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Living Well with Brain Injury

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Slow Stream Rehabilitation:
An Overview

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Introduction

Slow stream rehabilitation (SSR) refers to a model of service delivery provided to individuals whose recovery is considered to be slow or prolonged, and who are often regarded as being inappropriate for traditional, intensive rehabilitation, in particular those with severe to very severe brain injuries [1, 2]. There is a growing body of evidence that these individuals have significant potential for recovery, even several years post-injury, when provided with effective rehabilitation [3-11]. As such, there is increasing recognition of the role that appropriately timed and individually-tailored rehabilitation can play for people with severe brain injuries in optimising their function, supporting their independence and maximising their quality of life [12-14]. Additionally, SSR has been identified as an important factor in avoiding entry into residential aged care (RAC) for these individuals [15].

Several significant policy documents have provided impetus for further development of SSR programs across Australia [16, 17]. These documents have highlighted the need for enhanced access to these programs for young people with high and complex needs in RAC, as well as a greater consistency in service delivery across all Australian states and territories. At the conclusion of the Young People in Residential Aged Care (YPIRAC) initiative in 2011, the Young People in Nursing Homes National Alliance made several recommendations in relation to the role of SSR for young people at risk of entering, and currently living in RAC. In particular, the National Alliance recommended the implementation of "community based slow stream rehabilitation programs in all states" [16]. Further, the 2015 Senate Inquiry Report into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia recommended that the "COAG develop and implement a national rehabilitation strategy including a framework for the delivery of slow stream rehabilitation in all jurisdictions" [17]. These recommendations highlight the need to develop a shared understanding of the key features and principles of SSR in order to inform the development of a framework underpinning best practice and evidence-based SSR programs across Australia.

PURPOSE OF THIS BRIEFING DOCUMENT

The purpose of this briefing paper is to summarise the current state of knowledge regarding SSR from two perspectives:

- The perspective of people with direct experience with SSR in an Australian context (i.e. through the description of outcomes obtained from a workshop conducted in the second half of 2015); and,
- The perspective of existing research evidence reported in electronic medical databases and the grey literature identified by a recent scoping review [18].

The information provided in this briefing paper will provide a starting point for discussions that will take place at the upcoming SSR Roundtable on 16 June 2016, in Melbourne, Victoria.

Aims of the SSR roundtable

Through expert consultation, the aims of the SSR roundtable are:

- To develop a set of draft principles for the delivery of SSR for young people (< 65 years) with high and complex needs (due to a severe brain injury), and
- To identify characteristics of a framework that could support its implementation in the Australian context.

The experience of slow stream rehabilitation from multiple perspectives

In August 2015, a workshop was held to conduct a preliminary review of current SSR practice in Australia and to develop an understanding of a range of perspectives on the experience of SSR. In total, twenty-six people from four states participated in this workshop. Participants brought a range of relevant expertise, including personal and family experiences of SSR and RAC, service provision (in hospital and community settings), advocacy, and clinical and academic research experiences. Participants worked in small groups to consider and record their perspectives on the guiding principles of 'good' SSR and the characteristics of contemporary SSR.

OUTCOMES FROM THE 2015 WORKSHOP

Discussion spanned a broad range of topics converging on five key themes that were grounded in the experiences of people with ABI, their families and those who work with them (see Figure 1 below). Across the participants, there was unanimous agreement that the use of the word 'slow' in current nomenclature cast a negative light on an intervention that essentially encompasses a positive view of the functional and changing ability of people with severe ABI over time. Indeed, there was a unified recognition of the need for the development of a standard definition in the context of severe ABI that referred to an integrated model of care focussed on functioning, health and wellbeing and involved making small gains over an extended period of time. A further overarching point of agreement across workshop participants was that, although rehabilitation for people with severe brain injuries who have a chronic condition has largely been performed in the hospital setting, there needs to be an increased focus on shifting services to improve functional ability into the community and the disability sector.

