Report to: Senate Inquiry into Aged Care
From: Associate Professor Rosalie Hudson, RN, B App Sci, B Theol, M Theol, Grad Dip Geront Nsg, PhD. FRCNA (Fellow of the Royal College of Nursing Australia), FAAG (Fellow of the Australian Association of Gerontology).
Date: (amended) 12.01.05
Re: (c) the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness of specific conditions are met under current funding arrangements.

Summary

This submission is made by a former director of nursing (DON)/manager of Harold McCracken House, a 50 bed nursing home in North Fitzroy under the direction of the Board and CEO of Melbourne Citymission, a non denominational Christian welfare agency. The report comes from my experience of five years' supervision of the care of Mr Christopher Nolan who entered the nursing home in 1996, aged 28 years. Christopher had been in St Vincent's hospital for six months with an Acquired Brain Impairment (ABI) of unknown origin. When it was deemed no longer appropriate for him to be in an acute hospital his parents were advised to seek long-term nursing home care. Long-term rehabilitation in a centre suited to that purpose was not an option since his injury was non compensable.

The case study describes in detail my perceptions of the first five years of Christopher's care at Harold McCracken House. I have structured the account according to the 44 Commonwealth Standards of care issued from the *Aged Care Act 1997*, applicable to all aged care facilities in Australia. It is demonstrated that in each category, the care provided was inadequate to meet the very complex medical and nursing needs of this young person with ABI. Christopher's admission posed an enormous challenge for the nursing home. With our philosophy of *partnership in care* every effort was made, in consultation with Christopher's family, to overcome the obstacles and to 'give it our best shot'. This conclusion is reached, however, that accommodation in an aged care facility is totally inappropriate for a young person with ABI. The story of Christopher also exemplifies the inadequacy of current funding arrangements to meet his complex needs.

Christopher remains in the care of Harold McCracken House while facing a very uncertain future due to the impending closure of the nursing home. Some recommendations are offered for the type of accommodation best suited to Christopher's needs. These include (for the full list of recommendations, see p 16):

- decision-making by those who know him well;
- opportunity to explore creative options in a context where no existing model seems appropriate;
- a philosophy of partnership in care, where all decision making is shared with Christopher and his family;
- small unit where the needs of the individual are not subsumed by a large number of people;
- consideration of the social needs appropriate to his age;
- an environment where personalised care, tailored to meet his individual needs, is not constrained by bureaucratic decision-making; and

- a style of accommodation that will best allow him to pursue a ‘normal’ life in accordance with his personality, his age, and his values.

It is suggested that the Commonwealth funds already allocated to his care as a Category 1 ‘aged care recipient’ be re-allocated to a setting not only where his continuity of care will be maintained in accordance with best practice, but to a setting where the continuous narrative of his life is honoured and given creative expression. It is also imperative that suitable recurrent funding be allocated which addresses the inadequacy of the current Slow To Recover (STR) baseline funding.

A group of Christopher’s friends and families have been meeting regularly since June 2004 to develop a comprehensive model of care for Christopher, which may well be adapted to suit the needs of other young people with ABI or similar needs. This document provides historical and narrative continuity of Christopher’s life course and is supported by the latest research.

The urgency of formulating a policy for Christopher’s ongoing care is demonstrated by the fact that he has had seven case managers in eight years, none of whom carries the memory and continuity of who he is as a person, or the factors that will contribute to an optimum environment for his long term care. Christopher’s mother, Mary Nolan, has assumed the role of ‘quasi case manager’, coordinating all of his care on a daily basis in the absence of an appropriate professional advocate. As the research into ‘ageing carers’ shows, this situation is not sustainable in the long term and is neither in the best interests of Christopher or of his parents.

TABLE OF CONTENTS

A CASE STUDY OF ONE ABI RESIDENT IN HAROLD MCCRACKEN HOUSE 4

PREAMBLE 4

ADMISSION TO HAROLD MCCRACKEN HOUSE.. 4

PHILOSOPHY 5

THE NURSING HOME ENVIRONMENT.. 5

CHOICE.. 6

COMMONWEALTH STANDARDS FOR NURSING HOME CARE (1998).................. 6

STANDARD 1: MANAGEMENT SYSTEMS, STAFFING AND ORGANISATIONAL DEVELOPMENT.. 6

STANDARD 2; HEALTH AND PERSONAL CARE……………………………...…… 8

STANDARD 3: RESIDENT LIFESTYLE.. 11

STANDARD 4: PHYSICAL ENVIRONMENT AND SAFE SYSTEMS……………..14

CONCLUSION 15

RECOMMENDATIONS 16

CURRENT DECISION-MAKING PROCESS (JANUARY 2005) 17

A case study of one ABI resident in Harold McCracken House

Preamble
I was the DON/manager at Harold McCracken House for twelve years (1989-2001) and have recorded in some detail Christopher's journey in that place from his admission in 1996 until my resignation in 2001. My current role is Aged Care/Palliative Care Consultant, and (honorary) senior fellow in the school of nursing, University of Melbourne.

