Scoring Goals as a Team
Getting the best out of aphasia rehabilitation

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Session 1

• What do we mean by **aphasia rehabilitation goals** and what do they look like?

• Who is the **team**?
  • You, your clinicians, your family and friends.

• What might influence how we **score** our rehabilitation goals?
  • Why might someone not **score** their goal?
  • What makes a difference?
Goals... what are they?

Something to aim for... hopes and dreams

Something manageable and achievable

Something designed for me... with me!

Something to keep me motivated... so I can see progress
Rehabilitation goals... what are they?

• **What you want!**

• Complex and overlapping

• Individual

• **From different perspectives**
  • You and your family
  • Speech and language therapy
  • Occupational therapy
  • Physiotherapy

• **Changing over time**
  • Day by day goals
  • Week by week goals
  • Long term goals
Rehabilitation goal setting... why set them?

More **efficient**. Gives therapy direction

Allows **measures** of progress

Good for **teamwork**

Helps patient **motivation** and involvement in decisions
Rehabilitation goals... how are they set?

• In a team meeting

• With a single therapist

• As a contract

• But they should be **negotiated**...
What do rehabilitation goals look like?

Smart Goals

AIM FOR... THE STARS

Little Goals
Many different kinds of goals after a stroke...

- Balance
- Sitting up
- Standing
- Walking
- Talking
- Understanding
- Seeing around you
- Using your hand
- Lifting your arm
- Swallowing
- Eating your meals
- Feeling less tired
- Managing at home....
What do people with aphasia want?

1. Return to pre-stroke life
2. Communication
3. Information
4. Speech therapy
5. Physical health goals
6. Social/Work Leisure
7. Control/Independence
8. Dignity/respect
9. Contribution to society
Examples of people’s goals: Getting back to normal

- ...just to be normal and enjoy life. (Mavis)

- I trying to normal but not working. I want to 100 cent again. (Christopher)

- I thought I, I will just get better. (Neville)
Communication

- To be able to write...to be able to read and ...
  (Bert)

- ... so that I could actually read to my grandkids, a story
  (Neville)

- I sitted down and read. I can’t read, I can’t read, I can’t read. Help me. I can’t.
  (Anne)
More speech therapy

- If I could have spoken and did 12 hours a day I would have been for the whole 12 hours doing the whole lot (Simon)

- you know you’ve got to have as much as you possibly can from the very onset you know. Rehab, rehab, rehab (Helen)
A model to catch all the goals...

(World Health Organisation)

(Imairment level)
Examples of “Impairment” goals

• Finding words to say

• Reading letters and words

• Making sentences

• Understanding words which you hear or read

• Writing letters, words and sentences
Examples of “activity” goals

- Reading a bedtime story to a grandchild
- Making an arrangement on the telephone
- Typing an e-mail
- Reading a menu and ordering in a restaurant
- Filling in a form
- Understanding the news on the radio
- Following a recipe
Examples of “participation” goals

• Managing to get back to work

• Gaining the confidence to live independently

• Joining a bowls club and meeting new people there

• Joining an aphasia support group

• Volunteering at the university and working with students

• Taking a holiday overseas

• Working with others to raise awareness and understanding of aphasia – improving attitudes and knowledge of aphasia
Examples of “contextual” goals

• Personal:
  • Improving your confidence
  • Helping you make sense of the *new you*

• Environmental:
  • Educating your family
  • Giving your friends good communication strategies
  • Helping your employer find ways to get you back to work
  • Finding a group where you feel comfortable
  • Meeting new people socially
The model people with aphasia use (Kagan et al. 2008)
Living with Aphasia
Framework for Outcome Measurement (A-FROM)

Kagan et al. 2008
Use this tool to talk about your life

**Experiences**

**Participation**
- Activities
- Relationships
- Roles and responsibilities

**Personal**
- Aphasia and who you are
- The future
- Your view of yourself
- Your feelings

**Environment**
- Services, systems and policies
- Attitudes of others to you and the aphasia
- Help with communication and conversation

**Aphasia**
- Talking
- Writing
- Understanding and listening
- Reading

**Your A-FROM**

**Participation**

**Personal**

**Environment**

**Aphasia**

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Who is the team?

- You
- Your clinician
- Your family
- Your friends

- Recovery is easier if you are with others!
You are part of the team!

- Why is your opinion important in goal setting?

