People with profound intellectual and multiple disabilities: Understanding and realising their needs and those of their carers

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Summary

People with profound intellectual and multiple disabilities present significant challenges to those who care for them, and those who commission and manage the services they receive. Section 1 of this report notes, however, the significant changes that have occurred in recent decades with respect to society’s commitment to their inclusion in education and the wider community. The point is also made that such views are from static, and questioning of their right to life, educability and personhood still goes on. Section 2 discusses the problems associated with definitions and classification, adopting the term “people with profound intellectual and multiple disabilities” as a guide to the literature reviewed, but acknowledging its almost certainly temporary nature. A framework described as “ecological” is adopted which takes us from the individual outwards to her or his context in the family, the service setting and the wider community (Section 3). This pattern is followed by considering in turn the development of people with profound intellectual and multiple disabilities and the consequences of their disabilities (Section 4) with specific reference to: developmental expectations (4.1), their growth of understanding (4.2), increasing control of their environment (4.3), their sensory experience (4.4), the development of communication – particularly pre-verbal, and choice making (4.5), and their social and personal development, including issues to do with their sexuality (4.6). In the following section their health and healthcare needs are addressed (Section 5), particularly with reference to epilepsy (5.1), sleep difficulties (5.2), dysphagia (5.3), their medical vulnerability (5.4), and aetiology, specifically with respect to behavioural phenotypes (5.5.). Section 6 follows in which the relatively new area of people with profound intellectual and multiple disabilities and mental health is addressed (6.1), followed by an examination of challenging behaviour (6.2). Though the focus in the foregoing sections is never exclusively on the individual in isolation, in the following sections the framework is broadened in line with the ecological perspective described in Section 3. Thus we consider family caregivers (Section 7), and the wider life in the community (Section 8) with special reference to access – physical (8.1), social (8.2), and intellectual (8.3). The recent literature evaluating models, or types, of service provision for people with profound intellectual and multiple disabilities is then considered, first with respect to service costs, models and outcomes (Section 9), dealing specifically with benefits (9.1), costs (9.2), predicting service outcomes (9.3), and overall costs (9.4). Service models and the processes involved in delivery of a service are considered in (Section 10), where general background is provided (10.1), the importance of participation by service users described (10.2), issues related to specialisation addressed (10.3) and the crucial role of staff is dealt with(10.4). In the final Section 11 we draw the following conclusions:
As we would expect from the definition of people with profound intellectual and multiple disabilities we have adopted, they and those who care for them confront considerable challenges in meeting their personal, developmental and health care needs. What is encouraging is that in recent decades a more positive view has emerged with respect to all three of these areas of their lives. Viewed as people, they have had conferred on them the same opportunities and rights as other citizens, with clear implications for their entitlement to education, healthcare and social provision, ideally on an inclusive basis. Developmentally they are no longer viewed as un-assessable and ineducable. A growing body of careful research has drawn them into a wider developmental framework that allows us to see both their development and potential in a more optimistic light. Their often extreme needs with respect to healthcare are increasingly more adequately met, in part because of the applicability of wider advances in medicine to them, but also because of a growing awareness of the benefits conferred by good healthcare on their quality of life and their ability to function successfully.

These positive changes relative to their situation in the past should not lead us to believe that society as yet comes close to adequately meeting the full spectrum of their needs. We have seen in this review that in general people with intellectual disabilities are disadvantaged in relation to their peers without intellectual disability with respect to many valued aspects of life. In addition, relative to their more able peers, people with profound intellectual and multiple disabilities are most at risk for a wide range of poor outcomes, notably: less choice about their lives, less social integration, fewer chances of employment, a less active lifestyle, more chance of being underweight, and less access to leisure and community-based activities.

It is now quite clear from an extensive research literature that however desirable the move from institutional and congregate settings is for people with intellectual disabilities, placement in apparently “normalised” or “ordinary” settings is insufficient to guarantee a good quality of life. Indeed the message from much of this research, most recently and comprehensively that of Emerson and his colleagues, is that positive and proactive approaches have to be implemented to realise the apparent benefits that may accrue from such settings. This requirement emerges not only from the direct research concerned with beneficial outcomes and service characteristics, but is implicit in much of the information discussed with respect to the communicative and cognitive abilities of people with profound intellectual and multiple disabilities. For communication and understanding to occur, patterns of social interaction have to be significantly modified with respect to their content, form and timing. In addition, and crucially, the person with profound intellectual and multiple
disabilities is heavily dependent on carers to initiate and maintain social contact.

Since it is what occurs in residential and day settings that is crucial to the quality of life of people with profound intellectual and multiple disabilities, and there can be little doubt that this is the case, then commissioners of services, policy makers and service managers have clear obligations regarding the way in which a service operates. Such services require management that ensures that: close attention is given to the quality and quantity of interactions between staff members and users of the service, attention to the planning of activities both in the service setting and in the wider community, careful management of staffing resources and activities, and crucially staff training and feedback. To these we may add the need to support the development of relationships that encourage the achievement of such objectives. All of these requirements argue for knowledgeable and specialised input – dependent upon training that is grounded in the kind of knowledge that is described in this review.

Support requirements are equally pervasive when we turn to healthcare and other behavioural needs. The extensive range of difficulties – sometimes encountered in a single individual – of epilepsy, sleep problems, dysphagia, poor physical and mental health, as well as specific syndrome-related problems, present further challenges. While these have to be dealt with on a daily basis by both professional and family carers, they will increasingly have to be met through both community medical provision and specialist healthcare professionals. Similar challenges have to be confronted with regard to the extremely difficult behaviours that are prevalent in this group, and which damage the person physically and socially.

In all the foregoing areas, there is a need for a complementary input from both generic social and healthcare services, and specialist professionals. While present aspirations are towards an increasing balance in favour of the former, it is important that specialist knowledge and experience are not lost in the process. Whether the balance is re-dressed by passing on specialist knowledge to generic providers, or whether those with such knowledge are incorporated into generic settings, remains an important task for the development of local services. What clearly is crucial is that such knowledge is available to enhance the quality of life of individuals with profound intellectual and multiple disabilities.

The cost of services for people with profound intellectual and multiple disabilities – even within the same types of model – e.g. dispersed community housing, is highly variable. Nevertheless services tend to be more expensive than for more able peers with intellectual disabilities. The overall cost is increased further by the need for specialist therapeutic and
nursing support. Given the importance of staff practice and management already noted, the need to optimise the cost utility of such services is imperative. A failure to do so may lead to decisions that the investment is not worthwhile with a consequent reduction in resources and a lowering of service standards. This issue gains added emphasis in the context of best value assessments and the benchmarking of services.

We have considered above the implications of what is known about people with profound intellectual and multiple disabilities for providing services that enhance the quality of the person’s life. We have also drawn attention to the important role families can play and the need for staff to see them as partners in, rather than obstructions to, what it is hoped to achieve in the service setting. But it is also important to ensure that service providers view the individual’s family in its own right as meriting respect and support. Such a view is consistent with recent legislation relating to carers who confront a particularly onerous day-to-day task in meeting a multiplicity of needs. Services that complement family caregiving include both day and respite provision. In addition, however, approaches to ensuring that information and practice familiar to professionals are shared are being developed and should be made more widely available. Through such initiatives, family carers can enter into partnerships with those who provide services in order to attain a higher quality of life for people with profound intellectual and multiple disabilities than has yet been achieved.
1. Introduction: changing perspectives on people with profound disabilities

The belief that people with profound intellectual and multiple disabilities have the same rights to inclusion in society and to benefit from educational, social and medical provision relevant to their needs is relatively new, gaining coherence during the past 25 years. This is not to say that these rights and the individuals’ potential to develop have not been acknowledged at various times in the past, reaching far back into history as has been shown by Scheerenberger (1983). What distinguishes the contemporary situation is that their entitlements are now formally stated in various declarations of rights, manifestos and legislation. Improving practice supported by empirical research has increasingly revealed a capacity to benefit from a range of interventions with a resultant improvement in their quality of life.

Despite these assertions and general agreement that people with profound intellectual and multiple disabilities are entitled to humane treatment, conflicting positions are still being argued. It is important to acknowledge this state of affairs as no battles in human affairs are ever won in perpetuity and it is important to confront arguments that imply a different vision to that stated in the preceding paragraph. The issue of their right to life, for example, has not been laid to rest (Wolfensberger 1994) as may be evidenced by the recurrent medico-legal debates that are reported in newspapers on a regular basis. Nor is debate over whether they may be considered to have “personhood” anywhere near over. The view that children with profound disability do not possess personhood, on the grounds that they lack the capacity to reason, of consciousness of self, and of self-determination, has recently still had to be challenged. See: (Gruning 1996). While the educability of all people with disabilities has become an article of faith in many educational and adult service settings, a recent literature has emphasised the lack of evidence that all people with profound and multiple disabilities develop in a meaningful way, for example, (Bailey 1981) and hence the inappropriateness of educational provision.

