

Appendix 5.3: Case Study Report 3 Anton

Anton is 11 years old. He lives in Applevale on the semi-rural outskirts of a city with his mother (Kathleen), his father (Albert) & his younger brother (Jacque). He sustained a severe TBI age 6 years in a playground accident. Time since injury: 5 years. GCS: 3/15 at the scene. Hospitalized: 4 weeks. Inpatient rehabilitation: 11 months.

Anton attends school full time & is in Year 7 at Rimu Heights Special School. His teacher describe him as determined, hard working, & keen to be involved. As a result of his injuries, he experiences seizures, a tremor, & has severely uncoordinated movement. He regularly has

episodes where his behavior becomes challenging & disinhibited. He has sleep disturbances.

Anton has little safety awareness & requires supervision to mobilize. His verbal communication is very limited. He receives support with all daily activities, & is described in a rehabilitation assessment as being unable to interact with his peers without support.

He enjoys swimming, music, Toy Story, The Incredibles, & Finding Nemo.

Playing Chase at Scouts

“Anton is running around the room playing chase with another boy – he looks as though he is having a great time, laughing lots, falling over, scrambling up.... Pete [caregiver 1] says that the kids all like to muck around when they arrive – he likes to let Anton join in.... The boy stops suddenly & turns around & hugs Anton who promptly falls over. He helps pick Anton up. Then the boy falls over. Anton stops in time & looks at him. More running, then both boys fall & roll. Anton grabs another boy who drops to the floor” (Obs, Scout, pp. 2-4)

Anton’s Weekly Routine

Monday	School - Teacher aide. Scouts with relief carer. Stay overnight with relief carer.
Tuesday	School - Teacher aide. Stay overnight with relief carer.
Wednesday	School - Teacher aide. At home, After - school caregiver, summer soccer.
Thursday	School - Teacher aide. At home, After - school caregiver, videos, computer, treadmill, trampoline, walk.
Friday	School - Teacher aide, Music therapy, At home, after-school caregiver.
Saturday	Caregiver at home, swimming, videos.
Sunday	Church, stay overnight with relief carer.

Fragility

“Anton has continued to be very tired. Despite his height, I am reminded of his physical fragility when I see how he collapses down & rests his head on Albert’s lap. His skin is itching him, he shakes violently when he tries to take off his shoe, & he closes his eyes. Albert points out to Kathleen that he is having a small seizure. He tells me Anton has been on the full dose of his new medication for a week now” (Obs, Soccer, pp. 5-6)

Case Three: Anton

Contents of Case Study Three

- Introduction to Anton. Anton’s weekly routine.....
- Contents of the case study. Key to the abbreviations used to identify quotations.....
- Display of participants & data sources in the case study. Quotations provide information about the data..... sources & Anton
- Timeline of key events since Anton’s accident.....
- Anton’s recent occupation.....
- Diagram: Important aspects of Anton’s participation.....
- Discussion: Important aspects of Anton’s participation: The concepts in the diagram are explained & illustrated
- Qualifying the problematic situation.....
- Solutions to the problematic situation.....

Page	Key to Colors for Participation	
1	Green	Family
2		
3	Yellow	Community
6		
7	Blue	School
8		
9	Pink	Rehabilitation (medical)
21		
23		

Key: Abbreviations used in citations of data sources for Anton’s case study

MI	Mother Interview (Kathleen)	Rehab SNA	Rehabilitation Document: Support Needs Assessment
FI	Father Interview (Albert)	Rehab IRP S1	Rehabilitation Document: Individual Rehabilitation Plan: Section 1
TI	Teacher Interview (Esther)	Rehab IRP S2	Rehabilitation Document: Individual Rehabilitation Plan: Section 2
TAI	Teacher Aide Interview (Steve)	Rehab IRP S3	Rehabilitation Document: Individual Rehabilitation Plan: Section 3
Obs CV	Observations Classroom Visit	Rehab TI	Rehabilitation Document: Training for Independence Reports
Obs Swim	Observations School swimming	Rehab AsTech	Rehabilitation Document: Rehabilitation Document: Assistive Technology Assessment Report
Obs HV	Observations Home Visit		
Obs Scout	Observations Scouts	Educ Rpt	Education Document: Rimu Heights School
Obs Soccer	Observations Soccer	Educ IEP	Education Document: Rimu Heights School Individual Education Plan
Obs Hol Prog	Observations Holiday Program		

NB: Demographic details, including dates & the gender of some participants have been altered throughout the case study to support participant confidentiality.