Admission to Harold McCracken House
In 1996 I was approached, as director of nursing (DON)/manager of Harold McCracken House (50 bed nursing home in North Fitzroy under the direction of the Board and CEO of Melbourne Citymission, a non denominational Christian welfare agency), to consider admitting Mr Christopher Nolan, aged 28, for long-term care. Christopher had been in St Vincent's hospital for six months with an Acquired Brain Impairment (ABI). While working in Hanoi as a lawyer he was found unconscious on the morning after celebrating his birthday with an Australian friend. There was no identified cause for his hypoxic brain injury, and it was some time before he was given appropriate medical care and several weeks before he could be flown to Melbourne. When it was deemed no longer appropriate for him to be in an acute hospital his parents were advised to seek long-term nursing home care. Long-term rehabilitation in a centre suited to that purpose was not an option since his injury was non compensable. The aged care legislation allowed for admitting a younger person to a nursing home in circumstances where no other option was available.

Christopher's parents were advised to test the suitability of Harold McCracken House, a nursing home that enjoyed an excellent reputation and was geographically suited to Christopher's needs. Location was one of the most important factors guiding the family's decision; this nursing home being central to many of Christopher's friends from school, university, the legal fraternity and popular music venues. It was also essential for Christopher to be close to St Vincent's hospital where he was well known, and where he could receive emergency care when necessary.

The shock to his family and friends of this totally unexpected brain injury, of no known origin, cannot be measured. Further, the shock of finding him in a nursing home where the average age of residents was 82 years was something many of Christopher's friends and family found impossible to reconcile. It was clear that Christopher required expert 24 hr nursing care; however, his medical/nursing needs were outside the range of normal expectations of aged care. It was considered feasible to attempt to accommodate Christopher's needs at the time with the additional funding available through the Slow to Recover (STR) program. Without this additional funding for intensive allied health assistance, additional personal care, equipment and other therapies, his admission would not have been considered. At the time of his admission his long-term prognosis was unknown and his medical status was very fragile. His health status is now much more robust and he has a normal life expectancy. Christopher remains in the care of Harold McCracken House while facing a very uncertain future due to the impending closure of the nursing home. I offer this case study to the Senate Enquiry in order to demonstrate the *inappropriateness* of young people with acquired brain impairment being accommodated in a residential aged care facility. With reflection on eight years experience it is clear that the aged care environment is not a suitable long-term option. Christopher's story also exemplifies the inadequacy of current funding arrangements to meet his complex needs.

Philosophy

Basic to the care of any nursing home resident is the agency's philosophy. Harold McCracken House vision statement focuses on *partnership in care*; that is, partnership with the resident, family and all carers. Caring for people with Acquired Brain Impairment (ABI) also occurs within the cultural pre-suppositions of the times. One such presupposition is that nursing homes are 'the end of the line' and persons with ABI who have high support needs and show little hope of significant recovery are also at 'the end of the line'. While there is currently no alternative to 'placing' these (non compensable) people in nursing homes there is also outrage at the current state of affairs, such as the perceptions articulated in a 1999 SBS *Insight* program:

- 'languishing in nursing homes'
- 'forced to inhabit nursing homes'
- 'lock young people up in nursing homes and throw away the key'
- 'they're just left'
- 'unproductive care'
- 'it's a moral problem to discard people'

The nursing home environment

It is readily acknowledged that the care in some nursing homes is below the required standards. It is also acknowledged that, where no alternative exists, a cultural change is required to make nursing homes 'young people friendly'. One very strong prevailing attitude suggests power and control rather than partnership: "Staff are the carers and patients are the patients"[1]. Thus, a change of culture is required in which the family are considered part of the team and staff are open to learn from both the resident and their family. It is also interesting to note that nursing home care and rehabilitation are often perceived as mutually exclusive terms. A 'slow to recover' program is alien to the experience of most aged care staff and cannot be integrated without extensive staff education, for which there is clearly no funding. Aged care is provided in a context where older people enter 'the last chapter of their lives' facing impending death within (on average) 9-12 months. The concept of a younger person with much longer life expectancy requires different attitudes and values in order to achieve goals of care. It is clear that the approach to aged care is *not* rehabilitation, whereas a rehabilitative approach is *precisely* what a person with ABI requires.

Commenting on the reason why many nursing homes refuse to accept younger ABI patients, Tierney notes: 'Their increasingly loud, often offensive and aggressive behaviours disrupt the smooth running of the nursing home with both staff and residents feeling frightened and threatened.[2] While these factors were not an issue in Christopher's case, his lack of sight, movement and speech were, together with his younger age, indicators of specialised care well beyond the abilities of most staff. There were other components of his care (to be shown below) that were considered disruptive and threatening to the smooth running of the nursing home.

---

[1] Tierney, Joan. 'Building better practice - the challenge of institutional choice'. Headway conference 1998.

[2] Tierney, Joan 1995 (unpublished) Final Report., GPEP grant No 389, p1.

Choice
It is inferred by the prevailing negative view of nursing home 'placement' that families have been unable to exercise choice in the decision. While for some there may be no alternative and such placement is viewed as a 'last resort', for others the choice may be deliberate and planned. In this case, the family were faced with the dilemna of 'last resort' as well as carefully choosing the best of the very few options. There was an element of hope at the outset, that, in spite of the difficulties, we could make this 'work'.

A younger person with ABI who is admitted to a nursing home is subject to the same standards of care designed to meet the needs of older people. These standards form the basis of a comprehensive evaluation, demonstrating the inadequacy of an aged care facility to appropriately meet Christopher's needs.

Commonwealth Standards for nursing home care (1998)
Forty-four Standards are grouped under four main headings. Twelve of the forty-four standards relate to (1) continuous improvement, (2) regulatory compliance, (3) education and (4) staff development. All other standards fall within this framework.

