neighbours (Aubry & Myner 1996), and remain generally isolated from the non-disabled people in their proximity (Emerson 1985). Thus, even though most people are now located physically within the general community, they are often not socially a part of their community (Salzberg & Langford 1981; Myers *et al*. 1998).

Concern with integration is also enhanced through ideological-pragmatic tension. Within the Western world, segregated accommodation, schooling, and employment are still very much in evidence despite 30 years of official sanctions. So the link between service ideology and a serviced clientele who make the operationalization of the ideology difficult, acts to magnify the relevance of integration. This tension is also fuelled by an almost universal belief that integration with the general community confers benefits.

Benefits from a service provider perspective

There are several reasons why service providers regard general community integration as beneficial for people with an intellectual disability, but they are all contestable. These presumed benefits are as follows:
(1) The theory of Normalization decrees integration to be beneficial. However, this reason has little contemporary relevance in Western nations. The issue at hand is not whether people should be accommodated in institutions. That battle has been fought and won. The question now is how to optimize the life quality of people living in community settings, and normalization is silent on the issue of people's individual needs and desires. Moreover, as argued both in this paper and by other authors (e.g. Evans *et al*. 1988), there are considerable dangers in using deinstitutionalization as a basis for quality of life evaluations when the social consequences are ignored.
(2) Community resources are more likely to flow to groups that are publicly visible. Perhaps this is so, and perhaps it is not; but there are other ways to achieve government funding than through physical integration. Advocate groups and service providers can achieve appropriate funding by lobbying.
(3) Community integration is good for future generations of people who are disabled. That is, community exposure changes public attitudes for the better, and this will enhance community acceptance as a long-term strategy. Even if it were so, and even if the evidence is weak and equivocal (e.g. Krajewski & Flaherty 2000), ethical considerations demand that any imposed activity, such as community exposure, must be beneficial to the participants, not just to other people.
(4) Integration necessarily confers some tangible benefit to the participant.

In summary, none of the reasons (1) to (3) provides a justification for enforced integration with the general community. So it is time to examine the evidence for (4), that integration necessarily confers benefit to the participant. One source of data comes from an examination of how

other population groups choose to integrate with people who are non-family.

The fact is, when people are given free choice they evidence a preference for integrating with their own kind, not with the community in general (see Rhoades & Browning 1977). Thus, people who are rich congregate in exclusive and expensive suburbs, new migrants live close to others who share their culture and language, people who are elderly congregate in retirement villages, and people with particular medical conditions seek social affiliation with others who share their diagnosis (e.g. Heckman *et al*. 1998). So, how would such people define their 'community'? Would the rich banker regard the unskilled, newly arrived migrant as part of her community, and with whom she should 'integrate' to achieve an improved life quality? Would the elderly residents of a retirement village regard integration with the adolescent youth who surround their enclave as enhancing their sense of community? Perhaps not. Yet the philosophy of integration is so entrenched that writers on service policy simply assume that people with an intellectual disability are somehow different from other groups in society, such that integrated rather than segregated experience is necessarily of benefit to them (e.g. Gow *et al*. 1988; McGaughey *et al*. 1995). Authors do not usually explain why this should be the case. Especially they do not explain why such people should regard integration with the general community as being more desirable than integration within the community of people with an intellectual disability.

So, what is the evidence for direct personal benefit derived from general community integration? The evidence for tangible, objective benefit will be examined first, followed by an examination of benefit at the level of personal experience.

Objective benefits for the individual

Starting with the youngest groups, over the preschool to adolescent years, the effects of integrated, compared with segregated classroom environments, have been commonly researched. While results generally favour integrated settings, the differences are often small and not evident in all measured variables. A few examples will suffice to make this point. Advantages have been reported in pro-social behaviour (Gottlieb *et al*. 1975), less time alone (Cole & Meyer 1991), and social skill development (Cole & Meyer 1991). On the other hand, no changes or differences have been reported on verbally or physically hostile behaviour (Gottlieb *et al*. 1975) or general developmental skills (Cole & Meyer 1991).

