

DRAFT 2



“Ta Kupenga” “Net-Making”

**A KitSet to Help Children
Participate after Traumatic Brain
Injury**



Background

- Ta Kupenga has been developed from studies completed with Aotearoa New Zealand children who have had traumatic brain injuries, and their whānau/families, teachers, rehabilitation providers, and community support people.
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- In the studies, commonsense ideas or strategies were found that helped the children to be involved in activities. These have been put together into a kitset. Writings and research from others in teaching and rehabilitation fields provide further evidence for some of the strategies.
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- The focus of Ta Kupenga is on working with people's communities to assist children to participate. It can be applied to activities at home, in rehabilitation settings, at school, and in the wider community. It is designed for children aged 9-12 years.
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- Ta Kupenga can be used by Whānau/Family, Friends, Schools, and Community Support People and Rehabilitation Providers. People can choose the things they feel are useful for them to implement with a particular activity at a particular point in time.
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- There are a number of other approaches available that focus on developing the skills of the child to enhance participation. The strategies in Ta Kupenga can be used alongside these other approaches.

What is Participation?

Doing things together



Participation is like a woven net. It is about whānau/family being connected into the community with others. Like the way nets are used to provide food to nourish a community, a participation net helps keep people healthy.

At school participation is about contributing to, and feeling a part of things in the classroom, in the playground, and wider school life such as camps and outings. In the community participation involves joining in sports, art, recreational, cultural, and spiritual occupations.

"...how he fits into the scheme of things" (Julie, 2010).

Why Participate after a Traumatic Brain Injury?

- Build & Strengthen Social Networks
- Develop Friendships
- Opportunities for new Experiences
- Learning & Development
- Rehabilitation of Functional Skills
- Health

(Anderson & Catroppa, 2006; Bell, Pellis, & Kolb, 2010; Law, 2002; Lewis & Carpendale, 2009; World Health Organization,

Changes after a Traumatic Brain Injury Tear the Net of Participation

Change in Child and Whānau/Family

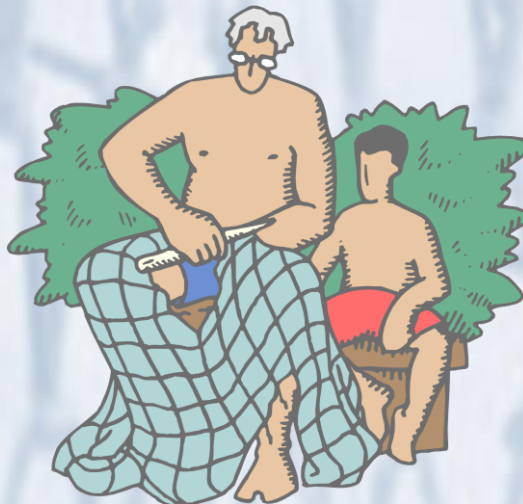
Change in Place

Change in Routines

Interruptions to Participation

Disconnection from people in the Community

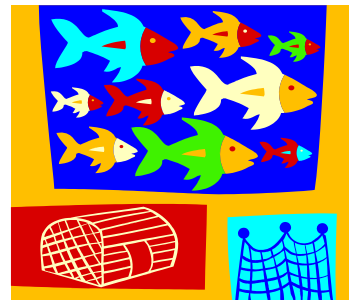
Fewer Opportunities



Sports? A big change. Robbie swam twice a week. He played soccer on Saturdays with two trainings. He played t-ball, he played tennis on Wednesdays. And all that stopped. All of it. So he's gone from, usually having a sport every, at least every second day during the week, some days, he'd have tennis and swimming on the same day. But... he went from being a very active, boy... To nothing." (Lynne, 2009)

How Does Ta Kupenga Work?

Ta Kupenga is based on the idea that after a child has a traumatic brain injury, through doing things together, people can make or maintain connections, and exchange understandings about each other. When this happens, they are better able to help that child join in, and can weave further opportunities for that child to participate.

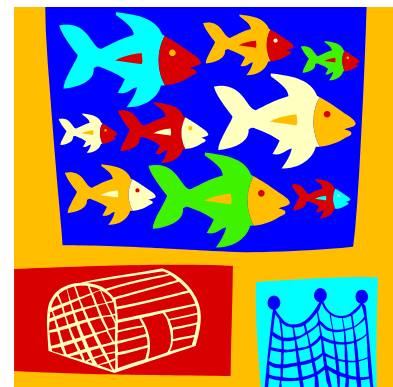


Ta Kupenga aims to increase participation by:

- Supporting others to Share Occupations with the child
- Making and Maintaining Connections with other people
- Meshing together the Child's needs, with an Activity, the Place it occurs, its Time Frames, Other's Understandings, and Other's Actions.
- Creating more Opportunities for Participation

Weaving a Participation Net: What's Important?

