National Mental Capacity Forum

Essex Autonomy Project

Supported Decision-Making Toolkit for People with Communication Difficulties

Developed by Hannah Atkinson, Dr Mark Jayes and Dr Anna Volkmer[1]

1. **Do your research**: Find out what helps this person to communicate and what doesn't help:
    - Check for any written recommendations (e.g. in a "communication passport" or advance care plan, from a Speech & Language Therapist (SLT), from carers)
    - Ask people who know the person (e.g. the service-user themselves, carers, family, members of the health and social care team)
    - Gather information on whether the person might need support/adjustments in any of these areas of communication:
        - Attention, listening and looking
        - Understanding the situation and others (understanding verbal and non-verbal information)
        - Expressing themselves (verbally and non-verbally)
        - Social interaction (e.g. eye-contact, proximity)
2. **Check you have the basics in place:**
    - Quiet, private and distraction-free environment
    - Person is well-positioned and comfortable
    - Person has working glasses and hearing aids
    - Person has dentures in situ (if this person will be required to speak)
    - Pen and paper (for writing or drawing)
    - Photos or images (e.g. photos of their home or specific equipment)
    - The person's Augmentative and Alternative Communication (AAC) equipment (if they have any)

[1] This toolkit was originally developed on behalf of the Royal College of Speech & Language Therapists (RCSLT) Mental Capacity Clinical Excellence Network in preparation for a national webinar on the theme: "Practicable steps for people with communication difficulties". The webinar was held in January, 2023, and was co-sponsored by the National Mental Capacity Forum and the Essex Autonomy Project. A recording of the webinar is available here: https://autonomy.essex.ac.uk/nmcfevents/. Please direct any queries to: a.volkmer.15@ucl.ac.uk.

3. **Plan ahead:**

    - Think about the language you are going to use beforehand (see 'Four tips for simplifying language on pages 2-3)

    - Think about non-verbal communication strategies e.g. gesture, videos, pictures. What could you prepare in advance to help represent key words/ideas? Does your service already have some appropriate resources you could access?

4. **Keep track**: document how you supported the person's communication needs to make a decision. What information did you communicate to the person and with what supports? How did the person communicate back to you and what did they express?

Four tips for simplifying language:

1. Choose **familiar words** to the person. These tend to be words used regularly in daily life (high frequency words). Avoid professional jargon or words that are less commonly used in everyday life (low frequency words).

Example:

Accommodation	versus	Home/house
Prescribe medication	versus	Give medicine/tablets

2. Use **active sentences** instead of passive sentences. Put the 'do-er' of the action at the start of the sentence.

Example:

Active sentence: "The doctor will check your heart."
Passive sentence: "Your heart will be checked by the doctor."

3. Avoid using **too many pronouns** such as 'he', 'she', 'they', 'us', 'this', 'that'. Use the person's name or title instead (e.g. doctor).

Example:

Lots of pronouns: "**They** will scan your heart. Then **they** will tell **us** your results."
Reduced use of pronouns: "**The heart doctors** will scan your heart. Then **the heart doctors** will tell **your GP** your results."

4. Avoid sentences with multiple parts (clauses). Try to make one point per sentence.

> Example:
>
> A multiple-part sentence: "Your swallowing impairment, which is a result of your brain injury, poses risks to your health, including weight loss and pneumonia."
>
> The same concept expressed in several simpler sentences:
>
> "Your brain injury has caused swallowing problems.
> Swallowing problems can cause health problems.
> Swallowing problems can cause weight loss.
> Swallowing problems can cause chest infections."

Suggested reading:

- NHS England (2017) 'Accessible Information Standard' Available at: https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/

- Department of Health (2010) 'Making written information easier to understand for people with learning disabilities' Available at: https://www.gov.uk/government/publications/making-written-information-easier-to-understand-for-people-with-learning-disabilities-guidance-for-people-who-commission-or-produce-easy-read-information-revised-edition-2010

- Stroke Association (2012) 'Accessible Information Guidelines: Making information accessible for people with aphasia' Available at: https://www.stroke.org.uk/sites/default/files/accessible_information_guidelines.pdf1_.pdf

Guidance on supported decision-making:

- Section 1.2 in NICE guideline (2018) 'Decision making and mental capacity' Available at: https://www.nice.org.uk/guidance/ng108

- Chapter 3 in MCA Code of Practice (2007) 'How should people be helped to make their own decisions?' Available at: https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice

- Chapter 3 in DRAFT MCA Code of Practice (2022) 'How should people be helped to make their own decisions?' Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1080137/draft-mental-capacity-act-code-of-practice.pdf