In terms of adults, again the results are neither clear-cut nor dramatic. Certainly, some researchers are successful in demonstrating that more integrated living conditions provide modest benefits to the recipients (e.g. Felce *et al*. 1985, 1986). It is noteworthy, however, that there appears to be a bias operating in the reporting of many studies, such that the benefits of integrated living are emphasized while the areas of non-benefit or even disadvantage, are de-emphasized.

Consider, for example, the recent study by Emerson *et al*. (2000). These authors compared cluster housing with community homes and concluded that people living in the latter 'enjoyed a significantly greater quality of life.' (p. 263). Their data, however, tell a more complex story.

In terms of living environment, observers rated the community homes as more homely and the social climate as less institutional. However, in terms of staff work practices, while the community homes rated higher in terms of procedural matters (activity planning and training/supervision of staff) and staff support to residents, this did not simply translate into direct benefits to the residents. Thus, there was no difference between the two living environments in terms of person-centred planning, assessment and teaching, or the frequency of resident contact by staff. This is particularly surprising as the community homes had a much higher staffing ratio (2.8) than the cluster housing (1.3).

They also reported the community homes to generate greater exercise of choice, social network size (including staff), less stereotypic behaviour, and more community exposure. Additionally, however, they found more disengaged activity within the community homes, no differences in network size after staff had been accounted for, and no differences in family contact or engaged activity. These seem rather flimsy grounds to support the authors' conclusion regarding overall life quality. Moreover, and as noted by the authors, the benefits that were evident to the community home residents were probably attributable to the greater staffing ratio rather than to the living environments per se.

Another example of exaggerated claimed benefits is provided by Inge *et al*. (1988). They compared 20 people (IQ 24–61) who had moved from segregated to competitive employment with a matched control group who remained in the segregated setting. Their measures included adaptive behaviour, physical health, and personal performance. Both groups were assessed at baseline, and again at a 6- and 12-month follow-up. The authors claim their study provides 'an encouraging picture of the positive effects of competitive employment on the quality of life of persons with mental retardation.' (p. 97).

In fact their analysis is severely flawed. They used a multivariate analysis of variance with participant numbers insufficient to support such a statistical approach, they failed to use a Bonferroni correction for significance levels following multiple paired comparisons, they failed to adequately acknowledge that many of their significant differences were influenced by the control group scores decreasing over time, and finally they found no significant main effects. The only convincing parameter of change was in terms of increased weekly income.

In summary, the gains these studies have recorded as a consequence of community living are positive but hardly dramatic. A similar conclusion had been reached many years previously by Birenbaum and Re (1977) in relation to the reduction of dependency and increased self-reliance.

Subjective benefit to the individual

As has been argued by Landesman (1986), the most crucial measure of community living success is how people feel about themselves and their lives. One approach to such assessment is to ask people what factors contribute most to their life quality, and the fact is, when such questions are asked, very few people regard integration with the general community as either a desirable or personally relevant form of activity. Let us give two examples:

1 In 2000, Disability Services Victoria conducted 14 focus group discussions and 444 personal interviews to discover the aspirations of people with a disability. What they found at the top of their list was not community integration but having an intimate friend.

2 The Comprehensive Quality of Life Scale (Cummins 1997a, b) has been extensively used with both general population samples and people with an intellectual disability. The scale asks people to rate a set of seven domains on importance and satisfaction, and the rank order is highly predictable. Practically everybody regards the domain of 'relationships' at the top of their list, and the domain of 'community' at the bottom. So this is substantial evidence that people regard connection to their community as one of the least relevant areas of their lives.

Another approach to judging the personal benefit of community integration is to compare the subjective well-being of people living in different types of accommodation. Eight studies have been reviewed by Cummins (2001a) and the findings were as follows:

1 One study involved people with an intellectual disability living in a nursing home (Heller *et al.* 1998). Their subjective well-being averaged 57%SM, which is way below the normal range of 70–80%SM for group means (Cummins 1995; Cummins *et al.* 2003; : Percentage of scale maximum, %SM, projects Likert scale data onto a standard 0–100 scale). However, two years after moving to a shared house in the community the score rose to 70%SM, which is the lowest margin of the normal range.

