The Connecting Me Tool Kit – Part 1

A resource to support people with communication difficulties to fully participate in their planning of individualised services using a co-design approach.

This resource was produced as part of the National Disability Services Community Inclusion Initiative.
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## PART 1

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About this Tool Kit

This Tool Kit was developed by Scope’s Communication & Inclusion Resource Centre as a product of the learnings from the Connecting Me project. This project was one of 11 projects selected in 2015 by National Disability Services as part of the Community Inclusion Initiative, which was funded through the National Disability Insurance Agency’s Sector Development Fund. The purpose of this Initiative was to increase community inclusion for people with a disability and their families, using a co-design model.

This Tool Kit contains resources and strategies to facilitate the engagement of people with communication difficulties to communicate choice and exercise participation, control and self-determination, using a co-design planning model. It is intended that the use of the resources and strategies included in this Tool Kit should be tailored to the skills and abilities of the person using it and used in conjunction with other tools and resources appropriate for the person, their circles of support, and the broader context in which the planning is undertaken.

This Tool Kit has two parts. Part 1 of the Tool Kit details strategies and resources which can be used when undertaking planning of individualised services using a co-design model with people with communication difficulties across the following stages:

- Preparation
- Planning – developing a plan
- Putting the plan into action
- Review and evaluation

Part 2 of the Tool Kit includes detailed fact sheets, examples and templates of the communication aids referred to in Part 1.

Acknowledgements

The authors would like to acknowledge and thank:

- the many people with a disability, and their families and support workers, who have assisted with the development of this Tool Kit
- the National Disability Insurance Agency who funded this project through the Sector Development Fund, and National Disability Services which led the Community Inclusion Initiative.
Co-design

Co-design is defined as ‘The process of deliberately engaging users of the system, deliverers of services and other experts, being led by experts such as designers, to actively understand, explore and ultimately change a system together’ (Huddle, 2015).

Huddle describe co-design as a divergent and convergent process that involves
- exploration of a problem and potential possibilities to overcome it
- trialling of possibilities
- decision making, reflection of decisions and consideration for the next steps in the process.

Co-design is founded on the principles of being
- person centred
- creative
- collaborative.

When working with people with communication difficulties it is critical to understand that co-design is about more than offering choices. It is essential to understand that this is a dynamic and evolving process that requires time, resource, creativity and skill. It is about knowing how the person communicates, supporting their communication and involving their appropriate circles of support throughout the co-design planning process, to achieve self-determination.
Communication

Watson and Joseph (2011) stated that ‘Communication is fundamental to understanding and expressing preference. The expression and understanding of preference are the building blocks of decisions’.

The opportunity to communicate is a basic human right and to use a meaningful co-design approach you need to know how a person communicates. Communication develops along a continuum beginning at the earliest (pre-intentional or unintentional) stage of communication. It usually progresses through a series of stages, to intentional, then symbolic (formal) and then linguistic (spoken) communication (Coupe-O’Kane & Goldbart, 1998). Most people move through these stages to become functional and independent communicators. Some people with a disability may not fully transition through these stages. In this guide we use different terms to describe stages of communication including:

Early communication

At this stage, a person communicates unintentionally using facial expression and body language, sometimes reaching out with their hands or looking at what they want. The person is unaware of the importance of communication partners and will demonstrate communicative behaviours whether there is a person present to help them or not. Communication partners need to interpret their behaviours.

Informal communication

At this stage, a person begins to recognise the importance of having a communication partner. The person may take the communication partner to get something they want, or look back and forth from the object to the partner, indicating what they want. The person may use informal ways of communicating intentionally such as natural gestures, pointing, showing or giving you things.

Symbolic communication

At this stage, a person recognises the importance of communication partners and can use some formal methods of communication. This includes words, signs or passing/pointing to pictures in order to get their need met.

The stages of planning with people with communication difficulties using a co-design approach

1. Preparation
2. Planning – developing a plan
3. Putting the plan into action
4. Review and evaluation
1. Preparation

This section includes recommendations about what to consider when ‘preparing to plan’ with a person with communication difficulties using a co-design approach.
The preparations undertaken prior to an initial planning meeting with a person with communication difficulties are critical when using a co-design approach, in order to ensure the planning will be meaningful for the person.

