MONASH University
Medicine, Nursing and Health Sciences

Disability Care and Support

Public inquiry Submission

Background to this submission

Libby Callaway, Sue Sloan and Di Winkler have a combined seven decades of experience in the field of slow stream inpatient and community based rehabilitation provided to people with severe to catastrophic acquired brain injury (ABI). As such, our focus and expertise within this submission is people with severe ABI. Key elements of essential care and service delivery, including accommodation, support and rehabilitation, for this group will be articulated.

This submission should be read in conjunction with the following publications by the authors, which have been provided as part of the submission:

- Sloan, S., Callaway, L., Winkler, D., McKinley, K., Ziino, C., & Anson, K. (2009a). The Community Approach to Participation: Outcomes Following Acquired Brain Injury Intervention. *Brain Impairment, 10*(3), 282-294.
- Sloan, S., Callaway, L., Winkler, D., McKinley, K., Ziino, C., & Anson, K. (2009b). Changes in Care and Support Needs Following Community-Based Intervention for Individuals With Acquired Brain Injury. *Brain Impairment, 10*(3), 295-306.
- Sloan, S. (2008). *Acquired Brain Injury Slow To Recover Program. Report of the Therapy Review Program.* Melbourne: Osborn Sloan & Associates Pty Ltd.
- Winkler, D., Sloan, S., & Callaway, L. (2007a). *Younger people in Residential Aged care: Support needs, preferences and future directions.* Melbourne: Summer Foundation.
- Winkler, D., Sloan, S., & Callaway, L. (2007b). *From a home to their homes: Alternatives to young people living in nursing homes.* Melbourne: Summer Foundation Ltd.
- Sloan, S., Winkler, D., & Anson, K. (2007). Long term outcome following Traumatic Brain Injury. *Brain Impairment, 8*(3), p251-261.
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Improved medical technology and rehabilitation have increased the survival rates and life expectancy of people with severe ABI (Department of Human Services, 2001; Papastrat, 1992). People who sustain very severe acquired brain injuries, who once would have died at the scene of the accident or in hospital, are now surviving with resulting complex care needs. This has led to a new population of people with catastrophic brain injury that challenge the disability service system, which is ill-equipped to cope with this increasingly numerous group. Disability services in Australia have largely been developed with a focus on the needs of people with congenital disabilities. In Victoria, “acquired brain injury” was only included in the definition of disability in the Disability Act in 2006 (State of Victoria, 2006). The development of services for this group, however, is likely to lag well behind the enactment of the Disability Act, particularly given the present resource allocations. Data regarding users of Commonwealth State Territory Disability Agreement (CSTDA) funded services in Victoria show that 4% of the people using these services have an ABI and 29% of users have an intellectual disability (Australian Institute of Health and Welfare, 2007a). Given the similar prevalence of intellectual disability (324,525) (Australian Institute of Health and Welfare, 2008) and ABI (351,000) (Australian Institute of Health and Welfare, 2007b) in Australia, these figures illustrate that people with ABI do not have equitable access to disability services.

Which groups are most in need of additional support and help?

People with a non-progressive brain injury, who do not have access to compensation for their injury, are one group who are in significant need of additional support and help and will be the focus of this submission. Evidence of this need is highlighted in the range of publications attached to this submission. Such individuals may be accommodated in a variety of institutional or community based settings, which do not adequately meet the individual's support needs, and impact on the health and wellbeing of the person and their primary caregivers, including:

- People who experience extended stay in acute hospital settings due to lack of suitable supported accommodation options and ineligibility for mainstream rehabilitation.
- Younger people living in aged care
- People returning home with support of family members
- People with severe ABI who return to live semi-independently in the community, but remain highly vulnerable due to profound cognitive behavioural impairment

How may they be practically and reliably identified?

Currently, people eligible for compensation following a brain injury are systematically identified and practically assisted to access required support by virtue of the nature of their injury and how it was sustained (i.e., road or workplace trauma). For people who are not eligible for compensation for the injury sustained, currently there is no consistent method for identifying rehabilitation potential or meeting their long-term support needs. Current methods for determining eligibility, which then determines discharge destination and access to services, are not well articulated or equitable. These methods include:

- Aged Care Assessment Service (ACAS) assessment;
- Acute hospital discharge planner opinion, in consultation with medical staff;
- Vocal or well-connected family members, who strongly advocate the person's needs within a service system and / or political environment;
- Availability of relevant targeted initiatives that are time and resource-limited (e.g., the 5-year COAG initiative targeting young people living in residential aged care).

