Practical strategies for promoting independence

The Brain Injury Case Management Taxonomy defines the action of 'planning long term supports' as:

*Identifying, promoting, and supporting the client's ownership and independence for management and coordination of their activities in key life areas, to resolve problems, **in order to reduce or cease their need for paid case management (to the extent possible** and including the family or significant others).*[1]

When and how should a case manager start planning long term supports and case management disengagement?

Commence the case manager disengagement process from your earliest contact with participants. In the early months following catastrophic injury, participants and their families may rely heavily on their case managers to guide their decisions and to do things for them. This is reasonable, but it can create over-reliance and pave the way for long term dependence. Case managers need to manage this to ensure they build the individual's health literacy, confidence and ultimately - self-efficacy and autonomy. Some practical strategies to achieve this include:

Strategies to build self-efficacy	Supporting tools *Information Sheets and Prompt Sheets in the toolkit*
From the first My Plan, ask questions of the participant such as: - what do you eventually want to be able to do for yourself? - what can you do yourself to progress towards your goal? Encourage participants and their families to be actively involved in all aspects of their plan and their program – setting goals, selecting providers, making appointments	My Plan template Selecting Service Providers Writing Goals for My Plan
Encourage participants to reflect on their strengths and capabilities; identifying what they, and their informal supports achieved or contributed to independently	Plan Preparation tools Goal Summary Sheet Thinking About You Personal Considerations
Focus on building Health Literacy – with the participant and with their family.	Supporting Health Literacy What is the CHAT? CHAT Prompt Sheet
Explain your role as a facilitator, not a personal assistant to do everything for them. Reinforce that a part of your job is to make yourself redundant	My Plan template

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[1] Lukersmith, S., Fernandez, A., Millington, M., Salvador-Carulla, L. on behalf of the CM nominal group (2015). The taxonomy (BICM-T) intervention tree table Contact: sluk3618.uni@sydney.edu.au

Help to educate participants about icare: what can and can't be funded; what is/is not injury-related; who they can call if they have a question or concern

Provide participants with information so that their involvement with icare is not a mystery or intimidating – but a support that they understand in terms of what they can expect | Participant Information Sheets
icare website
Guidelines Companions
My Plan booklet |
| Don't be available 24/7 – give people some scope to try and sort things out for themselves

Identify early in your relationship with the participant others in their formal and informal support network, who might be able to help with some day-to-day tasks – so it's not always you | Plan Preparation tools
My Plan template
My Plan to Help Keep Me Safe
My Plan to Manage My Affairs |

Remember:

- o   Becoming redundant is a measure of success
- o   icare will have an ongoing relationship with participants, long after you are no longer involved

Do with, not for

Take every opportunity to pass on your expertise to the participant (and their informal supports) – "This is how I would solve that problem. Let's do it together so in future you can do this too".

- whenever a participant calls to say, "I need this", or "this has gone wrong" – ask first "What have you done so far to resolve it?" and "This is what I would do, how about you try that?"
- show participants web-based resources they can browse in their own time – for example: accessible holiday accommodation; airline access information and protocols; equipment catalogues/buyers guides
- when organising equipment, involve participants in looking at options on the National Equipment Data Base (see link in Resources below) or via specific supplier websites
- sit with participants/family when arranging equipment repairs and maintenance services
- get participants to make their own GP/specialist appointments. Sit with them and brainstorm:

"What do I need to do to make sure I attend this appointment?"
- What reminders do I need to put in place so I don't forget it?
- What transport might I need to arrange and how do I do that?
- Is there parking? What is the access like?
- How long will I need to allow for the appointment?
- Do I need to take someone with me? And if so, who? Do I need help with language, comprehension, providing history/details, remembering?
- What will I need to do if I need to change my appointment?

Remember: Activities such as budgeting, time management, organisation skills, remembering appointments, paying bills and booking transport are 'care' supports. They should be identified in Care Needs Assessments for support by either formal or informal care supports. They are NOT case manager tasks.

- get participants to "chase things up" – if they haven't heard about something they are waiting for, get them to call. Sit down first and help them work out what they are going to say – identifying themselves, what they are calling about and what it is they want to know
- if participants or their family are dissatisfied with (or dismiss without good reason), a service provider such as a gardener or cleaner – get them to source quotes from potential replacement service providers
- if a participant initiates a goal, strategy, or action, don't be tempted take it over for them
- engage participants in selection of their service providers every time. Help them to use tools such as Yellow Pages/other service directory platforms and Private Practice Directories on professional association websites, to find out who is available, and how to determine if they are a good match. Involve participants and families in "interviewing" potential providers over the telephone – asking questions such as their skills & areas of expertise, the hours they work, access to their clinic and transport/parking

Remember: icare has developed a wide range of Participant Information Sheets to help promote independence. All are available on the icare website:

Go to: icare.nsw.gov.au > injured or ill people > forms and resources

Clear communication

- use plain language, avoiding medical terms and acronyms
- use interpreters as needed
- provide written summaries, notes or prompts to assist with future reference and memory
- have conversations specifically around "how you will manage things when there is no case manager?"
- feedback your observations of their growing independence when reflecting on progress
- help participants and families understand information early in their recovery so that they won't be dependent on you for communication assistance in the long term

Ensure there is a safety net

- you are not available 24/7 and nor are icare staff. Use the My Plan to Keep Me Safe tool to help participants and families brainstorm what could go wrong outside of normal work hours, and who to contact if they do. Make sure emergency contacts are easily accessible in the home – for participants, family and/or support workers
- develop charts and cheat sheets for people that need it
- use a transition plan to manage withdrawal of case management services across a 3 or 6 month period. Allow time for the participant to develop self-management strategies and their relationship with other contacts and supports including their icare contact