A number of questions should be asked to guide the preparation phase around the topics of

- who
- when
- where
- how.

Recommendations on the types of questions which can be explored include:

**Who**

- Who are all the appropriate people from the person’s circle of support who should be involved in the planning process?

  **Note:** this could include family and friends, partners, paid support workers, therapists and service providers.

- Does the person and/or family need an advocate, communication assistant or interpreter?

**When**

- When will the session be held? How long will the session go for?

  **Note:** consider factors such as the person’s best times of alertness and energy levels.

**Where**

- Where will the planning session be held?

  **Note:** consider the physical accessibility of the environment and the person's preferences and practical considerations. For example,
  - Is the location a quiet place/do you need to reduce background noise?
  - Is there adequate lighting?
  - Is it a familiar environment?
How

The most important step in supporting a person with communication difficulties using a co-design approach is to establish how that person communicates both *expressively* (how they get their message across) and *receptively* (how they understand language). This information is needed to be able to successfully communicate with the person in a way that is meaningful for them, build rapport and trust, and to be able to gather information which will be used in the planning process.

To establish how the person communicates:

- Gather information from the person’s circle of support.
- Check if the person has a recent speech pathology communication assessment and report. If so, review the report and any recommendations about how to support the person’s communication.
- Check if the person has any communication aids and make sure they are available and the people supporting that person are familiar with them.

*Note: look for aids such as*
- Communication profile
- Book about me
- Personal communication dictionary
- Speech generating device
- Chat book

Once it has been established how the person communicates consider the following:

- Can you present information in a way that will be meaningful to the person?

*Note: consider aids such as*
- Objects or Object symbols
- Photos
- Pictures or symbols
- Accessible written information

- Does the person have access to relevant vocabulary to communicate their goals, dreams and aspirations?

More information about the communication aids listed above can be found in Part 2 of this Tool Kit.

*Note: If there is incomplete information about how a person communicates, it is recommended to refer the person for a communication assessment with a speech pathologist prior to the planning session.*
2. Planning – developing a plan

This section includes recommendations about how to support a person with communication difficulties through the planning process using a co-design approach.
2. Planning – developing a plan

When co-designing a plan with a person who has communication difficulties, several sessions or meetings will often be required.

At the session, before planning starts, ensure that
- everyone present knows the person well and how they communicate
- the person has their communication aids available and can be supported to use them
- everyone present has an understanding of the co-design planning process
- materials are available to document the session in a way that is meaningful to the people present. For example, visual supports such as drawings, pictures and photos may be required to represent goals and life domains
- any previous planning documents have been reviewed.

As part of the co-design planning process all life domains can be considered including, but not limited to:

- Community inclusion
- Health and wellbeing
- Assistance with daily life
- Learning and education
- Work and employment
- Assistive technology
- Living arrangements
- Relationships
- Transport

Note: The person might only identify a selection of these life domains which they want to explore in the co-design planning process. For example, the person might be very happy with their living arrangements, however might identify that the area requiring most input is community participation and inclusion.
The Connecting Me Project conducted planning sessions based on the Huddle (2015) co-design model. This method identifies and explores problems and opportunities through brainstorming together. It groups these into categories and further refines and prioritises. It can be helpful to use sticky notes to record ideas provided in the planning session, group ideas into categories and then prioritise. Visual supports such as photos, pictures and tangible objects can also be valuable.

The following is an outline of suggested discussion topics to cover in the planning session.

- Who am I?
- My ideal world
- Challenges
- Outcomes
- Ideas/Actions
- Plan
Who am I?

Ask: What are the qualities that make up the person?

Once you have all the information, group this into categories. For example:
- Background information e.g. family, significant life events, religion and culture
- Communication e.g. how I express myself, how I understand, communication aids that I use
- Likes and dislikes e.g. activities, places, hobbies, sensory experiences
- What is important for the person to feel happy, safe, connected, valued and stimulated?
- Areas of strength and areas where support is needed.

My Ideal World

Ask: For each relevant life domain, what would make an ideal world?

For example, within the life domain of community inclusion, strategies could include:
- More opportunities to …
- Being able to do … more regularly
- Receive appropriate support and have maximum independence
- Participate to my full potential
- Social e.g. having friends my own age, having unpaid supports.
Challenges

Outline: What barriers limit a person’s ideal world from being achieved? These barriers could have multiple layers that need to be explored in detail and it can take several sessions to fully explore each domain.