In our experience, access to highly rationed services for people with brain injury is currently most often the result of strong advocacy, coupled with fortuitous timing of program vacancies. This current "system" exacerbates the inequity in resource allocation for this group. A key challenge for a national scheme is to document and maintain consistent application of eligibility guidelines for people with severe brain injury, acknowledging the finite resources available and the variable, and changing, lifetime needs of this group. Inconsistent application of eligibility guidelines in other existing initiatives for people with brain injury has led to inequitable resource allocation or service access.

Markers of injury severity may be employed in the acute phase of the injury to determine access to services. They include length of coma; length of post traumatic amnesia; level of physical disability and diagnostic medical imaging. However, in our view these markers should be considered in conjunction with a measure of the person's actual support needs, as individual outcomes vary, across both the spectrum of injury severity and over time (Sloan, Callaway, Winkler, McKinley, Ziino, & Anson, 2009b).

In our experience, and as reflected in many of the accompanying publications, the Care and Needs Scale (Tate, 2007) is a reliable and valid determinant of the person's level of support needs following brain injury. Refer to Appendix Two for a copy of the CANS. The CANS is a clinician rating scale, designed to measure support needs for everyday activities and community living. It measures the type and extent of support required (as opposed to the amount of care the individual is currently receiving) and the duration of time an individual can be left alone. Individuals are placed in one of five groups (A-E) depending on type of support, and then a Support Level is assigned depending on the length of time an individual can be left alone. Support Levels are hierarchically arranged as follows: 0 (*equivalent of does not need contact*), 1 (*needs intermittent contact, less than weekly*), 2 (*needs weekly contact*), 3 (*needs contact every few days*), 4 (*needs daily contact*), 5 (*can be left alone during the day, but not at night*), 6 (*can be left alone for a few hours*), and 7 (*cannot be left alone*).

People with severe to catastrophic brain injury, who are the focus of this submission, would typically be rated on the CANS as having support levels ranging from 3 to 7 and fall within Groups B and A. The CANS was developed for people with traumatic brain injury, and aims to capture the full range of potential support needs, from very high to minimal requirements (Tate, 2007). Thus, a measure of support need, rather than injury severity, offers a more relevant measure upon which to identify this group and begin to determine resource allocation.

In addition, a comprehensive and interdisciplinary approach to the assessment, monitoring and documentation of change in function over time is required. The Summer Foundation Planning and Assessment Framework utilises a mix of published assessment tools (including the CANS) and guided interview questions to elicit a comprehensive overview of the person, their needs and desires at that point in time. The Summer Foundation Planning and Assessment Framework was developed specifically for the Victorian government's younger people in residential aged care program (Winkler, Sloan & Callaway, 2007) and was also utilised in Tasmania (Winkler, Sloan, Callaway & Truscott, 2008). It offers a comprehensive assessment of the broad range of possible physical, cognitive behavioural, neuropsychiatric, communication, health, activity of daily living and participation support needs. Results obtained can be used for accommodation, service, support, and equipment planning. Components of this tool can be readministered over time to document change in skill level and support needs. It is recommended that people with an allied health background administer this tool after initial training (Summer Foundation Ltd., 2007).

In addition, Section 9 of the ABI:STR report titled ‘Program Outcome Measurement’, offers a systematic, efficient and comprehensive approach in documenting outcomes of assessment of people with catastrophic brain injury (Sloan, 2008). Section 10 of the same report outlines an allied health reporting procedure that further reduces the risk of duplication or overlapping assessment and provides an interdisciplinary approach, which reduces paper burden.

In 2007, we developed descriptions of support needs, support hours, accommodation and service models and associated costings for people with ABI across the spectrum of catastrophic brain injury (refer to the Table below of Winkler, Sloan, & Callaway 2007c). Associated Care and Needs Scale (CANS) ratings are provided under each band of support. The costings provided are based on 2007 direct support worker pay rates and do not include the cost of allied health / therapy support required. However, they provide a clear direction on the incremental level of funding and support necessary, based on a quantifiable measure of care and needs (using the CANS).

