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A Guide to Using Visual Communication Systems to Support People with Developmental Disability and Complex Needs Access to Medical Services

By Dolly Bhargava



Government of Western Australia
Department of Communities

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Enabling independence

Acknowledgements

This project is an NDIS Information, Linkages and Capacity Building (ILC) initiative. For more ILC events and resources please visit

<http://www.disability.wa.gov.au/wa-ndis/wa-ndis/information-linkages-and-capacity-building/resources/>

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Individuals with developmental disabilities with complex needs such as behaviours of concern and severe communication issues require additional support in various circumstances, including visiting medical professionals and receiving healthcare. This booklet provides a range of support strategies that can be used in these settings to facilitate better communication between individuals with developmental difficulties and their healthcare providers, thereby improving the quality of healthcare received.

This book has been developed by Dolly Bhargava in collaboration with staff, people with disabilities and families at Intelife. The images are sourced from and copyright of Boardmaker™ Version 6 (**www.boardmakeronline.com**) and Shutterstock (**www.shutterstock.com**). This book is available as a free download at **www.intelife.org**

Dolly Bhargava is a NDIS registered behaviour support practitioner and speech pathologist. She works with children, adolescents and adults with a range of disabilities in a variety of settings such as family homes, childcare centres, preschools, schools, and corrective services. She provides consultancy and training services on a range of issues relating to communication, behaviour management, literacy, emotional literacy, vocation and social skills both nationally and internationally. She has authored a number of books, apps and online courses on providing positive behaviour support to individuals with emotional and behavioural difficulties.

For more information, visit **www.behaviourhelp.com**

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Government of **Western Australia**
Department of **Communities**



About Intelife

Intelife is committed to providing services an inclusive environment in which people with disability can build skills, engage in meaningful work and enjoy tailored activities. Our services support individuals to engage with their community, learn life skills, and achieve their goals.

Lifeskills

Our Lifeskills area supports individuals to maintain and develop new skills, build meaningful relationships, and engage in community activities that are in their NDIS plan and are important to them.

Examples of the types of support we may be able to offer are:

- Getting out into the community for appointments and shopping
- Learning daily living skills and household tasks such as cooking
- Making friends and getting exercise for a healthy life
- Exploring new hobbies and interests

Supported Employment

Intelife has contracts with government agencies and private businesses to provide services. This allows Intelife to offer individuals with a range of work opportunities in small crews doing gardening, cleaning, litter and roadside collection, office work, car cleaning and more.

Our Supported Employment area offers a variety of options for individuals to:

- set employment goals and engage in paid employment
- gain new skills and receive ongoing training
- access work experience opportunities
- transition into open employment, with or without support

Customised Employment and School Leaver Support

Customised Employment is a flexible, personalised approach that supports school leavers or mature aged job seekers to get ready for employment.

Our customised employment approach has four steps. First, we work with individuals to discover what type of work they'd like to do, then we plan, make goals and find and test suitable opportunities.

Our team supports individuals to embark on a career in supported or open employment, start their own business, study, volunteer or do work experience to find out more about what suits and interests them.

Support Coordination

Intelife Support Coordinators help individuals to understand and use their NDIS plan. We work to make sure individuals get the best mix of supports so they can maintain relationships, live more independently and be included in their community.

We also offer support connection to build an individual's ability to connect with informal, community and funded supports enabling them to get the most out of their plan and pursue their goals.

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Introduction

People with developmental disabilities with complex needs have the same right to access community based medical services as any other community member.

The last few decades have seen a shift in community attitudes towards a more inclusive society. This has meant that individuals with developmental disabilities with complex needs have had increased access to community based medical services. However, being physically situated in a setting such a GP clinic, dental room or an optometrist's testing room does not necessarily mean equitable services are received.

People with developmental disabilities with complex needs encounter a number of barriers such as communication, cognitive, motor, self-direction, self-care, independent living, and economic self-sufficiency difficulties (National Association of Councils on Developmental Disabilities, 2012) that impact their ability to receive good health care.

Caregivers, disability staff and medical professionals need to be proactive in the construction and provision of supports that address the barriers impacting an individual's ability to receive equitable access medical services. This resource aims to provide a range of strategies to specifically address communication barriers experienced by people with developmental disabilities with complex needs.

This resource is divided into two sections.

Section 1 discusses strategies that can be used by family, friends and support staff to enhance, support and supplement the communication of individuals with disabilities pre-, during and post-visit.

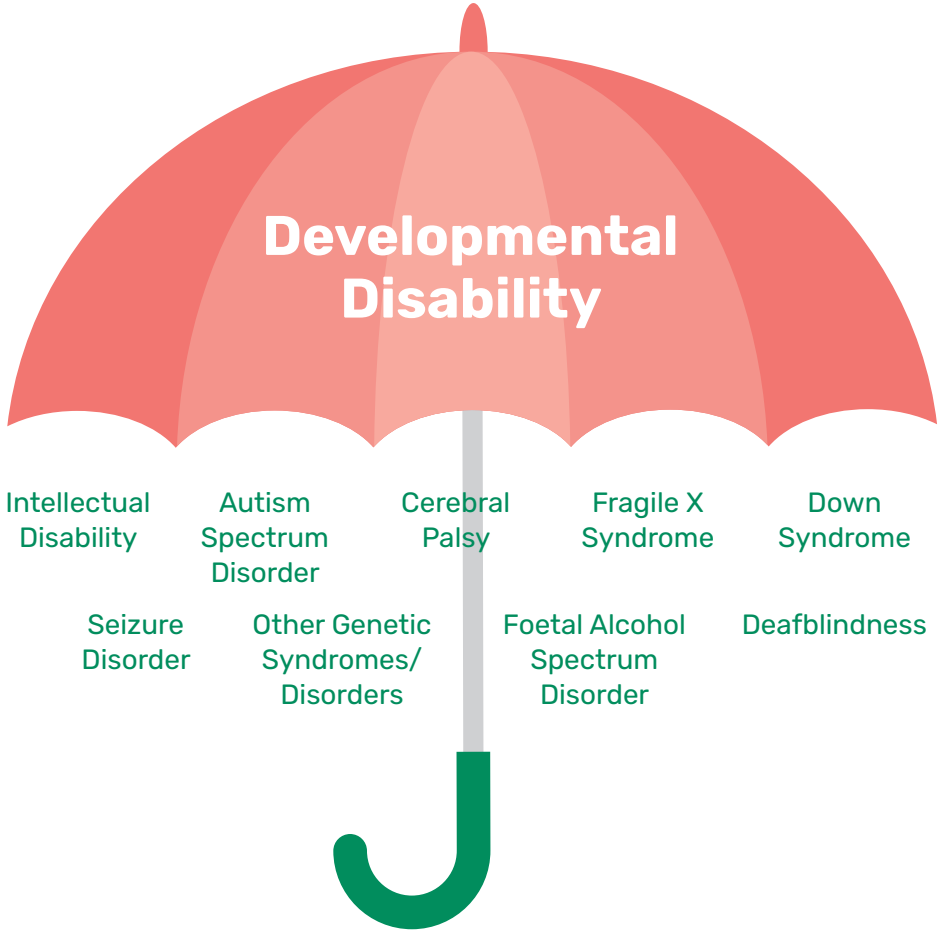
Section 2 provides suggestions and recommendations on improving communication between medical professionals and patients with developmental disabilities with complex needs.

Remember to select, design and implement the suggested strategies in accordance with the individual's level of understanding, unique needs and context. To adapt the strategies, it is recommended that you work with a speech pathologist, an Allied Health Professional who provides assessment, treatment and therapy for communication, feeding and swallowing difficulties. A speech pathologist will assess the individual's communication skills and recommend visual strategies that can be used based on their findings. The information contained in this resource should be used with the assistance of your local speech pathologist to empower the person you support.