2 In relation to the other studies, four of the groups living in institutions/cluster housing averaged 78%SM. In contrast, the six groups living in group homes average 81%SM, while the two groups living with their families had scores that differed markedly from one another (70 and 83%SM).

The conclusion that may be drawn from these studies is assisted by the Theory of Subjective Well-being Homeostasis (Cummins 2003; Cummins & Nistico 2002). This proposes that subjective well-being is held for each individual within a narrow positive range by a combination of personality and cognitive devices. These act to defend against the influence of negative external forces, thereby allowing the well-being of normative groups to remain within a 70–80%SM range.

An implication of homeostatic theory is that people adapt to a wide range of living circumstances and thereby maintain their well-being within the normal range. Thus, while group mean scores that lie below 70%SM are indicative of a highly negative environment that has defeated homeostasis, group mean scores that lie within the 70–80%SM range yield little information about the circumstances of living.

This understanding can be used to interpret the aforementioned data as follows. While the nursing home environment in Heller *et al.*'s (1998) study exerted a sufficiently negative influence to defeat the homeostatic system, the other living environments did not. Thus, from these data on subjective well-being, no clear indication can be obtained as to the personal benefits of living in institutions/cluster housing, group homes, or within the family environment.

The work environment is another source of differentiation with respect of the degree of integration, and one relevant study has been located that measured subjective well-being. Sinnott-Oswald *et al.* 1991) claimed to have demonstrated higher subjective QOL among people in supported employment within a general community work situation, compared with others in sheltered employment. For many reasons, however, this study cannot be regarded as providing reliable evidence for such a conclusion. Briefly, the workshop participants were drawn from a single location, the numbers of participants in each group were small ($N = 10$), no Bonferroni correction was made for multiple tests of significance, and some of the items were so complex and ambiguous that it is uncertain what meaning can be derived from the data (e.g. 'Do you feel within the past year your ability to make independent

decision is: worse, a little worse, about the same, better, much better').

In conclusion, while the nursing home environment of Heller *et al.* (1998) was clearly associated with a lower than normal level of subjective well-being, no clear discrimination is apparent within the other living or work environments that have been cited. This seems surprising given the enormous concentration of effort to create integrated living and working environments. Why are the benefits of integration not more clear-cut? Perhaps the level of physical integration needs to be increased for determined benefit to emerge. This possibility will now be explored.

Is more community integration better?

There is an implicit assumption, from the perspective of policy makers and service providers, that more objective integration is better. Integration frequently constitutes a service goal with no stated upper limit, personal plans rarely specify an upper limit to integration, and researchers, too, make this assumption. When comparative data are reported, the higher integration score is inevitably interpreted as superior.

But, of course, this cannot simply be the case. A frenetic lifestyle of socially integrated activities would leave no time for other aspects of life. Moreover, every person will have a limit to the duration and frequency of socially integrated activities that they can enjoy. Not only will this differ between individuals, but also may be quite low for some people.

So how much 'integration' do people generally want? One indication is to observe the level of general community interaction that occurs when people with a cognitive disability live with their families. After all, this is likely to be a non-coercive environment in this regard, where the wishes of the person with the disability are respected and where their best interests are kept in mind free of ideological dogma. And the data are interesting. In a study of leisure time, McConkey *et al.* (1981) found only one third of their family based participants with an intellectual disability took part in any form of community activity, and only 20% had a non-disabled friend. In a similar vein, Cheseldine and Jeffree (1981) found only 57% of adolescents living in such circumstances reported having a friend, and for those who did, the friend was almost invariably another adolescent with an intellectual disability. Moreover, only six percent of the parents considered the lack of friends to be a problem, reinforcing the idea that these families were relaxed in their approach to integration.