Band 1 - Support Needs	**Band 2 - Support Needs**	**Band 3 - Support Needs**		**Band 4 - Support Needs**	
CANS rating – Group A – B, Level 4 - 3	**CANS rating –** Group A, Level 5 - 6	**CANS rating –** Group A, Level 6 - 7		**CANS rating –** Group A, Level 7	
• Can be left alone for part of the day, or whole days • Does not require support overnight • Independent in selected, routine activities of daily living (ADL) eg personal care, simple meal preparation. • Requires mainly prompting or supervision for other daily activities, especially more complex domestic ADL and community ADL (eg shopping and banking) • Requires support for managing and maintaining interpersonal relationships and social connections. • Requires emotional support • Requires assistance with home and garden maintenance • Requires support for financial and legal affairs • Will require Case Management and targeted therapy support for skill development. • Has the potential to reduce support needs over time.	• Can be left alone for selected parts of the day • Requires inactive sleep-over support • Independent in some daily activities, or components of daily routines (eg once showered can dress self). • Requires a mix of hands on support, task set-up, prompts and reminders. • No complex medical needs • Ability to access appropriate community groups with shared support • Requires support for managing and maintaining interpersonal relationships and social connections. • Requires emotional support • Requires assistance with home and garden maintenance • Requires support for financial and legal affairs • Will require Case Management and targeted therapy support for skill development. • Has the potential to reduce support needs over time	• Requires 23-24-hour on site support • Sleepover generally inactive but each person may require 10-20 days active overnight support per year (eg when unwell) • Requires 1:1 support for all ADL (personal, domestic and community) • May be left for brief periods with set-up and distant supervision • Community groups with 1:1 support or shared with high staff ratio • Requires interdisciplinary team support • Requires significant amount of day to day co-ordination by family/house staff		• Requires 24-hour on site support at all times • Sleepover active • Requires at least 1:1 support for all ADL (personal domestic and community) • Requires 2:1 support for some ADL • Requires at least 1:1 support in the community • Requires interdisciplinary team support • Requires significant amount of day to day co-ordination by family/house staff • Continuous training of staff and debriefing • Requires implementation of complex care plans • Unstable care needs	
		3a Physical/Medical Requires hands on support of two people (2:1) for some tasks eg personal ADL, transfers Incontinence. Daily nursing care. Ongoing medical issues with some causing unstable care needs	**3b Cognitive/behavioural** 1:1 support mix of prompting and hands on cognitive support High behavioural support needs with high specialist behavioural input required May require secure environment	**4a Physical/Medical** High and complex medical needs Daily nursing care 2:1 for all personal ADL and medical procedures	**4bCog/Behavioural** Profound cognitive impairment Very severe challenging behaviours with high specialist behavioural input required - requires secure setting Additional diagnosis eg mental illness, drug and alcohol issues with associated complex needs
Support hours	**Support hours**	**Support hours**		**Support hours**	
• Up to 3 hours per day attendant care worker • Up to 2 hours per month Case Management	• 24 hour on-site shared support 1:5+ • 8 hours 1:1 community access support	• 24 hour on-site shared support 1:4 • Up to 3 hours 1:1 / day attendant care worker • 8 hours 1:1 community access support		24 hour 1:3 **PLUS** 1 hr/day 1:1 attendant care worker per person 2 hr/day nursing per person	24 hour 1:3 **PLUS** 3 hr/day 1:1 attendant care worker per person **PLUS** specialist behavioural intervention $10,000/year
Average Costs (* based on 2007 rates)	**Average Costs (* based on 2007 rates)**	**Average Costs (* based on 2007 hourly rates)**		**Average Costs (* based on 2007 hourly rates)**	
$45,217/year + therapy*	$62,904 + case management & therapy*	$107,359 + case management, therapy, RDNS*		$156,062 + therapy*	$126,433 + therapy*
Accommodation models	**Accommodation models**	**Accommodation models**		**Accommodation models**	
Own home or unit, by self with paid care Family home with other family members Cluster of units sharing support with others with disability	Family home with paid care Group home 5-8 residents Group home with co-located units 5-8 residents	Family home with paid care Group home 4 residents		Family home with paid care Physical and Medical = Young people's high care facility (10 beds) Cognitive-behavioural = Group home	

Neighbourhood ring	Cluster of units 5-8 residents		

The kinds of services that need to be increased or created

There are three key areas of service provision that need to be increased for people with severe to catastrophic brain injury: care and support; slow stream rehabilitation; and innovative, age appropriate accommodation models.

Care and Support

Chapter 4 of the attached report on younger people living in residential aged care in Victoria (Winkler, Sloan, & Callaway, 2007a) proposes future directions for the development of an integrated service system. This system addresses the complex and lifetime needs of people with high levels of acquired disability, where the desired outcome for the individual is to be supported to live in the community with a maximal level of participation in social and productivity roles. Refer to pages 4-5 of this submission for a brief description of the nature and range of care and support needs that may occur following severe to catastrophic brain injury. The varying nature and intensity of support detailed in this table highlights the spectrum of needs and points to a requirement for individualised support models (as detailed on page 5).