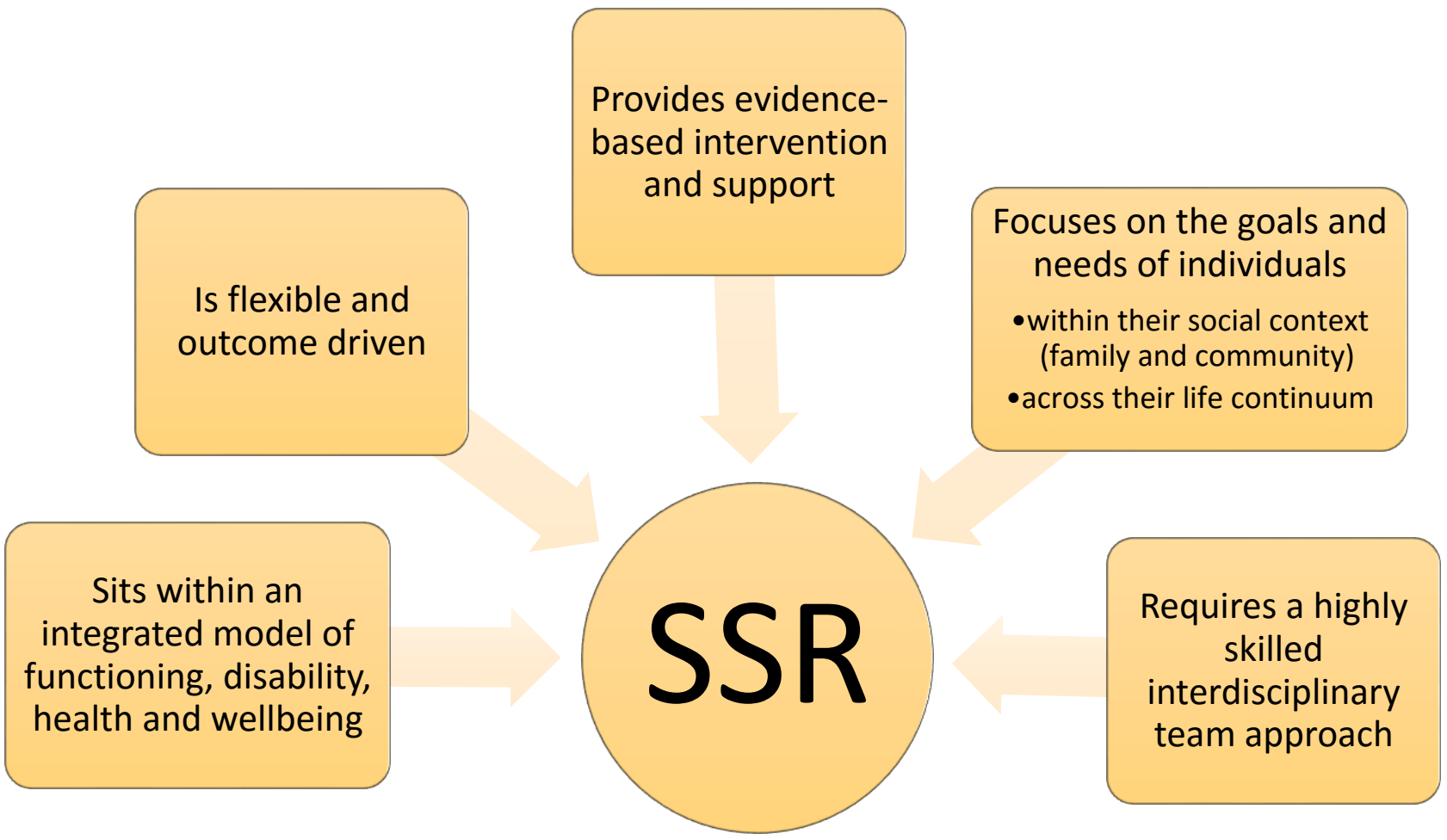

Figure 1: Key themes emerging from the 2015 SSR workshop.

Complexities around the five key identified themes were also highlighted. These included unclear and suboptimal clinical care pathways, incomplete national (state, regional and rural) coverage with respect to provision of long-term (slow stream) rehabilitation service provision, and lack of specialist training opportunities for support workers who need to be skilled in providing care to people with neurological conditions. The importance of consistency in staff (‘They ‘knew me, my quirks, I was not just another patient, I was a person’), community housing options, mechanisms that support outcome based (not price focussed) service choice, and research funding to develop and evaluate models of care and practice guidelines also attracted generalised consensus within the group.