Having said this, there is no doubt whatsoever that good personal relationships are beneficial to life quality. Intimate relationships act as a buffer against the effects of adversity (Lunsky & Benson 2001). They are associated with higher subjective well-being (see Okun *et al.* 1984 for a meta-analysis), higher positive self-image (e.g. Clegg & Standen 1991) with better physical health and longevity (Sherkat & Reed 1992), and so on. Humans are essentially social animals. We crave social interaction when it is absent, rate relationships with family and friends as the most important life domain (Cummins 1997a), and rate this domain as the one that provides us with the greatest sense of satisfaction (Cummins *et al.* 2003). Additionally, a major personality dimension (extroversion) is known to underpin these characteristics of affiliation at a constitutional level. But personal, intimate relationships can exist quite independently from community integration.

In summary, there is clearly an upper limit to the extent to which physical integration is going to be beneficial. It is also clear that this level will be idiosyncratic to some degree. So this gives rise to the question of whether community exposure, occurring in the absence of active social integration, can actually be harmful.

The negative side of community integration

The effects of integrated living are usually assessed in relation to the person who is disabled. But there is another side to the equation that receives scant attention from the literature, and this is the influence of the disabled person on their family. This emotive issue has been addressed in part by Cummins (2001b) who concludes, on the basis of a review, that severely disabled people living at home have a strong negative influence on other family members, particularly mothers. The statistics presented in this publication are alarming. All 17 studies that measured stress found a higher level among caregivers compared with non-caregivers. All 11 studies that measured anxiety found higher levels among caregivers. While in terms of depression, the five relevant studies agreed that around half of the caregivers were clinically depressed. The uncomfortable truth that seems to emerge from this analysis is that the physical integration of severely disabled people within the family home is generally damaging to the life quality of other family members.

What, then, of the people with a disability themselves? Is it possible that physical integration within the broader community places their own well-being at risk? The previous discussion has hinted at ways in which enforced community exposure might by harmful. This may involve stress because of the overexposure or being placed in an environment, such as a school or workplace, where the social environment is hostile. While this issue has received

little attention from within the disability literature, elsewhere much has been published that confirms common sense. Bad social relationships have a negative impact on the well-being. For example, Rook (1984) found negative social relationships to be far more strongly related to subjective well-being than positive relationships among widowed, elderly women. This issue will now be considered in relation to the specific types of environment to which people may be exposed.

The school environment

The simple belief that mainstreaming is a positive experience for all children cannot be sustained by reference to the empirical literature. For example, Meyer (2001) reports on a carefully conducted study which meticulously matched 20 pairs of children with 'very severe' disabilities attending either an integrated or a segregated program. Over a two year period she reports that the integrated students as a group outperformed the segregated students. 'However, this was not the case for all the individual children. There were several children in each group who made no progress or regressed on both measures, and nearly half of the children overall made no progress or achieved lower scores at post-test on at least one of the measures.' (p. 15).

Just as it cannot be assumed that all children with a disability will make better developmental and scholastic progress in an integrated environment, so it cannot be assumed that all intellectually disabled children will be embraced by their non-disabled peers. A recent study reported that a majority of non-disabled high school students did not agree that school classes should be integrated (Krajewski & Flaherty 2000). Confirming this view, Cutts and Sigafoos (2001) report naturalistic observations on nine children, Grades 8–12, with a mild/moderate level of intellectual disability, integrated within a large suburban high school in Brisbane. In terms of group average scores, they had a moderate degree of contact with the non-disabled students. However, outliers in small groups can distort average values, and this is apparent in their data.

When the number of contacts was standardized to a scale from 0 to 100, the five lowest ratings for the student as *initiator* of an interaction with a non-disabled student were 0, 2, 3, 3 and 5. The five lowest ratings for the student as *recipient* of an interaction with a non-disabled student were 0, 0, 0, 1 and 1. Moreover these ratings generally corresponded, such that over half of the group had very little recorded contact with their non-disabled peers (see also Margalit 1998).

A further risk factor for the integrated student is the attitude of the teachers to their inclusion in a mainstream classroom. Few teachers have a choice in this matter and may resent the child's inclusion for a variety of reasons. These may include feelings of personal inadequacy to manage a heterogeneous instructional environment, concerns of time distribution between the class members, or even philosophical opposition to inclusive education. And there is no doubt that teacher attitudes to disabled children in such classrooms can have impact on, for example, the child's self-concept (e.g. Jordan & Stanovich 2001).