What are the common challenges or barriers that stop (or could stop) these things from happening right now?

Once you have all the information, group common challenges into categories. For example:
- Resources e.g. not enough paid staff support, transport costs
- Access e.g. not having appropriate communication aids, not having appropriate mobility aids and equipment
- Attitudes e.g. negative community attitudes
- Knowledge and skills e.g. skills of support workers and communication partners to support use of a person’s communication aid/s.

For example, a specific challenge might be ‘I cannot fully participate in my community due to my communication difficulties and lack of appropriate communication aids’.

Outcomes

Review: List the common challenges and ‘reframe’ the statement to establish the positive outcome.

For example, ‘I have appropriate communication aids that meet my needs and allow me to communicate successfully’.

Ideas/Actions

Brainstorm: Ideas or actions that would overcome the identified challenges and result in positive outcomes.

For example, ‘I can be referred for a speech pathology review of my communication. Communication aids will be developed to meet my individual needs’.

Note: The following pages have examples of how to progress through the challenges to outcomes to achieve positive ideas/actions.
### Example Challenges – Outcomes – Ideas/Actions

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Outcome</th>
<th>Ideas/Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>I cannot fully participate in my community due to my communication</td>
<td>I have appropriate communication aids that meet my needs and allow me</td>
<td>I will be referred for a speech pathology review of my communication. Communication aids will be developed to meet my individual needs.</td>
</tr>
<tr>
<td>difficulties and lack of appropriate communication aids.</td>
<td>to successfully communicate.</td>
<td></td>
</tr>
<tr>
<td>I do not have enough support and transport options to do what I want.</td>
<td>I have appropriate support and transport to do the things I want to do.</td>
<td>I can get funding for support workers to support me to do the things I want to do.</td>
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<td></td>
<td></td>
<td>I can get funding for transport to get me where I want to go.</td>
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<td></td>
<td></td>
<td>I can get support from my family, friends and volunteers to help me do the things I want to do.</td>
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<tr>
<td>I have had some bad experiences due to negative community attitudes and</td>
<td>I feel welcomed and included in my community.</td>
<td>My local community receives information on disability to become more inclusive. My support workers also help by educating the people I come into</td>
</tr>
<tr>
<td>lack of understanding about my disability.</td>
<td></td>
<td>contact with regularly about my skills and abilities.</td>
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<tr>
<td>People don’t know how to use my communication aids.</td>
<td>The staff who support me know how I communicate and what aids and</td>
<td>My support workers have the appropriate set of skills (e.g. people skills such as communication and flexibility) to support me to achieve my</td>
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<tr>
<td></td>
<td>strategies I use to get my message across, and to help me understand.</td>
<td>individual goals, and can support my communication.</td>
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<td></td>
<td>When I go out, the people I see regularly in my local community know how</td>
<td>The staff support me when out in the community. People who I see regularly can observe and learn how to communicate with me.</td>
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<tr>
<td></td>
<td>to communicate with me.</td>
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<tr>
<td>I do not have appropriate equipment to meet my physical access and</td>
<td>I have appropriate mobility aids and can physically access the places</td>
<td>I can be referred for a physiotherapy/occupational therapy review of my mobility and receive appropriate mobility aids.</td>
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<tr>
<td>mobility needs.</td>
<td>that I want to go to.</td>
<td></td>
</tr>
<tr>
<td>Challenge</td>
<td>Outcome</td>
<td>Ideas/Actions</td>
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Plan

Select a goal from My Ideal World material and this becomes a goal statement. To make a plan to achieve that goal, complete the following sections:

Why are we doing this?

- Refer to the information from Who am I. For people who cannot tell you directly what they want, you will need to include information about experiences they have had and enjoyed, and how you know this.

What will it look like?

- Refer to the information from My ideal world and Outcomes
  Consider
  - When? (It may be dependent on when an activity is available if it is a pre-scheduled event. It may need to be flexible around the person’s medical and support needs e.g. best time of day for alertness etc.)
  - Where?
  - How often? (Some people may need repeated exposures of new activities, situations and environments).

How will we do this?