An overview of the research evidence

The following section of this paper outlines the results of a recently conducted scoping review into slow stream rehabilitation (SSR) [18]. Initially, a preliminary literature search was performed to identify any existing systematic reviews or literature reviews of SSR. Through this search, two literature reviews were identified [1, 12]. Both were narrative reviews which reported on a broad range of studies relating to recovery and rehabilitation in people with severe brain injuries. However, neither described specific features of existing models and/or programs of SSR. As a result, a scoping review was performed in order to identify key features of effective SSR reported in the literature. A further aim of the scoping review was to document SSR programs and/or models described in the literature.

A search of several electronic databases (MEDLINE, CINAHL, PsycINFO, AMED and Web of Science) and the grey literature was conducted within the publication period of January 1985 - March 2016. The search yielded 13,432 citations and following screening of full text articles, 18 studies were retrieved for the scoping review.[1]

OUTCOMES OF THE SCOPING REVIEW

An overview of the characteristics of the 18 included studies is presented in Figure 2 below [1, 3, 19-34]. Eight of the studies originated from Australia and six from Canada. The participants of 13 studies had severe acquired brain injury (ABI), two studies included participants with traumatic brain injury (TBI) only, and two studies included participants with stroke only. A final program had broader entry criteria, although the majority of patients had a neurological disorder. Most of the studies included people with a mean age in their early to late 30s (n=8). The mean age of participants was higher for those studies including participants post-stroke.

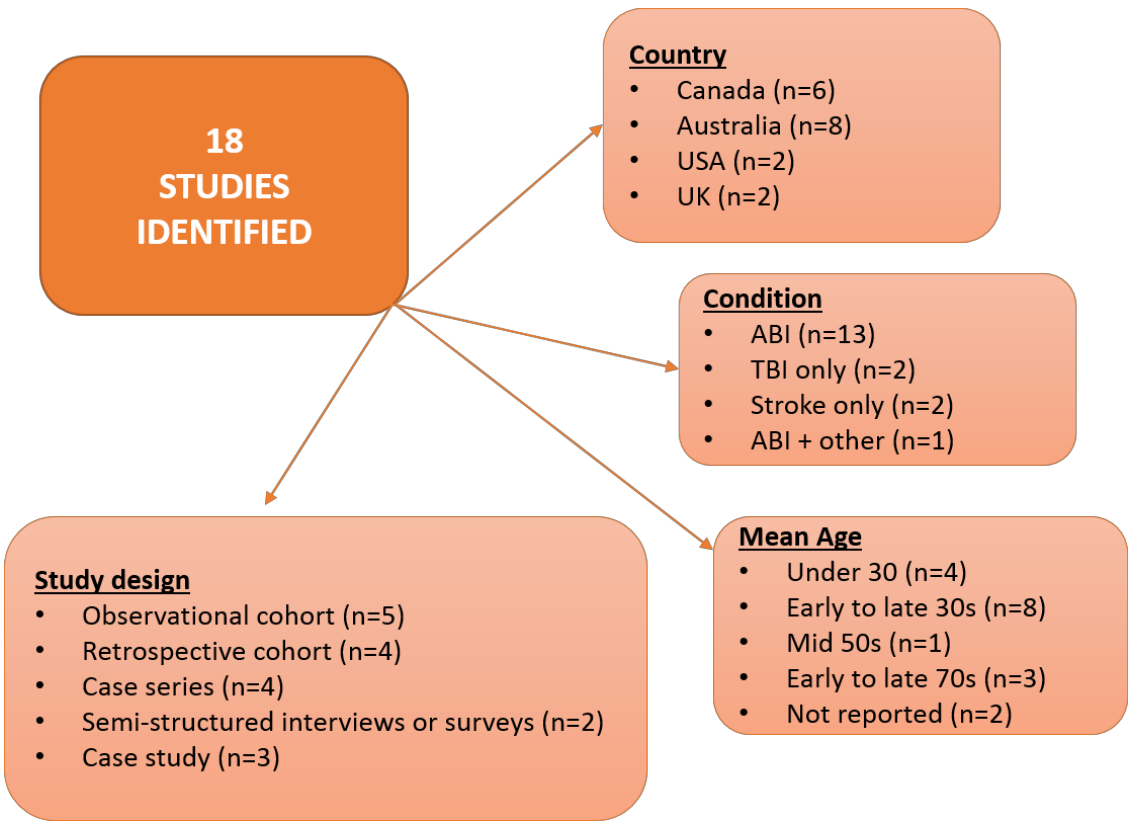

Figure 2: Summary of studies identified in the scoping review.