NB: Citations of some data sources are omitted to support confidentiality.

Contents & Key to Abbreviations & Colors

Kathleen & Albert: Anton's parents

Children, Anton (11) & Jacque (10). Kathleen: Part-time nurse aide. Albert: Sales manager. Carpenter. Live on lifestyle block. Home modified for Anton. Kathleen grew up locally. Her family live nearby. Her mother lives in a rest-home. Albert occasionally visits family overseas.

Being Part of the Landscape

"We don't feel completely confident that the taxi driver would know how to manage (a seizure)... The selfish side of me thinks ... "Let's just get him on the taxi" ... It's the, him being part of the landscape, being part of the group of children who go, & not being cosseted or as separated off. But on the other hand um, I can see the wisdom of [driving him myself] because the taxi journey is longer" (Kathleen, MI, p. 16).

A Constant Worry

"It's a constant worry in terms of, the way it's going now, I can't see him being independent... We can manage [caring for Anton] at the moment. And it's stressful but we can manage. If there's any improvement that will be welcome & if there's no further improvement then at some point in time we won't be able to do it, just from a strength point of view. If you can't reason with him, then you've got to sort of force him ... If he wants to get into the cupboards & you can't stop that. He can be violent, he's kicked out.... So how long we can do that, I don't know" (Albert, FI, pp. 23-24).

"If you talk about helpfulness in the terms of people come & help out of the goodness of their heart without the payment involved... We basically don't see that... They don't offer very often & if you don't get offered, then you don't tend to ask" (Albert, FI, pp. 24-26).

Researcher Visit to Family Home after School

Achievement

"Anton gets up onto the cross trainer. Jimmy [caregiver 2] holds his hand over Anton's on the handlebars & begins to count as Anton pushes on the foot pedals ... He can barely make it move through one cycle. 'One, two, three, I'll give you a raisin if you do 100.' Eventually Anton begins to coordinate the movements & recruits the strength to get the machine going. Faster & faster. Jimmy reaches a count of over 100 before Anton stops. Anton is looking up at me, a huge grin on his face, big effort, pride" (Obs, HV, p. 6-7).

Researcher Visit to Scouts Session.

Anton attends with his relief carer, Pete.

Tug of War

"Anton picks up the rope ... He knows what to do.... listening, chanting softly to himself as the two teams pull.... This is exciting, the kids are really enjoying the competition. Anton backs up with the others. 'Right, PULL!!!' Anton is not really pulling ... But he keeps his hands on the rope & watches his friend in front of him. He ... understands to change ends" (Obs, Scout, p. 7-9).

Researcher Visit to Soccer game for children with disabilities.

There is a sense of camaraderie, of companionship, teens joking with each other, calling each other nick-names. People are pleased to see acquaintances. The atmosphere is friendly, & greetings are warm & genuine amongst children & parents- smiles, & pats on the back, loud "happy to see you" hellos, calling others by their name (Obs Soccer, p.1).

Esther: Anton's Teacher, Rimu Heights Special School.

Age 26. Previously worked as a teacher aide. Has been teaching for 2 years, with additional training to work with children with disabilities. Has worked with Anton for 1 ½ years.

Values team contribution from all staff members. Anton receives occupational therapy, physiotherapy, & speech language therapy through school. He also receives intervention from an Expressive Arts Specialist, Music Specialist, & PE Specialist.

One on One

We only have three teacher aides & next year we're going down one. Um, so for Anton, I always make sure he has one on one. Other kids in our classroom don't get it in whole class activities.... He just cannot cope otherwise, on his own, he can't.... In my head I feel, I get in a struggle because I feel like they [all the children] do [need one on one teacher aide]. It is a dilemma & it upsets me because I think this child doesn't get that extra one on one because this child is at a lower level, but it doesn't mean that the child at a lower level deserves it more than that other child (Esther, TI, p. 15-16).