The work environment

Much of the literature in this area arrives at questionable conclusions because of the following kinds of investigation and reasoning. A sample of people who are disabled and employed at various time-fractions (e.g. full-time, part-time, or unemployed) are assessed in terms of their physical integration. It is discovered that the extent of employment is related to integration, and it is therefore inferred that employment *causes* integration (e.g. O'Neill *et al.* 1998).

An alternative explanation, of course, is that people with higher social skills are more likely to obtain employment, to remain employed, and to score higher on measures of integration. Social competence is solidly related to community integration (e.g. Kennedy 1989) and to subjective quality of life. So the most likely causal direction is shown in Figure 1.

Thus, it should come as no surprise to find that when people with poor social skills are placed into a workplace
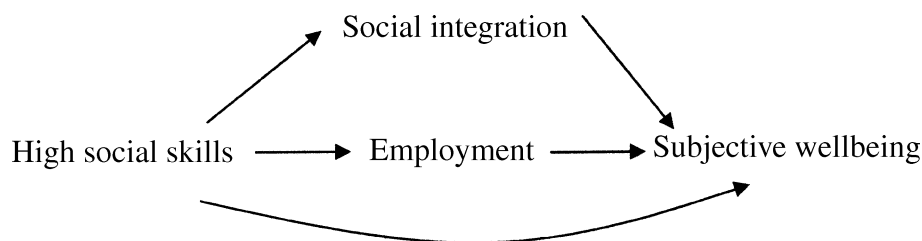

Figure 1 The influence of social skills.

environment, they do not integrate well with other employees.

The general community environment

General communities are not normally benign in their attitudes towards people who are different (see Throne 1979). To a greater or lesser extent people who differ from the norm in terms of their skin colour, religion, or body size will be initially regarded as outsiders more quickly than people who conform to the norms. So, people with a cognitive disability are always going to have an up-hill battle to be socially included in the general community. It is thus commonly reported that people with a disability report encountering prejudice, stigma and discrimination in this environment (e.g. Dewees *et al.* 1996). Such negative experiences are likely to impact negatively on self-esteem (Markowitz 1998) and to undermine the development of a sense of community through creating a sense of alienation. So it is hardly surprising to find that more of these people than normal experience loneliness (e.g. McDevitt *et al.* 1978) and social isolation (e.g. Schalock & Lilley 1986).

In conclusion, the literature suggests that physical integration may be damaging for some people. This reinforces the conclusion reached earlier. The belief that general community integration based on physical presence is necessarily beneficial to the individual, is false. Whether it is beneficial will depend upon many factors, including the level of physical integration that is optimal for the individual in a particular situation.

How can the optimal level of community integration be determined?

From the preceding discussion it is proposed that there are three different perspectives on the optimal level of community integration. These are from professionals, families, and the people who are disabled. For professional caregivers and researchers it seems more is better, as has been stated. For families, choice is important, most particularly in terms of support from services which enables them to retain control over their lives (see, e.g. Knox *et al.* 2000). For people with a disability there is quite a different perspective, and this is whether they enjoy the experience or not. Our view is that this should be the sole criterion for the exposure of people to general community environments. People should be in control of their own level of exposure, and this means an entirely subjective form of evaluation. So what constitutes the positive aspects of community integration at the level of subjective experience?

The first matter to reinforce is that it has very little to do with the objective parameters of community. The joy of community integration has no direct relationship with the number of times people go shopping or the frequency with which they use community recreational facilities. Instead it is a 'psychological sense of community' that is the key construct, defined by Sarason (1977) as 'the feeling that one is part of a readily available, supportive and dependable structure' (p. 14). This emphasizes a sense of community connectedness, of personal interdependency, and belonging. It is closely aligned with the sociological concept of 'social capital' and is inversely related to loneliness. So, in these terms, 'sense of community' obviously cannot mean simply being in the presence of the general public.