[1] Studies were included if they reported any service, program or model that involves 'slow stream' rehabilitation (tailored to the person's needs) delivered over the long-term or life for people with severe to very severe acquired brain injury (ABI).

THE EFFECTIVENESS OF SLOW STREAM REHABILITATION

Overall, it was found that in all of the identified studies slow stream rehabilitation (SSR) in people with severe brain injury was effective. However, there was considerable variation reported for the key findings of the studies. There were three main outcomes used to measure the effectiveness of SSR – length of stay, discharge destination, and improvement in function.

Length of stay and discharge destination

Length of stay was reported for nine out of the eighteen studies [3, 20-24, 32-34]. The mean length of stay ranged from 81 days to 5 years. A longer length of stay was observed in studies of people with severe TBI or where the majority of the sample had severe TBI [3, 21, 23, 24, 34]. All studies reported that the discharge destination for more than 40% of patients was to home or community living (semi- or independent) following SSR. The highest proportion of patients who were discharged into the community was 88% [23].

Measuring improvement in function

Thirteen studies reported that participants achieved improvement in function as a result of participation in SSR. This data is summarised in Table 1. Six of the studies assessed and reported levels of mobility and dependence either with clinical scales [22] or through the achievement of personal goals (relating to self-care or activities of daily living) [20, 24, 30, 31, 34]. Four studies used scores achieved on the Disability Rating Scale (DRS) at admission and at discharge, with all reporting reductions in mean scores (i.e., improved ability) following SSR [3, 21, 23, 32]. Six studies reported a change in the mean FIM score from admission to discharge or follow up [3, 21, 27-29, 31].

Table 1: Summary of most common measures used in included studies.

STUDY	NO. OF PARTICIPANTS	MEAN LENGTH OF STAY (RANGE)	DISCHARGE DESTINATION (% PARTICIPANTS) #	IMPROVEMENT IN FUNCTION
O'Neill et al. (1987) [22]	52	81 days (2-310 days)	42% went home	**Level of dependence*** 3.2 (admission) → 2.1 (discharge) **Level of mobility*** 1.8 (admission) → 1.1 (discharge) Both levels of dependence and mobility were maintained at 1 year follow-up
Tierney (1996) [32]	19	5 years (4 months to 8 years)	79% went home	**DRS scores (range)** 7-25 (admission) → 4-23 (discharge)
Gray et al. (2000) [21]	349	398 days (50 - >1000 days)	86% went home into community living	**DRS score **** **FIM+FAM motor score (mean)**** Approx. 61.5 (admission) → 88 (discharge) **FIM+FAM cognitive score (mean)**** Approx. 46.1 (admission) → 67 (discharge)
Wales & Bernhardt (2000) [34]	1	14 months (N/A)	100% went home (single participant)	Increased mobility and physical function. At 1 year follow-up – "walking independently with a frame for 20 metres, increased use of right hand, improved swallowing status, increased activity attendance and community engagement"
Sloan et al. (2004) [30]	1	NR	100% went home (single participant)	Increased functional independence – active participation in multiple life roles, use of motorised scooter in community, independence in shopping, cooking, laundry, and daily housework tasks. **CIQ score** - increased from 7/29 (baseline) → 16/29 (after the program)
Teasell et al. (2005) [31]	196	88 days (11-195 days)	43% went home	**Median FIM score:** 46 (admission) → 70 (discharge) 28% patients were able to ambulate independently at discharge Improvement in self-care tasks
Parish & Oddy (2007) [24]	4	11 months (7-15 months)		Increased functional independence in tasks targeted during intervention (personally and clinically significant)