- Plan for Participation as soon as possible
- Occupations should be Central
- Occupations are Shared With other Whānau/Families & Children
- Ensure your Child has a Say
- A Child & others involved should be Satisfied with the Participation
- Focus on Similarities not Differences
- Quality not Quantity
- Flexible
- Do-Able



Phases and Strategies in the Ta Kupenga Kitset

1: Participation in Hospital: Maintaining Connections

- a) Visit
- b) Keep in Touch
- c) Share Experiences

2: Participation during Rehabilitation: Growing Connections

- a) Begin to Weave!
- b) Quality not Quantity
- c) Record Experiences
- d) Weave a Pattern
- e) Crafting Visits Out

3: Participation back at Home & School: Shifting Connections

- a) Planning to Weave
- b) Weaving the Strands that Support Participation
- c) Teaching Others How
- d) Interwoven Participation
 - Other Children
 - Adult Support
 - Rehabilitation Activities
 - Rest Times
 - Parent's Participation



**1: Participation in Hospital:
Maintaining Connections**

1: Participation in Hospital: Maintaining Connections

After a Traumatic Brain Injury, children spend time with their whānau/family in hospital. Participation is very hard if you are not at home and are unwell. Parents talk of feeling overwhelmed, scattered, and in shock. Many parents want to remain near to their child's side, like a closely woven net, wrapping them safely and continuously in the face of change.

At these early times, when you and your child are away from family, friends and community in a medical setting, it can help to hold together connections in small ways with those people. Those who share the experiences with you after the accident can provide reassurance and support, both early on, and as recovery progresses. They can bring a sense of familiarity at a time of uncertainty. They will gain understanding of the challenges you and your child face, and can use this knowledge to help with participation when you return home.

a) VISIT

Visiting is a way of beginning to share in an activity again. Parents, with help from staff, might think about some special people in the community close to their child and whānau/family who could visit and provide support, such as a child's friend and their parent, a teacher, a special neighbor, or a coach. It may be possible to nominate a friend or person from the extended family to help with keeping in touch, and staff may also assist.

Visiting does have to be responsive to a child's need for rest. It is important that visitors check with parents and staff first.

Visitors might simply "be there". They can talk quietly about the things that your child has enjoyed doing, and let them know what their friends and classmates are doing. They might bring in a photo of a special activity or place, or might bring a familiar toy to talk about. Visitors can sometimes join in a rehabilitation activity.



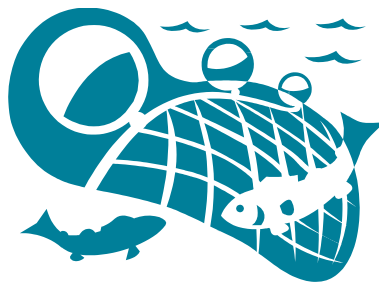
b) KEEP IN TOUCH

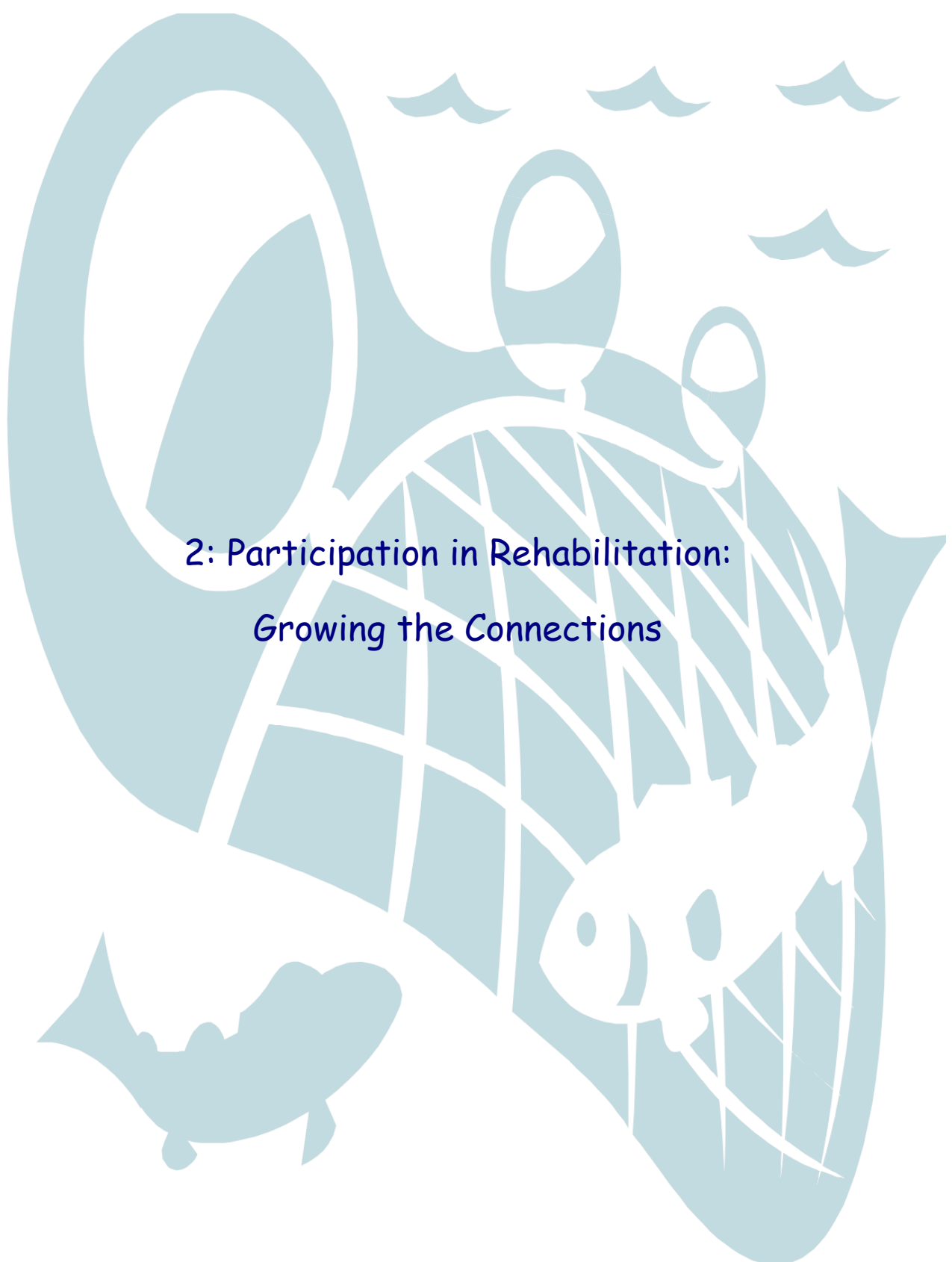
Classmates can also keep in contact and share participation experiences via email and other technologies such as web-cams, Facebook, texts, or phone.