In exploring this idea, it is important to realize that people belong to multiple communities. Extended family, sporting club, and ethnic group, for example, are all communities in their own right, but one of these will be primary. The person's primary community provides the values, norms, stories, myths, and a sense of historical continuity (Smith *et al.* 1991; Mankowski & Rappaport 1995). It also exerts the dominant influence over socialization and psychological development (Cox 1989). So which 'community' do authors target when they measure integration? The answer, almost inevitably, is the general community of non-disabled persons.

Measuring integration

The most common measure of community integration is an estimate, provided by caregivers, on the extent of activity within the general community (e.g. Crisp 1996). Such an approach clearly targets the world of non-disabled people as the primary community.

The most widely used scale for this purpose is the Community Integration Questionnaire (Willer *et al.* 1993). This entirely objective index has received substantial psychometric investigation (Corrigan & Deming 1995). It records which person in the household conducts various community based activities (e.g. who usually does the shopping), it measures frequencies of various activities (e.g. how many times each month the person visits friends or relatives), and whether and to what extent the person engages in employment or educational activities. The assumption underpinning the interpretation of the resultant data is that more activity is better for the person being integrated.

A second instrument used to measure general community integration is the Guernsey Community Participation and Leisure Assessment (Baker 2000). This comprises a

checklist of 35 types of community contact, and either the person with the disability or their primary caregiver indicates the frequency of contact over the past six month period. Qualitative data are also collected describing whether each contact was supervised, accompanied by others, or was undertaken alone. The scale author's investigations using this instrument revealed 'a significantly restricted range of activities/contacts', which again implies that more is preferred.

A third instrument is the Index of Community Involvement (Raynes *et al*. 1987, 1994). Again this is a purely objective index which records the participant's frequency of involvement in leisure and community-based activities in the preceding four weeks. A fourth is the Activity Pattern Indicators (Brown *et al*. 1980) in which caregivers provide objective ratings on 91 activities grouped in 12 different categories which include frequency of community contact.

The most recently developed instrument in the Assimilation, Integration, Marginalization, Segregation interview (AIMS: Minnes *et al*. 2002). Ten aspects of integration are rated as: community involvement, access to medical services, speciality medcial and dental services, educational services, employment opportunities, social, housing, spiritual needs, and volunteering. Caregivers provide objective ratings.

So how else is community integration measured in the disability literature? The following is a list of relevant variables, rank-ordered in terms of frequency determined from the studies accessed for this review:
1 The number of activities undertaken within the community (e.g. Felce 1989; Rowles *et al*. 1996).
2 The number or objective character of personal relationships (e.g. Crapps & Stoneman 1989; Smalley *et al*. 1997; McColl *et al*. 1998).
3 Frequency of access to community resources (e.g. Dewees *et al*. 1996; Anderson & Kloos 1992).
4 The number of leisure activities engaged in outside the home (e.g. Anderson & Kloos 1992).
5 Subjective well-being (e.g. Keith 1990).

While the last of these at least shifts the focus to personal experience, it is not by itself a sufficient indicator of community integration success. It seems amazing to note that none of the studies cited for this review measured the extent to which people desire community integration, the satisfaction derived from community integration, or indeed the nature of the community into which people desire to integrate.

From the above, it can be concluded that the vast majority of existing measures, and all of the formal scales, are concerned exclusively with objective integration. This fact creates a heavily biased literature which misrepresents

community exposure as integration because it fails to address the realm of personal experience. One consequence is that the effort to achieve physical integration has been, and continues to be, largely misplaced. With the person's well-being in mind, far more attention should be directed to the area of developing social capital and a sense of community.

How should a sense of community be facilitated?

As I observe the non-mentally retarded population, I see them seeking those with similar interests. It is not common for a so called normal person to seek social interaction, educational opportunities or living circumstances where they are forced to interact with others who are socially different, or who are intellectually superior or who have a totally different life style. We all tend to snuggle into the comfort of being with those whom we perceive to be like us. We don't want to stand out in a crowd. Why then do we suppose mentally retarded persons yearn to live apart from their peers? Do they not have the same right as we do to the comfort of being with others who are much like themselves? Must they always be forced toward a goal which may be unattainable just because many of us consider it normal?' (Hendrix 1981; p. 295).