STUDY	NO. OF PARTICIPANTS	MEAN LENGTH OF STAY (RANGE)	DISCHARGE DESTINATION (% PARTICIPANTS) #	IMPROVEMENT IN FUNCTION
Katz et al. (2009) [3]	36	162 days (NR)	50% went home, 47% went to a skilled nursing facility	**DRS (mean range)** *1-year follow-up (n=22)* 32% (12 – 21, severe to extremely severe) 41% (4 – 11, moderate to moderately severe) 27% (0-3, partial to no disability) **FIM score (mean):** 18 (admission) → 55 (discharge)
Sloan et al. (2009) [28, 29]#	85	N/A (average 51 hrs of intervention during 12 month intervention period)	NR	**a) FIM score (mean)*** Early group – 91.42 (baseline) → 96.42 (12 months) Late group – 89.20 (baseline) → 90.36 (12 months)
	43	N/A (3 year intervention provided)		**b) FIM score (mean)^** 84.28 (B), 87.49 (T1), 87.91 (T2), 88.70 (T3)
Ostapovitch (2010) [23]	24	4 years (TBI), 3 years (stroke) (NR)	88% went home in the community (60% personalised care homes, 27% their own home)	**DRS (mean score)** 12.3 (admission) → 10 (discharge)
Tourangeau et al. (2011) [33]	81	113 days (11 -181 days)	48% went into independent or semi-independent community living	
Sloan et al. (2012) [27]#	43	N/A (3 year intervention provided)	**T3:** 32.6% home with family, 20.9% shared supported accommodation, 16.3% home with partner and/or dependents	*Home-like setting (HLS) group (n=28)* **FIM score (mean)** 95.61 (B), 97.71(T1), 98(T2), 99.07 (T3) *Disability-specific setting (DSS) group (n=12)* **FIM score (mean)***** 67.33 (B), 71.50 (T1), 71.08 (T2), 70.0 (T3)
Bellisario (2015) [20]	1	20 months (N/A)	100% went home (single participant)	On admission – "severe cognitive impairment", incontinent, assistance required for all activities of daily living. On discharge – "walking independently, participating in ADL and fully continent."

*p<0.005; **p<0.001; *** p<0.05; ^ p=0.001

N/A – not applicable, NR – not reported

#Additional outcome data collected by the authors included the Care and Needs Scale (CANS), Community Integration Questionnaire (CIQ), Role Checklist, and number of hours of formal and informal care.

MODELS AND/OR PROGRAMS OF SLOW STREAM REHABILITATION

From the eighteen studies identified, eight SSR programs were described (see Table 2). Five of the programs were provided in a hospital or rehabilitation centre, two were community-based, and one included both onsite and community-based service provision.

Program Aims and Entry Criteria

In broad terms, the aims of each of the programs reflected the provision of long-term, specialised, sub-acute and slowly paced rehabilitation. Seven of the eight programs had been developed to meet the unique needs of individuals with severe acquired brain injury (ABI). Patients were generally required to be medically stable upon entry to the program, and have been assessed as unsuitable candidates for, or had an unsuccessful trial of, intensive rehabilitation. Eligibility for four programs was also partly determined by placement (or risk of placement) in a nursing home and/or the need for 24-hour care and supervision.

Program Structure

All but one of the programs were delivered by a multidisciplinary team. In seven of the eight SSR programs described, physiotherapists, occupational therapists and speech-language pathologists participated in program delivery. The remaining program described an approach based on occupational therapy intervention alone (although the authors noted that the majority of participants also received at least one other type of therapy during the intervention period) [27-30].

The structure of program delivery was described in varying levels of detail across the studies identified. In a number of programs, therapy consisted of a mixture of individual and group sessions at varying levels of intensity. Up to four hours of therapy daily was provided at the Parkwood program, depending on patient tolerance [31]. Patients in the Western Neuro Care program could access three 30-minute speech pathology sessions per week and 3 hours of physiotherapy and occupational therapy weekly, in addition to group therapy and/or supplemental stimulation from trained family or nursing staff [19]. The ARBI, ABI:STR and CAP models described a longer term focus in their delivery. The average length of enrolment in the on-site ARBI program was 4 years [23]. In 2008, 29 participants in the ABI:STR program had been enrolled in the program for 10 years or more [12].

Table 2: Overview of SSR models described in the literature.