It would be merely evasive to pretend that such debates do not have a reality in reflecting enduring, and honest, differences as to how society should sustain people with profound intellectual and multiple disabilities. This paper, however, is based on:

- the conviction (pace Wolfensberger) that people with profound intellectual and multiple disabilities share the same right to life as other members of society
- agreement with Gruning that their personhood and place as fellow human beings is not in question
agreement with (Baer 1981) that the occurrence of failures to achieve a
given educational goal does not constitute an argument against continuing
the enterprise of attempting to realise such objectives

2. About whom are we talking?

The past 30 years has seen a bewildering variety of terms for what in 1999 we
are referring to as “learning, or intellectual, disability”. In the 1960s “imbecile”,
“idiot” and “subnormal” were current together with “mental deficiency”. It is
interesting to ask who would have used the term “severely subnormal
institutionalised defectives” in a paper published in 1962? Surprisingly it was
someone who was to become the principal advocate of normalisation in the
coming years, Wolf Wolfensberger (Wolfensberger et al. 1963). “Mental defect”
and “subnormality” gave way to “mental handicap” which in turn was replaced by
“learning difficulty” and “learning disability”. The journal in which Wolfensberger
et al. published the paper cited above was then, and for some years after, the
“Journal of Mental Deficiency Research”, but is now the “Journal of Intellectual
Disability Research”. Indeed, “intellectual disability” is rapidly acquiring
international currency (even in the USA) where “learning disability” has always
been regarded as a misnomer, better associated with more restricted problems
affecting specific areas of ability such as reading.

With respect to people with very significant intellectual and physical disabilities
similar progressions can be seen. The use of “vegetative human organism”
(Fuller 1949) would today be viewed as totally unacceptable if not offensive,
though his choice of terminology did not prevent this author from becoming one
of the first psychologists to succeed in demonstrating a capacity to learn in a
person with profound and multiple disabilities. Despite the intention that “learning
disability” would be broadly be applicable to all pupils with special educational
needs, there has remained a need to qualify the term in the case of people who
typically are neurologically damaged and who have physical and sensory
difficulties of an extreme order. We therefore refer to “profound learning
disability” (as we did to “profound mental handicap”) and introduce the term
“multiple” to ensure we capture additional disabilities. Similarly “profound
intellectual disability” has also come into existence. These terms point up how in
the changing terminology we have typically, in the UK, hung on to basic
distinctions between “moderate”, “severe” and “profound” learning disability,
adopting as categorical an approach as was current thirty years ago.

Even as we have come to settle on “profound and multiple learning disabilities”,
(or “difficulties” in educational parlance), so other terms have proliferated.
“Profound and complex learning disability” has emerged with “complexity” also
transferring to the nature of the care required as in “complex support needs”. It is
difficult to know what the term “complex” refers to here as distinct from other
forms of complexity in human behaviour and needs. It is difficult to imagine anything more complex than high functioning autism or any activity more complex than meeting the needs of someone with Alzheimer disease. Perhaps the term conveys some of our bewilderment at the challenges that we have to meet in the face of these particular patterns of disability.

It is highly significant that the American Association on Mental Retardation has abandoned the tradition of distinguishing mild, moderate, severe and profound mental retardation in its latest classification system (American Association on Mental Retardation 1992). Here a system has been developed which reflects theoretical developments in the study of intellectual disability. The system brings into play a wide range of factors that include intellectual functioning and adaptive abilities, but place the person to a greater extent than in the past in an environmental context. For example, there is considerable attention to the person’s profile and intensity of support needs with reference to “intermittent”, “limited”, “extensive” and “pervasive” support. The last accords most closely with what has generally been referred to as “profound disability” in the past. AAMR refers to: “Supports characterised by their constancy, high intensity; provided across environments; potential life-sustaining nature. Pervasive supports typically involve more staff members and intrusiveness than do extensive time-limited supports.” (American Association on Mental Retardation 1992, p.26). In addition, an explicit place in the overall assessment is assigned to aetiology, with a wide range of causes listed (pp. 81-91). The importance of an understanding of aetiology has often been lost in the social-educational orientation that has evolved in the past two decades. The importance for services to individuals cannot be over-emphasised, however, and we return to this below in a discussion of behavioural phenotypes in Section 5.5.

In this paper we have chosen to refer to “people with profound intellectual and multiple disabilities”. It should be clear that we see the term as provisional and only helpful in so far as it focuses attention on those who are intellectually most impaired and who have significant physical and/or sensory impairments that over and above their intellectual status impede their day to day competence. One consequence of this combination is that, as defined above, their needs are pervasive. There is obviously no limit with respect to the degree of impairment or upper limit with regard to the extent of support they require. An upper limit does, however, become more difficult to specify as the range of people conventionally considered as having profound intellectual and multiple disabilities is in reality very wide. Setting such a limit is particularly bound up with intellectual ability, as it is apparent that many people with significant physical and sensory difficulties can cope competently with many communicative and adaptive activities given the appropriate support. To set a limit, however, can only be achieved through appropriate assessment. It has been suggested that a developmental level of 1/5th is appropriate for children (e.g. a ten year old with a developmental level of 2 years, or at 15 years, a three year level), with a mental age not over three years for those over 15 years. Certainly the breadth of abilities in the papers that
provide the basis for this review reflects the range covered by these criteria. Nevertheless, most practitioners in the UK tend to draw the line somewhat below this, with other factors influencing their judgement, including the medical vulnerability of the person. Most importantly, in adopting such criteria, the least able are not excluded, though information on them is in reality the most limited.

3. A perspective on profound intellectual and multiple disability

Explicit in the AAMR classification is the view that the relation between an individual and her/his environment is central to understanding the person and best to provide an adequate service. This view has become increasingly pervasive in the social sciences over the past 30 years, and is variously described as “interactionist” or “ecological”. Thus, the person is not seen simply in terms of some fixed combinations of disabilities, but is seen as acting on and being influenced by– for better or worse –the situation in which she or he lives and develops. This view has had profound consequences on many areas of study, from child development where a simple maturational view of development has been radically altered, through to the nature of psychotherapy. For people with profound intellectual and multiple disabilities, this position emphasises the extent to which their living situation can facilitate development and improve their quality of life, as well as having just the opposite effects.

In the following reviews of our knowledge, we emphasise studies that have shown us how the environment can be structured to benefit the person with profound intellectual and multiple disabilities. Such studies can be viewed in terms of increasingly broad environments, from one-to-one contact, through group settings including the family, to the wider service context.

We therefore follow this pattern by considering in turn the development of people with profound intellectual and multiple disabilities and the consequences of their disabilities (4) with specific reference to: developmental expectations (4.1), their growth of understanding (4.2), increasing control of their environment (4.3), their sensory experience (4.4), the development of communication – particularly pre-verbal, and choice making (4.5), and their social and personal development, including issues to do with their sexuality (4.6).

In the following section we address their health and healthcare (5), particularly with reference to epilepsy (5.1), sleep difficulties (5.2), dysphagia (5.3), their medical vulnerability (5.4), and aetiology, specifically with respect to behavioural phenotypes (5.5). An important area in which we are expanding our vision of the world of the person with profound intellectual and multiple disabilities is that of mental health, which we go on to consider (6.1), followed by an examination of challenging behaviour (6.2).
Though the focus in the foregoing sections is never exclusively on the individual in isolation, in the following sections we broaden the framework in line with the ecological perspective described in Section 3 (above). Thus we consider family caregivers (7), and the wider life in the community (8) with special reference to access – physical (8.1), social (8.2), and intellectual (8.3). We then draw on the recent literature that has evaluated models, or types, of service provision for people with profound intellectual and multiple disabilities, first with respect to service costs, models and outcomes (9), dealing specifically with benefits (9.1), costs (9.2), predicting service outcomes (9.3), and overall costs (9.4). Service models and the processes involved in delivery of a service are considered in (10), where general background is provided (10.1), the importance of participation by service users described (10.2), issues related to specialisation addressed (10.3) and the crucial role of staff considered (10.4). In the final section (11) we suggest how many of these findings are complementary and point the way towards the development of good quality services for people with profound intellectual and multiple disabilities.

4. Development and disability

4.1 Developmental expectations

While the aetiology of profound intellectual and multiple disability is highly variable, significant brain damage invariably leads to a wide range of development difficulties, compounded by significant health problems. While delay in development is an inevitable consequence, the extent and nature of such delay is highly variable. A five year follow-up study compared children with varying degrees of disability with respect to a variety of development outcomes (Eyman et al 1993). Among children who were tube-fed and lacked mobility it was found that the probability of their eventually feeding themselves or achieving mobility was relatively low. In addition, the probability of mortality was higher than for those who were not tube fed and who had mobility. Indeed, mobility itself was a good indicator of better developmental outcomes at all levels of intellectual disability (Rousey & Eyman 1995). Some degree of ambulation at three years of age was associated with continued development of basic skills well past the age at which such development would typically occur. One interpretation of these findings is that lack of mobility is itself a predictor of the degree of neurological damage. Difficulties are compounded, however, by the consequent physical and sensory impairments resulting from this damage. The effects are therefore self-reinforcing and cumulative.

4.2 Developing understanding

The movement to ensure that people with profound intellectual and multiple disabilities have opportunities comparable to their more able peers and those without disabilities has had important consequences with respect to assessment,
education and training. With regard to assessment, the way in which they can progress and their stage of development has been placed firmly within the perspective of child development theory. The most notable example of this approach is the work of Kahn (1987). In a series of rigorous studies he has demonstrated the feasibility of using assessment scales based on Piagetian theory with people with profound intellectual disabilities. Importantly, he has linked such assessments to training programmes aimed at enhancing cognition and communication.