Standard 1: Management systems, staffing and organisational development.
Comments and complaints
As for all residents in an aged care facility, the younger person has the right to expect that every aspect of care will be based on comprehensive review, with the goal of excellence and highest quality of care continually at the forefront. Essential to continuous quality improvement is the concept of a complaints procedure and grievance policy to be utilized by the resident and/or representative without fear of reprisal. In this situation, however, where the external professionals and the family were better acquainted with Christopher's needs than were the nursing home staff, there was a constant threat of reprisals when any complaints regarding suboptimal care were formalised. Rather than being seen as an occasion for dialogue, such comments and complaints were more often seen as a threat, signifying the lack of confidence felt by many nursing home staff in this new situation for which they were unprepared emotionally and educationally.

Planning and leadership. From the first day of negotiation for a place on the waiting list, the family's perceptions, expectations and priorities were paramount. However, partnership depends on good communication where all members of the medical, nursing and allied health team share with the family as part of the team. This requires planning and leadership from the DON and senior nursing staff. Responsibility for all care under the *Aged Care Act* 1997 remains with the director of nursing, who in this instance required additional time to co-ordinate Christopher's multi-faceted care and to ensure staff were adequately resourced and skilled. In this situation all these factors created an imbalance in the amount of time spent coordinating the care of this one resident compared to the other 49 aged residents. Also, as the care of a person with ABI was outside my own experience, my own research required an additional commitment to plan the best response to his needs. It is readily acknowledged that such a commitment leads other staff to regard this imbalance as 'unfair', resulting in a negative perception for many staff who refused to treat him as 'special'. In directing the focus of Christopher's care I was most fortunate in having Christopher's mother (Mary Nolan) as the 'expert' who had learned through her own direct 'hands on' experience of Christopher's care and from her own research. Planning for Christopher's care involved selecting a small

group of staff who were willing to learn about his care needs, and to commit to belonging to a 'primary care' team. This concept is alien to most nursing homes and while there were benefits for Christopher in having a group of 'experts' involved with his care, this model did not always sit easily with other staff.

Human resource management. In this 'slow-to-recover' model, much of Christopher's care was supervised by allied health professionals within the terms of a strict funding regimen. This posed its own difficulties with regard to coordination of services, space for visiting health professionals to write notes, make phone calls, etc. The ideal of these 'expert' professionals supervising the care of inexperienced staff was impossible to achieve, given the nursing home staffing resources. It also requires skilled ongoing communication to clarify roles of these visiting personnel. Then, as the 'slow to recover' funding was reduced from year to year, the expert physiotherapy, occupational therapy, speech pathology and many other services were no longer available, to Christopher's long-term detriment. Furthermore, in order to strive for coordinated care, it was important for the DON to liaise regularly with Christopher's 'case manager'. This is quite outside the normal expectations for coordinating the care of other aged residents, and imposes a significant resource burden. Residents are admitted to a high care facility when it has been assessed they require 24 hour nursing. Such residents have the right to suitably experienced and qualified nursing staff. There is no such expectation that staff will understand the complex care needs of a younger person with ABI, leading to an impossible matching of education needs with available resources. On many occasions, this led to suboptimal care; a distressing, potentially life threatening experience both for Christopher and the cause of incalculable anxiety for his family. There was also a clearly pervasive attitude by many staff: 'I'm experienced in aged care and I don't want to learn about this specialised ABI care'.

The increasing predominance of unqualified staff working in nursing homes can only be briefly alluded to here. In reality it means that only a very small proportion of staff have the professional capacity to meet the specialised nursing needs of a younger person with ABI. In reality this meant Christopher's safety was often compromised due to inadequate staffing resources.

Inventory and equipment. Younger ABI residents require access to specialized equipment for transport, daily hygiene and toileting needs, as well as space and equipment for therapeutic programs. Adequate storage space, together with adequate space to accommodate a team of therapists leads to a resource problem not required by older nursing home residents. The personal belongings of a younger resident may require additional space in order to create a 'homelike atmosphere'. Staff training in the use of specialized equipment and the maintenance thereof is an essential component of high standard care. Again, this requires complex management of scarce physical and human resources. While the initial funding regimen allowed for oversight of equipment by relevant specialists, as the funding reduced, so the care of the equipment was compromised. Nursing homes are not built to accommodate such complex equipment.

Information systems. Family members of ABI patients/residents may desire access to all file notes and wish to participate in documenting progress reports. This aspect is, of course, based on comprehensive assessment to identify the family's needs and choice. While such access applies to all nursing home residents or their families, the option is seldom taken up. This issue requires a climate of trust to prevent staff feeling threatened by family members reading

the case notes. However, it should encourage best practice in objective documentation, which fulfils legal requirements, but also acts as a comprehensive communication tool. The coordination of this documentation was beyond the capacity of the senior nurse (unit manager); hence, it became impossible to maintain an orderly record of Christopher's care. Documentation and the reading of same becomes a significant resource factor as the clinical records expand to proportions far exceeding those of other residents. The most efficient means of electronic communication is not a viable option, due to lack of resources. The size of Christopher's file notes exceeded by far the file notes of any aged care resident. Nursing homes do not have 'ward clerks' who would normally be responsible for the very important task of filing these legal documents.