Slow Stream Rehabilitation

One of the key components of an integrated service system is community based slow stream rehabilitation. We have a documented model of practice entitled the Community Approach to Participation (CAP). Three articles on the CAP provide both case study and group data evidence regarding the potential of people with severe to catastrophic brain injury to benefit from community based, slow stream rehabilitation, both in terms of reducing long term care and support and increasing participation and community living skills (Sloan, Callaway, Winkler, McKinley, Ziino, & Anson, 2009a; Sloan, Callaway, Winkler, McKinley, Ziino, & Anson, 2009b; Sloan, Winkler, & Callaway, 2004). In contrast, for people who do not receive this targeted rehabilitation, we found that, over an eight-year period, hours of support remained the same. However, there was a shift from paid care to gratuitous support, with associated increasing caregiver burden (Sloan, Winkler, & Anson, 2007). These findings point to the value of community based slow stream rehabilitation in reducing long-term disability, cost of care, support needs, and carer burden. With a long term approach and contextualized intervention targeted at skill development in the areas that underpin personally valued participation, increased role performance and community integration can be achieved by people with severe ABI, even many years post injury. This increased capacity has been found to be associated with a reduction in care and support needs, including paid and gratuitous care hours, over time (Sloan et al, 2009b).

Accommodation

Another key component of this service system is timely access to appropriate supported accommodation options for the target group. The influence of a person's physical and social environment on their activity choices and participation outcomes is well documented (WHO, 2010). Winkler, Sloan, & Callaway (2007a) documents evidence of the range of negative mental and physical health, participation and community integration outcomes for people inappropriately placed in aged care. Targeted, age appropriate accommodation and transition planning must occur with an understanding of the individual's care and support needs, preferences and potential future abilities. Refer to page 5 of this submission where accommodation models are listed and matched to the support needs and CANS levels of people across the spectrum of severe to catastrophic brain injury. "From a home to their home" (Winkler, Sloan, & Callaway, 2007b) and page 83-87 of the report, 'Younger people in Residential Aged care: Support needs, preferences and future directions' (Winkler et al, 2007a), provides substantial detail regarding the possible range of accommodation models for people living with severe brain injury.

Ways of achieving early intervention

There is evidence that, following severe brain injury, conscious state and functional skills will continue to improve over time (Callaway, 1996; and see literature review contained in Sloan, 2008). In our clinical experience, failure to adequately manage people in the early stages post injury invariably leads to high levels of secondary problems across the spectrum of disability. These may include: physical impairments such as contractures and pain; health complications including aspiration and skin integrity issues; mental health issues, including depression and anxiety; or behavioural outcomes, such as escalating levels of verbal and physical aggression. As a result, when the person does become rehabilitation-ready, the therapist and individual are faced with not only the original neurological impairments, but a host of secondary, and preventable, sequelae (Winkler, Sloan, & Callaway, 2007a; Sloan, 2008).

Seven key themes that were documented in the findings of the assessment of support needs and preferences of younger people living in residential aged care in Victoria (Winkler et al, 2007a) fell into two main categories: those that addressed basic or core daily needs (i.e., health; equipment and consumables; nutrition, swallowing and communication; and behaviour) and those directed towards attaining an improved quality of life (i.e., role participation; community inclusion; and social and family relationships). Best practice early intervention should focus on the management of core needs to prevent secondary problems and maintain function. This proactive management of core needs will ensure the provision of a platform on which skills can be built once a person's conscious level improves to a point they can more actively participate in slow stream rehabilitation (Sloan, 2008). An improved quality of life can then be targeted, with ongoing management of these basic or core needs. Page 88 to 95 of the Winkler et al (2007a) report provides specific and detailed recommendations to address basic or core health needs, in addition to quality of life outcomes. This critical early intervention could be achieved through the provision of “Step Down” units (refer to page 75-76 of the Winkler et al, 2007a for details) that provide a specialised environment for an extended time period, with a focus on proactive management of preventable secondary complications over an extended time frame, during which conscious state is monitored and rehabilitation potential can emerge. This specialised environment also allows for effective planning and case coordination that addresses the range of needs that must be considered in the lifetime support of a person with catastrophic brain injury and ensures timely access to appropriate services (refer to page 74 of Winkler et al, 2007a for details). This is a highly skilled and specialised area of clinical allied health practice and there is a need to support the development of workforce capacity in this area. Resource allocation and planning is required to ensure a skilled workforce is available to provide these services in the future.