The use of behavioural training techniques has also been introduced into work with people with profound intellectual and multiple disabilities during the past 25 years. Here a key issue is that of the relevance of the learnt behaviour to the individual. Though the demonstration that people with profound intellectual and multiple disabilities are capable of learning was important in identifying this capacity, the use to them of some of the simple motor behaviours acquired has been questioned (Reid et al 1991; Matson et al. 1997). What is perhaps most at issue is not the nature of the behaviour in itself, but the use to which it is put in influencing the environment. For example, a simple act such as raising a finger may have little meaning if trained in an experimental setting. If, however, it is used to indicate choice or activate a device associated with a leisure activity, it immediately has wider relevance to the person’s quality of life.

4.3 Facilitating environmental control

The feasibility of breaking the cycle of developmental deprivation referred to above has increased as technical innovations with the potential to circumvent the consequences of physical and sensory difficulties have become increasingly available. Responsive environments mediated by touch switches, ultrasound beams and other devices open up a wide range of possibilities for positive person-environment interactions (Ellis 1995).

Sensory impairments have well-known and adverse development consequences – as likely to affect people with profound intellectual and multiple disabilities as peers with less extensive difficulties. There is now a wealth of experience in the field of deafblind education relevant to people with profound intellectual and multiple disabilities. Specialist visual and hearing services should also be accessed to introduce expert approaches to sensory impairment and environmental adaptations. Underpinning all approaches to education and training must be careful assessment, particularly challenging in this group with respect to visual functioning (Aitken & Buultjens 1992) as well as hearing (Murdoch 1994). For a significant number of people with profound intellectual and multiple disabilities information on these abilities is lacking or inaccurate, calling into question any attempt made to enhance development through training or education.
4.4 Sensory experience

The importance of sensory experience to the development of people with intellectual disabilities has been acknowledged and documented since the early nineteenth century. In both the education of children with profound intellectual and multiple disabilities (Byers 1998) and adults (Lindsay et al 1997) there has been growing attention to the use of multisensory techniques. A comprehensive review of the research literature considering one specific approach to multisensory stimulation, Snoezelen, (Hogg et al, in press) concludes that the approach has received some support, though much is still to be learnt regarding what it is in the multisensory setting that leads to positive outcomes. In addition, there is considerable variation among individuals in their responses to the same multisensory environment, and as yet we have no idea on how to predict such outcomes.

4.5 Communication and choice

There has been a radical shift away from the view that communication is essentially spoken language to a growing emphasis on non- and pre-verbal forms of communication. The suggestion that someone does not communicate because they lack language, therefore, has diminished from the professionals' perspective, though a proportion of parents still report their daughter or son to be non-communicating (Hogg & Lambe 1988). There is also an acceptance of the fact that behaviour can be communicative even in the absence of an intention to communicate. Both these points and the functional nature of communication are captured in the following: "Traditionally, communication interventionists focused on teaching a beginning repertoire of communicative behavior, once learners with severe to profound disabilities had emitted intentional behavior. Increasingly, interventionists are recognizing that valuable opportunities may be lost if intervention does not begin at an earlier point. In part, intervention strategies at increasingly earlier points have resulted from a prevailing change from semantically-focused intervention logic to pragmatic, interaction-focused intervention logic. At the same time that intervention content has increasingly focused on pragmatics, there has been a wealth of information addressing the social functions served by repertoires of simple idiosyncratic (as well as socially unacceptable) behavior." (Reichle et al. 1993, pp. 25-26.)

This changed perspective has led to a growing exploration of “paralinguistic behaviour” in people with profound intellectual and multiple disabilities, with an emphasis on gesture and vocalisations as ways of regulating the behaviour of others (Ogletree et al 1992). Such a view has naturally led on to the assessment of such behaviour (e.g. Coupe O’Kane & Goldbart 1998) and behaviourial training approaches (e.g. Duker et al 1993). Coupe O’Kane & Goldbart’s “Communication before speech” was developed in a school framework, but with minor modifications is a valuable tool for work with adults.
Awareness has also grown that staff has a responsibility to the person with profound intellectual and multiple disabilities when they attempt to communicate. The nature and quality of interactions has become a prime concern of educators and research workers. Good quality interactions are very infrequent (Hile & Walbran 1991) and tend to be under the control of carers. Efforts have been made to redress this balance and hand control back to the person with profound disabilities. This has involved emphasising reciprocal interactions between the person with disabilities and her carer, as in the example of the technique of "intensive interaction" (Nind & Hewett 1988). The approach of "contingent responding" by the carer to the person's attempt as communication has also been described and studied (Ware 1994). Here staff are trained to give the person time to respond or communicate, and to ensure that an appropriate response is given in return - the "contingent response". This is particularly so when a communication breaks down and the person attempts to repair it. Staff must be sensitive to such attempts by giving more time to the communicative interchange (Brady et al 1995). Time is an important factor here, with carers having to be prepared to wait for what will typically be a slow interaction. Without this, however, the person with profound intellectual and multiple disabilities will have little control over her environment, and attempts to communicate will decline.

The approaches just noted have clear implications for day to day interactions as well as more formal, programmed teaching. Opportunities occur during greetings and farewells as personal care activities (Sommers & Vincent 1996). Group work as well as one-to-one teaching may be employed making efficient use of staff resources (Chia 1995). That interactions can be improved is shown in the work of Nind & Hewitt and that of Ware noted above. Staff attitudes to communication training tend to be highly positive (Golden & Reese 1996).

Despite the encouragement of these positive studies, communication about the person with profound intellectual and multiple disabilities is an important part of the total communicative environment. “Listen to Me: Communicating the needs of people with profound intellectual and multiple disabilities.” (Fitton 1994) describes an approach that ensures that crucial information regarding the person with profound intellectual and multiple disabilities is readily transferable across different situations. “Personal Communication Passports” have also been developed to achieve similar aims.

Any consideration of communication needs must also take into account the use of both manually signed and graphic systems. Makaton, for example, is widely used in services for people with profound intellectual and multiple disabilities. Such systems have the limitation of requiring the “listener” to orientate visually to the sign (Schepis et al 1996). Electronic and microelectronic aids, adaptations and equipment, provide a growing alternative form of augmentative communication (Reichle et al 1993). Electronic switching devices may also be used in choice making (Lancioni et al 1993). Studies describing carefully
evaluated interventions in this area are increasing (Hegarty et al. 1995; Schepis et al 1996), but such work points towards the need for interdisciplinary work between a number of professionals including speech and language therapists and clinical rehabilitation engineers. What is a major concern here is that care staff often have little awareness of what is available or its applicability to their service users. Developments that ensure communication is facilitated to the highest degree are therefore likely to be stimulated by members of such interdisciplinary teams in the light of their assessments.

Among the several functions of communication is the indication of choice. There are two aspects to consider, the methods by which choices by people with profound intellectual and multiple disabilities are determined, and how choice making is made a part of the wider activities the person accesses such as leisure time pursuits.

Much of the work on choice making has focused on how happy or unhappy the person is judged to be by careful observation of facial expressions, vocalisations and bodily movements (Green & Reid 1996). These authors have successfully trained classroom staff in the systematic use of such approaches, and their work is receiving increasing replication (Ivancic et al1997). The latter author did, however, find a subgroup of people with profound intellectual and multiple disabilities who had almost no movement and were not observed to indicate happiness-unhappiness during the programme. Hogg et al (1995) have shown that staff familiar with people with profound and multiple disabilities agree significantly not only on whether a response is positive or negative, but also on the behaviours that lead them to make these judgements. The possibility of using such approaches to evaluate and accredit facilities has also been suggested (Ivancic et al 1997).

For such choice making to be meaningful it has to be integrated into real life settings and affect the course of a person’s activities. A recent review (Lancioni et al 1996) considered what evidence there was that is beneficial, and how choice making affects the quality of everyday life. Certainly there is now clear evidence that it is possible to offer activities on the basis of choices by people with profound intellectual and multiple disabilities. Students with profound intellectual and multiple disabilities have been shown to be able to choose from among a range of occupational activities (Kennedy & Haring 1993; Lancioni et al 1993). Both studies involved the use of electronic devices of varying degrees of sophistication. Observational techniques have more recently been used to determine leisure preferences (Green & Reid 1999).

There are important issues to be considered in responding to choice making by people with profound intellectual and multiple disabilities. It is possible that choices that are damaging to, or at least less than optimal for, the person may result. (Lancioni et al 1996). This issue is addressed in a paper titled: "Balancing the right to habilitation with the right to personal liberties: The rights of people
with developmental disabilities to eat too many doughnuts and take a nap”. (Bannerman et al’s 1990). These authors emphasise that our right to exercise choice is dependent upon learning how to do so in a responsible manner, and that learning about choice making is an essential part of the total curriculum. While this conclusion offers an approach to the exercise of choice, it does not provide a clear prescription as to how this is to be achieved. It does, however, invite us to look at the wider context in which choices are made – i.e. is the choice informed and in the person’s best interest, and suggest that we build opportunities for choice into the life of the person on a long-term basis.

4.6 Personal and social development

It will be apparent that both effective communication and the expression of choice are the basis of social development and maintaining meaningful relationships. Within such a framework, the pattern of a person’s life is established and will determine our expectations regarding the way in which a service should be provided.

An important facet of social development is that of sexuality. Until recently this subject has remained taboo when considered with respect to people with profound intellectual and multiple disabilities. Studies of sexual behaviour have, however, been undertaken (Reid 1995). Here the prevalence of various types of sexual activity are noted. Sexuality, however, is viewed more widely than explicit sexual activity (Downs & Craft 1996), embracing feelings of safety and health, feelings and emotions, self-image and identity, as well as control of one’s life. It has also been proposed that staff become involved in facilitating explicit sexual activity in people with profound intellectual and multiple disabilities (Downs & Farrell 1996), raising important issues for staff, management and relatives. It is clear that the conditions under which such intervention is permissible (or otherwise) and the assumptions and policies underlying such activities must be explicit and transparent. Where intervention contravenes the person’s wishes or is actually illegal, then it will effectively constitute abuse – with the well-documented, adverse consequences.