c) SHARE EXPERIENCES

Classes or teams can put together posters of activities they have been doing, with messages, letters, photos and drawings. It will also be reassuring to them to hear news of their absent classmate or team member.





**2: Participation in Rehabilitation:
Growing the Connections**

2. Participation during Rehabilitation:

Rehabilitation is a process that unfolds over time. At earlier phases of their rehabilitation, children may participate by simply watching and being with their peers, while at other times, they are ready to be more involved. What is important is that during rehabilitation, children are helped to share activities with their family and community.



a) BEGIN TO WEAVE!

Start early in rehabilitation to talk with your child, their friends and family, their teacher, and others from your community about your child's interests, activities they would like to try out, places they have been, and activities they have enjoyed. Some of these activities will be built into their rehabilitation and school sessions, while other activities become future goals. As your child becomes more able, the rehabilitation team can help you set up opportunities for short visits and outings. Communication aids and other media can help your child's involvement.



b) QUALITY NOT QUANTITY

Think carefully about your child's energy levels after participating in activities. Quality not quantity of Participation is important, as are Time Frames such as the time of day and for how long. Within reason, children may have some Safety restrictions. If you are unsure if an activity is Safe for your child, talk with the neurologist or rehabilitation specialist.

c) RECORD EXPERIENCES

As in the hospital, your child and their peers will benefit from exchanging information about the things they have been doing. It can be useful to keep a folder or scrapbook, or an electronic resource that records progress and activities. Records like this help your child to remember and share their experiences later on. Messages from classmates and team-mates that are kept can remind your child they are still part of the group, and help them recognise familiar faces and settings.



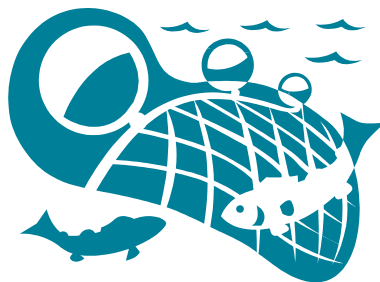
d) WEAVE A PATTERN

When time nears to returning home, it can be helpful to develop a routine of things your child will be able to do, and places they can visit when they go back. Your rehabilitation team will be able to help you with this. The pattern will often include some time at school, and some "quiet" time, but the pattern should also be balanced with time for some activities your child would like to do. Having a pattern for the day builds your child's confidence, and will help them to adjust back.

e) CRAFTING VISITS OUT

As your child progresses, they may be helped to take part in an initial visit to their school or to another setting such as church or their marae. This can be an opportunity for them to be welcomed back, and to take part in a low-key activity for a short time.

It is also an opportunity to communicate a little of their experience, and, at school, to interact with their teacher and classmates. Your rehabilitation team will be able to help you with ways to do this. What is important is that the focus is on them sharing their experience of the things they have been doing. Your child might be able to show pictures of where they have been, or with help could explain some of the things they do in rehabilitation.





**3: Participation Back at Home & School:
Shifting Connections**

3: Participation Back at Home & School: Shifting Connections

Moving out from hospital and rehabilitation to go back home is an important step. There will be times when the weaving of a child's participation net needs to be moved along. Participation might need addressing when there is a change in a child's life such as a school camp, a trip, or a new class or school. Sometimes some new occupations may need to be introduced.

a) PLANNING TO WEAVE

Planning is needed for Participation to be successful!

WEAVE ONE KNOT AT A TIME

Rather than trying to increase participation across a whole range of occupations, focus on One Occupation at a Time. This might be participation in a class-room occupation, an activity in the playground, a social occupation at the weekend, an occupation at school camp, a cultural occupation, or a sports-based occupation. When this is working, then you can start to focus on another occupation.

PREPARE

Some background information is required. Your rehabilitation team will be able to help with this process. Check out:

- The Physical Setting
- Time Frames (when, how long, the things that happen before and after),
- What the children will be doing
- Who else is involved (other children and other adults).
- How others Know your child and their abilities, and if they can support their involvement in some way.

- Whether things can be Changed to fit with your child's abilities.

ALLOW TIME

Planning takes time. It can be really difficult to check out and organize things at short notice, so whenever possible, begin planning early on. This way, people can work together to come up with solutions that Fit.

EXAMPLE

Jonathan was going on the school camp, and it was decided with his teacher for his father to go with him. At the camp, an adventure tramp was organized as the first activity of the day. Jonathan enjoyed walking, and although he needed a bit of extra time to get places, and some reminders of obstacles, he was looking forward to going. As it happened, information that the walk was happening was not communicated to Jonathan and his father until that morning. The class with the teachers and parent-helps needed to finish the walk within an hour so they could be ready for the next activity, and the walk included some steep ground. As there were concerns that Jonathan couldn't finish the walk quickly enough, and might not cope safely with the steep bits, his teacher decided it would be best if he stayed behind. Jonathan and his father were disappointed.