Standard 2: Health and personal care

Clinical care. A pivotal factor in the maintenance of good clinical care is the availability of a medical officer who understands the particular needs of the person with ABI. It is also essential that resources allow for appropriate education directed by the doctor to the nursing staff and other team members. It is also assumed that such medical leadership of the team derives from best practice. The nursing home has the responsibility to assure appropriate medical oversight for all residents. How is this to be achieved when so few doctors have any experience or knowledge of the care needs of a person with ABI? In this situation, Christopher's care required additional resources beyond what is normally available in a nursing home. His complex medical needs required a continuously updated care plan to be followed in the case of a variety of medical/surgical crises to which he was prone; and to liaise with his several medical specialists outside the nursing home. This also required coordination with family and medical personnel, and clear lines of communication with the acute hospital; all this is well beyond the range of 'normal' aged care medical oversight. In other contexts the medical officer would also play a role in educating other members of the health professional team. This procedure is beyond the scope of most GPs, and is not remunerated.

Specialized nursing care needs. In Christopher's situation, the following factors required significant time and expertise, in excess of requirements of the other 49 residents:

- **Medication management**. Staff were unfamiliar with many of Christopher's medication needs, posing a daily challenge for safe practice. Staff should be thoroughly educated about all medication they administer; however, it could never be confidently claimed that this level of expertise was reached, given the unique properties of Christopher's medication requirements and the lack of appropriate resources to provide ongoing education for all staff involved.
- **Pain management**. Caring for an ABI resident with very limited means of communication requires skill in determining levels of pain. Family members who know the person well, are often in a position to note such symptoms. However, this collaboration is difficult to achieve unless there is a climate of trust. It also requires ongoing education for all staff, particularly when caring for a non-speaking person, to note the cues indicating the need for pain to be treated. Of course, this includes a high level of skill in understanding the psychological, spiritual and emotional causes of pain as well as the physical. While Christopher was never able to articulate the level of pain and discomfort derived from contracted limbs, gastrointestinal complications of artificial feeding (to name only two of many probable sources of pain), it required skilled assessment followed by consistent pain management to be effective. Again, the lack of resources resulted in fragmented care; the level of pain Christopher endured as

a result, can never be calculated. It was often left to Christopher's mother to advocate on his behalf, at times having repeatedly to request pain medication for him. In many instances this exacerbated staff's feelings of 'threat and interference by a relative'. The resolution of these complex communication challenges could not always be met within the available resources.

- **Nutrition and hydration**. In the care of an ABI resident nursing staff are directed by the consultant dietician who establishes and reviews goals, particularly for PEG or PEJ feeding (tube feeding into the stomach or jejunum), together with the speech pathologist who assesses the person's ability to swallow with safety. Because of funding cuts and the lack of nursing home resources Christopher was not able to enjoy what should have been a gradual transition from tube feeding to oral feeding. This requires skill and time beyond the resources of the nursing home; both in terms of nursing expertise and the catering department's requirement to meet the nutritional needs of aged residents. Therefore, a young man with eclectic tastes in food was unable to enjoy this aspect of 'quality' in his life; pragmatic issues of time and other resources took precedence over the meeting of one of his basic needs – the enjoyment of food.
- **Skin care.** While aged care staff are familiar with the requirements for skin care in the older population, the same staff were totally inexperienced in caring for a person with ABI who has contracted limbs and the continual threat of bedsores. While initially staff were guided by an appropriately qualified physiotherapist, as funding was reduced, so the expertise was lost. Resources did not allow for the continual education needed to allow nursing home staff to acquire new skills in this area.
- **Continence management**. Bowel and bladder care require particularly sensitive attention; particularly in a younger person. When communication is compromised, the younger resident may not be able to convey his embarrassment, frustration and anxiety over lack of control of these normal bodily functions. Staffing resources and educational preparation were inadequate to meet these needs, which required a consistent approach to ensure regular timing of continence management and to regularly evaluate the success of the program, with a clear focus on issues of dignity. While staff were accustomed to the importance of continence management for the older adult, they would have benefited from additional education with respect to the younger adult. In Christopher's case, he was unable to articulate his need for assistance with bowel and bladder function; therefore staff who were unskilled in his communication needs were unable to respond to his toileting needs. It was impossible to educate every staff member appropriately, with the regrettable outcome that Christopher's personal dignity and comfort were often poorly addressed.
- **Behavioural management**. Failure to understand the communication needs of a person without sight and without speech gives rise to value judgements from staff who do not understand the implications of an acquired brain injury. Because of this ignorance, many staff treated Christopher as though he could neither hear nor understand. Family members contribute to a greater understanding of this area of care, provided staff have the time to converse with them. A person with no sight or speech, and with minimal independent movement does not manifest the difficult or challenging behaviours common to some other brain impaired younger people. However, Christopher's basic human right to have his communication needs met required a level of understanding, education, perception and experience well beyond the capacity of most nursing home staff. With adequate resources, staff can be guided by appropriately qualified 'experts' in this area. While a small group of dedicated staff

took time to learn how to communicate with Christopher, in reality his communication and behavioural needs remained largely unmet by other staff.