It is now well established that people with profound intellectual and multiple disabilities are more vulnerable than their peers of the same gender and age to abuse (Sobsey 1994). The prevalence of such abuse among this population is difficult to determine with any accuracy, and estimates in different studies vary considerably (Fenwick 1994). We do know, however, that abuse is most likely to be by paid staff in managed settings (Sobsey 1994). There is a growing literature on developing practices to minimise the possibility of abuse and deal with occurrences of abuse (Thompson 1996). Much of the relevant information will be found in “Approaches to Sexual Abuse of Adults with Learning Disabilities” (Campbell et al 1997), a distance learning course developed in Scotland.
5. The health of people with profound intellectual and multiple disabilities

The healthcare needs of people with profound intellectual and multiple disabilities are high, and their vulnerability to illness and mortality well established. Here we consider the prevalence and management of epilepsy, sleep difficulties, dysphagia and the general of vulnerability, concluding with a brief consideration of the relevance of recent work on behavioural phenotypes to service providers.

5.1 Epilepsy

Of particular concern is the prevalence of epilepsy with 64% of children and 59% of adults reported as having seizures “occasionally” or “frequently” (Hogg 1992). The linkage between epilepsy and profound intellectual and multiple disabilities has been described as epidemiological, aetiological, clinical and therapeutic (Aicardi & Chevrie 1986). Of those with epilepsy, the majority receive prescribed anticonvulsants in a wide range of permutations. Training in the management of epilepsy for both professional and family caregivers is now widely acknowledged as essential, both in their every day lives and with respect to their expectation regarding treatment (Clarke 1990). In Scotland practical steps towards conveying helpful information to caregivers has been undertaken by a collaboration between the Epilepsy Association of Scotland and the Profound and Multiple Impairment Service (PAMIS) through a series of three day evaluated workshops with supportive follow-up.

5.2 Sleep difficulties

The prevalence of sleep difficulties among people with profound intellectual and multiple disabilities is high. Parents reported 86% of their daughters and sons had “occasional” or “frequent” sleep problems, of whom 32% were prescribed drugs with a sedative effect (Hogg 1992). However, it has also been reported that adults with profound intellectual and multiple disabilities and epilepsy spend a disproportionate amount of time in bed, a matter of some concern as noted by the study’s authors (Espie et al. 1998). The impact on the family of sleep loss can be profound and chronic. There is general agreement that protracted use of sedatives is undesirable and that alternative management procedures should be employed. To this end Sleep Scotland, working with PAMIS, have developed a workshop and follow-up intervention to assist family caregivers.

5.3 Dysphagia

Difficulties with feeding are prevalent among people with profound intellectual and multiple disabilities and arise from a variety of causes (Rogers & Campbell 1993). Both dehydration and undernourishment can result from such difficulties. Individualised treatment programmes based on interdisciplinary team working are widely acknowledged to be the most effective approach to such difficulties.
(Arvedson 1993). For individuals whose nutritional needs are not met orally, enteral feeding involving direct introduction into the gastrointestinal tract or paraenastral feeding in which nutrients are introduced directly into the blood stream may be undertaken. With respect to the former a wide range of techniques are now available including orogastric and nasogastric tube feeding or use of a gastrostomy tube. While these medical interventions are well developed, use of such methods can provide challenges to service providers lacking specialist medical provision on a day-to-day basis. This has led in some cases to withdrawal of both day and respite service provided by social care staff. The issue of organisational support for people with intellectual disabilities and nutrition/dysphagia disorders in community settings has been addressed in a Scottish context (Kennedy et al 1997). These authors suggest that caregivers should be supported by a specialist team whose availability ensures those with severe nutrition/dysphagia disorders: “can be competently looked after at home or in community residential facilities, with the resulting improvements in quality of life which a combination of good nutrition and a stimulating environment provide.” (p. 435). The provision of training to social care staff would be a natural extension of such a service and would assist in overcoming some of the difficulties mentioned above. With respect to family caregivers, we can again cite the national workshop programme concerned with feeding and communication undertaken by PAMIS in conjunction with various, specialist NHS staff.

5.4 Medical vulnerability

Comparative data on the prevalence of other medical conditions in people with profound intellectual and multiple disabilities relative to the rest of the population are generally unavailable. Even where comparative large scale studies have been undertaken, it is not possible to extrapolate such information (Kapell et al. 1998). However, the prevalence of medical conditions does appear to be high with family caregivers reporting in one survey (Hogg & Lambe 1988) that 17% of their children had one or more medical conditions, the equivalent for adults being 11%. This difference between children and adults is probably due to differential mortality with the more medically vulnerable children dying during childhood. The principal conditions reported other than epilepsy related in both groups to diseases of the circulatory, respiratory and digestive systems.

The compounding of difficulties arising from the variety of conditions from which people with profound intellectual disabilities suffer may be illustrated by a recent US case study (Lohiya et al 1999). Here a 39 year old with generalised tonic clonic epilepsy sustained 18 fractures over a 19 year period, the majority caused by falls related to the onset of seizures. A predisposition to fractures in such cases may be the result of prolonged anticonvulsant medication leading to osteomalacia or immobility-related osteoporosis. In belated response to this situation, a strategy involving bone-strengthening medication, increased staff supervision, wheelchair safety and careful housekeeping to maintain a safe environment have all been introduced. This case has added significance in the
light of a recent case in Scotland in which during the first six months of a man’s residence in a group house he has sustained five fractures as a result of tonic clonic seizures – in reality a higher rate of injury than that described in the US study.

Research into mortality among people with intellectual disabilities has indicated that the developmental and health aspects associated with profound intellectual and multiple disabilities are highly predictive of mortality. In a recent review (Hayden & DePaepe 1998) the authors draws on ten studies which show that the most frequent predictors of mortality were: nonambulation, tube feeding, lack of feeding skills and major medical problems. In addition, the mortality rate increased with the degree of intellectual impairment. The author’s recommendation, therefore, that there is a need to develop strategies that enable the medical community to become responsive to the needs of people with intellectual disabilities is particularly applicable to those with profound intellectual and multiple disabilities.

5.6 Behavioural phenotypes

As noted above, the justifiably strong emphasis on a social-educational perspective on intellectual disability over recent decades has sometimes led to a failure to perceive the relevance of aetiology to meeting the person’s needs. This has been compounded by the strong behavioural emphasis through which such social-educational objectives have predominantly been met, an approach in which in the past the origins of a behaviour were viewed as unknowable and irrelevant.

One aspect of aetiology that has received increasing attention is that of the behavioural phenotypes of different biologically determined intellectually disabling conditions. Some such syndromes are associated specifically with profound intellectual disability, and those working with service users with these syndromes need to understand the nature of the condition and how best to assist the person. Thus Rett syndrome is thought to occur in every 10,000 to 12,000 female births, and following apparently typical early development, regression occurs with loss of early development skills. Language fails to develop and there is extensive fine and gross motor impairment. Epilepsy may develop and hyperventilation may alternate with periods of breath-holding. Aicardi syndrome similarly affects only females, and again, epilepsy is closely associated with the syndrome, as are visual problems and a failure of language to develop. With respect to some syndromes, the range of ability can be great, with only a proportion having profound intellectual disability, as in the case of Down syndrome.

A detailed account of the full range of syndromes that are entirely or partially related to profound intellectual disability is beyond the scope of this review. What is crucial is for staff and parents to understand fully the behavioural and
healthcare implications of the condition, and the best practice associated specifically with management and education. To this end diagnosis and comprehensive assessment are called for, with appropriate briefing of management and staff. Several books provide brief overviews of a range of syndromes, while fuller information can often be found from specific associations concerned with the various syndromes. The fullest information on such organisations will be found in the regularly updated Contact a Family Directory (Contact a Family 1999).

6. Awareness of mental health and challenging behaviour

6.1 mental health difficulties

In the foregoing we have addressed the multiplicity of health-related problems that the person with profound intellectual and multiple disabilities will almost certainly encounter in some kind of combination. It is important that the existence of these conditions coupled with evident profound intellectual disability do not diminish our awareness that, like any other sector of the population, people with profound intellectual and multiple disabilities can experience significant mental health difficulties. Communicative barriers may increase the difficulty of making a diagnosis and treating such problems. Certainly diagnostic problems exist, especially when we consider diagnosis in relation to the standard international instruments used for psychiatric diagnosis such as DSM-III-R (King et al 1995; Sturmey 1995). The problem of not being able to undertake a psychiatric interview has led researchers to employ physiological techniques such as the measurement of heart rate, use information from carers familiar with the person and behavioural observation. The diagnosis of affective disorders in this population has been attempted with respect to major depression and mania using informants who based their reports on the relevant DSM-III-R criteria (Charlot et al 1993), as well as with respect to depressive disorders (Meins 1996). Stress in people with profound disabilities has been investigated by physiological recording methods (Chaney 1996). This author suggested that stress arises because of the inability of people with profound intellectual and multiple disabilities to control their environment through prevention of, or adjustment to, threatening situations. The diagnosis of anxiety through the identification of behavioural indicators has also been shown to be feasible (Matson et al 1997). The link between epilepsy and mental health problems has been suggested in the wider literature on intellectual disability (King et al 1995; Steffenburg et al 1996), and given the high prevalence among people with profound intellectual and multiple disabilities described above, requires investigation in this population.