- Refer to the information from Ideas/Actions.

How we will know?

- Refer to the information in Outcomes and also include information about how the person communicates. It is important that you include information on how the person expresses likes and dislikes.
The goal: *I have the right tools, resources and supports to develop meaningful relationships with people who have shared interests, and to maintain old friendships.*

<table>
<thead>
<tr>
<th>Why are we doing this?</th>
<th>What will it look like?</th>
<th>How will we do this?</th>
<th>How we will know?</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have indicated some of the things I want to do using my communication aids and Key Word Sign. People in my circle of support have provided information about my reactions to previous experiences.</td>
<td>• I will meet up with old friends doing activities that I enjoy (e.g. going out for coffee, go-karting)</td>
<td>• Arrange a speech pathology review of my communication.</td>
<td>• I express ‘like’ by looking happy, looking engaged, interacting, smiling and laughing.</td>
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<tr>
<td></td>
<td>• I will join groups in my local community to meet new friends with similar interests (e.g. fishing and remote control car clubs)</td>
<td>• Update and/or develop appropriate communication aids.</td>
<td>• I express ‘dislike’ or that I want to stop doing something by looking away, appearing frustrated or using the Key Word Sign for ‘No’.</td>
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<td></td>
<td>• I will be supported to be as independent as possible in my interactions and exercise choice and control</td>
<td>• Support workers will support my use of communication aids and educate members of my local community whom I see regularly.</td>
<td>• Keep an updated learning log and communication profile noting what I appear to ‘like’ or ‘dislike’ so that my plan can evolve.</td>
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The goal:

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<th>Why are we doing this?</th>
<th>What will it look like?</th>
<th>How will we do this?</th>
<th>How we will know?</th>
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At this stage it is important to document the plan in a way that is meaningful for the person and/or their circles of support.

Did you know that 44% of Australian adults have difficulty reading and writing? (Australian Bureau of Statistics, 2013). It may be appropriate to consider documenting the written information in an accessible format, such as Easy English or Plain Language.

Easy English is a style of writing that
- is simple and concise
- focuses on presenting key information rather than the detail
- uses visual supports by way of images that illustrate headings and key messages.

An example of an Easy English version of the plan can be found on the following pages.

For more information on how to write documents in Easy English you can view Scope’s Clear Written Communications – The Easy English Style Guide in Part 2 of this Toolkit or at www.scopevic.org.au

Note: The following pages contain an example of a plan written in Easy English.
Easy English Plan Example

My Plan

I would like to

- see old friends and make new friends
- go to the go karts with friends
- go fishing with friends
- go out for coffee with friends
- do as much as I can.
To do these things I need:

- to meet and talk to people

- communication aids with photos and pictures

- people who
  - know me well
  - have similar interests
  - know how to support me.

- to get around
  - get taxis
  - have a good wheelchair.
It is important to give me opportunities to find out

- what I like
- what I do **not** like
- how things could be better for me.

Scope’s Communication and Inclusion Resource Centre wrote the Easy English. February 2016 [www.scopevic.org.au](http://www.scopevic.org.au)

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3. Putting the plan into action

This section includes recommendations about how to support a person with communication difficulties to make their plan happen.
3. Putting the plan into action

Everyone who has been involved in the planning process shares responsibility for putting the plan into action, however it may be helpful to allocate people to specific tasks based on their skills, abilities and interests. It is important to make sure that all of the people involved are aware of the documented plan and that it is accessible for those who need to access it.

Through the process of identifying barriers, a number of challenges can be considered and addressed at a local level. There may be other barriers which will require further resources to be met.

This resource has a focus on supporting people with communication difficulties, and to successfully implement a plan, the person must have tools that enable them to be as independent as possible and have communication partners who understand how the person communicates.

For people with communication difficulties, who use less than 50 words or signs, the following communication aids are examples of some aids that may be useful.
Communication aids for different communication stages

For people who are early communicators:

- Communication profile
- Book about me
- Personal communication dictionary
- Introduction card
- Chat book

For people who are informal communicators:

- Communication profile
- Book about me
- Personal communication dictionary
- Introduction card
- Chat book
- Objects or Object symbols

For people who are symbolic communicators:

- Communication profile
- Book about me
- Personal communication dictionary
- Introduction card
- Chat book
- Talking Mats™ (www.talkingmats.com)
- Timetable
- Community request cards
- Communication book/board
- Speech generating device
- Key Word Sign

**Description of communication aids**

**Communication profile**
This aid is useful for communication partners who are unfamiliar with the ways that a person communicates. It has information about a person’s communication needs, skills and abilities. It is designed to be a ‘quick glance’ guide that documents what the person understands and the ways in which he or she communicates.