Dolly Bhargava

What is Developmental Disability?

'Developmental disability' is an umbrella term that includes a diverse range of diagnoses which arise from an impairment of the central nervous system (Statewide Child and Youth Clinical Network, 2013). Some of the common types of developmental disabilities have been listed below:



Developmental disability results in significantly reduced capacity in three or more of the following developmental areas:

- communication
- cognitive function
- motor function
- self-direction
- self-care
- independent living
- economic self-sufficiency

(National Association of Councils on

Developmental Disabilities, 2012).

Individuals with developmental disabilities with complex needs such as behaviours of concern and severe communication issues require additional support in various circumstances, including visiting medical professionals and receiving healthcare. This resource specifically focuses on providing practical strategies to address severe communication issues and facilitate better communication between individuals with severe communication issues and their healthcare providers.

What is communication?

Sending message

Receiving message



Receiving message

Sending message

Communication is a two-way process involving an exchange and flow of information and ideas between at least two people.

This two-way process can be broken down into three broad categories:

- 1. Receptive communication** is the process of **receiving, processing** and **understanding** messages. Receptive communication difficulties may result in an individual misunderstanding information or recommendations they are given by medical professionals about their health and care, or questions asked by medical professionals to determine the most appropriate care to provide.
- 2. Expressive communication** refers to the way the individual **conveys** a message. Messages can be conveyed verbally (i.e. speech) and/or non-verbally (e.g. facial expressions, vocalisations, gestures and body movements). Expressive communication difficulties may result in the individual having difficulties reporting their symptoms, describing the history of their symptoms and discussing the effectiveness of the recommendations they have been given. This may be due to limited or no speech, reduced speech clarity, narrow range of vocabulary, word finding problems or difficulties with elaborating their messages.
- 3. Social skills** refer to non-verbal and/or verbal skills that enable the individual to establish and build relationships with others. Social skill difficulties may result in the individual not understanding the social rules applicable in medical appointment settings. This may result in the individual interacting with people in socially inappropriate ways, for example standing too close to someone, difficulty understanding the consequences of their actions or not knowing how to engage in a conversation.

Visual supports are a useful strategy to support, enhance and supplement the individual's communication skills. A visual support refers to the use of a visual item such as an object, photograph, computer line drawing, or written word to help the individual understand, express and interact with others. There are a range of visual supports that can be utilised depending on the individual's current abilities.

What are the different types of visual supports?

Least abstract / Least difficult to understand / recognise visual support

START HERE

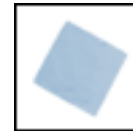
and depending on the individual's response, gradually progress to

Most abstract/most difficult to understand/ recognise visual support

1. Objects refers to the use of an item to represent people, places, activities and things. Examples of object visual supports include showing the individual a stethoscope to represent going to the GP, toy teeth to represent going to the dentist, or red-green anaglyph glasses to represent going to the optometrist.



Object symbols refers to using a whole or part of an item to represent an activity, person or thing. The item is attached (e.g. with Velcro, glue or string) to a board (e.g. cardboard, laminated card), which is especially useful when it is difficult to carry the whole object. An example of a part object symbol is an empty Panadol box to represent medicine; while examples of whole item object symbols include a thermometer to represent the GP taking the individual's temperature, or a microfiber cleaning cloth to represent that the individual needs to clean their glasses.



2. Photos refers to the use of photographs to represent people, places and activities. This includes non-digital and digital photos, Polaroid photos, pictures cut out from magazines or catalogues. Examples of photo visual supports include a photo of scraped knee that the individual can show to their siblings to explain why they went to the GP, using a photo of the dentist to inform the individual that they are going to see the dentist, or a photo of an eye test to help the individual understand what will they be doing during their visit to an optometrist.



3. Computer line drawings refers to the use of coloured or black and white line drawings (hand drawn or commercially produced) to represent people, places, activities and concepts. Examples of commercially available programs include Clipart, Boardmaker, Softpics with Fantasticpics, and COMPIC. Examples of computer line drawing visual supports include a Boardmaker symbol for sore head to help the individual express where they are sore, a cartoon drawing of a sick person to help the individual understand what would happen if they don't take their medication, or an eye test chart to help the person understand what they will be doing during their visit to an optometrist.



4. Written word refers to the use of the written words to explain concepts. Examples of written word visual supports include a written list of the behaviours allowed in the GP waiting room, a list of steps the individual needs to follow when brushing their teeth, or a written cause-effect link that shows 'If I don't wear my glasses when using the computer > I will get a headache'.

What are visual systems?

As the saying goes, “A picture speaks a thousand words...” A visual support on its own can communicate a variety of meanings. A photo of an optometrist could mean “I’m going to see an optometrist today” or “I saw the optometrist today” or “This is my optometrist”. However, if the photo of the optometrist was embedded in a visual system, it would help convey a specific message. For example, to convey the message “I’m going to see the optometrist today”, the photo of the optometrist can be embedded in a schedule system, which outlines the activities an individual will be doing on a given day (Figure 1). To convey the message “I saw the optometrist today”, the photo can be embedded in a chat book, a tool for helping an individual talk about what they have done on a given day (Figure 2).

Figure 1 – Schedule “I’m going to see the optometrist”









 AM morning	 breakfast	 car	 optometrist
 PM afternoon			
 PM evening			

Figure 2 – Chat Book “I saw the optometrist today”

26/06/19 – Special Activity	
When? On Saturday at 9am	 Saturday
Where? I went to the optometrist (Mr. Jones)	
Who? I went with Mum and Dad	
What? He checked my eyes. I got glasses.	

To help clarify the meaning and purpose of visual supports, it is best to embed them into a visual system. There various types of visual systems that can be used:

- Calendars
- Schedules
- Mini schedules
- Choice systems
- Cause-effect links
- Social stories
- Category books
- Circles concepts
- Activity checklists
- Chat books
- Feeling-problem-solution charts
- Behavioural rules
- Comic Strip conversations
- Shopping lists
- Cue cards
- PECS (Picture Exchange Communication System)
- ALS (Aided Language Stimulation) boards
- PODD (Pragmatic Organisation Dynamic Display)

The following pages describe of some of these visual systems. Visual systems that require comprehensive assessment by a speech pathologist have been omitted. Remember that you **do not** need to use all the visual systems, and should select the visual systems that you think would best suit the individual you are supporting pre-, during and post-visit to a medical professional.

When putting together your visual strategies, consider:

- What will your visual system look like?
- What visual support to represent the activity/person/place/thing best suits the individual's ability level?
- How detailed will your visual system be?
- Once an activity/person/place/thing has ended/left, what should happen to the visual support representing it? (e.g. does the individual remove it and put it in a finished envelope/box, or tick or cross it off a checklist?)
- How will you teach the individual to use the visual system?
- Will you need to use a motivator or reinforcer to encourage the individual to do the things that have been outlined in the visual system, especially if they are non-preferred?

What do you need to make visual systems?