Steve: Anton's Teacher Aide

Has worked with Anton 2 ½ years. Has also provided some attendant care support.

Speak to the Kids as if They're Mainstream Kids

I'd been relieving in other classes & I tried to work with a lot of the boys, you know, because it's a very female dominated industry & you know, to have a positive male take on the job.... Just sit down, chat. Speak to the kids, as if they're mainstream kids you know. I try not to speak down to them ... you know I treat them more as a bit of a friendship with them, rather than a teacher, pupil sort of relationships.... Rather than being this sort of figure that barks at him all the time or tells him what to do. I want him to associate a bit with me as positive (Steve, TAI, pp. 1-2).

Researcher Visit to Classroom

Participant observations for puzzles, language, maths, story-time, & lunch.

"Anton is at a small table which has a screen placed around two sides.... Anton is very focused on the activity on his table. 'Are you ready?' cues Esther. 'Good matching'. Anton is leaning right over, his nose almost on the table. 'Looking Anton' he is prompted to keep focused. This is a number matching activity. 'Good matching! Kapai [well done] to that" (Obs, CV, p. 4-5).

Display of Data Sources

Researcher Visit to Holiday Program

“Anton is brought back into the room. A teacher aide holds out a basket of plastic toys. Anton starts picking out toys, but is prompted, ‘Choose. You can’t throw them on the floor. Choose one. You can’t throw them. Choose a toy’. Anton picks out one small coloured toy & is taken back over to the black couch where he sits down with his toy in his hand in front of the TV.... He rests down on the couch, just looking at his small toy, carefully holding it still between two hands, staring fixedly at the plastic wheel with a small coloured object inside it. He looks momentarily at the TV, then returns to staring at his toy” (Obs, Hol Prog, p. 3-4).

Researcher Visit to Swimming Session in School Pool.

“Anton climbs up & stands precariously at the side [of the pool].... Anton jumps, launching himself at Steve, nearly knocking him over. I have never seen Anton so excited. He has a huge open grin on his face, waving his arms & splashing the water, laughing out loud with pleasure. He beats the water hard with both arms together, splashing. He flings himself forwards & makes swimming attempts towards Harry [another child], & tries to take Harry’s body board.... I observe Anton using Harry’s body board, & Harry coasting a ride on his back” (Obs, Swim, p. 3-5).