NAME OF PROGRAM	COUNTRY	YEAR COMMENCED	REFS	ONSITE OR COMMUNITY BASED?		TEAM MEMBERS								PARTICIPANTS				
														Etiology			Age	
				Onsite	Comm	Med	Nur	PT	OT	SP	SW	DT	Other	TBI	CVA	Mixed	<65	65+
Greenwich	Australia (NSW)	1982	[22]	✓		✓*	✓	✓	✓	✓	✓	✓	Dent, Pod, Ψ	✓	✓	✓	✓	✓
Western Neuro	USA (California)	1985	[19]	✓		NR	NR	✓	✓	✓			Act	✓			✓	✓
Vaucluse	Australia (VIC)	1988	[32]	✓		✓*	NR	✓	✓	✓			Ψ, hydro	✓	✓	✓	✓	
BIRP - Ponoka	Canada (Alberta)	1991	[21]	✓		✓	✓	✓	✓	✓	✓	✓	Ψ, NP, RT, PS	✓	✓	✓	✓	?
ARBI	Canada (Alberta)	1978	[23, 25]	✓	✓			✓*	✓	✓			Volunteers	✓	✓	✓	✓	
Parkwood	Canada (Ontario)	NR	[31]	✓		NR	NR	✓	✓	✓	✓	✓	RT		✓		✓	✓
ABI:STR	Australia (VIC)	1996	[12, 32]		✓			✓	✓	✓			Program manager, CM, ACW	✓	✓	✓	✓	
CAP	Australia (VIC)	2004	[27-30]		✓	#		#	✓	#	#	#	#	✓	✓	✓	✓	

NR: Not reported, ? unknown

BIRP – Brain Injury Rehabilitation Program; ARBI – Association for the Rehabilitation of the Brain Injured; ABI:STR – Acquired Brain Injury-Slow to Recover Program; CAP – Community Approach to Participation

Team members (*indicates team leader): Med-medical; Nur-nursing; PT-physiotherapy; OT-occupational therapy; SP-speech pathology; SW-social work; DT-dietitian; Dent-dentistry; Pod-podiatry; Ψ-psychology; Act-activities staff; Hydro-hydrotherapy; NP-neuropsychology; RT-recreation therapist; PS- psychiatry; CM-case management; ACW-attendant care worker

The described intervention was delivered by an OT alone although the authors noted that the majority of participants also received at least one other type of therapy during the intervention period.

Delivering SSR best practice in the Australian context

The following figure provides an overall summary of the key features of SSR identified across the sources of evidence presented in this briefing paper - at the level of experience in current practice (workshop) and at the level of synthesised evidence (scoping review).