To create the visual systems described in this booklet, you will need the following materials and resources:

- Velcro (rough & smooth or hook & loop)
- A4/A3 laminator
- A4/A3 laminating pouches
- Scissors
- White/coloured paper
- Digital camera
- Colour printer
- Magazine and catalog pictures
- Internet access
- Google Images
- Computer line drawing picture software programs if appropriate. There are several picture software programs available. The programs that were used for the examples in this booklet are listed below:

Boardmaker	Lessonpix	Clipart
<p>Boardmaker is a flexible and easy to use image library and software package for creating visual systems. It contains over 4,500 Picture Communication Symbols (PCS) images.</p> <p>www.boardmakeronline.com</p>	<p>Lessonpix is a flexible and easy to use image library and software package for creating visual systems. It contains over 40,000 images.</p> <p>www.lessonpix.com</p>	<p>Clipart is a flexible and easy to use image library that can be used to create visual systems. It contains over 13 million images on a range of different topics.</p> <p>www.clipart-library.com/healthcare-cliparts.html</p>

What are some considerations for choosing appropriate visual supports and visual systems?

Each visual system should be individualised to meet the needs of the individual.

To ensure the systems created will be effective tools, a variety of factors must be considered:

- 1. Choice of visual supports** – The way a message should be represented (i.e. objects, photos, computer line drawings or written word) will depend on what the individual understands. The ability to understand different degrees of abstraction will vary between individuals.

Begin by using visual supports that the individual understands. For example, if the individual responds best to photos, the visual system should be photo-based. Remember to always use speech to accompany the visual support.

If you are unsure of what type of visual supports to begin with, researchers suggest that it is best to start with objects and gradually move to photographs before then moving to computer line drawings. The aim is to start with simple representations, then gradually work towards more abstract representations as the individual gains more understanding. If you are unsure how to begin to use visual systems with the individual, contact a speech pathologist.

It is important to combine the visual support with a written word. Labelling the visual support ensures that everyone using it with the individual will use the same language when interacting with them. Use a minimum font size of 18 point and in a standard non-cursive font (e.g. Comic Sans MS, Arial or Century Gothic).

- 2. Number of visual supports** – You will need to consider the number of objects, photos, computer line drawings and written words your individual can use at a time. Researchers suggest that you should gradually build the number of visual supports you have in the visual system. You may begin with one or two visual supports, and as the individual's understanding develops you can gradually add more.
- 3. Size of visual supports** – The way you present the visual support may need to be modified depending on the individual's visual skills. It is important to make sure the individual can see the visual support, so you may need to change its size for optimum viewing. If the visuals need to be distinctive, highlighting and darkening the outline of the picture may help. In some types of visual impairments, presenting the visual support on a contrasting background is beneficial (e.g. a dark object/photo/computer line drawing/written word on a white background or a light object/photo/computer line drawing/written word on a dark background).
- 4. Time** – It is important that the individual is given enough time to focus on the visual support.
- 5. Presentation of visual supports** – Depending on the individual's visual scanning abilities (i.e. horizontal scanning – looking from left to right; vertical scanning – looking from top to bottom), present the visual support from left to right. This is to encourage horizontal scanning, which is used when reading.

- 6. Location of the visual system** – The visual system should be easily accessible by the individual.
- 7. Portability of the visual system** – This is an important consideration which will determine how big or small, heavy or light, or fixed or portable the system should be. If the individual has difficulty with mobility, then you will need to determine ways for them to access the visual system as independently as possible.

8. Tips for taking photos

- Use a good camera, preferably digital.
- Make sure that there is enough light so that the photograph comes out clear. Use the flash as necessary.
- When taking photographs to use for communication, it is helpful to make the photograph as simple as possible. Include only one object in the picture or make the background blank.
- When taking a photo, focus on what is important and try to avoid any extraneous aspects that may be distracting. For example, compare figure 1(target – toothpaste) vs. figure 2 (target – toothpaste) vs. figure 3 (target – toothpaste).

Figure 1 uncluttered



Figure 2 cluttered



Figure 3 distracting background



- If you do have extraneous details, you can remove them by either cutting around the extraneous areas or using computer programs like Photoshop to crop the important detail in your picture or enhance the image.
- Take the photo from a good distance, and from the individual's perspective.
- Take a variety of shots so that you can choose the most appropriate photo (i.e. the one that conveys the information most accurately).
- You can print the photos at most photo shops.

What are the different types of visual systems?

> Calendar (Pre-visit)

What?

A calendar is a visual system that represents time (i.e. week, months and years) in a concrete manner. You can mark appointments with a GP, dentist or optometrist on the calendar alongside holidays, trips and other important events. The calendar can be weekly, monthly or yearly, based on the individual's understanding.

Why?

Time is an abstract concept. By using a calendar, you can associate each day and date with the main activity for that day. The main activity for each day marks the passage of time and helps the individual countdown to a particular day.














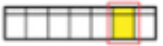







Where?

Display the calendar in an accessible area so that the individual and caregivers can refer to it as necessary to see upcoming appointments.

How?

Choose calendar layout suitable for the individual's abilities and understanding and add appointments with a GP, dentist or optometrist. At the beginning of each day, refer to the calendar to identify the day and the main activities the individual will be participating in on this day. If an appointment with a GP, dentist or optometrist has been marked on this day of the calendar, inform the individual that they will be visiting a medical professional. An example of calendar is shown on the next page.

Figure 3 – Below is an example of a calendar system that was put in place to inform Edmond of when he will be visiting the GP.

<p>Mo </p>  <p>Monday</p>	<p>Bowling </p>
<p>Tu </p>  <p>Tuesday</p>	<p>Visit Dr Tom </p>
<p>W </p>  <p>Wednesday</p>	<p>Work </p>
<p>Th </p>  <p>Thursday</p>	<p>Work </p>
<p>Fri </p>  <p>Friday</p>	<p>Work </p>
<p>Sa </p>  <p>Saturday</p>	<p>Cinema </p>
<p>Su </p>  <p>Sunday</p>	<p>Pub </p>

Topic 7 – What are the different types of visual systems?

> Schedule (Pre-visit)

What?

A schedule is a visual system that provides information about the sequence of activities that will occur within a specific time period. A simple schedule is called a 'Now' schedule, which highlights the upcoming activity. The next more complex schedule is called a 'First-Then' schedule, which informs the individual about the sequence of events that will be occurring in a specific period of time (i.e. first... and then...). The most complex schedule presents all activities that will occur throughout the day. Schedules can be used to explain to the individual what will happen before, during and after an appointment with a GP, dentist or optometrist, and help motivate them to attend the appointment.

Why?

Schedules can assist the individual in transitioning from the preceding activity, to their appointment, then to the activity that follows it, as they know what they will be doing after each activity concludes. A schedule can also motivate the individual to attend a non-preferred appointment with a GP, dentist or optometrist, especially if they can see that it is followed by a motivating activity.

A schedule can provide the individual with a sense of security and control because they can refer to it to see how their day is planned and structured. This can help them avoid feeling anxious about things seeming to be happening randomly to them.

Schedules also provide a means to represent abstract concepts such as time (e.g. morning, afternoon and night) in a more concrete and manageable form.

Where?

Keep the schedule in an easily accessible area so that the individual and caregivers can refer to it as necessary to see each upcoming activity on the day of the appointment. You can also create a portable copy of the schedule (e.g. on a clipboard, key chain or photo album) to take with you to the appointment.

How?

On the day of the appointment, put together a daily schedule suitable for the individual's abilities and understanding that you can use to discuss with them when you will be going to visit the medical professional (i.e. morning, afternoon or evening) and what will be happening before and after the visit. Examples of schedules are shown on the next page.

Figure 4 – Below is an example of a ‘Now’ schedule informing Nina that she is going in the car to visit the optometrist.



Figure 5 – Below is an example of a ‘First-Then’ schedule informing Edmond that first he will visit the dentist, then he will go to the movies.