Looking forward

- use the health professionals involved during rehabilitation to support the disengagement process. For example, have the occupational therapist also pass their expertise on to the participant
- understand Lifetime Care's Self-Managed Support program and help suitable participants move towards self-managed supports
- encourage participants to access support groups & networks where they can interact with people who share similar situations or interests – disability sporting groups, SCIA, Physical Disability Council NSW, Synapse, etc.
- make building Health Literacy for the participant and their informal supports a priority in your early case management role. Include injury management knowledge, how to access local/remote formal and informal supports, how to appraise if those supports are meeting needs

Resources and websites for promoting independence

General resources

- Steps to independence (Synapse):
  - synapse.org.au/fact-sheet/steps-to-independence/
- NSW Agency for Clinical Innovation (working with people with TBI - self study modules. Tool Kit B Promoting Independence):
  - www.tbistafftraining.info/ToolkitB/S1/S1.0.html
- Lifetime Care and Workers Care (icare website):
  - www.icare.nsw.gov.au/injured-or-ill-people/forms-and-resources/

Returning to work or study after brain injury

- Brain injury Australia:
  - www.braininjuryaustralia.org.au/resource-category/brain-injury-links/employment/
- Synapse Fact Sheets:
  - returning to work: synapse.org.au/fact-sheet/returning-to-work/
  - brain injury information for employers: synapse.org.au/fact-sheet/brain-injury-information-for-employers/
  - returning to studies: synapse.org.au/fact-sheet/returning-to-studies/
- Headway UK:
  - www.headway.org.uk/about-brain-injury/individuals/practical-issues/returning-to-work-after-brain-injury/
- NSW Agency for Clinical Innovation (Working with people with TBI - self-study modules. Tool Kit D: Return to Work):
  - www.tbistafftraining.info/ToolkitD/ReturnToWork1.html
- Spinal cord injuries Australia (SCIA):
  - employability.org.au/disability-employment-resources/

Social communication

- University of Sydney Acquired Brain Injury Lab:
  - TBIexpress (for people with brain injury): www.sydney.edu.au/medicine-health/our-research/research-centres/acquired-brain-injury-communication-lab/tbi-express.html
  - TBIconneCT (for clinicians and families: www.sydney.edu.au/medicine-health/our-research/research-centres/acquired-brain-injury-communication-lab/tbiconnect.html
- Social-ABI-lity (an online course to help people with brain injury use social media):
  - abi-communication-lab.sydney.edu.au/having-better-conversations-after-brain-injury-the-social-brain-toolkit-project/
- Synapse:
  - synapse.org.au/fact-sheet/social-skills-and-confidence/

Legal and advocacy

- Synapse (including guardianship/decision making and further references):
  - synapse.org.au/understanding-brain-injury/legal-and-advocacy/
- Spinal cord injuries Australia (SCIA):
  - scia.org.au/advocacy-policy/

Driving

- Driving After Traumatic Brain Injury (Brain injury Australia):
  - www.braininjuryaustralia.org.au/resources/fact-sheets-brain-injury-australia/driving-traumatic-brain-injury/

Holidays and travel

- Accessible transport and travel (SCIA):
  - scia.org.au/living-with-paralysis/transport-and-travel/
- A definitive guide to travelling with disabilities:
  - www.comparetravelinsurance.com.au/resources/travel-insurance-disabilities-guide
- Australian Beach Accessibility:
  - www.ideas.org.au/facts/australian-beach-accessibility.html/
- Access at 5 iconic Australian destinations (accommodation, accessible paths, tour operators, theatres):
  - www.ideas.org.au/blogs/travel-access-australia.html/
- Lonely planet (accessible travel resources):
  - www.ideas.org.au/blogs/lonely-planet-accessible-travel-resources-3rd-edition-out-now.html/
- Lonely Planet (wheelchair-accessible travel destinations):
  - www.lonelyplanet.com/articles/most-wheelchair-accessible-destinations
- Australian Government National Public Toilet map (information on accessibility, opening hours and amenities across Australia):
  - toiletmap.gov.au/

Miscellaneous

- eBility (connects buyers and sellers of all things disability):
  - www.e-bility.com/

Programs supporting people with brain injury:
- 3 Bridges Community:
  - 3bridges.org.au/
- Spinal Cord Injuries Australia (SCIA):
  - scia.org.au/resource-hub/
- Brain Injury Australia:
  - www.braininjuryaustralia.org.au/resource-category/brain-injury-links/sport/
- Driving after TBI:
  - msktc.org/tbi/factsheets/driving-after-traumatic-brain-injury

Equipment

- Assistive Technology Australia (formerly ILC NSW/Australia):
    - www.askned.com.au/
- Assistive technology, equipment, modifications (SCIA):
    - scia.org.au/assistive-technology-equipment-modifications/
- Contact details for icare equipment panel/consumables providers:
    - **AIDACARE**
      P: 1300 216 898
      E: icare@aidacare.com.au
      Portal: icare.aidacare.com.au/

    - **ALTER TECHNOLOGY/CHEMTRONICS**
      P: 1800 134 732
      E: icare@alter.technology
      Portal: icare.alter.technology/

    - **BRIGHTSKY**
      P: 1300 886 601
      E: icarecc@brightsky.com.au

    - **ALPHA LIFECARE**
      P: 1300 930 930
      E: info@alphalifecare.com.au
      Portal: www.alphalifecare.com.au/

    - **INDEPENDENT LIVING SPECIALISTS**
      P: 1300 558 947
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- For Easy Order enquiries, please email easyorder@icare.nsw.gov.au

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