**Book about me**
This aid is suitable for people who can recognise photos or pictures and for communication partners who are unfamiliar with the person and how they communicate. It contains more detailed current, relevant information about a person’s needs and abilities. It may also provide communication partners with information on the person’s likes and dislikes, interests, history and hobbies.

**Personal communication dictionary**
This aid is useful for communication partners who are unfamiliar with the ways that a person communicates. It contains information about a person’s unique or idiosyncratic communication behaviours. It provides information about what the person does, what this means and what communication partners should do in response to the communication behaviour seen. A gesture or sign dictionary can also be used to include the signs and gestures that people understand or use to communicate.
Introduction card
This aid is designed to be used when meeting new people for the first time. It enables the person to introduce themselves. It can include information about how the person communicates expressively (how they get their message across) and receptively (their understanding) and how the communication partner can best support their communication.

Chat book
This aid is designed so that people who find it difficult to express themselves can relate information about activities and events that they have experienced. They can include topics of conversation, information and/or ‘keepsakes’ about the activity/event and some interactive statements to engage others in these conversations.

Objects and/or Object symbols
These aids are designed to represent things, activities or events and can be used to help the person understand what is going to happen or to make a simple choice. The objects selected look like, feel like or have something to do with the item or activity they represent. Object symbols may be suitable for people who can understand that whole or parts of real objects can be used to represent an activity. This can also be used as part of an object based timetable.

Talking Mats™ (www.talkingmats.com)
This aid is suitable for people who understand photos, pictures or line drawings. It is a strategy that allows people to express their opinion on certain topics or events that happen in their life. The person is offered a selection of activities or emotions relevant to the topic that they want to discuss. They then need to place the symbol somewhere along a continuum to reflect their feelings or experience of the specific issue.
Timetable
This aid may be useful for people who need visual supports in symbol form to display daily or weekly activities and events. It uses pictures, photos or line drawings to show the sequence of activities in a day or a week.

Community request cards
This aid may be suitable for people who want to request items and services in the community. They can be represented in photo, picture or object form. They include information about what the person wants and what the communication partner should do. A number of different cards can be developed for different situations in the person’s life.

Note: Factsheets, examples and templates of these communication aids can be found in Part 2 of this Tool Kit.

4. Review and evaluation

This section includes recommendations about how to support a person with communication difficulties to evaluate and review their plan.
4. Evaluation

For people with communication difficulties, the evaluation process needs to be unique to the individual and relies on the people who know that person well assisting. This includes knowing how the person communicates (especially how the person expresses like and dislike) and relating this to other information known about the person before and after the plan was implemented. Some of the communication aids mentioned earlier in this tool kit are very useful as references for this phase including:

- Book about me
- Personal communication dictionary.

For people with communication difficulties, it is important they have sufficient opportunity to try new activities, situations and environments to ensure there is meaningful evaluation of their preferences.

The evaluation process should include regular reviews to monitor change and to identify if goals are being achieved.

Documentation is an essential part of this process. It identifies key people accountable for the plan’s success and monitors what works well and what needs to be reviewed.

Documentation can take many different forms. An example, which may be particularly relevant for people who use Symbolic Communication, is to record photos and videos of the person engaged in activities. These can be made into specific resources such as chat books (paper based and/or electronic), which the individual can also use to communicate to others about what they have done.

More formal outcome measures should also be recorded, which are linked to the plan’s goals. Evaluation will provide important information and evidence for continuing or modifying plans. An example and template of the Outcome Measure document from the Connecting Me project can be found on pages 33-35.
**Name:** Tom Citizen  
**Date:** 01/02/2016

**Name and role of person/s filling out form:** Julie Smith (key support worker)

**Overall goal:** I have the right tools, resources and supports to develop meaningful relationships with people who have shared interests, and maintain old friendships.