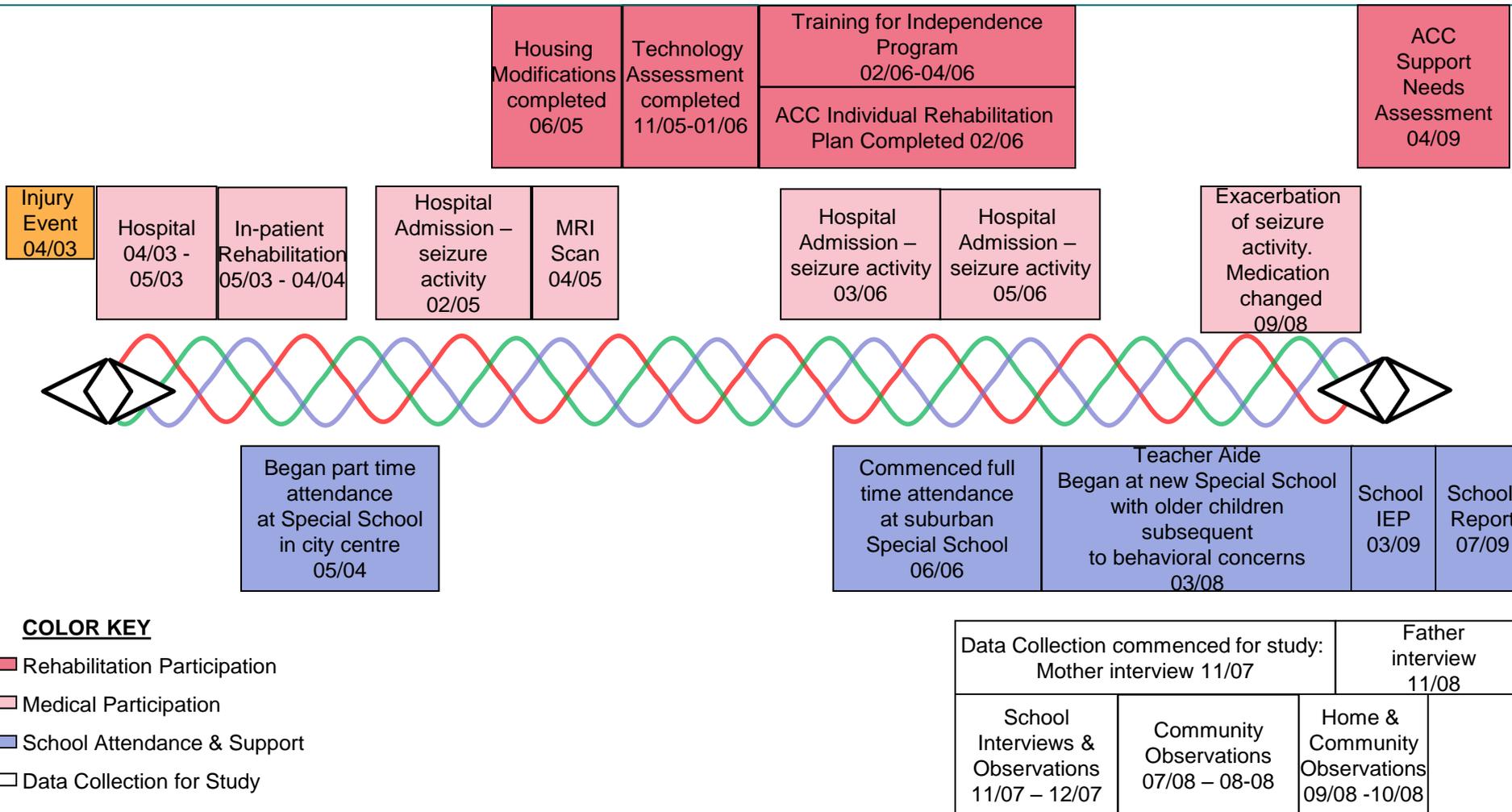
Education & Rehabilitation Documents

Rimu School Report (07/09), Individual Education Plan (03/09), ACC Individual Rehabilitation Plan (02/06), Support Needs Assessment Report (04/09), Assistive Technology Report (01/06), Training for Independence report (04/06).

Not currently receiving ACC funded therapy.

Considerations for Future Planning: Social: Increased independence in activities of daily living, social interaction & community participation.... Anton lacks ability to plan & initiate social contact & participate in age appropriate but safe activities. He requires attendant care support to determine what recreational activities are safe & appropriate. Occupational Therapist to assist family to identify local sports/leisure groups in the community & school that Anton could potentially be involved in. Occupational Therapy support to target increased independence at home & in the community ... (Rehab IRP S1, p. 10).