- **Rehabilitation**. The concept of ‘slow to recover’ requires education and an attitudinal change in nursing home staff who do not generally see much ‘recovery’ in other older residents. It is beyond the experience and capacity of most nursing home staff to consider focussing on short and long term rehabilitation goals, when the majority of their focus is on aged residents who will die within several months of entering the nursing home. Without such a positive focus on goal-setting, the ABI resident has to ‘make do’ with the most basic tasks necessary to be attended on each shift. The demoralising effect on the ABI resident can only be imagined; and the physical affects are noted under the various headings throughout this case study.
- **Oral and dental care**. One would think this routine component of care should be unproblematic. However, in my experience, this area of Christopher’s care was fraught with difficulties, largely due to inconsistency and lack of sensitivity to his needs. When a person’s swallowing is compromised it becomes a matter of extreme importance to see that oral and dental care is performed with the utmost safety. In caring for a person with ABI, expertise is needed to guide staff who have no experience with the complexity of care required. The implications of inadequate oral and dental care for a young person in Christopher’s situation cannot be overestimated in terms of dignity, comfort and self respect; particularly when he is totally dependent on his carers for every aspect of his personal hygiene. Sadly, attention to this area of his care often took a low priority while staff were busy attending the needs of the other 49 residents.
- **Sensory loss**. Christopher gives every indication that he hears well. While he has no sight his other senses appear to be sharpened; particularly his capacity to respond to voices and to atmosphere, as well as to touch. Because of the nature of his brain injury, however, it requires heightened awareness and skill of staff to understand the implications of his sensory changes. The person best placed to counsel and teach staff in this area is the occupational therapist and the physiotherapist. However, when these resources are restricted to a minimum, aged care staff are denied the opportunity to sharpen their skills, resulting in failure to understand the implications of sensory deprivation. Again, one cannot begin to imagine how this loss is experienced by the person with ABI.
- **Sleep.** Nursing homes have traditionally played out the pattern of ‘early to bed’ for most residents. As there are few options available, older residents usually comply with the prevailing attitude of ‘in bed before the night staff come on’. Questions need to be raised as to whose needs are served by this expectation of early bedtime for residents of any age. Clearly, another set of criteria is needed in order to understand the sleep patterns of the younger person with ABI. Christopher’s life pattern was ‘late to bed and late to rise’ (particularly on weekends) and the nursing home routine needed to be adapted to suit his preferred pattern. In practice, however, this meant that if Christopher was taken out in his wheel chair late at night, suitably qualified, experienced staff were not always available to meet the complex, time consuming process of settling him to bed. The responsibility would inevitably fall on his family or carers to perform duties that clearly belonged to the professional carers. To care adequately for a younger ABI person means the accepted nursing home routines have to be questioned; a challenge beyond the capacity of most aged care staff. For those who have the understanding, the resource problem is a continual constraint. This has seriously impacted on Christopher’s quality of life, as one of his joys in life is to go

out with his mates and return *late.*

Standard 3: Resident lifestyle

- **Emotional support**. Family members are best placed to advise staff on the younger resident’s need for emotional support. Issues of fear and anxiety, the need for reassurance, the encouragement to express feelings, are all essential components of care, requiring sensitivity and understanding. While emotional support clearly belongs with the mandate ‘holistic care’, the emotional needs of a younger person with ABI are generally outside the experience of staff accustomed to caring for older persons. Few staff understand the need for ‘normal’ companionship in this context; nor is there any guidance available for those staff who may become ‘emotionally attached’ to the younger ABI resident. Conflicting opinions inevitably arise and staff are prone to making judgements about their colleagues whom they perceive to be overstepping professional boundaries. There is no guidance for aged care staff in this area and additional resources would be required for the required continual dialogue and education.
- **Independence**. One of the main areas of independence for Christopher is in the area of friendship. Long term care has the potential for creating a complex array of relationships and the younger (and older) nursing home resident has the right to pursue such friendships without fear of judgment. All residents also have the right to be protected against unwanted friendships or unprofessional relationships. Because of his complex disabilities Christopher has very little capacity to exercise independence with respect to developing friendships. He has the ability to indicate ‘yes’ by making a long eye blink. However, many staff have not taken the time to ‘learn’ the style of communication required for Christopher to exercise this right, with the result that his independence in making choices is often compromised.
- **Privacy and dignity.** Christopher cannot see his immediate environment. It is therefore important to reassure him he has privacy for toileting and hygiene as part of his routine daily care. Treating him with dignity also encompasses the issue of sexuality. The needs of all nursing home residents include the expression of their sexuality, which in broad terms covers intellectual, emotional and psychological needs as well as the specifically sexual. However, the sexuality needs of a younger ABI resident require additional education and discussion within a sensitive environment based on sound knowledge and advice from appropriate consultants where necessary. The younger resident has the right to sexual expression without fear of judgement, humiliation or loss of dignity. Sexuality deserves a place in the care plan along with all other physiological and emotional needs. However, normal sexual function should not be ‘problematised’ unnecessarily. It is also essential for the nursing home to develop policy statements within clearly defined parameters which guide staff and prevent a clash of conflicting interests.[3] However, as one staff member commented: ‘I came here to work with older people. I don’t want to be involved with this stuff.’ The issue of understanding the sexual needs of a young man regaining consciousness following months in a coma requires expertise and skill completely outside the resources

---

[3] Nay, Rhonda and Gorman, Don. ‘Sexuality in aged care’, pp193-211. In Nay, R and Garratt, S (1999) *Nursing older people.* Sydney: Maclennan+Petty. While this book is clearly for aged care nursing, this chapter contains some helpful guidelines towards a comprehensive sexual health policy for any institution.

available in a nursing home. Hence, another of Christopher's 'quality of life' needs remained largely unmet.