It is front-line staff and family caregivers who will be most sensitive to changes that may indicate mental health problems. What is important is that as well as noting change, they should be aware that they can refer the person for fuller
examination and treatment. Training of staff typically neglects this aspect of the carer’s role and its importance needs to be dealt with explicitly. Some of the skills required in communicative settings noted above (Section 4.5) will be called for to ensure that changes in the person indicative of mental health difficulties are observed.

6.2 Challenging behaviour

Many people with profound intellectual and multiple disabilities exhibit significant challenging behaviours, particularly making disruptive sound or noises, self-injurious behaviour and eating inappropriate objects or substances (Hogg & Lambe 1988). The consequences may be not only physically damaging to the person, but make access to the community difficult and preclude opportunities to learn more valued skills. The causes of such behaviours are generally highly complex and may arise from biological, behavioural and ecological influences, or some interaction between these factors (Murphy 1994). Given the diversity and complexity of causation, no single approach to therapy or training is likely to, or has been demonstrated as being, effective. The recent fashion for “Gentle Teaching” has been shown to be theoretically questionable and without support from research (Mudford 1995). This view has received added support from a recent study in Scotland with adults with profound intellectual disabilities who showed challenging behaviours comparable to those just noted. The authors of the paper reporting this work comment: “...we recorded no changes in any of the individual challenging behaviours we recorded using a hand-held computer.” (Cullen & Mappin 1998, p. 209). It is important, therefore, to distinguish between the humane aspirations that motivate the uncritical adoption of “gentle teaching” from the entitlement of people with profound intellectual and multiple disabilities to be treated both with dignity and through demonstrably effective techniques.

The scant claims for “gentle teaching”, therefore, should be set against the extensive empirical findings developed in the framework of applied behaviour analysis, and the growing knowledge of the biological mechanisms that underlie some challenging behaviours (Emerson 1995). The diversity of approaches that have been employed may be illustrated through a consideration of the wide-ranging literature on self-injurious behaviour (SIB) and is indicated in the titles of the following reference (Lockwood & Williams 1994; Turner et al 1996; Mudford et al 1995; Sisson et al 1993; Realon & Konarski 1993). These papers all report some success in suppressing SIB and some considered transfer of the techniques to wider settings. Similar literature may be identified on behavioural work with other key challenging behaviours in people with profound intellectual and multiple disabilities, i.e. stereotyped behaviour and excessive vocalisations.

Despite the existence among non-medical providers of services of what has been described as “an anti-drugs culture”, pharmacological treatment continues to be employed, sustained in part by a growing understanding of the involvement of biological factors in the development and maintenance of challenging
behaviours. Family caregivers reported that major tranquilisers were prescribed for their daughters and sons for 8% who were “making disruptive noises”, 13% who engaged in SIB, and 5% who ate inappropriate substances. Of the total sample of people with profound intellectual and multiple intellectual disabilities, 8% were in receipt of major tranquilizers (Hogg 1992). While pharmacological intervention remains one option for treatment, especially where the behaviour may be life threatening or extremely damaging, the need for interdisciplinary review of such options should be an inherent part of service planning. Behavioural intervention and the exploration of health-related causes such as pain should be the first option in any analysis of causation and intervention.

Staff training in the management of challenging behaviour is a priority in service development, with the availability of support from specialist input. There is now a wide range of training options available including open learning material developed in Scotland (Campbell et al 1996). Specialist support may involve clinical psychologists and/or community intellectual disability nurses or teams established specifically to address issues of challenging behaviour, as in the Additional Support Team in Greater Glasgow. Important considerations arise with respect to the effect of the way in which staff conceptualise challenging behaviour on their ability to manage the behaviour. It has been shown, for example, that such views may not be consistent with the assumptions underlying intervention methods (Hastings & Remington 1994). This situation holds for family caregivers as well (Turnbull & Ruef 1996), and may account for the incompatibility between the coping strategies they have developed, and the way they view the behaviour, and the difficulties they encounter in assimilating formal training.

7 Family needs and aspirations

Parental commitment to caring for their daughter or son with intellectual disabilities is widely acknowledged to be both unconditional and typically long term (Hogg & Lambe 1999). This situation pertains equally when the caregiving is for a relative with profound intellectual and multiple disabilities. It will be apparent from the developmental and healthcare issues described above that such families will encounter additional demands to those families whose relative is more able and in better health. The variety and range of daily care activities is extensive and attention has been drawn to the stress that can arise from coping with such basic care (Lambe 1998). These tasks typically include physical management - lifting, handling and positioning - care activities including dressing, bathing and toileting, as well total assistance at mealtimes. The management of epilepsy and tube feeding as well as other meeting other healthcare needs will also require close attention. Parents report that on average they spend 7.5 hours per day in these activities, with some occupying most of their waking life engaged in these tasks (Hogg & Lambe 1988). This activity is superimposed on, and has
to be integrated into meeting not only the wider social and leisure needs of the person, but also those of the entire family.

While attendance at school or a day service provides an invaluable complement and support to such activities, the way in which families should be supported directly requires consideration. Though not concerned exclusively with profound disability, the following comment is highly applicable to those caring for a relative with profound disabilities: “...Service providers tended to judge them as too overprotective and as inhibiting the social development of their offspring.” (Shearn & Todd 1996) (p. 53.) These authors draw attention to key considerations that service providers have to address if they are to develop true partnerships with parental caregivers: “...how might services offer support to parents that permit them to have a type of lifestyle enjoyed by their peers while at the same time not diminishing their commitment to the parental role? How might advice be offered to families that takes into account the broader social context in which the families operate rather than attributing the issues of overprotectiveness to parental failing alone?” (p. 59.) The implications of these questions requires a radical reorientation of professional perspectives, but fit well with growing awareness of what true consultation and partnership entails. This is clearly captured in the following statement: “The new commitment to listening to the consumer voice goes further than...satisfaction surveys and public meetings. It is about participation of consumers in decision making and meaningful consultation.” (Scottish Consumer Council 1994, p. 1).

A complementary study on staff attitudes to family members with a relative with profound disabilities provides more information on the family-staff relationship (Clegg et al 1997). Here, though the focus was on staff attitudes to the individuals with profound disabilities, view as to how parents treated their adult daughters and sons also emerged. Differing perspectives were expressed, with some staff wishing to challenge parents,— in line with the work cited above (Shearn & Todd 1996), with other staff accepting that family carers were the prime influences in their relatives’ lives and accepting that different types of relationship were beneficial to the person. Staff acknowledged that parents had information and experience relevant to their own, professional, activities. The authors suggest, with respect to the individual’s personal history that this should draw on: “...information from a variety of sources, family members being vital informants; services should explore ways to create an alliance with families so that their knowledge can be used to contextualised clients.” (p. 260.) This suggestion is particularly relevant were the person’s background is culturally or ethnically different, and where less familiar perspectives may come into play.

This need for advice and support to families has been established surveys throughout the UK (Hogg & Lambe 1988; Lambe & Hogg 1995). Information on family needs led to the setting up of a Scotland-based voluntary organisation concerned specifically with profound intellectual and multiple disabilities - PAMIS (Profound & Multiple Impairment Service). The model of support and
empowerment has been described elsewhere (Lambe & Hogg 1999). Extended workshops on subjects chosen by family caregivers are undertaken with relevant, expert professionals. These lead to parent-professional special interest groups who work together to increase opportunities for community inclusion and improve the quality of service provision. The overall model brings together parental carers of people with profound intellectual and multiple disabilities and a wide range of professionals from both health and social services. The partnership acknowledges the special expertise and experience of all involved and provides a context for the development of mutual respect.

8. Life in the wider community

Despite the extensiveness of the developmental and healthcare needs of people with profound intellectual and multiple disabilities, it is important to view them as individuals with rights and capabilities to enjoy the same opportunities as both their more able peers with intellectual disabilities and, indeed, members of the wider community. Thus the aspiration towards increased inclusiveness in society is equally applicable to them, though in achieving this additional significant barriers will have to be overcome. This aspiration can usefully be approached from the perspectives of physical, social and intellectual access.

8.1 Physical access

Legislation is progressively placing increased demands on architects, planners and private and public agencies to ensure that buildings and facilities are fully accessible. Here a wide range of building features related to entering, moving within and leaving a building require specific design attention, as do fixtures, fittings, furnishings, furniture, equipment and materials. Similar considerations apply to access to public transport where minimum standards are to be set.

In most of these areas, however, the specific needs of individuals with people with profound intellectual and multiple disabilities have not been addressed. Conventional toilets for people with wheelchairs are wholly inadequate. Carers report having to lay the person on the floor to change them. There is inadequate space for a wheelchair and transfer to and from it problematical. A design for an appropriate changing facility which includes a height-adjustable changing bench and adequate space for non-standard wheelchairs has recently been both published (PAMIS 1999) and realised in a number of public facilities in Scotland. In addition, a UK-wide campaign has recently been initiated involving over 40 local and national organisations with the aim of ensuring changing rooms meeting this specification are made available in key facilities and areas in the community.
8.2 Social access

Opportunities for people with profound intellectual and multiple disabilities to access a wide range of facilities available to the wider public have increased in recent years. In part this has reflected increased disability-awareness and a policy commitment on the part of, for example, recreation and leisure departments to be fully inclusive in delivering their services.