First	Then
 <p data-bbox="303 1153 414 1187">dentist</p>	 <p data-bbox="646 1153 758 1187">cinema</p>

Figure 6 – Below is an example of a daily schedule informing Nina that she will be visiting the GP in the evening after she has returned from work.

<p data-bbox="255 1422 367 1478">AM</p>  <p data-bbox="255 1534 367 1568">morning</p>	Breakfast	Get dressed	Blood sugar	Go to work
<p data-bbox="255 1579 367 1635">PM</p>  <p data-bbox="255 1691 367 1720">afternoon</p>	Relax	Go in taxi	Go to GP	Go home
<p data-bbox="255 1724 367 1780">PM</p>  <p data-bbox="255 1836 367 1870">evening</p>	Dinner	TV	Shower	Bed

Topic 7 – What are the different types of visual systems?

> Mini Schedule (Pre-visit, during the visit)

What?

A mini schedule is a visual system that represents a task analysis of an activity from the schedule. It can be used to break down the visit to a GP, dentist or optometrist into simple, clear and manageable steps for the individual to understand and follow.

Why?

By breaking down the visit into simple, clear and manageable steps, the individual can understand the sequence of steps they need to complete before, during and after the visit. This can help reduce confusion, anxiety and frustration caused by not understanding what is happening.

Where?

Create a portable copy of the mini schedule (e.g. on a clipboard, keychain or a photo album) that you can take with you to the appointment so that the individual, caregivers and the medical professional can refer to it as they complete each step.

How?

Several days before the appointment, list the steps that will be followed during the visit to the GP, dentist or optometrist and include visual supports for each step. To prepare the individual for the upcoming visit, go through the steps outlined in the mini schedule a few days in advance. On the day of the visit, you can go through the steps in greater detail. During the visit, you can cross out or tick off each step as it is completed, or remove the visual support and put it in a 'finished' envelope. Examples of mini schedules are shown on the next pages.



Figure 7 – Below is an example of a mini schedule to guide Edmond step-by-step on how to take his medication.

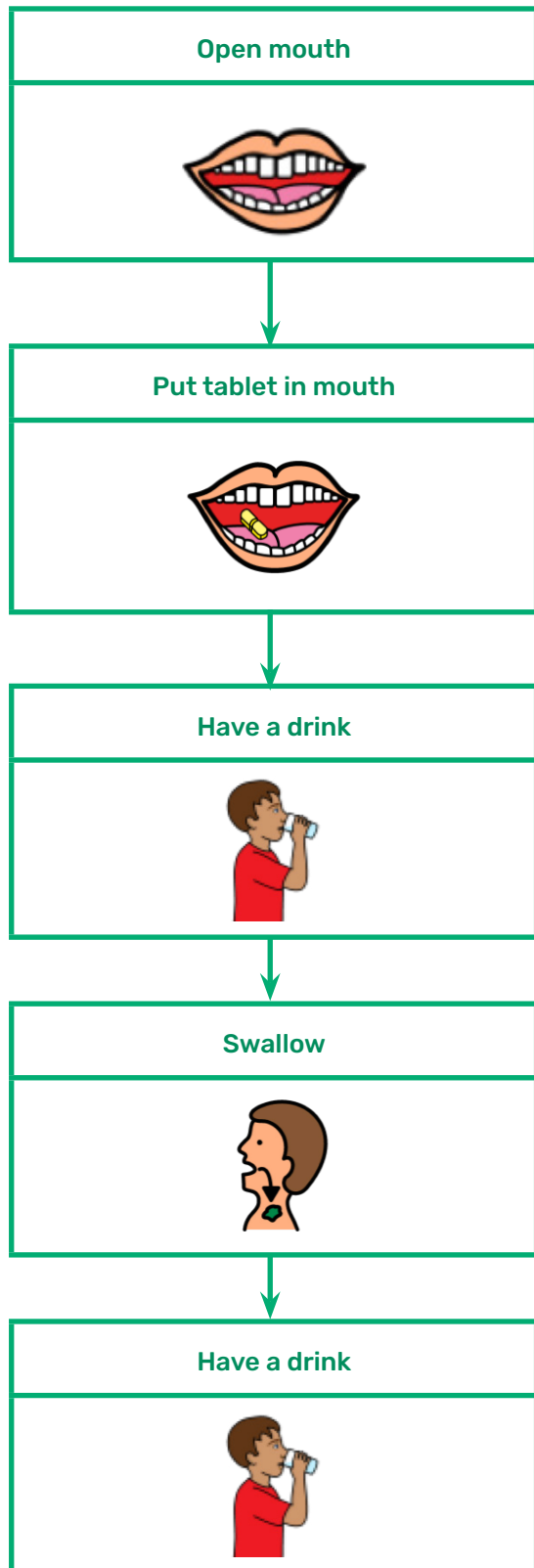















Figure 8 – Below is an example of a mini schedule to prepare Nina step-by-step for what will happen during her visit to the GP.

1. Go to front desk 
2. Sit in waiting room 
3. Wait for Dr 
4. Play with toys in play area 
5. Doctor will call my name 
6. Walk to Dr's office 
7. Sit on table 
8. Dr will use stethoscope to listen to my breathing 
9. Dr will check my ears  and my mouth 
10. Dr will take my temperature 
11. Dr will give me sticker 
12. Dr will say goodbye 

Topic 7 – What are the different types of visual systems?

> Choice Systems (Pre-visit, during the visit, post-visit)

What?

A choice system is a visual system that offers the individual a set of options that they can select from. Choice systems can help the individual feel empowered during a visit to a GP, dentist or optometrist.

Why?

Going into a medical setting may feel like a powerless situation. Providing the individual with opportunities for control and choice can help them feel empowered. Being able to make a choice promotes a sense of control over the environment, promotes independence, increases motivation to participate, facilitates personal satisfaction and fosters self-esteem.

Where?

Create a portable copy of the choice system (e.g. on a clipboard, keychain or a photo album) that you can take with you to the appointment to offer choices to the individual before, during and after the visit.

How?

It is important to go through the rules prior to the visit and refer to them throughout the visit to remind the individual of expected behaviours and reinforce the individual for exhibiting the expected behaviours. When writing behavioural rules, ensure that they are specific, observable and realistic. For example, “Sit in dental chair for 10 minutes” is a more effective rule than “Behave”. For some individuals, you may need to include additional information, such as “What am I not allowed to do? Why am I not allowed to do that? What am I allowed to do instead?”. For example, “I am not allowed to run around the GP room. I could trip and hurt myself. I am allowed to sit in the GP room. After the visit I can run in the park.

To assist everyone interacting with the individual recognise, acknowledge, interpret and respond to the individual’s communication signals consistently please put together a Personal Communication Dictionary (PCD). A PCD is a combination of photographs, videos and written descriptions of the individual’s communicative behaviours, what they possibly mean and ways others can best respond to them. Below is a list of steps to develop the PCD:

Step 1 – Collaborate with the individual’s parents, teaching staff, therapists and other key people who know the individual well to identify the non-verbal communicative behaviours the individual currently exhibits. Look at the examples of non-verbal behaviours provided in the table on the next page to identify them. The information in the table is not a comprehensive list of all the possible non-verbal behaviours a individual may exhibit.