Conclusion

Our research supports clinical observations over many years that, given detailed assessment and participation-focussed intervention which is personally meaningful and contextualised, people with severe to catastrophic ABI can achieve positive changes in their functional independence, and level of participation in meaningful life roles within the community. Gains in role participation are possible irrespective of injury severity or time post injury. Further, with targeted intervention, individuals with severe ABI can achieve a significant reduction in support hours even many years post injury; however, such gains are reliant on the individual receiving an adequate level of support and rehabilitation within an age-appropriate and encouraging community environment. In addition, significant variability within this population points to the need for individualised assessment, support models and targeted programs of community-based intervention provided over an extended time frame.

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Appendix One: References

Australian Institute of Health and Welfare (2008). *Intellectual disability* (No. AIHW Bulletin No. 67. Cat. No. AUS 110). Canberra ACT: Author.

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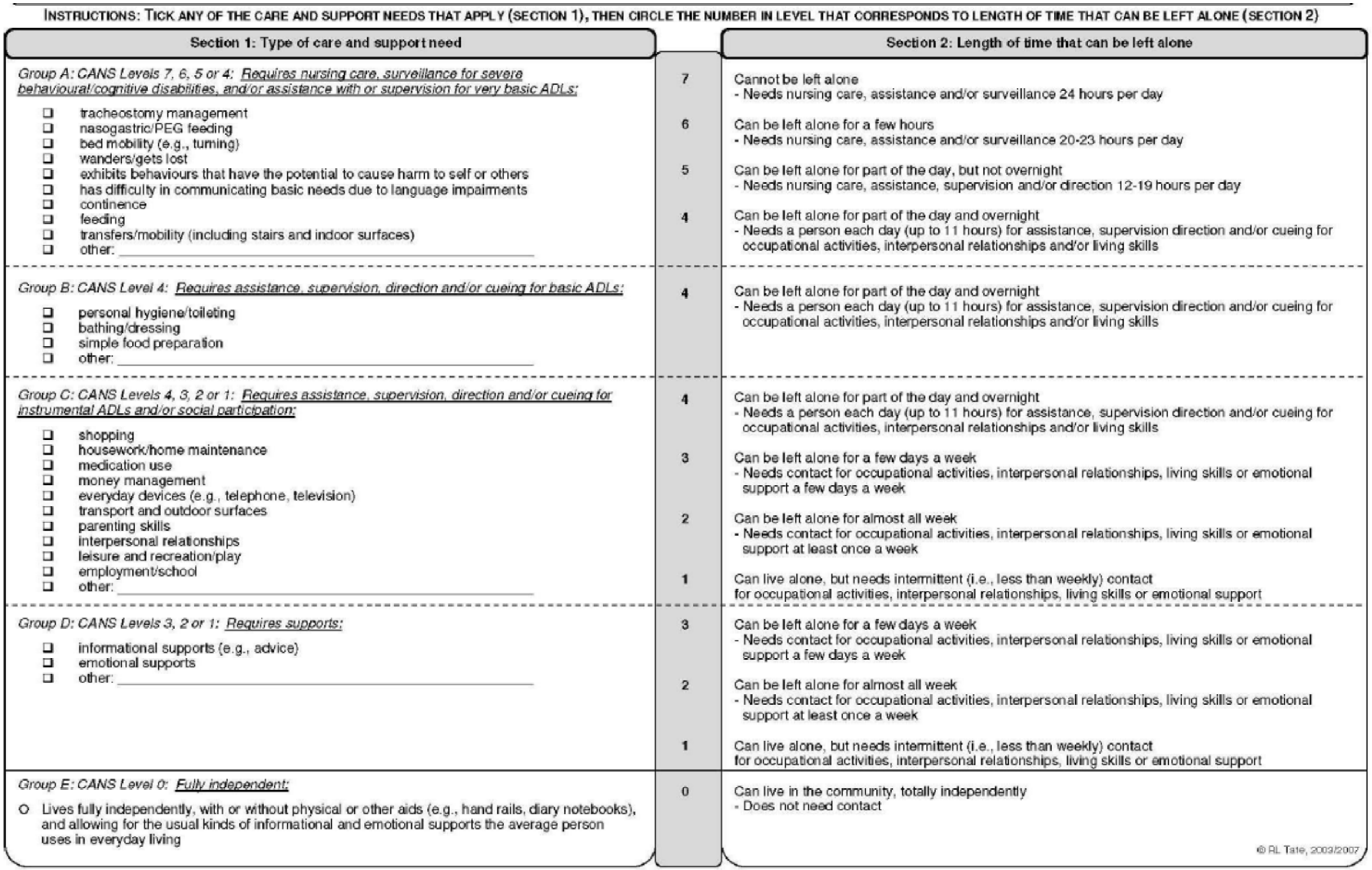
World Health Organization. (2001). *International classification of functioning, disability, and health (ICF).* Geneva, Switzerland: Author.