BRING IN OTHERS TO HELP WEAVE

Setting up for a child to Participate in an activity can be really challenging on your own. Involving another person or a small group shares the responsibility, and they may be able to contribute additional experience, skills and ideas. Parents /whānau are usually the first involved, or if the Participation involves a school-based activity, it may begin with a teacher. The child themselves, and sometimes other children must be part of the team; they may be consulted first, or after some adult-team discussion. Sometimes there is a support person, such as a family friend, a community caregiver, rehabilitation staff, or a teacher aide. If there is

a key person involved, such as a coach for a sports activity, or a bus-driver when learning to get home from school, they might be the first person to approach.

FORMAL AND INFORMAL

A formal planning session may be needed (Bernabe & Block, 1994). People are invited and there is a formal goal-setting and problem solving process. Formal team planning for Participation may be incorporated with an Individual Education Plan meeting (an IEP) at school, or as part of a Rehabilitation Planning meeting.

At other times, an informal discussion is fine to work things through.

Planning needs to consider people's roles in helping the Participation- who will do what.



COMMUNICATE WITH EACH OTHER

Communication is essential to good Planning. When people have busy schedules, it is helpful to be able to get hold of others in the team easily to give an update, to share happenings, or to raise an issue or a new idea. Be sure to identify the best ways and times to contact each other, and regularly review your communication strategies. Some ways to keep in

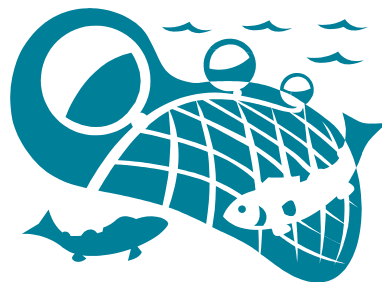
contact are through phone, by text, by email, via a web-site, through regularly calling in (e.g. checking in with a teacher after school), or through a communication notebook.

PRACTICE RUN

Some whānau /families and children find it helpful to visit a participation setting first for a "practice run", at a time when fewer people are around. This means they can scope the environment and activities out at a pace that suits them.

EXAMPLE

When Mary moved to intermediate school, she was keen to join in her school cross country. A week before practices started, her Dad checked out the course with her teacher. He and Mary walked around the course at the weekend. They decided that as this was her first cross country since her accident, she would do the first half of the course, and also the final lap.



b) WEAVING STRANDS THAT SUPPORT PARTICIPATION

Some types of occupations support participation more than others. Occupations can sometimes be presented differently to better involve your child.

STRUCTURE

Occupations with more Structure facilitate Participation. When the processes, rules, and actions required for an occupation are loosely defined, all children need to think harder to actually organize and carry it out. They have less capacity to concentrate on interacting with each other, and sharing in the occupation together. We all benefit from some loosely structured activities which we can direct as we please (e.g. children enjoy some undirected time for free play at lunch-time). However clear requirements for how an occupation is to be done will support participation. Structured activities are more likely to incorporate familiar routines, which support involvement for children after traumatic brain injury (Ylvisaker, 1998)

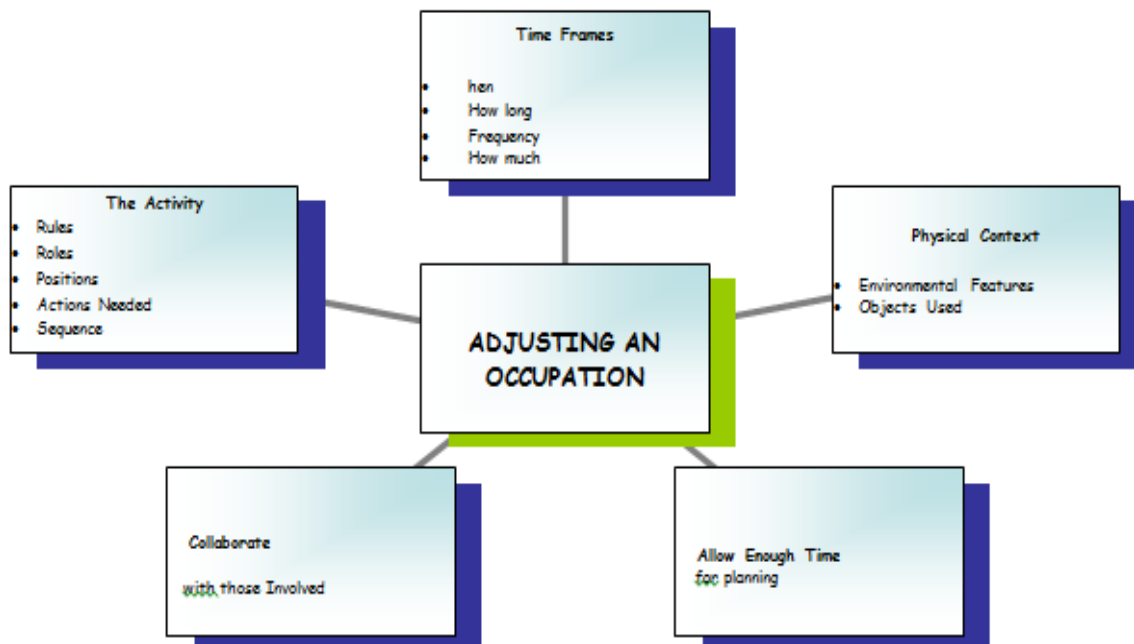
WORKING TOGETHER

Participation is supported by occupations that require Group Cooperation, where children need to work together to complete a task. This gives all children an opportunity to contribute their own special skills, and to share in Problem-solving. For this to work effectively, establish clear ground-rules for the task, communication, roles and time-frames. Children should be given recognition for how well they worked together as a group, as well as for their achievement. (Zionts, 1997)