Examples of Non-Verbal Behaviours			
Arms and hands	Trunk	Legs	Head
<ul style="list-style-type: none"> • Hands (reaching, grasping, squeezing, shaking, releasing, stretching, turning, tearing, waving, picking, feeling, scratching, throwing, dropping) • Lifting arms • Lowering arms • Flapping arms • Relaxing arms • Tensing arms • Becoming still 	<ul style="list-style-type: none"> • Stiffening trunk • Leaning towards object or person • Leaning away from object or person • Turning away from object or person • Relaxing trunk • Becoming still 	<ul style="list-style-type: none"> • Extending legs • Extending feet • Moving feet (e.g. kicking stamping, shaking, raising, lowering) • Becoming still 	<ul style="list-style-type: none"> • Turning head • Protruding tongue • Opening mouth • Moving head by nodding, shaking • Change in breathing pattern • Change in oral motor pattern • Becoming
Vocalisations	Eye gaze	Face	Challenging behaviours
<ul style="list-style-type: none"> • Whining • Crying • Grunting • Screaming • Babbling (sound play) • Quietening • Changing voice (loudness, pitch, intonation) • Sounds (e.g. /aaaaa/, /wheeee/, /uuuuu/) 	<ul style="list-style-type: none"> • Looking towards • Looking away • Shutting eyes • Making eye contact with a person • Eyes widening • Brief eye contact • Staring 	<ul style="list-style-type: none"> • Smiling • Surprise • Grimace • Frowning • Becoming still • Tensing facial muscles • Relaxing facial muscles 	<ul style="list-style-type: none"> • Stereotypic behavior (e.g. rocking, flapping) • Self-injurious behavior (e.g. head banging, hand biting) • Aggressive behaviour (e.g. pinching, kicking) • Destructive behaviour (e.g. throwing or breaking things)

Step 2 – Record the individual’s name, the names of the contributors and the date the information is recorded in the spaces provided. Describe the individual’s behaviours by using a combination of photographs, videos and written descriptions in the ‘what does the individual do’ column:

Individual name:
Names of people who have contributed:
Date:

What does the individual do?

Step 3 – As a team, determine what these behaviours mean. Examples of messages include:

- Expressing feelings (e.g. hunger, thirst, pain, tired and discomfort)
- Requesting attention/affection/interaction
- Rejecting attention/affection/interaction
- Requesting an object or action
- Rejecting an object or action
- Write down the meaning of the corresponding behaviour in the ‘what it possibly means?’ column:

Individual name:
Names of people who have contributed:
Date:

What does the individual do?	What it possibly means?

Step 3 – As a team, agree on an appropriate way to acknowledge, label and respond to the individual’s behaviour by completing the ‘What should you do?’ column:

Individual name:

Names of people who have contributed:

Date:

What does the individual do?	What it possibly means?	What should you do?



Step 4 – Review and update the information in the personal communication dictionary regularly.

The Model of Choice Diversity (Brown, Belz Corsi & Wenia, 1993) can help you identify opportunities for choice making. The model discusses seven categories of choice that are available in any situation. The aim is not to offer the individual all seven choices at once, but to use the different categories to identify choice making opportunities in situations that appear to have minimal choice. For example, going to a GP, dentist or optometrist may not be a negotiable, but within that situation we can identify some choice making opportunities.

7 Ways to Create Opportunities for Choice Making		
Category	Choices Offered	Example
Within activity	Choices of materials used within an activity	What colour of braces would you like to have? Red or pink?
Between activities	Choices among different activities	While I am talking to the doctor, would you like to colour or build Lego?
Refusal	Choice to refuse participation in an activity or a certain part of the activity	Do you want the doctor to check your eyes and ears or only the ears today?

Who	Choice of people to be included or excluded	Would you like Mum or Dad to hold your hand while the blood pressure is taken?
Where	Choice of location of an activity	Would you like to sit on this chair or the other chair as the doctor looks in your ear?
When	Choice of when an activity should occur	Would you like to have ice-cream before or after the visit to the optometrist?
Terminate	Choice of when to end an activity	Would you like to do two or three mouth rinses before we finish?

Figure 9 – Below is an example of the choices that were offered to Nina as a reward after she had been to the dentist.

My outside activity choices	
	Shops
	Beach

What are the different types of visual systems?

> Cause–Effect Links (Pre-visit, during the visit, post-visit)

What?

A cause–effect link is a visual system that helps the individual understand the consequences of their actions. The aim is to help the individual choose an appropriate course of action. Cause–effect links can help explain to an individual why they should follow the advice they are given by a GP, dentist or optometrist.

Why?

The cause–effect link visual system explicitly outlines the consequences for one’s behavioural choices. This visual system allows caregivers to explore the behavioural choices we can make and explain consequences for each choice.

During an appointment, a cause–effect link can help explain to an individual why the medical professional needs to perform a certain action or conduct particular test (e.g. if doctor can’t look in the individual’s mouth, they may not be able to find out why the individual’s throat hurts and how to make it better).

After a visit, a cause–effect link can help the individual understand why they should follow the medical advice a medical professional has given them (e.g. explaining the consequences that drinking fizzy drinks every day and not brushing our teeth can have on teeth and gums, and the consequences of unhealthy teeth and gums).

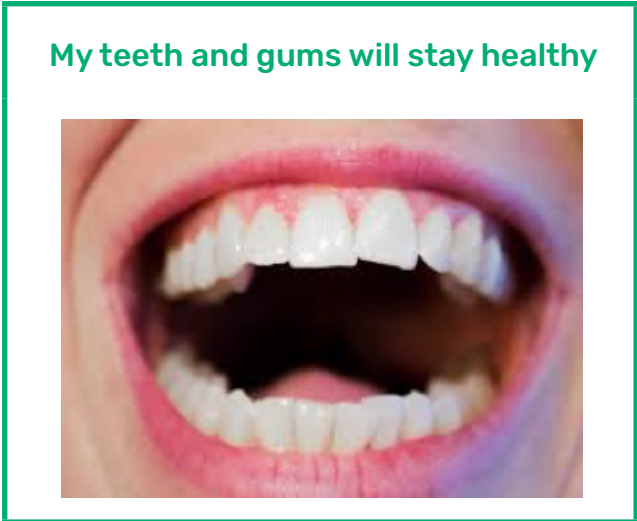
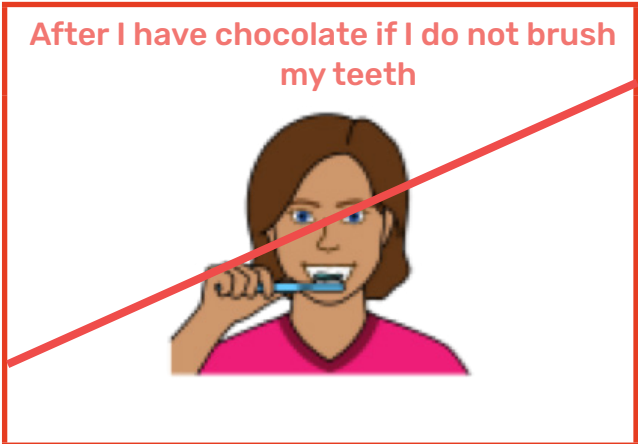
Where?

Keep the cause–effect link visual system in an accessible area near the related activity so that the individual and caregivers can refer to it as necessary (e.g. cause-effect links relating to oral health can be kept near the individual’s toothbrush). You can also create a portable copy of the cause–effect link visual system (e.g. on a clipboard, keychain or a photo album) that you can take with you to the appointment.

How?

Using visual supports, create a cause–effect link that contains information on consequences that would be meaningful and motivating to the individual. For example, “If I don’t take my medicine I will feel sick” may be less effective than “If I don’t take my medicine I will not be able to go to the carnival”. Use the visual system to help the individual understand the importance of going to the GP, dentist or optometrist and following their recommendations. An example of a cause-effect link is shown on the next page.

Figure 10 – Below is an example of a cause-effect link that helps Edmond understand the consequences of not brushing his teeth after eating chocolate.



What are the different types of visual systems?