Access to further education has also emerged as an additional option throughout the UK. The Further and Higher Education Act 1992 introduced new legal requirements in England and Wales with respect to further education provision for adults with intellectual and other disabilities. Parallel legislation was enacted in Scotland Further and Higher Education (Scotland) Act 1992. Adults with profound intellectual and multiple disabilities are covered by such legislation, though the extent to which it has impacted on them nationally is limited. The Tomlinson Committee (Further Education Funding Council 1996) addressing the situation in England and Wales examined available research (Bradley et al 1994), and concluded that together with those with mental health difficulties and emotional and behavioural problems, adults with profound intellectual and multiple disabilities remained mainly excluded. The report recommends the Department of Health and the Department of Education and Employment create a joint strategy and provide guidance and advice to purchasers and providers with reference to adults with “profound and complex learning difficulties.” No specific reference is made to this group, however, in documents dealing with the situation in Scotland (Scottish Office Education & Industry Department 1996; Scottish Office Education Department 1996).

At issue here is the realisation of truly “inclusive learning”. This means “...redesigning the very processes of learning, assessment and organisation so as to fit the objectives and learning styles of the students...” in contrast to “…offering courses of education and training and then giving some students who have learning difficulties some additional human or physical aids to gain access to those courses...” (Further Education Funding Council 1996, p.4). While examples of the latter approach can be found - albeit in a limited way - there is little to indicate that strategic policies of inclusion in further education exist in Scotland or elsewhere.

If leisure and education offer two principal means for people with profound intellectual and multiple disabilities to gain social access to the community, then the issue of the public’s attitudes also merits comment. Given the general segregation of both children and adults with profound intellectual and multiple disabilities from the mainstream of the community’s activities, it is unsurprising that lack of comprehension and hostility are often reported by carers. As with other areas of disability, there is a need to enhance public awareness through both the media and through their enhanced presence in the community.
8.3 Intellectual access

The concept of intellectual access for people with intellectual disabilities has recently gained increasing currency following an arts and museum project in Scotland (Rayner 1999). Intellectual access reinforces and complements social and physical access. It is achieved when understanding and appreciation of a concept or work of art occurs because there is a match between the person’s capacity to understand and appreciate and the way in which the relevant experience is presented. The concept is by no means limited to people with intellectual disabilities. Television programmes explaining complex scientific concepts through careful commentary, analogy and animated graphics aim to make technically difficult material available to a wider non-specialist audience. Through appropriate preparation of the person, and rate and manner in which material is presented, similar improvements in intellectual access can be achieved for people with intellectual disability generally, and those with people with profound intellectual and multiple disabilities in particular (Hogg 1999).

The intellectual access movement is complemented by a growing involvement of both children and adults with profound intellectual and multiple disabilities in a wide range of activities from horticulture (Lambe 1995) to the creative arts (Lambe & Hogg 2000). Both teaching techniques and the availability of the new technologies are making music, the visual arts, literature, drama and dance accessible as both educational and leisure opportunities.

9. Service costs, models and outcomes

Service models for people with profound intellectual and multiple disabilities have been shaped by a combination of explicit and implicit values, as well as by resource availability. This has led to a wide range of different service models with their own adherents, models which have increasingly become the subject of detailed evaluation. This work has focused specifically on the complex relations between types of service provision, their respective costs, and outcomes associated with the quality of life of the users of the service. Of particular help in drawing conclusions from this work is the recently published, Department of Health commissioned study: “Quality and Costs of Residential Supports for People with Learning Disabilities.” (Emerson et al 1999a) The purpose of this study was to identify and explore quality and costs in relation to dispersed, community houses, village communities and NHS managed residential campuses. All facilities studied were recommended as examples of good quality provision by their proponents, and do not in any sense constitute a random sample. Though undertaken in England (a parallel Irish study is on-going), there is little in the characterisation of either the facilities or residents to suggest that similar results would not be found in Scotland.
Before considering the findings with respect to people with profound intellectual and multiple disabilities, we will note some of the broad conclusions drawn regarding residential provision for people with intellectual disabilities in general. It should be noted that in the study, care was taken to ensure that all comparisons were based on equating the level of ability and the extent of challenging behaviour across models, so that like was compared with like. This was undertaken through both statistical control procedures and the comparison of matched sub-samples:

9.1 Benefits

- Forms of provision and benefits: dispersed housing – both group houses and supported living, as well as village communities, all had their own particular strengths and advantages relative to each other. The authors conclude that with respect to the spectrum of available provision, all merit consideration as acceptable options.
- NHS residential campuses that have replaced traditional institutions, however, fared poorly relative to community and village community provision. The authors argue that in completing hospital closure, such campuses should not be considered an acceptable alternative relative to dispersed community provision.
- Nevertheless, the quality of life of people in all types of facility is judged poorer than for those in the wider population without disabilities with respect to inclusion (impoverished social networks), employment (only 4% between 18-60 years were employed), opportunities for choice affecting their lives, and health.
- Further, the broad trends just noted are only trends, and poor benefits can occur in any of the models considered.

9.2 Costs

- For the full sample total adjusted costs, see Table 39, (p.58) (Emerson et al 1999a) followed by the accommodation/non-accommodation split, were respectively: village communities: £44,030 (£36,324/£7,706); residential campuses £45,820: (£41,760/£4,060) and dispersed housing £52,791: (£45,917/£6,874). These adjusted costs take into account differences in the ability, challenging behaviour and age of residents.
- When residents in dispersed housing and village communities were matched for ability, however, there was no significant difference in overall cost or the accommodation/non-accommodation costs. However, following a similar matching procedure, the cost of residential campuses was still significantly cheaper than community provision.
9.3 What predicts outcomes?

- statistically, the type of residential provision was not strongly associated with any particular benefit – though weaker associations in line with the relative benefits of the three main types of provision were found.

- by far the strongest predictor of benefits was the residents’ ability. This was associated with “…greater choice; greater social integration; greater chances of employment; a more active lifestyle; greater overall risk; greater use of leisure and community-based activities.” (Emerson et al 1999a) (p. 12).

- smaller size of residences predicted a number of benefits including greater choice, greater community access and reduce risk of abuse.

- The association between resource inputs and benefits was complex but weak, leading the authors to the important observation: “In light of the generally weak associations between resource inputs and outcomes, it has been suggested that specific internal organisational procedures are likely to play a crucial role in determining the effectiveness and efficiency with which resources are allocated in practice”. (Emerson et al. 1999a, p. 13).

Before drawing out some of the implications of these general findings for people with profound intellectual and multiple disabilities, we will review further the aspect of this study that focused specifically on people directly comparable to those who are the subject of the present review, i.e. a group Emerson et al (1999b) describe as “people with severe and complex learning disabilities”. Here the comparison was between people living in NHS residential campuses and those in dispersed community houses. Across 26 indicators of quality related to service delivery processes, the latter was the preferred model on 14 measures, with no difference on a further 11. On only one measure, staff nursing qualifications, residential facilities were superior. Perhaps surprisingly, however, level of staff contact did not differ between the two models.

Indicators of quality outcomes for residents again favoured dispersed housing in nine out of 24 indicators, with no difference on a further 13, and on only two of which were residential campuses superior – diet and participation in day centres. Level of participant activity was one outcome on which the two models surprisingly did not differ.

Correlational analyses across the whole sample did suggest potentially important aspects of service provision that were associated with higher levels of support and greater engagement by residents. Among there were:

- the amount of assistance and praise given by staff
- the quality of planning for the individual and his/her activities
size of the setting
lack of institutionalisation

9.4 Overall costs

We can now consider the overall cost of service provision and the dis-aggregated accommodation and non-accommodation costs for people with profound intellectual and multiple disabilities. It should be noted that “non-accommodation” cost refers almost entirely to day activities as accommodation plus non-accommodation costs accounts for over 97% of total costs.

Table 1: Accommodation & non-accommodation costs per annum of dispersed housing and NHS residential campus provision for a resident with profound intellectual and multiple disabilities

<table>
<thead>
<tr>
<th>Residence</th>
<th>Breakdown</th>
<th>Cost p.a. (£s)</th>
<th>Range Lowest</th>
<th>Range highest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dispersed community housing</td>
<td>Total</td>
<td>62,140</td>
<td>23,712</td>
<td>107,692</td>
</tr>
<tr>
<td></td>
<td>Accommodation</td>
<td>54,132</td>
<td>22,308</td>
<td>89,180</td>
</tr>
<tr>
<td></td>
<td>Non-accommodation</td>
<td>8,008</td>
<td>1,092</td>
<td>31,356</td>
</tr>
<tr>
<td>NHS Residential Campus</td>
<td>Total</td>
<td>49,452</td>
<td>31,356</td>
<td>62,920</td>
</tr>
<tr>
<td></td>
<td>Accommodation</td>
<td>44,564</td>
<td>27,664</td>
<td>51,438</td>
</tr>
<tr>
<td></td>
<td>Non-accommodation</td>
<td>4,888</td>
<td>364</td>
<td>11,492</td>
</tr>
</tbody>
</table>

First, total costs were significantly higher for the dispersed, community housing than for the NHS residential campuses by 25.7%. Though not statistically significantly different, the accommodation component is also higher by 21.5%. Non-accommodation costs, principally day provision are 63.8% higher for dispersed services, presumably because day activities tend to be campus based in the NHS provision and are not costed separately. However, it is important to note the remarkable range in both settings, particularly the dispersed housing facilities, and the overlap between the facilities in the two types of provision. Thus the lowest cost placement in dispersed provision is cheaper than the cheapest in NHS provision.