Most authors who discuss techniques designed to increase community integration concern themselves only with the physical aspects (e.g. Orelove *et al*. 1982; Willer *et al*. 1993; Brewer *et al*. 1994). However, as has been argued, physical exposure is a necessary but not sufficient condition to create a sense of community, and may instead create a sense of alienation. Subjective well-being is linked to social integration, not physical integration (e.g. Burleigh *et al*. 1998), and there is manifest evidence that contact with members of the public tends to be very minimal during periods of community exposure (e.g. Felce *et al*. 1986). A direct observational study of people with severe/profound levels of disability by Saxby *et al*. (1986) found that, during trips to the community, the average proportion of time each person spent in contact with a member of the public was about two percent. The recognition of such limitations requires a re-evaluation of how, precisely, a sense of community can be best facilitated for these people. To this end we propose the following four statements as conceptual building-blocks:
1 The process of normalization involves both physical integration and active participation (Kebbon 1982).

2 People with intellectual disabilities have smaller social networks than is normal for the non-disabled population. Indeed, people in group homes can feel lonely even though they are almost constantly in a social environment (see Malin 1982; Flynn 1987).

3 The social (non-caregiver, non-family) networks of people with intellectual disabilities consists mainly of other people with an intellectual disability (see Romer & Heller 1983; for a review).

4 Well-being is reliably correlated with social connectedness (see Brewer *et al*. 1994). Thus, authors argue that interventions should be directed to creating social opportunities (Brewer *et al*. 1994; McColl *et al*. 1998) and teaching social skills (e.g. Burleigh *et al*. 1998).

One conclusion that may be derived from these four statements is that social integration and well-being can be increased by providing social opportunities and teaching social skills. Unfortunately, however, there are conceptual and technical problems with this approach which few authors address. These are as follows:

1 Increased social opportunity and network size may not cause increased well-being. An alternative possibility is that people with low levels of well-being have difficulty relating to other people, and so create small social networks. If this direction of causation is valid, then interventions should target personal well-being, not network size or social opportunity.

2 Simply bringing people together for some recreational purpose may not generate social connectedness, as assumed by Salzberg and Langford (1981), and Frith *et al*. (1980). This may work for people with normal social skills, but not necessarily for people with cognitive disabilities. While this approach to intervention has high appeal because of its simplicity, evidence of effectiveness in the terms being discussed is lacking.

A technical problem lies with the assumption that people with low social skills can actually increase their skills to a level that substantially benefits their sense of social connectedness with non-disabled people. This is very complex issue and, again, the evidence that this can be achieved for people with severe cognitive disability is slim. As is well understood, cognitive disability is a limiting factor to general social integration (e.g. Fleming *et al*. 1999; Colantonio *et al*. 2000).

In his review of community integration in Britain, Felce (1988) comments: 'Progress towards facilitating a rich social network of friends and acquaintances for people with mental handicap is an aspiration of community service proponents but it is a barely realized reality.' (p. 357). From the literature reviewed here, over a decade later, little seems to have changed, and two conclusions can be drawn. The first is that a sense of community, based on social integration within the general community, is so difficult to achieve for some people with an intellectual disability that it is not a realistic option. The second is that the general community may not be the primary community for people who have an intellectual disability. Solutions to the integration problem may then be proposed based on valuing the community of people with an intellectual disability.

If we, the authors, want to increase our sense of community, we do not go to fun parks, eat at McDonalds, or go shopping. Nor do we associate deliberately with tattooists, bankers or horse trainers. We have nothing at all against such people, but neither do we have much in common with them either. Our sense of community is enhanced by active association with selected members of our own families, and non-family friends with whom we share a common interest of some kind. And if we want to increase the number of people who fulfil this role we search among people who have a similar life profile to ourselves.