> Social Story (Pre-visit, during the visit)

What?

A Social Story explicitly describes a situation, skill, or concept in terms of relevant social cues, perspectives and common responses in a specifically defined style and format (Gray, 2010). A Social Story can help the individual feel more comfortable during visits to a GP, dentist or optometrist.

Why?

Explicitly describing the steps involved in an interaction with a GP, dentist or optometrist helps the individual better understand the social expectations within that situation. This makes the situation more predictable, less confusing and provides the individual with knowledge on socially appropriate behaviour.

Where?

Incorporate the Social Story into the individual's daily routine prior to the appointment. Set aside a special time for reading the Social Story or read it if a discussion about the visit comes up. Reading about the upcoming visit weeks before it taking place can help the individual develop confidence.

How?

Before writing the Social Story, analyse the visit in terms of beginning, middle and ending. When writing the Social Story, consider if it should be written in the first person or third person. Also consider the individual's reading ability and attention span.



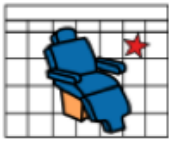







A social story is made up of up to five different sentence types. Each sentence type is used like a prescription called the Social Story Ratio.

- 0-1 sentence which is either a directive or a control sentence
- 2-5 sentences for each type i.e.
 - Descriptive - Answers where does the situation occur, when does it occur, where does it occur and what happens.
 - Perspective - Answers the 'why' by providing details about the thoughts, feelings, ideas, beliefs or physical/mental wellbeing of others.
 - Directive - Suggests a desired response/s for behaviour in a particular situation in a positive and flexible manner.
 - Affirmative - Provides reassurance.
 - Control - Strategy/prompt to assist the person to recall, remember and apply appropriate response.

- Cooperative - Sentences which identify how others may be of assistance to the person

When you have written the Social Story, it is important to provide the individual with multiple opportunities to practise or rehearse it in staged situations that emulate the actual visit. Use a variety of teaching techniques such as role playing and videotaped interactions. Having practised the steps associated with the medical appointment, the individual will be more likely to be comfortable in the real-life situation. An example of a Social Story is shown on the below.

Figure 11 – Below is an example of a Social Story that was read to Nina several weeks prior to her visit to the dentist, as the upcoming visit made her nervous.

<p style="text-align: right;">1</p>  <p style="text-align: center;">Visiting the Dentist</p>	<p style="text-align: right;">2</p>  <p style="text-align: center;">Dentists help people keep their teeth clean and healthy</p>
<p style="text-align: right;">3</p>  <p style="text-align: center;">Sometimes I may visit the dentist for a check-up</p>	<p style="text-align: right;">4</p>  <p style="text-align: center;">The dentist will ask me to sit on a chair</p>
<p style="text-align: right;">5</p>  <p style="text-align: center;">The dentist will look in my mouth</p>	<p style="text-align: right;">6</p>  <p style="text-align: center;">The dentist will check and clean my teeth with special instruments</p>
<p style="text-align: right;">7</p>  <p style="text-align: center;">I will try to sit still and stay quiet when the dentist is checking my teeth</p>	<p style="text-align: right;">8</p>  <p style="text-align: center;">When I feel nervous, I can hold my mum's hand</p>
<p style="text-align: right;">9</p>  <p style="text-align: center;">I am proud of me for staying calm</p>	<p style="text-align: right;">10</p>  <p style="text-align: center;">Everybody is proud of me for staying calm</p>

What are the different types of visual systems?

> Category Book (Pre-visit, during the visit)

What?

A category book is a visual system in which items, activities and people that belong to a particular group are placed together. A category book can help the individual familiarise themselves with different medical professionals and appointments.

Why?

Exposing the individual to the items, activities and people related to an upcoming medical activity can help them prepare for and familiarise themselves with the upcoming activity, enabling them to feel more confident about the visit.


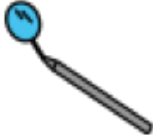





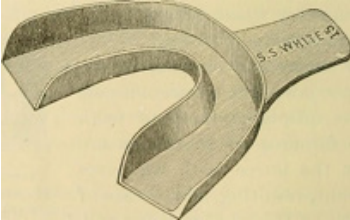



Where?

Create a portable category book to ensure the individual and caregivers have access to it prior to and throughout the appointment. They can refer to the category book throughout the appointment to understand and express messages.

How?

Identify the number of sub-categories within the appointment type. For example, 'Going to the Dentist' could include a people's page (e.g. dentist, dental nurse and receptionist); item page (e.g. bands, dental chair, filling) and activity page (e.g. gargle, open, close). Put together visual supports for each item of each sub-category. An example of a category book page is shown on the next page.

Figure 12 – Below is an example of a category book page for ‘Going to the Dentist’, showing a list of the different types of dental equipment that Edmond may see when he goes to the dentist.

Dental Equipment		
 <p>dental chair</p>	 <p>dental mirror</p>	 <p>dental x-ray</p>
 <p>dental drill</p>	 <p>dental scalar</p>	 <p>mouthwash</p>
 <p>floss</p>	 <p>Teeth impression tray</p>	 <p>glasses</p>
 <p>toothbrush</p>	 <p>toothpaste</p>	 <p>cotton balls</p>

What are the different types of visual systems?

> Circle Concept (Pre-visit, during the visit)

What?

The Circle Concept, as discussed in Smith, S. (1987) Enhancing Self Concept and Social behaviour skills through THE CIRCLE CONCEPT. Vic: Social Biology Resources Centre, The Circles Concept, is a visual system that helps to reinforce appropriate and inappropriate behaviours in different types of relationships. The Circle Concept can help the individual learn what social behaviours are acceptable when interacting with medical professionals and staff.

Why?

The Circle Concept is a visually structured approach that helps the individual clarify the different types of relationships they have with the different people in their life. It helps them learn the social behaviours that are acceptable to express with different people depending on the type of relationship they have with a person (Smith, 1987). Creating a Circle Concept for interacting with their GP, dentist or optometrist will help teach the individual what social behaviours are appropriate when attending medical appointments.

Where?

Keep the Circle Concept in an accessible area so that the individual and caregivers can refer to it as necessary. You can also create a portable copy of the Circle Concept (e.g. on a clipboard, key chain or photo album) that you can take with you to the appointment to remind and prompt the individual to exhibit the appropriate behaviour.

How?