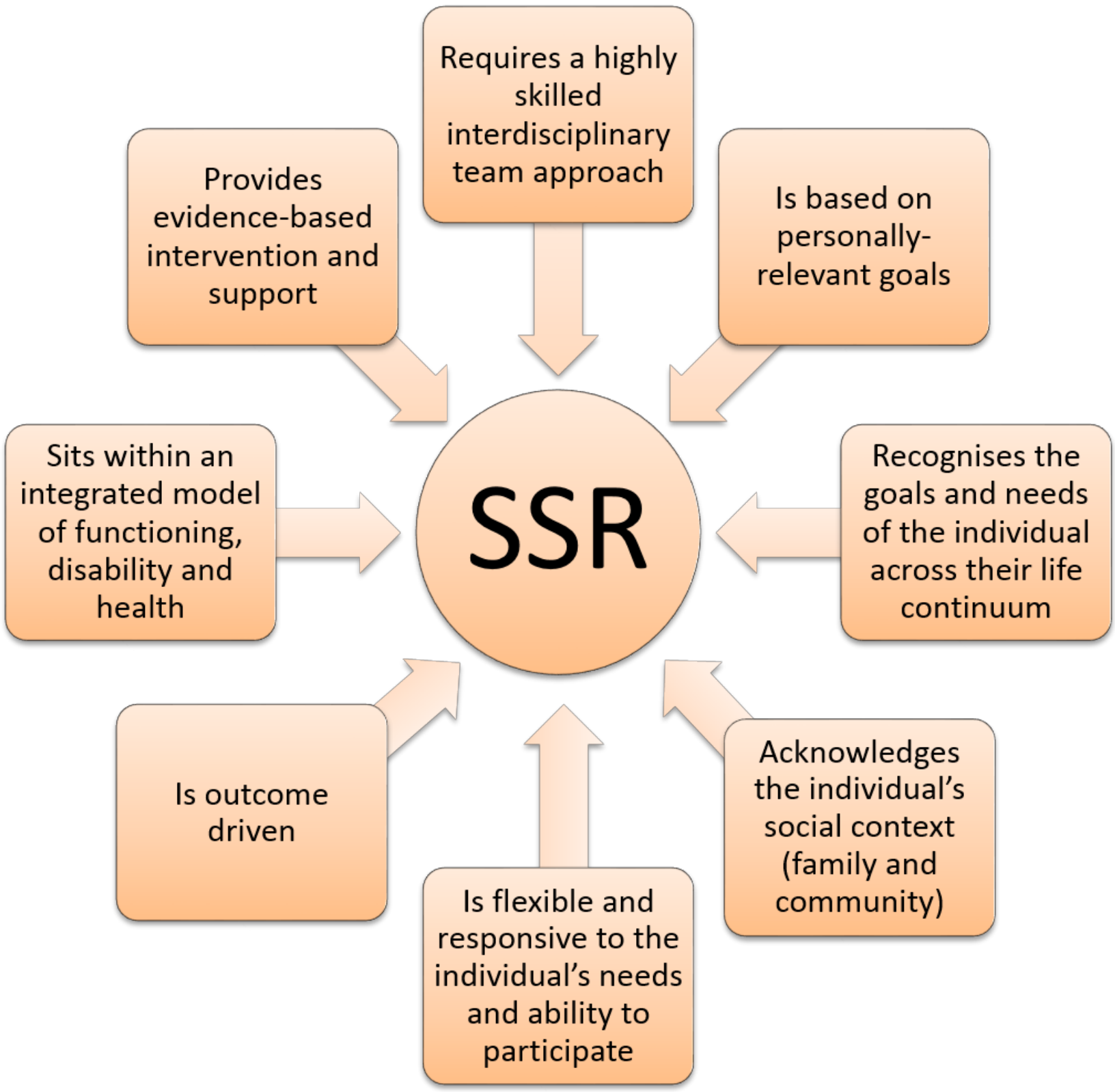

Figure 3: Common features of effective SSR programs.

