Total Communication Approach and It’s Role in Decision Making

Grainne Tinney & Christine Delany
Overview

• What is Total Communication (TC)
• The role of Total Communication in decision making
• How to use Total Communication
• Case study
What is communication?

1. 2 people or more

2. Common communication system – can be verbal or non-verbal (e.g. sign language, communication app etc)

3. **Understanding**

4. Ability to use that system by both people

5. 2 way

6. A reason to communicate
Communication difficulties experienced by up to 90% of people with ID (RCSLT, 2006)

May be:

- comprehension difficulties (understanding)
- Expressive language difficulties
- Memory and attention difficulties
- Social interaction difficulties
- Behavioural difficulties
- Sensory difficulties (vision, hearing, touch, smell)
- Literacy difficulties

One or several more of the above
What Is Total Communication?

• Total Communication (TC) is an approach which encompasses and values all forms of communication equally.

• Non verbal communication (body language, facial expression, gestures, pictures and written forms) is valued as much as spoken language.

(Hassiotis, Barron & Hall, 2013)
Understanding

• Recognising and correctly understanding what is being communicated regardless of how it is being communicated

• Need to hear something, process it and formulate response – can take time

• It may appear that the person is understanding more than they actually are

• Might answer ‘yeah’ because of..
  – Difficulty understanding question
  – Expected response (agreeable)
  – no experience of asking for clarification

  e.g.
  Q: Do you want a coffee?
  A: Yes
  Outcome: Person is given a coffee but does not drink it
Total Communication - Understanding

- Total communication allows for greater clarity and increased likelihood of understanding the message e.g. “do you want a coffee?”

- Through use of Total Communication the person is receiving the message through multiple senses e.g. hearing AND seeing etc.

- Total communication input increases success in understanding.
Expressing yourself

• Communicating thoughts and feelings to others – default tends to be through speech

• People with ID may have difficulties with using language to express themselves

• They may have difficulties with vocabulary, grammar, word-finding, articulation etc.

• Total Communication allows the person to use multiple ways of expressing their thoughts and feelings e.g. through signing, pointing at pictures, speech etc.

• Total Communication greatly increases success in getting their message across.
Why is TC Necessary

- Without total communication people with ID are at risk for
  - Being unable to exercise their right to communicate
  - Being unable to exercise real choice in their lives
  - Being unable to consent to interventions
  - Get needs met
  - Being excluded from local communities

(RCSLT, 2006)
Why now?

• Communication is a basic fundamental human right

• Effective communication is key for people to achieve independence, make choices, be included and to be self determined

• National policy – HIQA, New Directions, Assisted Decision Making (capacity) Bill

• Personal planning integral part of policy to support improved quality of life

• The voice of the SU hasn’t been heard as much as it should have been
Who needs TC?

- We all have comprehension difficulties at some stage and need information explained.
Who needs TC?

• We all benefit from Total Communication!
Decision Making

To make a decision I need:

1. To know and understand what my choices are  
   (being informed)

2. Understand the outcome from choosing one  
   thing over something else  
   (predicting outcomes in future)

3. Understand the choice is mine to make – not  
   acting under duress.

N.B. Making an informed choice might mean  
making a choice that carers/significant others do  
not agree with - Might involve refusing e.g. a  
medical treatment
Decision Making & the role of TC

- Decision making is a developmental process and is a capacity which is learned over time.
- Adults with ID may not have developed this capacity due to a lack of opportunity and experience in making important decisions in relation to their lives.
- Important decisions are often made by someone else.
- This capacity can be developed through experiences and opportunities.
How to use TC with people with an ID

Step 1: Consider what you want to get out of the discussion/conversation

Step 2: Consider the Individual and the skills you have as a communication partner

Step 3: Be prepared - knowing WHAT to be prepared with is vital and can be the main challenge

Step 4: Have a discussion using TC and validate and record the information from the discussion
Step 1: Aim of Discussion

• Think about the aim of the discussion you want to have:
  To gather information?
  To provide information?
  To elicit choices/decisions?

• What do you want to have a record of at the end of the discussion?

• This will influence all other steps
Step 2: Consider Communication Skills

• Do you know how they communicate?
• Can you use the same communication system as them?
• Can you understand their system?
• Do they bring their system into work/day centre etc with them?
• Does anyone else need to be involved?
Step 2

Ask yourself these questions:

• Have I training in any other mode of communication apart from speech?

• Do I know how to really listen?

• Do I know how to simplify my language?

• How fast do I speak?