This Standard (privacy and dignity) also covers the issue of death and dying. A 'terminal care wishes' assessment form is completed for all nursing home residents. This ensures wishes regarding hospitalisation are noted, together with other religious or cultural factors surrounding death. The issue of resuscitation has been faced many times by Christopher's family, who have formulated clear guidelines that are documented and require regular review. This issue has different implications for a younger person than for older nursing home residents, requiring careful and sensitive communication and understanding of complex ethical issues – factors often beyond the experience of aged care staff.

Privacy and dignity are also essential factors in considering shared room accommodation or private room accommodation. In this nursing home there are four single rooms only; so for the first few years of Christopher's accommodation he shared a room with three older men (usually well over 80 yrs and in various stages of dementia). While Christopher's family described him as a 'gregarious young man who loves people of all ages' nothing could have prepared him to share his *whole life, day and night* in such a confined space with these other residents, many of whom died in the years he shared a room with them. The effect on the other residents and their families was mixed; some welcoming the arrangement and others resenting the 'inordinate' amount of time spent on Christopher's care. When he was finally transferred to a single room, the effect was positive in terms of privacy, notwithstanding the inadequate size of the room which is totally unsuited to more than two visitors at any time.

- **Leisure interests and activities.** Based on careful assessment with maximum input from family and friends, Christopher pursues as many 'normal' activities as possible within the limits of his confinement to wheelchair and dependence on others for movement. A major factor is the regular home visits and 'late outings' which require careful co-ordination. Night staff in nursing homes are not usually prepared for a 3am homecoming by a resident after a night out, so this area requires a re-adjusting of attitudes. A welcoming atmosphere is not easy to foster in an environment where night staff are accustomed to seeing all residents in bed by the beginning of their shift. It is almost impossible for Christopher to experience 'normal' evening and night time activities to which he'd been accustomed. As one friend commented:

  'I feel restricted when visiting him at a nursing home, and feel I have to whisper for fear of waking the other elderly patients. Christopher needs raucous conversation, sometimes with an 'R' rating to keep him stimulated. . . I need to feel that I can talk, joke, swear, play music, or turn on a game of footy, and not feel that I will be upsetting any senior citizens when doing so' [4]

  While it is necessary to restrict one's expectations when visiting a person in a short-stay hospital environment, the nursing home is supposed to be the resident's 'home'. However, it is also home to 49 older residents. It is therefore difficult, if not

[4] Craig. 'Inability Possability' (2004) 'Still the doors are open – writings of life.'

impossible, to meet the needs of the younger ABI resident in this environment. Space is restricted, limiting the number of visitors at any one time, and the lack of lounge and external space makes it an uninviting place for friends to visit. The catastrophic result is, of course, that many find the difficulties insurmountable, so they stop visiting.

- **Cultural and spiritual life.** Understanding Christopher's background is the determining feature to understanding his spiritual needs. As far as possible, Christopher's family continue a regular pattern of religious rituals that have been a continuing part of their life. There is no guidance for staff to understand this vital component of 'holistic care'; so these needs remain largely left to the family. While there is no particular 'ethnicity' factor in Christopher's cultural needs there are many cultural factors of lifestyle and belief systems, which guide Christopher's life and require some understanding on the part of his carers. The cultural context of Christopher's life includes his professional life as a qualified lawyer, his abiding interest in music and sport, together with the normal cultural pursuits of a young, single male. These issues are not necessarily understood in the context of staff caring for older people who are far removed from active involvement in these cultural pursuits.
- **Choice and decision making**. Many of these issues are taken up (above) in the section 'independence'. To exercise choice Christopher requires the skilled framing of questions so that he can respond within his limited capacity. In reality, however, resources do not allow the time and skills required; therefore, apart from the committed 'primary care team' Christopher is at the mercy of those who *assume* they know his needs. *This issue is now critical as Christopher now has to leave the familiar, if inadequate, environment of the nursing home, to seek other accommodation. He needs to be as fully involved as possible in the choice of his future 'home'.*
- **Security of tenure and responsibilities**. This issue comes into sharp focus as Melbourne Citymission has stated its intention to close Harold McCracken House before the 2008 certification restrictions are imposed. What are Christopher's options now and who will guide the family to consider options for his future care? Although Christopher's disabilities are profound, he has a normal life expectancy. Who will take responsibility for his relocation, not merely by providing him with another nursing home bed, but to creatively examine alternatives more appropriate to his age and special needs? What happens when his parents (his main carers) are no longer able to speak for him? What happens to the nursing home's obligation (under the Aged Care Act) to provide security of tenure in these circumstances?

  On the issue of responsibilities, no resident has the right to impose unfair burdens on resources to the detriment of other residents' care. However, where a nursing home is required to care for a younger ABI resident, there are obvious competing interests. The younger resident shares with *all* residents the responsibility of not intruding on others' privacy or access to care; however, this imposes enormous challenges as the younger person's needs are *unequal* to those of the older residents. The harmony of the nursing home requires a balance of these rights and responsibilities which is almost impossible to achieve. While Christopher's family have taken every care not to impose on the rights of other residents, it is inevitably seen by some staff, residents and relatives, that his accommodation in this context is totally inappropriate.