Second, total costs in making provision for people with the high level of need of people with profound intellectual and multiple disabilities exceed the average total costs for these models for people with intellectual disabilities generally, £62,140 Vs. £52,791 (17.7% increase) in the case of dispersed housing and £49,452 Vs. £45,820 (7.9% increase). These estimates of increases are on the conservative side given people with
profound intellectual and multiple disabilities are included in the wider figures.

For people with profound intellectual and multiple disabilities there emerges a picture of better quality of care in dispersed community housing with respect to resource inputs, the social environment, approaches to dealing with residents and beneficial outcomes. The costs of small scale community provision are higher, though there is appreciable overlap among the facilities from the two classes of residence. Similarly, the authors of these studies report variability in quality of provision within facilities in a given model, e.g. among group homes.

It will also be noted that there is considerable variability in the non-accommodation costs between models and across facilities within a model. As in the case of accommodation costs, however, needs have an important bearing on day provision, costs that will increase with the severity of the disabilities. Against the background of the overall non-accommodation costs and the associated ranges for people in dispersed houses, it is relevant to compare day service costs from three adult resource centres in a local authority in eastern Scotland. Centres 1 and 2 deal with a broad spectrum of intellectual disabilities but typically not people with profound intellectual and multiple disabilities. The third provides a five day a week centre-based service to adults with profound intellectual and multiple disabilities as defined at the outset of this review, and closely in line with Emerson et al’s (1999b) criteria. It is a highly specialised service established specifically to meet the needs of this population and its caregivers. The numbers vary considerably across the three services, and again we present average costs per annum. The percentage of the total social work department budget allotted to staff costs, property costs, supplied and services and transport costs in the financial year 1999-2000 appears in columns 3-6.
Table 2: Annual total cost per services users and relative costs of day service provision for a service user with intellectual disabilities in three local authority centres

<table>
<thead>
<tr>
<th>Facility</th>
<th>Total cost (£s)</th>
<th>% staff costs</th>
<th>% property costs</th>
<th>% supplies &amp; services</th>
<th>% transport costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4,095</td>
<td>80</td>
<td>3.1</td>
<td>8.2</td>
<td>9.7</td>
</tr>
<tr>
<td>2</td>
<td>4,955</td>
<td>79.7</td>
<td>3.9</td>
<td>7.5</td>
<td>8.9</td>
</tr>
<tr>
<td>3</td>
<td>18,490</td>
<td>74.1</td>
<td>13.2</td>
<td>6.5</td>
<td>6.2</td>
</tr>
</tbody>
</table>

It will be seen that though the cost of the specialist facility 3 (£18,490) falls within the range of non-accommodation costs reported by Emerson et al (1999b) (£1,092-£31,356), it is 4.5 times more expensive than Facility 1 and 3.7 times more expensive than Facility 2. However, proportionally staff costs contribute slightly less to the overall cost, while property costs are proportionally higher, due to the specific character of this facility's building.

Social work input to Facility 3 in complemented by nursing and therapy provided by the associated Primary Healthcare (NHS) Trust. These costs appear in Table 3.
Table 3: NHS contribution to costs of Facility 3

<table>
<thead>
<tr>
<th>Service Component</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse (FT)</td>
<td>21574</td>
</tr>
<tr>
<td>Dietician (0.2)</td>
<td>5267</td>
</tr>
<tr>
<td>Senior Occupational Therapist (FT)</td>
<td>22219</td>
</tr>
<tr>
<td>Senior Physiotherapist (0.8)</td>
<td>18731</td>
</tr>
<tr>
<td>Travel</td>
<td>1666</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>...............69544</td>
</tr>
</tbody>
</table>

These additional costs represent a further £4,636 p.a. per person, adding to the total Social Work Department contribution of £18,490 to a total of £23,126, 36% less than the highest non-accommodation cost in Emerson et al’s study as given in Table 1 (above), though nearly three times greater than the average non-accommodation for people living in dispersed housing. For notional purposes, if we add the non-accommodation cost of Facility 3 to the mean accommodation costs for dispersed housing in Table 1 (£54,132) we arrive at a total of £77,258 p.a. for each person with profound intellectual and multiple disabilities living in dispersed housing and receiving a day service comparable to Facility 3. It is important to note, however, that with respect to Facility 3 a majority of the service users live with their families and overall cost is therefore reduced. In addition, no claim is made to this figure being representative, but is cited here as indication of possible overall cost of community care for a person with profound intellectual and multiple disabilities.

Information on further NHS costs related to the extensive health needs of people with profound intellectual and multiple disabilities is not available. Nor, with one exception, do we have an indication of the cost utility of specific healthcare interventions. In an exploratory study of orthopaedic and surgical interventions for people with profound intellectual and multiple disabilities, it has been shown that the cost of such interventions...
compared favourably with routine surgery in the wider population and resulted in measurable improvements in the health quality of life of people with profound intellectual and multiple disabilities (Neilson et al. 1999). What is needed is a fuller study of such costs and the benefits of such interventions across this population and employing representative sampling. This will permit an overall costing of services for people with profound intellectual and multiple disabilities other than routine healthcare.

10 Service models: processes and specialisation

10.1 Background

The information considered above presents a picture of relatively high cost of services for people with profound intellectual and multiple disabilities, coupled with a clear indication that their environmental circumstances can lead to distinct benefits – or disadvantages - for them. In particular, living in relatively normalised housing, whether group houses or supported living, offers the potential for a beneficial option relative to NHS campus style provision. However, it is equally clear now from several years of research, including most recently, that of Emerson and his colleagues, that the particular models of provision does not in and of itself automatically lead to beneficial outcomes. While a domestic setting provides an optimal base in which to provide for a person, attention also needs to be focused on what has been called the “micro-organisation of settings” (Felce 1998).

In considering what goes on in the service setting, however, it is also important to consider what the person brings to it and the risks to which they may be exposed. Emerson et al.’s finding that a resident's ability is the strongest predictor of the benefits experienced has a particular resonance for provision for people with profound intellectual and multiple disabilities who are by definition the least able among people with intellectual disabilities. They therefore at risk because of a number of factors identified by Emerson et al (1999a). They have:

- less choice
- less social integration
- fewer chances of employment
- a less active lifestyle
- more chance of being underweight
- less access to leisure and community-based activities

The challenges posed by these risks - coupled with healthcare issues be dealt with above - indicates that considerable thought needs to be given to individual planning and the processes involved in working with the people
with profound intellectual and multiple disabilities. These risks also raise a fundamental question as to how within the current ethos of inclusion and non-segregation the obvious need for specialist support and input can be incorporated.

10.2 Enabling participation

There is now widespread agreement that life in an ordinary setting does not automatically guarantee a productive, engaged life either in that setting or in the wider community. What needs to be undertaken to achieve such aims involves active intervention with those who are at risk as noted in the previous section. This is admirably captured in the following statement. The pursuit of these aims: “...also involves changing performance away from the traditional allocation of activity to residents on the basis of their ability to do activities independently and creating an alternative which emphasises the absence of exclusion of residents from participation and the provision of support to help those people who lack skills to accomplish activity successfully. It also involves changing performance away from traditional laissez-faire attitudes to what activities residents may or may not do and creating an alternative which gives positive motivation to achieving that level of functional activity which everyone else transacts to live an ordinary life. Finally, it involves changing performance away from the traditional low emphasis on the organisation of opportunities to participate in activity and creating an alternative which establishes a level of commitment, staff competence and managerial monitoring to ensure this happens.” (Felce 1998) (p. 116).

The principal elements that will enable us to achieve such aspirations in the context of small, ordinary, non-institutionalised settings are by now clear. They entail:

- close attention to the quality and quantity of staff-person interactions
- attention to the planning of activities
- careful management of staffing resources and activities
- staff training

The growing body of detailed studies of people with profound intellectual and multiple disabilities with respect to the ways in which they communicate their experiences and choices, and the effect of the context in which they communicate, provides an essential contribution to this agenda.

10.3 To specialise or not to specialise?

The clear implication of the work described immediately above is that apparent normalisation or “ordinary” living circumstances do not produce the benefits for people with profound intellectual and multiple disabilities
that have been anticipated by the proponents of such views. Indeed, the evidence suggests that this conclusion applies equally to their more able peers with intellectual disabilities, though here ability in itself confers numerous advantages. As noted, this signals the need for carefully thought out and managed interventions. In what setting can such interventions be made most effective with respect to enhancing choice and participation? What is the place of specialised practice and expertise?

A small number of studies have addressed this issue with respect to residential and day provision. Though not focusing specifically on profound intellectual and multiple disabilities, comparison has been made between four models of provision for people with intellectual disabilities and sensory impairment (Hatton et al, 1995). These facilities consisted of residents integrated into ordinary group houses, specialised group houses, and campus-style facilities, one model in the community the other within a traditional institutional setting. Using a number of measures, the specialised group house model emerged as offering the highest quality service and best resident lifestyle. The service was not associated with higher costs or staff-resident ratios. This reflected many of the processes noted above, notably high levels of structured activities, staff assistance and positive contact and encouragement. In contrast, the other three models were judged as less well able to provide the combination of structure and skilled learning environment observed in the specialised group house. While the ordinary group house fared well in certain community indicators, the lack of specialisation was reflected in low overall staff contact and assistance. As in the later work by Emerson and his colleagues reviewed above, however, Hatton et al emphasise the within-model variability, and the overlap in quality that results.