Display of Data Sources



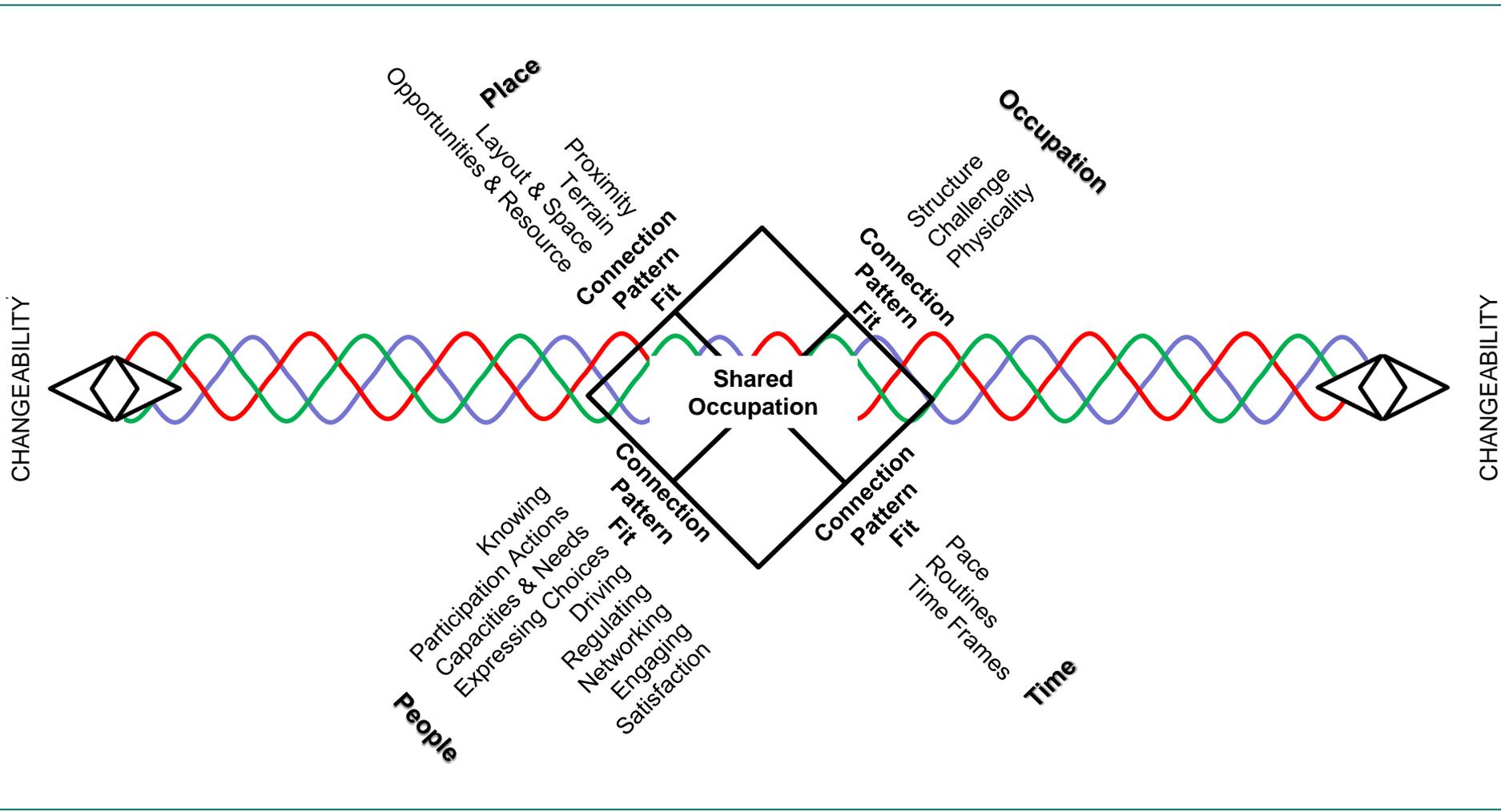
COLOR KEY

- Rehabilitation Participation
- Medical Participation
- School Attendance & Support
- Data Collection for Study

Time Line Of Key Events since Anton’s Accident

Personal Care Occupations at Home	Toileting, getting dressed, bathing, grooming, eating
Leisure Occupations at Home with Parents or Caregivers	Puzzles, playing on the computer, rolling toy cars down tube, trampoline, sandpit, cross trainer, riding tricycle, watching TV/DVD's, waking/running around, taking off, climbing around the fence, throwing leaves in the stream, chasing chickens, petting the animals, throwing toys from toy-box onto floor, raiding the pantry
Family Occupations	Going to church, going to the market, mealtimes, visiting grandmother in rest-home, Christmas carols in rest-home
Community Activities with Peers	Soccer, Scouts – mucking around, flag ceremony, tug of war, news, Kayaking, Swimming, Visiting school playground
Playground Occupations with Teacher Aide	Climbing, running, chasing, T ball, adventure playground, walking, stepping stones
Holiday Program with Teacher Aide	Cooking, craft – making a model, holding a toy & resting, lunch, toileting, throwing toys & materials, pressing dough, rolling items, making a model, dropping & retrieving items, walking
School Occupations	Traveling to school, putting away bag, gym at local facility, warm up, warm down, fitness, jump jam, swimming, music therapy, physiotherapy, speech language therapy, art therapy, “experiencing sharing” with specialist teacher, puzzles, playdough, toy cars, literacy, numeracy, lunch, toileting, buddy reading, chill out with tv, time out, sensory room, cooking, shopping, shared assembly
Medical, Rehabilitation, & Assessment	Meetings with ACC Case Manager – 2/year, Support Needs Assessment – 1/year, Individual Education Planning at school – 2/year. Assistive Technology Assessment – 6 sessions, Dietician Assessment & Monitoring – monthly, Pediatric Neuropsychiatrist & Psychiatrist review, Pediatric Neurologist Review, Developmental pediatrician review – 3-6 monthly

Anton's Recent Occupations



What was important about Anton's Participation?