Standard 4: Physical environment: safe systems
This Standard covers occupational health and safety issues, infection control, security, cleaning and laundry services. Both direct care staff (nursing and allied health) and indirect care staff (maintenance, catering, domestic, etc) require education and information regarding the complex needs of a younger resident in an aged care facility. Issues of confidentiality, inappropriate judgements (eg regarding the cause/s of ABI), competing needs, fears and anxieties need to be carefully monitored. However, in reality, many non nursing staff expressed resentment at the unrealistic expectations placed on them in having to meet the needs of a younger person when they sought employment in an *aged care* environment.

Living environment. While institutionalized care cannot replace the intimacy and freedom of home life, it should be acknowledged that the facility becomes 'home' for the person requiring care and for their visitors. In contrast to the stereotypical view of nursing homes as 'smelly ghettos for the dying and demented', any facility accepting the long term care for *any person, regardless of age* is challenged to provide a warm and welcoming atmosphere where families and friends have free access to 24 hour day visiting. A profound change is needed in order to reverse the abhorrence felt by some family members who cannot bring themselves to visit a nursing home.[5] This common perception is compounded for Christopher's friends, who had no prior experience of visiting a nursing home. In reality, some find it impossible and so they withdrew. If the living environment were more amenable to visitors of all ages, Christopher's quality of life would be vastly improved.

This Standard also includes the issue of *restraint* which involves any restriction on free movement. In Christopher's experience it may best be described as *considered risk taking versus duty of care*, illustrated by the following *vignette* (some details changed to protect confidentiality):

Christopher enjoys being taken out by his friends. This involves wheeling his large custom made wheel chair over the uneven footpaths of the suburban street, to the welcome and refreshing greenery of the nearby park. Christopher feels the wind through his hair, the sun on his face and even the rain when unexpectedly caught in a downpour – all fairly normal events for most of us. On a particularly hot summer day Christopher was taken on his usual outing. His friend later recounted they'd had the "best outing ever" and had stayed out longer then expected. When they returned to the nursing home the new, well meaning nurse was outraged. Why were they back so late? Didn't they know it was 30 minutes past his (tube) feed time? "And look at him! He's perspiring from heat exhaustion. He must go straight to bed. Are you not aware he could easily suffer from dehydration?" His friend, deciding retreat was the best defence, hurriedly bid his good-byes to Christopher and left.

What may be learned from this episode? Had the nurse realised a little more of Christopher's background she would have known how much he enjoyed the sun, and extreme heat never bothered him. Christopher was accustomed to sweating profusely when expending energy in the heat. He was a risk taker and coming home late would not have filled him with anxiety. The nurse, on the other hand, was concerned for his welfare, afraid perhaps she would be blamed if he became ill. Another nurse decided it was time to write a prescriptive care plan governing such incidents in the future; for example, 'He can only be taken out if the temperature is below … .' Thankfully, this idea was abandoned following discussion with

[5] Tierney, Joan. 'Rehabilitation following very severe brain injury – patient/family satisfaction with outcome''. *International perspectives in traumatic brain injury*, p376.

family. Some staff were reassured by the family's insistence that Christopher be 'allowed' to take risks, while others wanted to erect tight and secure boundaries - for whose protection?[6]

This vignette only touches the surface of this complex issue: how to balance the person's rights for risk taking with the agency's duty of care. While this is an issue for all older residents in nursing homes the issue is far more complex in the context of a younger person with ABI. It is also well documented that in the area of residential aged care, factors of *loneliness, isolation and boredom* are frequently experienced. These are of course issues of vital concern to all older residents; they are significantly heightened in the experience of a younger person. These problems of loneliness, isolation and boredom could be largely overcome for Christopher if the accommodation were more suited to his social needs.

Factors not covered by the Standards

Adequate funding base. The Commonwealth RCS (resident classification scale) at its highest level (category 1) does not adequately cater for the needs of this younger person with ABI. Additional (State government) funding provides case management, including occupational therapy, physiotherapy, speech pathology, dietary support and some medical oversight. However, in order to provide holistic care 24 hours per day, the care team requires adequate supervision and direction from the qualified consultants. Funding for ongoing education, support and de-briefing is essential for the provision of high quality care based on best practice. While the RCS provides for support for resident and family and for some liaison with other services, the requirements of an ABI resident far exceed the intention of this funding scale. The RCS is also a reductionist framework devised merely as a funding tool and which takes no account of 'slow to recover' programs. The 'slow to recover' program is, itself, severely limited in terms of resources; the needs of newer people being admitted to the program mean that Christopher's needs (as one of the longest on the program) go to the bottom of the resource allocation list.

Conclusion

Christopher's eight-year residency at Harold McCracken House has provided an opportunity for a small group of committed carers to become intimately acquainted with his needs, and to develop skills that are transferable to other people with similar disabilities. While at many points his care has been sub-optimal, at others he has enjoyed trusting relationships with his 'primary care team' in whose care he feels secure. Being admitted to a residential aged care facility seemed to be the only option at the time, and through the ensuing eight years much has been learned. Now that the nursing home is closing the need to seek alternative accommodation has become urgent. This situation has called for a careful review of the past eight years, in order to learn both from the negative and the positive outcomes. Hence, a comprehensive evaluation of every aspect of his care provides unparalleled data on which to base his future model of care.