- Sharing decisions keeps you motivated.
- You live with your condition.
- You can suggest tasks which are useful and relevant.
- You’ll do tasks better if you understand them.
- You’ll do more if it is meaningful to you.
Your family is part of the team

• Why should **families be involved in goal setting?**

  • Families like to have **information**

  • They want to know what is happening and to be **involved in rehabilitation**

  • They need to learn a lot to have ways of **coping after discharge** from hospital

  • They need support to manage **changes to routines and relationships**

  • They may need respite and time for themselves
Your friends might be part of the team

- Some people rely on close friends as much as family

- Friends might be **practice partners** or **conversation partners**

- Friends might **speak up for you** when you cannot speak for yourself

- Friendships support longer term recovery and **reduce social isolation**
What might influence how we score rehabilitation goals...

• Why might someone not score their rehabilitation goal?

• What makes a difference?
Why might someone not score their rehabilitation goal?

- Problems with **you and your stroke**!
- **Too unwell** at the time to have input into choice of goal
- Not enough energy... **too tired** to do the work
- Worrying about something else
- Severe aphasia... **hard to understand** the goal
- Severe aphasia... **hard to say** what you want
- Not feeling motivated
Why might someone not score their rehabilitation goal?

- Problems with your therapist!
  - Setting the wrong goal
  - Not listening to you
  - Not finding out what you want to achieve
  - Setting the right goal but to the wrong level
  - Not explaining the connection between your goal and the therapy
  - Not enough support to reach it
Why might someone not score their rehabilitation goal?

• Problems with the **system**!

  • No opportunity in the meetings to be involved

  • Not enough **accessible information** about rehabilitation or what the team was doing

  • Not enough time to work through the tasks

  • Discharged home before rehabilitation was finished (in your opinion!)

  • Not enough support after discharge
Different perceptions of goal setting and rehabilitation:

**People with aphasia**
- Need **lots of time**
- Difficult to express themselves - **aphasia**
- Often choose **big goals** (*I want to get better!*)
- In shock and tired
- New to stroke rehabilitation
- Experts on themselves, their lives, and priorities

**Clinicians**
- Under **time pressure**
- Big caseloads
- Often focused on **swallowing** first... language second
- Choose neat, **small SMART goals** they can work on
- Expect patients to be **enthusiastic**
- Experts on stroke rehabilitation
The way your therapist sees your progress...

Your stroke → rehab
The way you see your progress...

Your stroke
What makes a difference?

• **Accessible information** for you and your family
• Building a **good working relationship** with your therapists
• **Family involvement** in rehabilitation
• Shared decisions about goals
• Shared decisions about what to work on
• Being involved in discharge decisions
• Support in hospital, rehabilitation and after discharge
• Doing rehabilitation tasks which are meaningful and important
• Having a **positive attitude**
• Having time and energy to **practice**
• Having people around you for **support**

• Having a sense of **hope for the future**
Session 2

• Making SMART goals SMARTER

• Turning rehabilitation goals into life goals
Therapists often like little goals...

Create S.M.A.R.T. Goals

- Specific
- Measureable
- Achievable
- Realistic
- Timely
Recovery is a big goal
Goal setting in rehabilitation is about the **steps or sub-goals** towards your big goal...
**SMARTER** goal-setting

- Shared
- Monitored
- Accessible
- Relevant
- Transparent
- Evolving
- Relationship-centred

• All about **HOW we set our goals**
Developed from previous research (2006-2008): Goals in aphasia project

- to **describe** the goals of people with aphasia and their family members

- **compare** these to the goals of their speech pathologists

- 50 people with aphasia
- 49 family members
- 36 speech pathologists

- Brisbane, Newcastle, Adelaide

- Funded by Australian NHMRC
Paper on SMARTER published in 2012

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SMARTER goal setting in aphasia rehabilitation

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Background: There have been numerous calls for rehabilitation professionals to involve patients or clients in decisions about the goals of therapy. And yet collaborative goal setting in rehabilitation remains uncommon and is particularly difficult to achieve for people with aphasia.

Aims: This discussion paper describes a new framework for conceptualising and structuring collaborative goal setting in aphasia rehabilitation. The framework has been developed based on the results of a large, multi-centred Australian study, the Goals in Aphasia Project, which explored client, family, and speech pathology experiences of rehabilitation goal setting. This framework, called SMARTER Goal Setting, describes a process of goal setting that is Shared, Monitored, Accessible, Relevant, Transparent, Evolving and Relationship-centred.