• Do I ever try and explain something using my hands as well?
Step 3: Getting Prepared

• Gather all the information you can about the person’s communication i.e. how they understand language and how they express themselves

• Talk to family, staff and significant people

• Read communication passports, communication reports, recommendations etc.

• If you need information explained, ask their key worker or the supporting Speech & Language Therapist

• If you think you will need help then ask
Step 3: Getting Prepared

- Compile resources based on information about the person’s communication e.g. photos versus symbols, images of personal relevance versus more generic images
Step 3: Getting Prepared

Think about the concepts to be discussed:

- Are they concrete and easily referenced from the person’s experience?
- Are they abstract with little pre-existing knowledge for the person? E.g. PCP and ISP

Think about the vocabulary that may be used within the discussion:

- Can it be simplified e.g. “support” becomes “help”
Vocabulary and Concepts
Step 4: Have a Discussion using TC

• From the beginning
• Introducing communication approaches half way through a process may be too late because it may make information already gathered questionable
• Make sure that the person understands the information
• Isabelle and John – associating a colour with a concept. mov011
Step 4: Having a Discussion

- Information is only good if it is valid.
- Ask the person what you have said.
- If the person replies correctly: delve deeper to confirm they DO understand and are not just repeating back.
- Isabelle and John – talking about likes and dislikes. Isabelle clarifies one of John’s choices.
- mov012
Key Points to build capacity

• TIME to build capacity is most important factor

• Experiential learning e.g. John being asked if he consented to video

• Mapping language/vocabulary to concrete experiences

• Video as a learning tool – can show person over time e.g. if they have memory difficulties or find it very hard to expressively recall information from week to week

• Photographic evidence of what people have said
Case Study

“Jack”
Jack

• In early 30’s
• Mild learning disability
• Excellent conversational skills
• Recently moved from day service for adults with moderate ID to independence-focused community service for people with mild ID
Transitioning Problems

• Difficulties in the new service with:
  – Personal relationships
  – Managing conflict
  – Dealing with stress of everyday life
  – Lack of routine

• Jack decided he wanted to leave the new service

• He suggested a 2 year course in horticulture
SLT Involvement

• VEC literacy tutor felt that Jack’s literacy skills were not adequate for course
• Jack was referred to SLT for an assessment of literacy skills as “second opinion”
• He presented with difficulties in spelling, reading and writing and language comprehension
• SLT felt he would require one-to-one support for reading and writing in order to participate in course
Supporting Decision Making

- SLT explained to Jack verbally that she felt he would need someone to help him if he decided to do the course.
- Jack’s keyworker contacted to see if this support would be available - no such supports available.
- Right to reasonable accommodation.
- Concern that he would lose his place in his current community service.
- Jack continued to express desire to go on course.
- Explored support to make an informed decision.
Visual supports

• Used photographs
• Sorted into things that would be easy or hard about the course
• Visuals were presented by SLT and sorted by Jack
• Jack engaged readily and at no point appeared uncomfortable with visuals or reluctant to use them
Things that would be easy

- Planting
- Cutting hedges
- Cutting grass

- Named these as “practical skills” – things you do with your hands
- Jack could identify they would be easy as he has experience of doing them previously
Things that would be hard

- Studying at home
- Writing
- Reading
- Listening and taking notes in class
- Labelled as “non-practical” things
- The bottom picture was identified by Jack as a man who was “stressed out”
Feeling Stressed Out

- Used this picture to discuss how Jack might feel if he has to do lots of reading and writing or “non-practical skills”
- Explained again there would be no-one available to provide support for reading and writing
- Used photographs of people who currently support Jack
Making an Informed Decision

• Jack went to visit centre where course would be held with his father and keyworker
• Had opportunity to ask questions about the course work and the supports available
Outcome

• Jack agreed to think about the pros and cons over the Christmas holidays
• given him a print out of the pictures and Jack accepted
• We agreed to meet again on 13/1/2014 to discuss
• At meeting Jack expressed that his decision was to stay with current service and not attend course – mainly due to concern of losing his place
• In Jack’s words he would risk “losing everything” if he went on the course
Outcome

• Issue of Jack’s unhappiness with current service not resolved by this decision so...
• SLT and Jack to meet with his keyworker weekly and come up with ideas for individualised timetable and support Jack to come up with an alternative to attending the course
• Jack also meeting with psychologist and social worker for support with personal issues
Summary

• Total communication is about valuing all ways that people communicate
• Valuable resource in supporting decision making
• Communication is a basic fundamental human right
• Effective communication is key for people to achieve independence, make choices, be included and to be self determined
• Total Communication to support decision making takes time