Changeable Participation over Time with Others

The central intertwined line represents the way strands of Anton's participation were bound together with others who also participated. It also represents the way this participation very slowly evolved over time. Anton had positive changes in his physical capacities, but despite participating with special therapists & teachers, made only "little steps" (Steve, TAI, p. 19) in his learning. *"He's growing, so there's a change from that point of view. He's getting stronger. His mental age hasn't improved much. Some abilities have improved. Um, but.... It looks like ... There won't be sudden improvement to make him aware of these [social boundaries] things so.... That part of the brain has been damaged too much.... I don't think he will ever comprehend"* (Albert, FI, pp. 36-40). Fluctuations in his health contributed to episodes of progression & regression in his capacities & behavior, & changeability in his participation. *"Oh he can be very easy, & he can be extremely difficult"* (Albert, FI, p. 20).

Nonetheless, it was by participating that changes in his capacity to take part in things with others had occurred. *"He started going underwater [at swimming]. We had dropped a toy underneath.... And that was when he started being able to hold his breath.... it was a breakthrough"* (Kathleen, MI, p. 40).

Change also occurred with other people, time, place, and occupations. Sudden change in these aspects could hinder Anton's participation. A focus at school was alerting & preparing Anton for such changes, such as easing him into a new way of performing an occupation, or alerting him to a shift of activities in the daily routine. As others participated they too changed. Anton's teacher described the reaction of children from the mainstream classes who visited the special class; *"If you've got kids*

who haven't worked with your kids, they get nervous. And they'll keep their distance until they warm up. It's just because our kids are so new for them, a lot of mainstream kids have never been in a special needs classroom. But when they get used to it, they just come in & they know, they get to know the kids as people" (Esther, TI, p. 13).

Changeability also refers to the ease with which aspects of participation could change. Anton's preferred occupations changed little over time. Occupations such as raiding the kitchen, trampolining, swimming, sending toy cars down tubes, playdough, or puzzles were long-standing. Kathleen & Pete proactively instigated change. *"There are times when he just seems to be, wanting to stay in the same place. And yet he will get bored & he'll start to get naughty ... So we'll get him outside playing with the cars & I'm just thinking in terms of variation"* (Kathleen, MI, p. 35). Kathleen described changeability in other people as "helpful" (p. 17). Most people when approached were willing to change, but where people were not open to change, new opportunities for participation were closed off. *"The taxi driver we've got presently ... He's quite helpful & accommodating.... We had a replacement one ... She was quite unhelpful & quite rude"* (Kathleen, MI, p. 17).

Anton's father, Albert had concerns for his son's future participation, & also for his own ability to participate in Anton's cares & other occupations, given his present & past experiences. *"Well it was easier when he was smaller to take him out because you know you would just, able to guide him along a lot easier.... In two years time he may be taller than me & stronger than me, so how are you going to do it then?"* (Albert, FI, p. 36).

What was Important about Anton's Participation?

Shared Occupation

Anton's participation was seen in terms of occupations that were shared with others. *"It's good for him to, to do things with other people ... You could say he's living in his own world, & of course we want to shake him out of that, & you know, let him experience that he can have fun when you do things you know, games with other people"* (Albert, FI, p. 18). Even what appeared to be solitary play for Anton usually involved a small toy or a movie character as a participation partner. *"He adores Nemo. He thinks Nemo is his buddy. And he walks around with the [DVD] cover, um, and looking at the picture for quite lengthy periods. He likes to take it in the car with him"* (Kathleen, MI, p. 7). Because Anton required a high level of support, almost all of his occupations were shared with adults.