ADJUSTING THINGS

Adjusting an occupation or the context in which it is carried out can enable Participation. This will improve the Fit between your child's skills and abilities, and the requirements of the occupation. Aspects of the occupation that can be adjusted include Time Frames, the Physical Context, and the Activity itself. As described in Planning, for more formal activities such as a team sport, some time may be needed to work this through. Collaborate with the key people involved, including your child and other children.



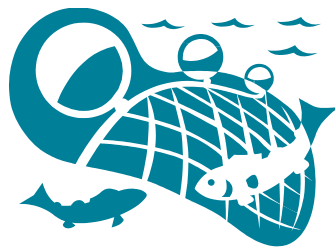
EXAMPLE:

Millie's class was learning about Leadership. The teacher decided that the children would work in small groups to make posters. She re-scheduled the activity to early morning to ensure Millie would not be too tired. Millie's group made a poster about Sir Edmund Hillary. With Brandon, who had finished his research early, Millie typed out a 3-sentence summary about Sir Edmund using Publisher. Two of the children drew a picture of Mt Everest, and Millie coloured it in. Another child took responsibility for making a title for the poster. Each child cut out their own research summary, Millie glued them, and Jasmine stuck the summaries onto the poster. Together the children brainstormed ideas about what made Sir Edmund Hillary a leader. Because they worked so well together, their group got extra points (Zionts, Vannest, & Devore, 2005).

LET SOME THREADS GO

Remember that at this age, Participation is often about children "Having a Go" at things. Some of the things your child tries simply may not be right for them. Talk together about how it went when they tried it. You might decide to persevere, or to change something. For other activities, having tried it out, it is also OK sometimes to just let it go.

For some activities, there may not be a choice, and they just have to be done (e.g. a classroom activity). In these cases, strategies can be used to make the activity more achievable (Ylvisaker, 1998) - you could talk with your rehabilitation provider about some of these options, and also refer to Adjusting Occupations (p.21) and Adult Support (p. 28).



c) TEACHING OTHERS HOW

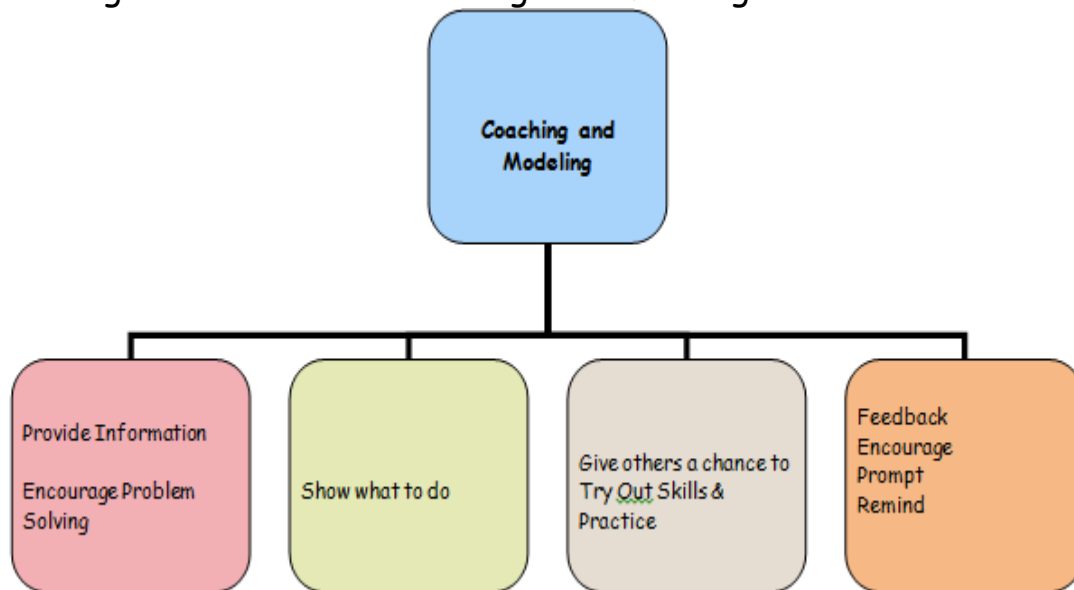
People's understandings about their world form a basis for their actions, or what they do. Sometimes, after a child has a traumatic brain injury, adults and other children lack understanding, or have understandings that do not match with the child's actual abilities and needs. This can prevent the child sharing in an activity.

Katie wasn't invited to a party with other girls in her class. "Yeah the kids' parents didn't include her or didn't encourage to be included. And, I kind of understand that they didn't know Katie's capabilities..... I guess these people sort of, the thought of having to change her, or something like that. She never needed it, but no one ever came and asked. They just stayed away if you can understand. And the only, reasoning maybe to keep myself sane, is that they just, never knew or if they could cope with her or not". (Katie's Mum).