REFERENCES

1. Gray, D.S., *Slow-to-recover severe traumatic brain injury: a review of outcomes and rehabilitation effectiveness.* Brain Inj, 2000. **14**(11): p. 1003-14.
2. Pereira, S., et al., *Rehabilitation of Individuals With Severe Stroke: Synthesis of Best Evidence and Challenges in Implementation.* Topics in Stroke Rehabilitation, 2012. **19**(2): p. 122-131.
3. Katz, D.I., et al., *Natural history of recovery from brain injury after prolonged disorders of consciousness: Outcome of patients admitted to inpatient rehabilitation with 1-4 year follow-up.* Prog Brain Res, 2009. **177**: p. 73-88.
4. Lammi, M.H., et al., *The minimally conscious state and recovery potential: a follow-up study 2 to 5 years after traumatic brain injury.* Arch Phys Med Rehabil, 2005. **86**(4): p. 746-54.
5. Nakase-Richardson, R., et al., *Longitudinal outcome of patients with disordered consciousness in the NIDRR TBI Model Systems Programs.* J Neurotrauma, 2012. **29**(1): p. 59-65.
6. Whyte, J., et al., *Functional outcomes in traumatic disorders of consciousness: 5-year outcomes from the National Institute on Disability and Rehabilitation Research Traumatic Brain Injury Model Systems.* Arch Phys Med Rehabil, 2013. **94**(10): p. 1855-60.
7. Olver, J.H., J.L. Ponsford, and C.A. Curran, *Outcome following traumatic brain injury: a comparison between 2 and 5 years after injury.* Brain Inj, 1996. **10**(11): p. 841-8.
8. Myburgh, J.A., et al., *Epidemiology and 12-month outcomes from traumatic brain injury in australia and new zealand.* J Trauma, 2008. **64**(4): p. 854-62.
9. Braakman, R., W.B. Jennett, and J.M. Minderhoud, *Prognosis of the posttraumatic vegetative state.* Acta Neurochir (Wien), 1988. **95**(1-2): p. 49-52.
10. Groswasser, Z. and L. Sazbon, *Outcome in 134 patients with prolonged posttraumatic unawareness. Part 2: Functional outcome of 72 patients recovering consciousness.* J Neurosurg, 1990. **72**(1): p. 81-4.
11. Tuel, S.M., et al., *Functional improvement in severe head injury after readmission for rehabilitation.* Brain Injury, 1992. **6**(4): p. 363-372.
12. Sloan, S., *Acquired Brain Injury: Slow to Recover Program Report of the Therapy Review Project*. 2008, Osborn Sloan & Associates Pty Ltd: Melbourne.
13. Mazaux, J.M. and E. Richer, *Rehabilitation after traumatic brain injury in adults.* Disability and Rehabilitation, 1998. **20**(12): p. 435-447.
14. Bender, A., S. Bauch, and E. Grill, *Efficacy of a post-acute interval inpatient neurorehabilitation programme for severe brain injury.* Brain injury, 2014. **28**(1): p. 44-50.
15. Leung, G., et al., *Slow Stream Rehabilitation: A New Model of Post-Acute Care.* Journal of the American Medical Directors Association, 2015.
16. Young People in Nursing Homes National Alliance, *YPIRAC2: The next steps*. 2011, Author: Melbourne, VIC.
17. Senate Community Affairs Committee Secretariat, *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*. 2015: Canberra.
18. Piccenna, L., L. Knox, and J. Douglas, *Features of effective slow stream rehabilitation for individuals with severe acquired brain injuries (ABI): A scoping review.* 2016. **Manuscript in preparation**.
19. Ansell, B.J., *Slow-to-recover patients: Improvement to rehabilitation readiness.* Journal of Head Trauma Rehabilitation, 1993. **8**(3): p. 88-98.
20. Bellisario, J., *Reduced dependency and decreased care costs following rehabilitation in a specialist nursing home*, in *Physiotherapy UK Conference*. 2015: Liverpool, UK.
21. Gray, D.S. and R.S. Burnham, *Preliminary outcome analysis of a long-term rehabilitation program for severe acquired brain injury.* Arch Phys Med Rehabil, 2000. **81**(11): p. 1447-56.
22. O'Neill, T.J., K. McCarthy, and B.M. Newton, *Slow-stream rehabilitation: Is it effective?* Med J Aust, 1987. **147**(4): p. 172-5.
23. Ostapovich, M., *Making life better: Positive outcomes for individuals with severe TBI*, in *7th Annual Brain Injury Canada Conference*. 2010: Regina, Canada.
24. Parish, L. and M. Oddy, *Efficacy of rehabilitation for functional skills more than 10 years after extremely severe brain injury.* Neuropsychol Rehabil, 2007. **17**(2): p. 230-43.
25. Reimer, M. and C.L. LeNavenec, *Rehabilitation outcome evaluation after very severe brain injury.* Neuropsychol Rehabil, 2005. **15**(3-4): p. 473-9.
26. Sloan, S., *Acquired brain injury slow to recover program: Report of the therapy review program*. 2008, Osborn Sloan & Associates Pty Ltd: Melbourne.
27. Sloan, S., et al., *Accommodation outcomes and transitions following community-based intervention for individuals with acquired brain injury.* Brain Impairment, 2012. **13**(1): p. 24-43.
28. Sloan, S., et al., *The community approach to participation: Outcomes following acquired brain injury intervention.* Brain Impairment, 2009. **10**(3): p. 282-294.
29. Sloan, S., et al., *Changes in care and support needs following community-based intervention for individuals with acquired brain injury.* Brain Impairment, 2009. **10**(3): p. 295-306.

30. Sloan, S., D. Winkler, and L. Callaway, *Community integration following severe traumatic brain injury: Outcomes and best practice.* Brain Impairment, 2004. **5**(1): p. 12-29.
31. Teasell, R.W., et al., *A rehabilitation program for patients recovering from severe stroke.* Can J Neurol Sci, 2005. **32**(4): p. 512-7.
32. Tierney, J., *Rehabiliation following very severe brain injury: Final report (GPEP #393)*. 1996, Primary Health Care Research and Information Service: Canberra.
33. Tourangeau, A.E., et al., *Post-acute stroke patient outcomes in Ontario, Canada complex continuing care settings.* Disabil Rehabil, 2011. **33**(2): p. 98-104.
34. Wales, L.R. and J.A. Bernhardt, *A case for slow to recover rehabilitation services following severe acquired brain injury.* Aust J Physiother, 2000. **46**(2): p. 143-146.