Connections

Connection was about being a part of a group & occupation. There were connections across those who shared in occupations with Anton, & different time-points, places, & occupations. *"Kathleen gets Anton to sit beside another boy- the other boy greets Anton, they are in the same class at school, & Kathleen is friendly with his mother. Anton looks at the boy's face, then relaxes beside him. The boy rubs Anton's back gently, seeming to sense how tired he is today. The other boy is aware of Anton's presence, & has learned how to interact with him in a way that fits for Anton. Kathleen touches my arm to gain my attention, to see this moment"* (Obs, Soccer, p. 6). Where occupations were not shared, connections could not be made. *"I don't really see the point of it [a playground in the garden]. It's probably attracting more children, round.... If you have a playground there it's going to be used by all sorts*

of people.... I don't want them there. I don't want to be unfriendly, but you know, you want to keep your private life sort of together. We've got so much interference with caregivers already that I don't really want others there every day" (Albert, FI, pp. 10-11).

Fit

The fit between different aspects of participation affected the quality of the connection. Anton's extremes of behavior often resulted in a misfit with other people, restricting his involvement. *"To take him [shopping] would slow me down. Plus I've taken him in the past & he would kick other people, other kids & that's not the greatest & I don't want to be having a confrontation with him.... Having no concept of you can't, just grab it & consume it [food] right there & then.... So I don't, really, have the desire to take him out on those social things"* (Albert, FI, pp. 18-19).

Patterns

Anton's shared occupations were also patterned in terms of the people, times, places & occupations involved. A pattern was evident in Anton's enjoyment of physically-based, shared occupations. However, an imbalance was present in that many of Anton's occupations were indoors, reflecting the influence of weather, & concerns for his safety outdoors. *"He's only had about six [soccer] meetings, because of the bad weather, over the winter. But they're starting summer soccer on Wednesday evenings (Kathleen, MI, p. 32).... Summer is coming he'll be outside a lot.... To keep him enjoying the fresh air, to keep him physically active but easily watched. I think the caregivers have struggled to get him outside sometimes, & so have I"* (p. 35).

What was important about Anton's Participation?

The pattern of Anton's occupations was further imbalanced, in that occupations were all shared with adults, & in only a limited way with his peers. Additionally, many of the adults involved with him were specialists, or paid caregivers, & he had less involvement with other adults from the wider community. Steve, Anton's teacher aide, felt that where possible, it was important to give Anton some space away from adult support. *"I tend to step back.... Yeah, yeah, stand back just let him.... Yeah, let him do what he wants to do"* (Steve, TAI, p. 24). Children in Anton's class interacted in play & learning occupations, but these interactions often needed to be halted, in order to *avoid "winding each other up"* (Steve, TAI, p. 6). A need to focus on the task further hampered shared occupations. Few occupations were shared with peers, & those that were shared emphasized the occupation rather than interactions between those who shared it. *"Anton is slightly distracted by & shows interest in what the other child at the one-on-one station behind the screen is doing. Esther prompts him away.... Other children are sitting around the table. They show different degrees of concentration at their activities, looking up at the teachers, other children, the cupboard.... Esther gets another puzzle out. "Good boy. Looking. Looking". She lays the pieces out for him.... Anton looks around again. 'Anton! Looking! Anton! What side does it go on?' Anton looks at another child on his right, watching him. Another child makes a comment out loud about Anton. 'Right. Warning- one ... two ... three! You can do this or go & do time out' Esther admonishes.... Esther offers encouragement, & points, then Anton puts the piece into place & steadies the board. The children are not interacting with each other at the table"* (Obs, CV, p. 10-12). School staff had introduced a weekly sensory-play session called *"experience sharing"* (Esther, TI, pp. 5-6;

Steve, TAI, p. 12) but again, this was carried out with a specialist teacher, & not with peers.

Rehabilitation reports suggest that play with other children was either not of interest to Anton, or was discouraged due to instances of aggression (Rehab, SNA, p. 17). This was not borne out by research observations or parent report; *"He also does like the company of other children"* (Kathleen, MI, p. 42). Scouts provided a valuable opportunity for Anton to participate with non-disabled children. Other parents in this setting showed they had readily adjusted to involving him in the occupations there.