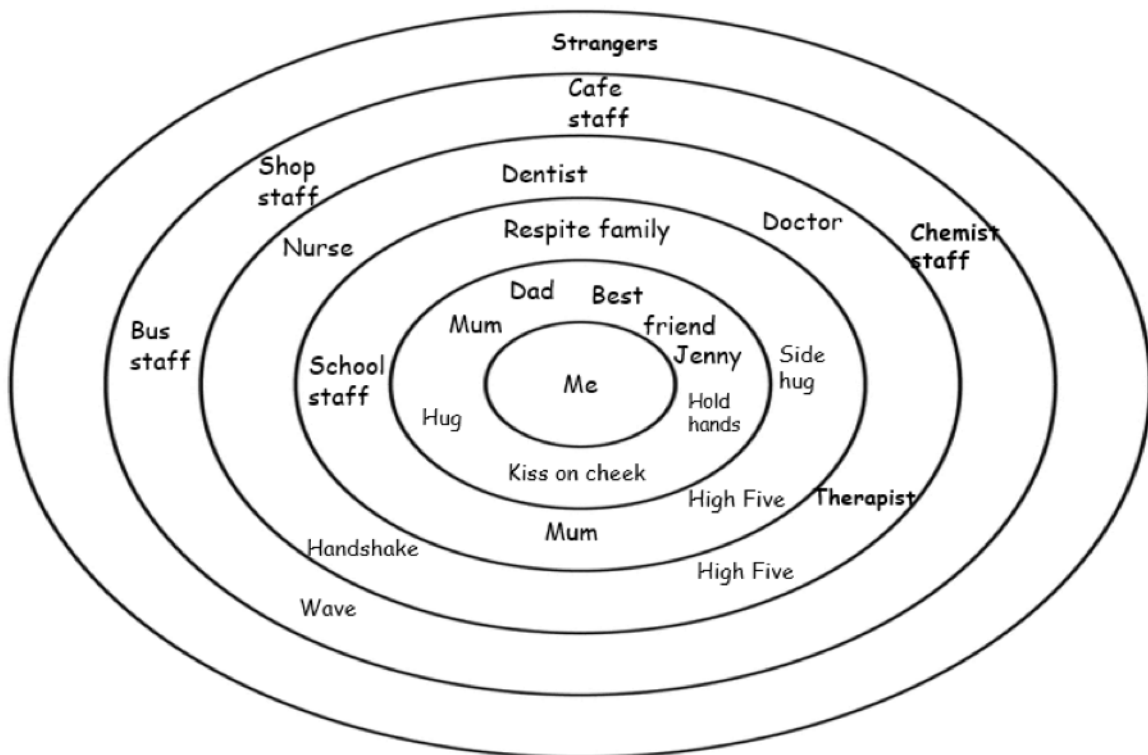
Based on the suggestions in Smith (1987), below are some things to consider when putting together a Circle Concept:

1. Look at the circles that can be included and identify the number of circles that are appropriate for the individual you are supporting in the context of interacting with medical professionals:
 - a) Me circle – The individual's photograph and/or name.
 - b) Close hugs circle – Photographs and/or names of people that are closest to the individual (e.g. family members, close relatives, best friends).
 - c) Side hug circle – Photographs and/or names of people that are liked by the individual but not very close to (e.g. friends, support staff)

- d) Handshake or high five circle – Photographs and/or names of people that are in organisations that the individual has some involvement with (e.g. doctors, dentists and other medical professionals).
- e) Wave circle – Photographs and/or names of people that are seen often (e.g. bank tellers, bus drivers, shopkeepers).
- f) No contact Circle – A visual representation and explanation of a stranger as a person who we don't know or is not on the Circle chart.

Refer to the Circle Concept visual system to prompt the individual to exhibit the appropriate social behaviour before and during the visit.

Figure 13 – Below is a Circle Concept that was developed for Edmond to help him understand what behaviours are appropriate or inappropriate in various settings involving various people.



What are the different types of visual systems?

> Activity Checklist (Pre-visit, post-visit)

What?

An activity checklist is a visual system that identifies the materials, items or tasks that need to be carried out for an activity. An activity checklist will help the individual remember what they need to have or do before and after visiting a GP, dentist or optometrist.

Why?

Activity checklists are a reminder of what an individual needs to have or do to complete an activity to enable them to become as independent as possible. This will help them feel more comfortable and confident in medical settings.

Where?

Keep the activity checklist in an easily accessible area so that the individual and caregivers can refer to it as necessary before and after medical appointments. You can also create a portable copy of the checklist (e.g. on a clipboard, key chain or photo album) that you can take with you to the appointment to remind and prompt the individual about what they need to have or do.

How?




Help the individual learn how to refer to and follow the checklist to get organised or complete the tasks.

Figure 14 – Below is an example of a checklist that Edmond needs to follow before he goes to bed in order to look after his glasses.

Before going to bed:

1. Use the microfiber cloth to clean the lenses
2. Put the glasses in the case
3. Put the case on the dressing table

Figure 15 – Below is an example of a checklist that Nina needs to follow when she goes on an outing.

Before I leave the house check:		
 epi pen	 keys	 purse

What are the different types of visual systems?

> Chat Book (Pre-visit, post-visit)

What?

A chat book is a visual system that allows for a recount of events that have happened in the past to be recorded in a systematic manner. A chat book provides an opportunity for the individual to reflect on the positives of a visit to a GP, dentist or optometrist.

Why?

The purpose of the chat book is to create a recount that the individual can refer to and share with others about the event or experience. Reflecting on the experience provides an opportunity to focus on the positives and what can be learnt from the event. The chat system can be used to discuss with the individual their past experiences with medical professionals and encourage them to attend future appointments with less fear.

Recording the experience by using a consistent format can also help the individual learn how to focus and share the important aspects of the experience. This can help the individual remember important information they are given, such as basic health recommendations and why they should be followed.

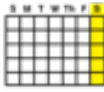



Where?

Keep the chat book in an easily accessible area so that the individual and caregivers can refer to it and chat about past appointments with others as necessary.

How?

If a previous visit to a GP, dentist or optometrist was a positive experience or included specific positive experiences, encourage the individual to record it. After the event, encourage the individual to provide a recount by incorporating visual supports.

Figure 16 – Below is an example of a chat system that Edmond filled out after he visited the optometrist.

<p>26/06/19 – Special Activity When? On Saturday at 9am</p>	 Saturday
<p>Where? I went to the optometrist (Mr. Jones)</p>	
<p>Who? I went with Mum and Dad</p>	
<p>What? He checked my eyes. I got glasses.</p>	

What are the different types of visual systems?

> **Feeling–Problem–Solution Charts (Pre-visit, during the visit, post-visit)**

What?

The feeling–problem–solution visual system allows the individual to acknowledge the emotions they are experiencing, identify the cause of the emotions or the problem they are facing, and focus on identifying possible solutions. This is an important life skill and will help the individual regulate their emotions if they are anxious about visiting a GP, dentist or optometrist.

Why?

Everyone encounters problems on a daily basis. Having a visual resource that guides the individual through the process of discussing feelings, identifying the problems they're facing and working out solutions can help the individual develop emotional regulation skills. This will help them approach visits to a GP, dentist or optometrist more comfortably over time, as the individual and caregivers will learn to understand why the individual does not like these visits and come up with solutions that will make the situation more comfortable for the individual.







Where?

Keep the feeling–problem–solution chart in an accessible area so that the individual and caregivers can refer to it and chat about as issues as they arise.

How?

Create a system that allows you to coach the individual step-by-step to work through their problems in an effective manner. An example of a feeling–problem–solution book is shown on the next pages.

Figure 17 – Below is an example of Nina’s feeling–problem–solution book, which helps her caregivers talk to her about what she may be feeling, what problem she could be experiencing and possible solutions.

My Feelings – Problem – Solution Page	
 I am feeling	 uncomfor- ble
 The problem is	 leg
 The solution is	 stretch

Feelings



happy



sad



angry



cold



sore



hurt



hot



uncomfortable



worried



hungry



thirsty



tired

Problem - My body parts



head



ear



eye



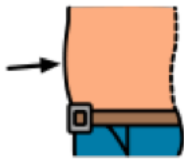
throat



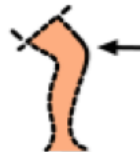
teeth



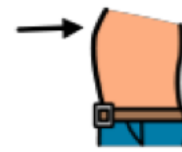
arm



tummy



knee



chest



leg



foot



ankle

Solution



drink



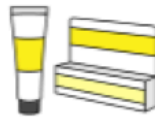
rest



eat



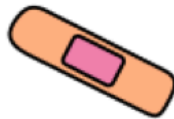
doctor



heat cream



medicine



bandaid



ice pack



massage



relax



walk



blanket

What are the different types of visual systems?

> Behavioural Rules (Pre-visit, during the visit)

What?