A similar conclusion was drawn with respect to day provision by Rose et al (1993) who found specialised day provision (within a learning disability service) produced more favourable outcomes than integration within the service. These authors are at pains to argue, however, that the findings do not argue against the possibility of more integrated provision providing an equally good or better service. To effect more positive outcomes in a more integrated setting, improved staff practice and management, in line with the findings of Emerson and his colleagues reported above, would probably be critical influences.

10.4 The crucial role of staff

The importance of staff in creating a good quality living environment and positive outcomes for people with profound intellectual and multiple disabilities is well documented, though the relations between staff and outcomes is complex. There is a weak relation between staff ratios and
the contact actually received by service users in residential settings (Emerson et al 1999a), though these same authors report that user engagement in constructive activities is dependent upon specific assistance provided by staff. The extent to which such positive outcomes are realised are dependent in large measure on management policies and practice, one aspect of which is staff training.

Training models and curricula abound, and have increasingly focused on training relevant to community settings (Mörch & Eikeseth 1992; Demchak & Browder 1990). While evaluation of the degree to which staff acquires competence has been central to such training, the benefit for service users represents the ultimate desired outcome. (Parsons et al 1996). These authors investigated such outcomes with respect to a “Teaching-skills Program” and its evaluation with staff working with “students who had profound mental and physical disabilities”. They demonstrated positive outcomes for staff following brief training and practice. Outcomes for service users were more limited, but are reported. The overall approach also addressed the issue of efficiency with respect to time and resources available for training. These authors acknowledge the important role of feedback through discussion between staff and management as well as systematic record keeping. The balance between time spent in record keeping and active intervention is one which each service must determine, and daily record keeping may weight this activity too heavily (Matson et al 1998).

While good management and staff training in the context of a community setting represent the bedrock on which a good service is developed, staff attitudes towards relationships have also been shown to be highly significant (Clegg et al 1997). In this study staff in a range of service settings for people with profound disabilities were given the opportunity to conceptualise their relationships with service users. The “snapshots of relationships” (p. 253) they reported were analysed and suggested four types of mutually exclusive relationship: (i) “The provider”: This type of relationship is one in which the staff member sees him/herself as caring for the person’s basic needs, but not providing emotional warmth or developing a two-way relationship. Nor is the person with profound disabilities seen as entering into any relationships with others. The provider relationship had negative aspects to it, with staff sometimes feeling they had failed to engage the person in a social relationship. None of the staff who viewed their relationships as of the provider type considered this desirable, and some experienced strong feelings of rejection, sometimes referring to the relationship as being one of “love-hate”. This did not stop staff trying to develop the relationship, and none of the relationship types should be viewed as necessarily permanent; (ii) “The Meaning-maker”: The meaning-maker is engaged in trying to understand the person as a person, not just his/her attempts at
communication, but also the moods and feelings of the person. The effort put into understanding was great, and the importance of interpreting gestures and expressions, acquiring background information and having discussions with family and colleagues were emphasised; (iii) “The Mutual relationship”: The authors here refer to the “…shared joy concerning teaching and learning or developing knowledge of the client…”, and “…an element of companionship…” (p. 253). The descriptions of mutual relationships are emotionally very positive and staff are confident in their understanding of the person. Staff had known service users for at least two years. They were aware that the rewarding nature of the relationship posed difficulties for maintaining a balance in order to meet their responsibilities to other service users in the facility. (iv) “The Companion”: Again, the authors’ description conveys this relationship clearly: “…a quiet component of shared time. It often involves touch, people holding hands or just sitting together. The sense of trust and emotional comfort exists without demand or excessive stimulation.”(p.254).

These relationships are valued in different ways by staff themselves, with that of “the provider” giving most cause for negative feelings. The study does not offer any firm picture of the relationship between service users’ characteristic and carer-types, though the authors suggest that unstable epilepsy and other health-related problems were more likely to be associated with “the provider” and “meaning-maker” relationships. The authors emphasise that management should encourage:

- support for relationship building through encouragement of staff-user contact, in and out of the service setting, and through discussion with colleagues and family;
- supervision of relationships, which would include staff having a say as to which service users they have special responsibility for;
- support for staff where relationships are difficult, particularly where the service situation has a detrimental effect, e.g. where there is high staff turnover or no key worker system;
- the development of histories of service users through preparation of reports, video diaries or photograph albums. An annual record of events may be documented in the same way; families may contribute to such records.

11. Conclusions

As we would expect from the definition of people with profound intellectual and multiple disabilities we have adopted, they and those who care for them confront considerable challenges in meeting their personal, developmental and health care needs. What is encouraging is that in recent decades a more positive view has emerged with respect to all three of these areas of their lives. Viewed as people, they have had conferred on them the same opportunities and rights as other citizens, with clear
implications for their entitlement to education, healthcare and social provision, ideally on an inclusive basis. Developmentally they are no longer viewed as un-assessable and ineducable. A growing body of careful research has drawn them into a wider developmental framework that allows us to see both their development and potential in a more optimistic light. Their often extreme needs with respect to healthcare are increasingly more adequately met, in part because of the applicability of wider advances in medicine to them, but also because of a growing awareness of the benefits conferred by good healthcare on their quality of life and their ability to function successfully.

These positive changes relative to their situation in the past should not lead us to believe that society as yet comes close to adequately meeting the full spectrum of their needs. We have seen in this review that in general people with intellectual disabilities are disadvantaged in relation to their peers without intellectual disability with respect to many valued aspects of life. In addition, relative to their more able peers, people with profound intellectual and multiple disabilities are most at risk for a wide range of poor outcomes, notably: less choice about their lives, less social integration, fewer chances of employment, a less active lifestyle, more chance of being underweight, and less access to leisure and community-based activities.

It is now quite clear from an extensive research literature that however desirable the move from institutional and congregate settings is for people with intellectual disabilities, placement in apparently “normalised” or “ordinary” settings is insufficient to guarantee a good quality of life. Indeed the message from much of this research, most recently and comprehensively that of Emerson and his colleagues, is that positive and proactive approaches have to be implemented to realise the apparent benefits that may accrue from such settings. This requirement emerges not only from the direct research concerned with beneficial outcomes and service characteristics, but is implicit in much of the information discussed with respect to the communicative and cognitive abilities of people with profound intellectual and multiple disabilities. For communication and understanding to occur, patterns of social interaction have to be significantly modified with respect to their content, form and timing. In addition, and crucially, the person with profound intellectual and multiple disabilities is heavily dependent on carers to initiate and maintain social contact.

Since it is what occurs in residential and day settings that is crucial to the quality of life of people with profound intellectual and multiple disabilities, and there can be little doubt that this is the case, then commissioners of services, policy makers and service managers have clear obligations regarding the way in which a service operates. Such services require
management that ensures that: close attention is given to the quality and quantity of interactions between staff members and users of the service, attention to the planning of activities both in the service setting and in the wider community, careful management of staffing resources and activities, and crucially staff training and feedback. To these we may add the need to support the development of relationships that encourage the achievement of such objectives. All of these requirements argue for knowledgeable and specialised input – dependent upon training that is grounded in the kind of knowledge that is described in this review.

Support requirements are equally pervasive when we turn to healthcare and other behavioural needs. The extensive range of difficulties – sometimes encountered in a single individual – of epilepsy, sleep problems, dysphagia, poor physical and mental health as well as specific syndrome-related problems, present further challenges. While these have to be dealt with on a daily basis by both professional and family carers, they will increasingly have to be met through both community medical provision and specialist healthcare professionals. Similar challenges have to be confronted with regard to the extremely difficult behaviours that are prevalent in this group, and which damage the person physically and socially.

In all the foregoing areas, there is a need for a complementary input from both generic social and healthcare services, and specialist professionals. While present aspirations are towards an increasing balance in favour of the former, it is important that specialist knowledge and experience are not lost in the process. Whether the balance is re-dressed by passing on specialist knowledge to generic providers, or whether those with such knowledge are incorporated into generic settings, remains an important task for the development of local services. What clearly is important is that such knowledge is available to enhance the quality of life of individuals with profound intellectual and multiple disabilities.

The cost of services for people with profound intellectual and multiple disabilities – even within the same types of model – e.g. dispersed community housing, is highly variable. Nevertheless it tends to be more expensive than for more able peers with intellectual disabilities. The overall cost is increased further by the need for specialist therapeutic and nursing support. Given the importance of staff practice and management already noted, the need to optimise the cost utility of such services is imperative. A failure to do so may lead to decisions that the investment is not worthwhile with a consequent reduction in resources and a lowering of service standards. This issue gains added emphasis in the context of best value assessments and the benchmarking of services.
We have considered above the implications of what is known about people with profound intellectual and multiple disabilities for providing services that enhance the quality of the person’s life. We have also drawn attention to the important role families can play and the need for staff to see them as partners in, rather than obstructions to, what it is hoped to achieve in the service setting. But it is also important to ensure that service providers view the individual’s family in its own right as meriting respect and support. Such a view is consistent with recent legislation relating to carers who, as we have seen, confront a particularly onerous day-to-day task in meeting a multiplicity of needs. Services that complement family caregiving include both day and respite provision. In addition, however, approaches to ensuring that information and practice familiar to professionals are shared are being developed and should be made more widely available. Through such initiatives, family carers can enter into partnerships with those who provide services in order to attain a higher quality of life for people with profound intellectual and multiple disabilities than has yet been achieved.
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