Methods & Procedures: The methods and results from the Goals in Aphasia Project have already been published elsewhere but involved in-depth interviews with 50 people with aphasia, 48 family members, and 34 treating speech pathologists. This paper reviews the broader literature and summarises relevant findings from the Goals in Aphasia Project as a basis for discussion of each category of SMARTER.

Conclusion & Future: One aim of SMARTER Goal Setting is both challenging and complex.
Shared

Clear materials

Time

Preparation

Mutual respect

Get to know each other

Regular inclusive meetings
Monitored

- Discussion about change
- Document change
- Lots of feedback
- Focus on your goals
- Is therapy making a difference?
- Looking at change over time

Is therapy making a difference?
Accessible

- Supported conversation
- Extra time
- Aphasia friendly materials
- For you and your family
- Clear information
- Clear options

For you and your family
Relevant

- What is useful for you?
- Include artefacts about you
- More than assessment results
- Does therapy reflect your goals?
- Includes family and friends
- Home visit
Transparent

- Clear links
- Big goals – small goals
- What is the rationale?
- Records of meetings and who was there?
- What are the steps?
- Clear records of agreed goals
Evolving

Goals change over time

You and your therapist learn together

Recovery is a journey

You can ask to change your goals

You can change your therapy

Document your change

Evolving
Relationship-centred

With your therapist
Get to know each other
Trust
Honesty and openness
Include family and friends
With the team
Turning rehabilitation goals into life goals

- Rehabilitation does not stop when you finish formal therapy
- Goals change with life’s challenges!

GOAL

Act as if what you do makes a difference. It does.

~William James
Example

• “Andy”
• Lawyer
• Recently married
• Suffered a stroke aged 31 (nearly 15 years ago)
• Severe aphasia and right sided weakness
• Had inpatient rehabilitation for 6 months
• Outpatient therapy for several years
• Couldn’t get back to work

• Young... wanted to do something useful
• Joined committee of aphasia group in his city
• Helps to edit the newsletter for the group
• Gives talks to students at the local university
• Has stayed busy and active
• Language skills have continued to improve year by year...
Example

- Gillian
- Stroke in her 50s (14 years ago)
- Aphasia and right sided weakness
- Recorded her story in the “Celebrate!” book
- Speaks to students and Secretary of Communicate WA
Short, medium and long-term goals

• (Adapted from Ashford and Turner-Stokes, 2014):
Research on living successfully with aphasia...
- What are the ingredients?

Importance of activities (Cruice et al., 2003)
- Keeping busy!

Positive attitude (Brown et al., 2008)

Four ingredients: (Hinckley, 2006)
- Social support
- Adaptation of perception of self
- Ability to look forward and set goals
- Taking charge of communication improvement
Living successfully with aphasia
(Holland, 2006)

• ‘fitting the aphasia in’
• ‘moving beyond’
• ‘choosing and living one’s options’
• ‘dynamically accepting aphasia at a level that is far from passive and looking back’
Insider perspective on living successfully (Brown et al., 2010)

- Much of focus on **impact of aphasia has been negative outcomes**
- This study - investigates **positive examples** of living with aphasia: why do some people adapt well?
- Ideas borrowed from: positive psychology/ ”happiness” research/successful ageing

- **Interviewed 25 people with aphasia**
  - (12 F and 13 M; 38-86 years).
  - Also asked to take photos which represented living successfully. Interviewed again to discuss these.
Results from Brown et al., 2010

• 4 core themes:
  • Doing things
  • Meaningful relationships
  • Striving to maintain a positive way of life
  • Communication
You see, it took me three years... I was angry at the world. Why should I be this way? Why should I learn to speak? It was like for a little baby starting all over again, sort of thing. And it was very, very frustrating...

but one day I said “what’s the point?”, you know, “it doesn’t help anybody... I’ll be happy for the world, in the world, not against the world...” (Keith)
Session 3

- Learning the skills of the game from each other
How have people achieved their goals after stroke and aphasia?

• An example:
  • Improving confidence
  • Hope jars (Elena Adams)
Improving sense of self and educating other people through personal stories
By joining a group...
Conversation practice, making friends and increasing confidence
What has worked for you?

- To set recovery goals...
- To set life goals...
- To make your future positive...
- To live successfully with aphasia?
References

References