People's understandings can be changed through learning, and this way they can better support the child to take part.

TEACHING OTHERS HOW TO HELP PARTICIPATION THROUGH COACHING AND MODELING

When other children and adults are sharing an occupation with a child, such as at Girl Guides, or in class, there are opportunities for a leading adult who is familiar with that child's abilities and needs, to Coach and Model ways to involve them. The diagram shows what Coaching and Modeling involves.



Children and adults use particular actions when they share in an activity together. Encouraging other children and adults to use these actions with a child who has had a traumatic brain injury helps the child fit in and participate in the activity, supporting others' further understanding. These actions include:

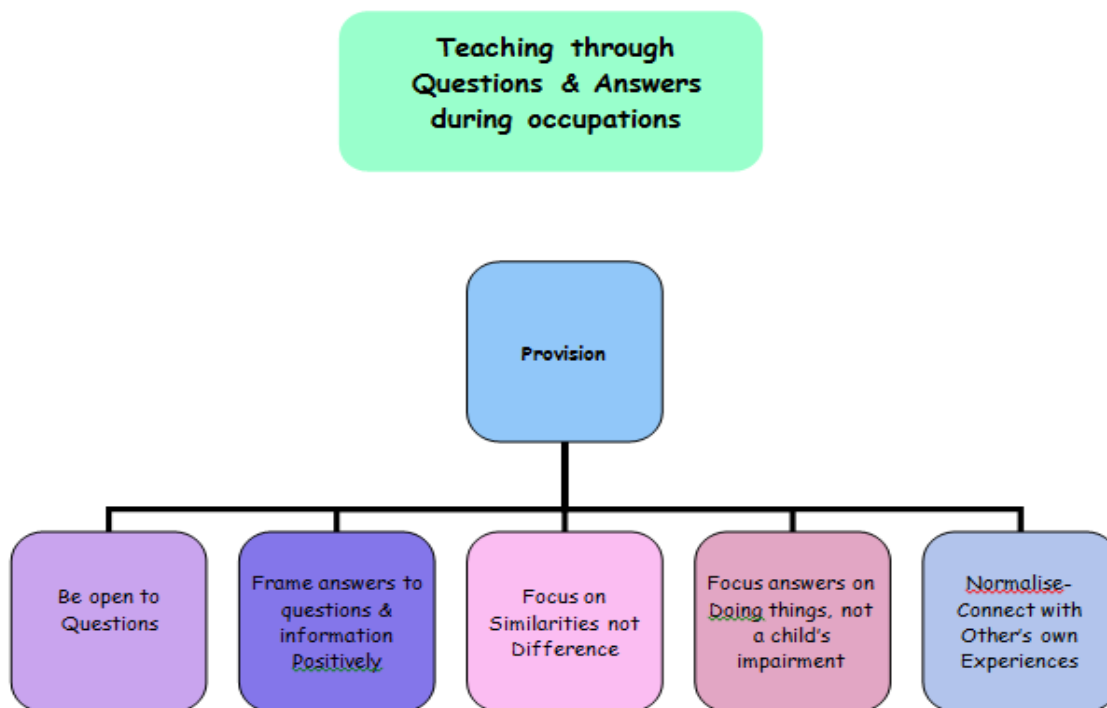
- Noticing (needing help/wish to join in)
- Greeting
- Inviting Contribution
- Planning
- Offering Help
- Reciprocating/Taking Turns
- Competing
- Encouraging
- Sharing (Products, Objects)
- Farewelling



TEACHING THROUGH QUESTIONING AND INFORMATION

Children explore their environment through touch, observation, experimentation, and questioning. When people get older, as in Katie's case, they may refrain from asking or getting involved. However, by asking questions and getting answers, others can learn how to assist someone to participate.

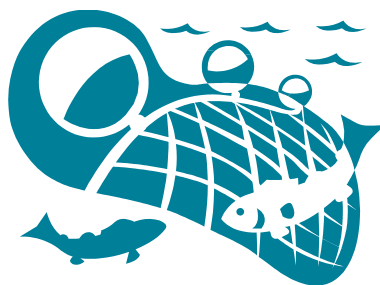
Sometimes, information needs to be directly provided to ensure other people in the community have adequate information. Information can be shared in writing or verbally. Some parents advocate having a small booklet of Positive stories or pictures that inform about the child's needs (DeZonia, 2009), or key points could be noted on a card.



TEACHING THROUGH SHARED EXPERIENCE

When children are occupied together, they routinely share information about their experiences. They show work to each other, give comments, and exchange ideas. Shared experiences support reflection and learning about each other and other areas of their lives.

It can be more difficult sharing Participation Experiences after a Traumatic Brain Injury. Information can be forgotten, and may be difficult to communicate. The need to attend to doing the activity may limit the degree to which the child can simultaneously share information. Media such as photo books, drawings, written stories, poems, and other symbols such as awards, or objects produced during the participation become particularly important tools to help in sharing the participation with others. Providing regular opportunities to formally share participation experiences (e.g. at mat time, for class speeches, after a sports game, after school) also assists the exchange of information.



d) INTERWOVEN PARTICIPATION

INTERWEAVING WITH OTHER CHILDREN

Impromptu Peer Participation

Adults can prompt, invite, or request other children "on the spot" who are familiar with your child to share an occupation. Often, some children in a group finish a task early, or have good skill-sets for a particular task, and enjoy the chance to share their skills. Other children may enjoy having a special support role in an occupation. If there is already an established culture of children helping each other, this is seen as a normal part of the activity, and the approach does not place a child who has had the traumatic brain injury as being in a position of having a "special" need.