So what are the dread consequences of people with a intellectual disability being encouraged to seek companionship, friendship, and a primary sense of community from other people who also have an intellectual disability? Where is the evidence that it is harmful to construct living environments for such people that facilitate the development of a sense of community drawn from themselves, such as cluster housing? The answer seems to be that there are no reliable empirical data that indicate harm through such arrangements, but there is ideological prejudice. In our view, and that of a few previous authors (e.g. Romer & Heller 1983) the crucial issue for the well-being of people with an intellectual disability is their self-perceived social connectedness. Therefore, as many of these people socially bond most readily with others who are similarly disabled, the furtherance of community connectedness, defined within the community of people with an intellectual disability, is a desirable goal. The valorization of social roles as advocated so passionately by Wolfensberger (2000) can be achieved far more easily within a community of people with similar levels of ability than within the general community.

We are not, of course, advocating a return to institutional living. Nor are we suggesting that people with an intellectual disability be inhibited in any way from engaging in voluntary social interaction with non-disabled people. What is being suggested is that we stop devaluing relationships between people who have an intellectual disability, and that we lay to rest the implicit belief that associations with non-disabled people are in some sense superior.

The second kind of action that should be considered is a change in emphasis for the role played by service providers. This would involve a reduced instrumental role concerned with the activities of daily living, which dominates most staff–client interaction (e.g. Felce & Repp 1992), and an enhanced social role. A very cogent argument for such an approach has been provided by Marquis and Jackson (2000). They note, in agreement with the data we have presented, that contact between people with severe disabilities and members of the general public is almost entirely at a casual acquaintance level, if it is there at all. But more importantly, they note from their own research and that of others (e.g. Schalock & Genung 1993), that service providers provide the most frequent and often enduring form of social contact. Indeed, people with severe cognitive disabilities very commonly name their service providers in their list of friends. So surely it makes sense to include the friendship role in the formal job description of service providers? We believe the answer to this is, maybe.

There are, of course, substantial problems in the implementation of such a strategy. A logistic problem would be in the redirection of staff training away from a preoccupation with instrumental support to include active social engagement. This may pose a considerable challenge. Many data are available to indicate that staff do not generally seek to adopt such a role (see Felce 1996; for a discussion of this issue), and that staff training aimed at increasing client engagement results in heightened activity assistance rather than increased social engagement (Jones *et al*. 1997). For example, simply increasing the number of staff does not necessarily result in more staff–client interaction (e.g. Felce *et al*. 1991) even at a formal, let alone informal level. Further, for those staff who are able to adopt such a role, other problems emerge. These include ethical concerns that relate to differential power between the two parties, and problems in the impact of job termination. Despite these issues it is certainly a topic worthy of debate. As Marquis and Jackson (2000) put it:

> Although not a substitute for natural friendships, validating relationships between people living and working in services have potential to provide people with disabilities with a sense of attachment, emotional integration and stability, reinforcement of worth, and the development of confidence in entering other relationships. (p. 422).

Conclusions

Over 20 years ago, Lakin *et al*. (1981) addressed the issue of service policy in the USA as follows:

> The history of our society's policies regarding mentally retarded persons is replete with examples of how, in the absence of systemic scrutiny, sheer belief that what we are doing is appropriate, has led us to faithful adherence for years to counterproductive treatment models. . . . [There is the need for] new and refocused directions in our research, not only to increase understanding and to improve opportunities for retarded people, but also to assess carefully the social consequences of what we do in attempting to reach these goals. (p. 213).

The conclusions we draw from this review are as follows:

1 For community integration to be beneficial for the person being integrated, it must involve a 'sense of community' such that they feel part of a readily available, supportive and dependable social structure.

2 In these terms, community integration is subjective. Thus, objective indicators are not valid for this purpose. They describe levels of community exposure, not integration.

3 For many people with an intellectual disability, the primary community from which a sense of community may be derived is unlikely to be the general community. It is far more likely to be found within families or groups of people who are intellectually disabled.

4 A new literature is required, and new policies need to be implemented that redefine and recognize community integration at the level engendering a sense of community.

Acknowledgements

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