<table>
<thead>
<tr>
<th>Co-design Plan (Prompt Guide)</th>
<th>Outcome Measurement</th>
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<tbody>
<tr>
<td><strong>What will it look like?</strong></td>
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<tr>
<td>- I will meet up with old friends doing activities that I enjoy (e.g. going out for coffee, go-karting)</td>
<td>Where did Tom go? What did he do? Tom caught up with some friends who he used to live with while out go-karting. After go-karting they stayed on for a coffee together at the café. Contact details were exchanged to enable further catch ups.</td>
</tr>
<tr>
<td>- I will join groups in my local community to meet new friends with similar interests (e.g. fishing and remote control car clubs)</td>
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</tr>
<tr>
<td>- I will be supported to be as independent as possible in my interactions and exercise choice and control</td>
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<tr>
<td><strong>How will we do it?</strong></td>
<td></td>
</tr>
<tr>
<td>- Arrange a speech pathology review of my communication</td>
<td>How was Tom supported to achieve his goals?</td>
</tr>
<tr>
<td>- Update and/or develop appropriate communication aids</td>
<td>- Speech pathology review completed and communication aids developed. Mobility review is booked for next week.</td>
</tr>
<tr>
<td>- Support workers will support my use of communication aids and educate members of my local community whom I see regularly</td>
<td>- Tom was shown what would be happening today using his visual timetable which contains photos. We have previously provided community education to staff at the go-karting complex and they know how to support his communication methods including using Key Word Signs. Tom has previously received modelling and support for how to use his community request cards and now uses them to independently order drinks at the café. Tom’s other communication aids, including his Chat Book, have been updated so Tom could show his friends what he has been up to.</td>
</tr>
<tr>
<td>- Arrange an assessment to review my current wheelchair (it currently limits my physical access in certain situations)</td>
<td></td>
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<tr>
<td>Co-design Plan (Prompt Guide)</td>
<td>Outcome Measurement</td>
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<tr>
<td><strong>How will we know?</strong></td>
<td><strong>What did Tom appear to like about what he did today? How did he show this?</strong></td>
</tr>
<tr>
<td>• I express ‘like’ by looking happy, looking engaged, interacting, smiling and laughing</td>
<td>When we arrived at the go-karts and Tom saw his old friends, they gave each other a ‘high five’ and Tom’s face lit up with a smile. Tom could not stop laughing and smiling when he was out in the go-karts. He appeared very engaged when having coffee with his friends and was also looking around him to see what else was happening at the café, sometimes he bumps into other friends there.</td>
</tr>
<tr>
<td>• I express ‘dislike’ or that I want to stop doing something by looking away, appearing frustrated or using the Key Word Sign for ‘No’</td>
<td><strong>What did Tom appear to dislike about what he did today? How did he show this?</strong></td>
</tr>
<tr>
<td>• Keep an updated learning log and communication profile noting what I appear to ‘like’ or ‘dislike’ so that my plan can evolve</td>
<td>A new staff person was at the café who had not met Tom before and kept looking to me to ask what Tom would like to order. Tom appeared frustrated and started to disengage. I assisted Tom to hand the staff person his introduction card which has information about him and how he communicates and how to best communicate with him. The staff person was friendly and responded well to this and Tom was able to order his drink independently using his community request cards.</td>
</tr>
</tbody>
</table>
**Plan & Prompt Guide**

<table>
<thead>
<tr>
<th>What will it look like?</th>
<th>Where did ____ go? What did ____ do?</th>
</tr>
</thead>
<tbody>
<tr>
<td>How will we do it?</td>
<td>How was ____ supported to achieve his/her goals? (For example how was ____ supported to achieve his/her communication aids and participate?)</td>
</tr>
<tr>
<td>How will we know?</td>
<td>What did ____ appear to like about what he/she did today? How did he/she show this?</td>
</tr>
</tbody>
</table>

**Outcome Measurement**

| What did ____ appear to dislike about what he/she did today? How did he/she show this? | |
|----------------------------------------------------------------------------------------|
References


Resources & Links

Communication difficulties


Co-design/Human centred design

- Huddle http://wearehuddle.com/

Easy English

- Scope’s Accessible Information & Easy English www.scopevic.org.au

Planning


Supported Decision Making

Disclaimer

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