Formal Peer Participation

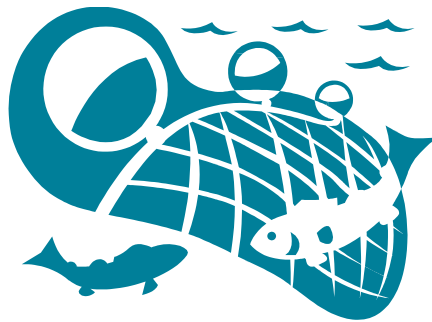
Formally nominating a group of children to be part of a Friendship circle, or nominating a Buddy or a Peer Tutor involves making specific, longer-term arrangements for peers to join the child in activities, or to teach them skills for a particular activity. The approaches generally involve a meeting between a child, their family and/or teacher, and non-disabled peers, along with a clear recognition of others' responsibilities, and commitment to carry

out the role. Monitoring is provided, and outcomes are identified (Zionts, 1997). This arrangement can work as a catalyst for others' involvement.

There is a place for such arrangements, and they can support the child to take part in activities. However, by routinely allocating a special person or group to the child, there is a possibility that the arrangement may contribute to understandings of a child as being different and as requiring help. By ensuring that having Buddies for activities or taking turns at being a Peer Tutor is normal for all children in the class or group, there is no longer a concern.

Position for Participation

Children need to be near others to participate with them. Situating your child as part of a group will help, although some thought might need to be given as to the best people for your child to be beside. Rotating classroom group seating positions is a strategy some teachers use to support children to learn how to work at activities with a variety of children. While there can sometimes be personality clashes, there can always be another adjustment if required. Regularly changing group positions for school and for community based activities is also a way of supporting children to share activities with peers who have different abilities.



INTERWEAVING WITH ADULT SUPPORT

After a traumatic brain injury, children tend to spend greater amounts of time with grown-ups, and less time with other children. Unfortunately, the close, constant presence of adults can also limit interactions between children, and reduce the quality of participation (Batchelor & Taylor, 2005).



There is a fine balance between providing adult support to enable a child to engage in an occupation, whilst optimizing a child's interactions with other children. It is important that adults negotiate with your child about the help they need, then "step back" when they can, and nominate children to work in pairs or teams to support each other. This helps other children to join in, to learn about how your child can contribute, and about how they can interact with them.

Weaving Flexibly

Effective provision of Adult Support requires skill and flexibility. It should limit barriers to peer interactions, should facilitate the child to use their own skills as far as possible, and should also ensure the child has a say in the support that is provided. That is not to say that there is no need for support, but that the way the support is delivered needs to be carefully tailored. A number of strategies can be used by Adult support people that facilitate participation (Causton-Theoharis, 2009).

- Position adult seating away from the child's occupation or group, and move in and out as needed.
- Work with a small group of children rather than an individual child.
- Whenever possible, use environmental cues rather than verbal cues, such as marking a page with an adhesive label, providing a sheet of clear steps, or providing only a few steps or aspects of a task at a time.
- Develop a plan with the child about aspects of the occupation they can do themselves, and environmental cues or help they might need, then move away to a monitoring and responding role.
- Encourage peer support with activities. Ask other children to help, or give some children an "Ask Me" role on a rotating basis. Get children to check things with their

neighbours. Allocate partners for all children for particular activities, such as Lunch-Time Partners, or Moving Room Partners, or Maths Partners.

- Plan to Fade the support. This means developing a plan from the start with strategies that will gradually make a shift from "hands on assistance" through to provision of environmental cues, and task adaptation.
- Share the support with other people. If one adult consistently shares with the child during Activities, then that adult will become very skilled in providing support, but other adults will not have that chance. As opportunity presents, hand over to other adult supports, particularly other parents (e.g. a parent help) or activity leaders. This facilitates Connection with other adults and children in the community. The key support person can still be available for information or to step in if needed.

EXAMPLE

Ten year old Tony was attending Scouts with his Attendant Care person, Stephen. On arrival, other parents were standing at the door, and they greeted Tony and Stephen enthusiastically. In the hall, Stephen stepped back from Tony, and sat on the bench at the side of the room. Other children came up to Tony, and they played games of "chase and fall over" together. If Tony became over-enthusiastic, Stephen stepped in and calmed him. When the session began, Tony sat with the other children and listened to the scout leader. He watched the flag-raising. Part of the scout session was relays, with teams of children going across the room using different ways of moving such as running, hopping, or commando crawling. Stephen physically supported Tony to stand in line with his team, then called another senior scout to come and help Tony. The scout accompanied Tony each time it was his turn to do the relay. Other children encouraged and laughed with Tony if he went off line. A few times Stephen stepped in and prompted the scout on how to support Tony if he was not keeping to the activity.

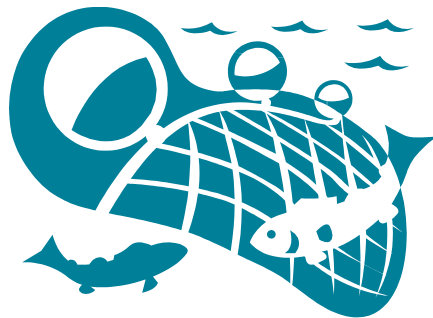
INTERWEAVING WITH REHABILITATION ACTIVITIES

Rehabilitation Activities have the potential to limit participation if the child is "Taken Out" to do different, therapy activities on their own. Rehabilitation can involve skill development for normal classroom occupations and other occupations directly. While individual rehabilitation sessions in a quiet area are appropriate for some issues, at other times

rehabilitation is best integrated into classroom or group routines and environments.