The behavioural rules visual system explicitly shows the behaviours that are expected and allowed in different social situations. Behavioural rules will explain to the individual what is expected of them during a visit to a GP, dentist or optometrist.

Why?

Every setting has different behavioural expectations. Explicitly outlining the behaviours expected in a specific situation ensures that the individual knows what is expected of them in different situations and gives them opportunities to practise these behaviours.

Where?

Keep the behavioural rules visual system in an accessible area so that the individual and caregivers can refer to it and remember what is expected at all times. You can also create a portable version (e.g. on a clipboard, keychain or a photo album) that you can take with you to an appointment with a GP, dentist or optometrist as a visual reminder during the visit.





How?

It is important to go through the rules prior to the visit and refer to them throughout the visit to remind the individual of expected behaviours and reinforce the individual for exhibiting the expected behaviours.

When writing behavioural rules, ensure that they are specific, observable and realistic. For example, "Sit in dental chair for 10 minutes" is a more effective rule than "Be good".

For some individuals, you may need to include additional information, such as "What am I not allowed to do? Why am I not allowed to do that? What am I allowed to do instead?". For example, "I am not allowed to run around the GP room. I could trip and hurt myself. I am allowed to sit in the GP room. After the visit I can run in the park."

Figure 18 – Below is an example of behavioural rules that help Edmond understand what is and isn't appropriate behaviour when he visits the optometrist.

When I am visiting the optometrist, I need to:			
Use an inside voice 	Keep hands and feet to self 	Be kind to others 	Follow instructions 

Tips for Families, Caregivers and Staff to Support Individuals with Disabilities with Complex Needs during Medical Appointments

Below are some tips that can be used to **EMPOWER** the individual and smoothen the process of medical appointments, including the time before, during and after the appointment.

Before the appointment

Ensure that you select an appointment time that is less subject to delays, such as the first appointment of the day or the first appointment after lunch.

Make sure to provide the medical professional and their team (especially reception staff) with as much information as possible about the individual's needs so they can be better prepared and make adjustments before the visit.

Prepare the individual for the upcoming appointment by informing them as early as possible. Use the visual systems described to help prepare them.

Organise back-up activities that the individual can engage in to help occupy and/or distract them whilst they are waiting or during the appointment (as appropriate). For example, reading a book, listening to music with headphones, watching a favourite video, favourite toys or sensory items.

Waiting in the main area of the clinic may be difficult, so identify a place where there are fewer people, less noise and movement and organise with reception to call you when it's your turn.

Explain to the individual what is happening and what is going to happen using short sentences and visual systems.

Remain calm, as the individual can sense your emotions. Have a drink of water, take deep breaths or use other strategies to relax.

During the appointment

Ensure the individual can access communication supports during the appointment. By referring to the visual systems on a regular basis, you can remind the individual of what is going to happen and what is expected. Also, by checking in with the individual you can create opportunities for them to express themselves and actively participate during the appointment.

Monitor the individual's emotional reactions. Request breaks and provide reassurance and support to help the individual remain calm during the appointment.

Permission should be sought from the individual before you provide information, respond or speak on their behalf.

Offer praise and reinforcement to the individual on a regular basis for cooperating with requests and/or completing the steps during the appointment.

Work out a cue or signal that can be used between the medical professional and the caregiver to indicate when it is best to or not to proceed.

Enquire with the individual if they are understanding what is being recommended. If they aren't, encourage the medical professional to simplify their explanations, along with writing down their recommendations.

Remember that it's OK throughout the appointment to be an advocate by reminding staff of what works for the individual.

After the appointment

Explain to the individual that the appointment has finished.

Move with the individual outside the clinic so that they understand that the appointment has finished.

Praise and reinforce the individual for their participation in the appointment.

Organise a calming, relaxing activity and/or fun reward after the appointment based on the individual's needs.

With the individual, put together a recount for the visit in their chat system.

Explore different visual strategies for recording the recommendations in an accessible format so that the individual understands their importance and can follow them.

Reflect on the positives and considerations for future appointments with the medical professional and their staff via phone call or email.

Tips for Medical Professionals and Staff for Promoting Effective Communication with Individuals with Developmental Disabilities with Complex Needs

Individuals with developmental disabilities with complex needs have severe communication impairments, which results in difficulties with understanding, expressing and social interaction. There are a range of **COMMUNICATION STRATEGIES** we can use to promote effective communication.

Commence by getting the person's attention (e.g. using their name, making eye contact).

Offer choices if the person doesn't respond to an open-ended question (e.g. Ask a specific question such as "Do you have a sore head or ear?" or "Do you have a sore ear? Yes or No?" if they do not respond to an open-ended question such as "Where are you experiencing pain?").

Messages should be short and simple (e.g. "First clean teeth then polish" rather than "We are going to first scale your teeth to remove plaque and tartar from the tooth surfaces. We can do this by hand or with electric scalers depending on your preference. The second step will be polishing to remove any final plaque and buff the teeth. Do you have any questions?").

Messages should be supported with visuals (e.g. body language, gestures, objects, signs, pictures, or written words. "I'm going to be using this to look at your eye" or "I'm going to see what your eyesight is like using this chart").

Use pauses and wait time in between messages to allow the individual to process the information and respond.

Need to use literal language to avoid confusing the individual (e.g. avoid metaphors, sarcasm, figures of speech or colloquialisms).

Inform the person of any changes (e.g. "Nina, I'm going to listen to your breathing through your back now.").

Check for comprehension (e.g. "Edmond, can you show me how you should brush your teeth.").

Avoid abstract language (e.g. idioms, multiple meanings, metaphors and sarcasm).

Talk about one idea at a time (e.g. "Nina, we're going to see what letters we can see on this chart" rather than "Nina, first we're going to read the letters on the chart, and then I'm going to take a closer look at your eyes.").

Instructions should be broken into small steps (e.g. get the toothbrush > get the toothpaste > unscrew the lid of the toothpaste > lay the lid on the countertop).

Order, predictability and structured routines help the person's understanding, so try to follow the sequence of steps that maybe highlighted in the individual's visual systems or as previously explained to the individual (e.g. if their visual system shows that visits to the GP follow the sequence Check breathing – Take blood pressure, Ask about medication, then follow this order during the appointment).

Need to sequentially list events to help the person understand (e.g. “Edmond, first teeth clean, then teeth polish, then lollipop.”).

Speak clearly and slowly.

Tone, rate and volume of speech needs to be respectful of the person.

Reduce visual and noise distractions (e.g. close the door of the examination room, turn off computer monitor when not in use during eye test).

Allow breaks to prevent overload (e.g. allow a break between cleaning and polishing teeth).

Timers can help the person see how long a procedure or appointment is for (e.g. bring up a timer on your computer or have one sitting on your desk in the examination room).

Eye contact should not be forced.

Give the person a variety of communication methods (e.g. signing, visual strategies, devices) to show you what they mean.

If the person doesn’t understand, repeat or rephrase your message with more visual prompts and cues (e.g. “Edmond, which one?” while showing him two different toothbrushes.)

Explain to the individual if you can’t understand them (e.g. “I’m sorry, I cannot understand”) and ask for permission if you can speak to the caregiver.

Support the person by being calm, patient and reassuring.

Conclusion

Communication is the basis of all human interaction.

The ability to communicate and process communication varies from person to person, influenced by a wide variety of factors. Individuals with developmental difficulties with complex needs may experience difficulty in developing communication skills, which can negatively affect how they receive medical care. The strategies discussed in this resource aim to enhance, support and supplement the communication between individuals and medical professionals, thereby improving access to medical settings.

Notes

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