Long-term relationships require a climate of trust in which to thrive and develop. Long-term care requires a community atmosphere where mutuality and reciprocity take the place of hierarchical structures. In Christopher's case, the knowledge acquired during his eight years of care needs to be acknowledged and documented and transferred to others where appropriate. Growth also occurs where there is readiness to learn from mistakes, and to share the knowledge. Knowledge about ABI is not congruent with an aged care environment, as stated

[6] This vignette is taken from the DON's journal. Some details are changed to protect anonymity.

by one nurse: ‘I work here because I’m good at caring for older people. If I wanted to care for younger people I’d work somewhere else.’ The person with ABI also has much to teach his/her carers. In the aged care environment very few staff have either the capacity or the desire to extend their knowledge in this way. In this case Christopher’s long-term residency exceeds almost all other residents. An environment is needed where the continuity of his life and his needs is understood. Christopher is a young man with a vibrant past, now dependent on carers for every one of his most basic needs. He remains, however, an intensely social being, with normal human desires to feel loved, secure and involved as a valued member of society. To ensure his past is now continuous with his present and his future he requires accommodation in a setting where the narrative of his life will regain its vibrancy. With the very best of intentions, and for all the reasons outlined above, this cannot be achieved in a nursing home.

Christopher remains in the care of Harold McCracken House while facing a very uncertain future due to the impending closure of the nursing home. As his family and friends are profoundly aware, the decisions about Christopher’s immediate and long term care are too important to be ‘satisfied’ merely by the offer of another nursing home bed (in a location absolutely *unsuited* to his needs as outlined above). Christopher’s parents are also aware of the need to consider a future when either (or both) of them are no longer able to continue their current role of main carers. This relocation issue therefore requires creative and imaginative thinking; particularly in the absence of any other suitable model. As Michael Kendrick says, these decisions need to be made by the people who know the disabled person well; not by someone isolated from the situation by the processes of bureaucracy.[7]

Recommendations

Some recommendations are offered for the decision-making process best suited to Christopher’s needs. These include:

- policy statements which clarify who has the responsibility for his ongoing care;
- procedures and guidelines that obviate the need for his parents to maintain the daily intensive coordination of his care;
- decision-making by those who know him well rather than by bureaucratic pragmatism;
- opportunity to explore creative options in a context where no existing model seems appropriate;
- an emphasis on community-building, rather than a problem-solving approach directed to an individual in isolation;
- sufficient funding to ensure his long term care needs are met at an optimum level;
- timely processes that allow for thoughtful, imaginative and creative options to be explored rather than hasty decision making constrained by competing forces; and
- exploring options that will be suited to Christopher’s immediate and medium-term needs, while acknowledging those needs may continue to change throughout his life time.

With these factors in mind, the kind of accommodation Christopher needs would include the following:

---

[7] Michael Kendrick is the Assistant Commissioner for Program Development with the Massachusetts (US) government. He has written extensively in this area, and made many visits to Australia propounding his ‘model’ of ‘thinking and doing differently’ for the severely disabled person. He promotes processes of decision making that put the person first, not the system.

- a philosophy of partnership in care, where all decision making is shared with Christopher and his family/carers;
- geographic location best suited to Christopher's personal, family and social needs;
- 'normal' residence that is not separated from the surrounding community;
- a communal rather than an 'institutional' atmosphere;
- a small unit where the needs of the individual are not subsumed by a large group;
- consideration of the social needs appropriate to his age; e.g., adequate space and privacy for his visitors, adequate provision for him to 'come and go' without disturbing others;
- an environment where his unique lifestyle preferences can be met without impinging on others;
- an environment where personalised care, tailored to meet his individual needs, is not constrained by externally imposed standards;
- access to the highest quality medical, professional nursing and allied health care according to best practice and contemporary ABI research;
- a context that also allows for the continuous supervision and training of other (unqualified) carers to be used as appropriate;
- a setting where the continuous narrative of his life is acknowledged and given creative expression;
- flexibility that allows for ongoing rehabilitation in response to his changing needs; and
- a style of accommodation that will best allow him to pursue a 'normal' life in accordance with his personality, his age, and his values.

It is suggested that the Commonwealth funds already allocated to his care as a Category 1 'aged care recipient' be re-allocated to a setting appropriate to his needs.

Current decision-making process (January 2005)

A group of Christopher's friends and families have been meeting regularly since June 2004 to develop a comprehensive model of care for Christopher, which may well be adapted to suit the needs of other young people with ABI or similar needs. This document provides historical and narrative continuity of Christopher's life course. His environmental and social needs are given the highest priority. His medical, nursing and therapy needs are supported by knowledge gained through eight years experience and further validated by the latest best practice and research data.

The urgency of formulating a policy for Christopher's ongoing care is demonstrated by the fact that he has had seven case managers in eight years, none of whom carries the memory and continuity of who he is as a person. None of them has the intimate knowledge base from which to recommend an optimum environment for his long-term care. Melbourne Citymission's offer of another aged care bed at Eltham is unacceptable for the reasons outlined above, not least of which are Christopher's human rights and his choice in the matter. There is no other option available than to seek the relevant funding to create a sustainable environment for his long-term care. The urgency is further compounded by the fact that Christopher's mother, Mary Nolan, has assumed the role of 'quasi case manager', coordinating all of his care on a daily basis in the absence of an appropriate professional advocate. As the research into 'ageing carers' shows, this situation is not sustainable in the long term for Christopher or for his parents.