Appendix Two: Care and Needs Scale (Tate, 2007)



INSTRUCTIONS: TICK ANY OF THE CARE AND SUPPORT NEEDS THAT APPLY (SECTION 1), THEN CIRCLE THE NUMBER IN LEVEL THAT CORRESPONDS TO LENGTH OF TIME THAT CAN BE LEFT ALONE (SECTION 2)

Section 1: Type of care and support need		**Section 2: Length of time that can be left alone**
Group A: CANS Levels 7, 6, 5 or 4: Requires nursing care, surveillance for severe behavioural/cognitive disabilities, and/or assistance with or supervision for very basic ADLs: ☐ tracheostomy management ☐ nasogastric/PEG feeding ☐ bed mobility (e.g., turning) ☐ wanders/gets lost ☐ exhibits behaviours that have the potential to cause harm to self or others ☐ has difficulty in communicating basic needs due to language impairments ☐ continence ☐ feeding ☐ transfers/mobility (including stairs and indoor surfaces) ☐ other: ____________________	7	Cannot be left alone - Needs nursing care, assistance and/or surveillance 24 hours per day
	6	Can be left alone for a few hours - Needs nursing care, assistance and/or surveillance 20-23 hours per day
	5	Can be left alone for part of the day, but not overnight - Needs nursing care, assistance, supervision and/or direction 12-19 hours per day
	4	Can be left alone for part of the day and overnight - Needs a person each day (up to 11 hours) for assistance, supervision direction and/or cueing for occupational activities, interpersonal relationships and/or living skills
Group B: CANS Level 4: Requires assistance, supervision, direction and/or cueing for basic ADLs: ☐ personal hygiene/toileting ☐ bathing/dressing ☐ simple food preparation ☐ other: ____________________	4	Can be left alone for part of the day and overnight - Needs a person each day (up to 11 hours) for assistance, supervision direction and/or cueing for occupational activities, interpersonal relationships and/or living skills
Group C: CANS Levels 4, 3, 2 or 1: Requires assistance, supervision, direction and/or cueing for instrumental ADLs and/or social participation: ☐ shopping ☐ housework/home maintenance ☐ medication use ☐ money management ☐ everyday devices (e.g., telephone, television) ☐ transport and outdoor surfaces ☐ parenting skills ☐ interpersonal relationships ☐ leisure and recreation/play ☐ employment/school ☐ other: ____________________	4	Can be left alone for part of the day and overnight - Needs a person each day (up to 11 hours) for assistance, supervision direction and/or cueing for occupational activities, interpersonal relationships and/or living skills
	3	Can be left alone for a few days a week - Needs contact for occupational activities, interpersonal relationships, living skills or emotional support a few days a week
	2	Can be left alone for almost all week - Needs contact for occupational activities, interpersonal relationships, living skills or emotional support at least once a week
	1	Can live alone, but needs intermittent (i.e., less than weekly) contact for occupational activities, interpersonal relationships, living skills or emotional support
Group D: CANS Levels 3, 2 or 1: Requires supports: ☐ informational supports (e.g., advice) ☐ emotional supports ☐ other: ____________________	3	Can be left alone for a few days a week - Needs contact for occupational activities, interpersonal relationships, living skills or emotional support a few days a week
	2	Can be left alone for almost all week - Needs contact for occupational activities, interpersonal relationships, living skills or emotional support at least once a week
	1	Can live alone, but needs intermittent (i.e., less than weekly) contact for occupational activities, interpersonal relationships, living skills or emotional support
Group E: CANS Level 0: Fully independent: ○ Lives fully independently, with or without physical or other aids (e.g., hand rails, diary notebooks), and allowing for the usual kinds of informational and emotional supports the average person uses in everyday living	0	Can live in the community, totally independently - Does not need contact