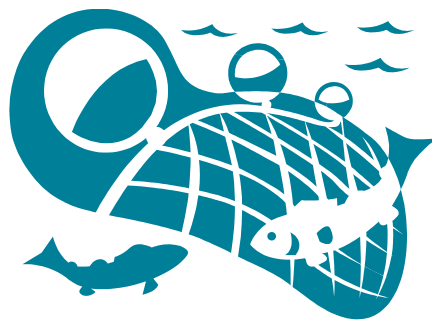
One approach that optimizes participation is to include other children in the therapy activity, working directly with a small group. There are usually a range of abilities in a group or class, and other children may also benefit from training and skill development. This approach has the added benefits of increasing motivation through involving peers, and building in an element of safe competition, as well as supporting other children's understandings about how to share activity. Strategies can be modeled for others in the setting (The Early Education Team- The Capper Foundation, 1990).



INTERWEAVING WITH REST TIMES



Fatigue is a common symptom after Traumatic Brain Injury and some regular "down-time" is important. However going away from school, or going out of class for a rest reduces participation alongside peers. When rests need to happen, share information about the need in a way that normalizes the experience, and which helps other children link this need with their own experience. Often, the rest-times can usefully be incorporated into the normal school routine, and it might be possible for 1-2 other children to share in the rest activity. Going to a quiet area close to the classroom, and using relaxation techniques, or listening to a very quiet tape of music or a story is a way of supporting participation while still managing fatigue.

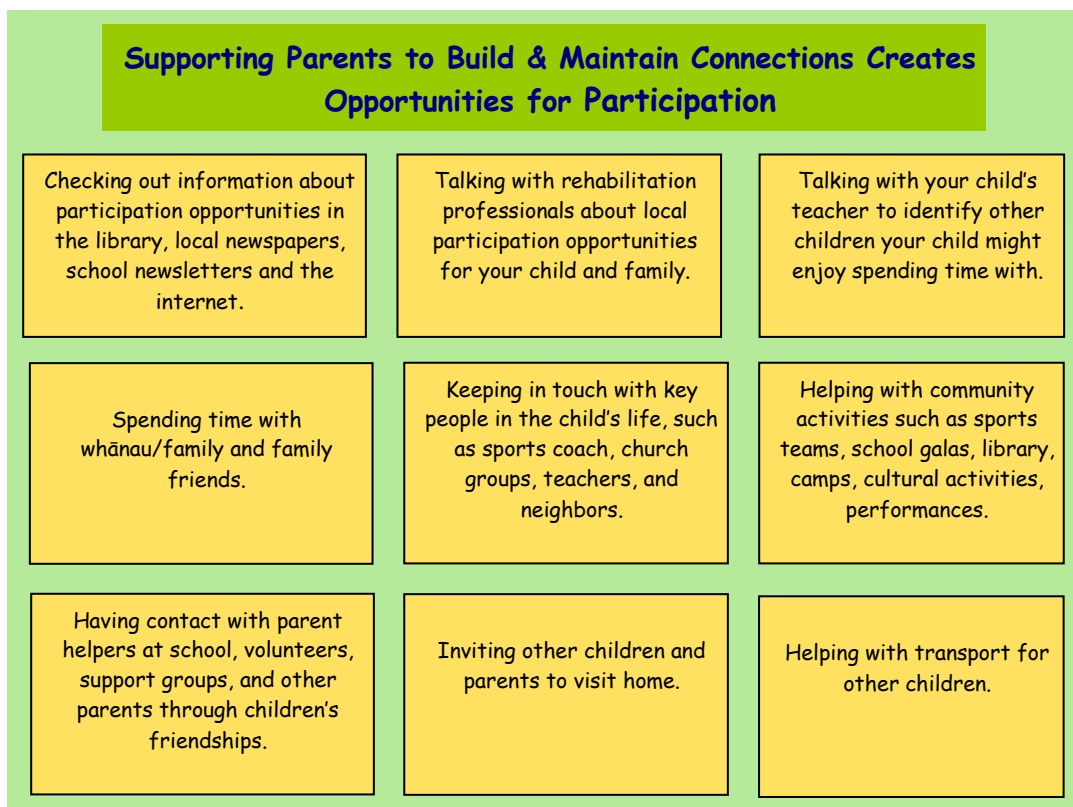


INTERWEAVING WITH PARENTS' PARTICIPATION

It is important that parents are supported to participate and build connections too! After a child has a traumatic brain injury, studies show the important role played by community in family and child wellbeing (Jones, Hocking, & Wright-St Clair, 2010; Robson, Ziviani, & Spina, 2005). As a child moves through the rehabilitation process after a traumatic brain injury, their parents' connections with whānau, extended family, friends, the school, and people in the community all play a very important role in providing ongoing opportunities for this child's participation.

Parents' connections help others in the community to learn about changes and how to be involved (Hendrickson, Shokoohi-Yekta, Hamre-Nietupski, & Gable, 1996). The process is two-way! While whānau/family might start the process, it equally needs input from people in the community around them.

The diagram shows different ways parents talk about being involved with their community to help build and maintain connections



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