What was Important about Anton's Participation?

Knowing: knowledge of, or learning about an occupation, & how to engage with other people in that occupation. Anton's participation was limited when others didn't know him. Getting to know occurred in the context of shared occupation, & took time. People came to know through questioning, observation, modeling, & direct instruction.

Anton & his teacher took time to get to know each other; "I was his teacher so he had six months of adjustment there & then, another six months of me actually getting to know him.... I had him in my class when I just first started teaching, so um, six months was just getting to, really know the kids. And adjusting to the class system & class routines (Esther, TI, p. 10).

"The mainstream kids pull back.... they're a bit frightened of him.... Understanding that's all part of his disability... he sort of runs at ... he can be quite loud sometimes.... It can appear aggressive.... that would hold him back with mainstream kids" (Steve, TAI, pp. 7-8).

"There were quite a bunch of boys [at the local playground] who were really nice to him ... similar age. They'd ask me questions, 'oh why is he' ... they'd ask me why he was a bit different so that I would explain it.... They would play with him" (Kathleen, MI, p. 20).

"Pete [caregiver] goes over to Bevan [a Scout who is helping Anton] & encourages him to deal with Anton's behavior when he goes off- track. He demonstrates how to hold Anton, & explains what to do if Anton is wandering out of line, running when he's not meant to, or fidgeting with other children. He says that it ... takes Anton a long time to learn" (Obs Scout, p. 7).

Participation Actions: actions directed towards including other people into shared occupation. Actions included noticing another person or their activity, greeting & farewelling, welcoming, inviting, asking & answering questions, sharing items, helping, teaching, following, encouraging, praising, turn-taking, adapting, touching, & inclusive leadership.

Some emergent participation actions were observed between children at Anton's school & holiday program, although these were not well recognized by adults. Following was a strategy Anton used to good effect to learn how to perform the occupations involved in participation situations. However, adults used a variety of participation actions, & these helped to include Anton into occupations. In community-based occupations, peers spontaneously used participation actions to include Anton. These were more common where group leaders took a lead & modeled the actions for children.

"Quite often you'd get kids [at the community playground] saying 'Hi Anton, bye Anton' They wouldn't do a lot more than general greetings.... I would say 'Come on Anton let's chase this boy' you know & we were on the monkey bars.... So we'd go round & the others climbing ahead of us & um, we'd follow them on the monkey bars.... He likes the football. I've seen him going to one or two children on the field, & they're the ones who know him ... they'd say 'Anton do you want to kick the ball?' Or throwing hoops with the basketball, he would go over & want to um, observe or try & get the ball & have a turn. So ... There was a bit of interaction. Hmmm" (Kathleen, MI, p. 26).

Important Aspects of Anton's Shared Occupation - People

Capacities & Needs: People's potential & actual performance & the things they need to enable them to participate in shared occupation. Anton's needs for support restricted his participation in family outings & trips. Albert was aware of his own need for support with Anton's care occupations. This need was not effectively met, &, restricted Albert's participation with family outside the home. However, Kathleen & Pete emphasized Anton's capacities. This informed decisions about new avenues for participation. Where there was diversity in people's capacities, the differences between them were less obvious, & Anton fitted in.

"Anton sits in a height adjustable chair with arms at the table to provide ... a supported position in order to maximize his fine motor skills.... Once his plate (a high sided plate with a rim) is set up for him on some ... (non-slip matting) he is able to use a spoon (large handle) to feed himself a variety of foods with his right hand.... Anton is able to drink from a cup but is using a cup & straw to assist in developing the muscles of his face" (participation in eating) (Rehab SNA, p. 11).

"If you look at other families & other kids, they do soccer & rugby & tennis.... For Jacque we do that, but, because Anton demands that extra level of care ... it's easier to do, to do nothing & sit at home" (Albert, FI, p. 33).

"[Pete - caregiver] thinks because Anton's got a strong upper body he would be good at kayaking. And he can imagine him kayaking to [a local beach].... X... said 'what happens if he has a seizure in the canoe?' Pete said 'if he does, which is unlikely, we've got Stesolid [medication]'" (Kathleen, MI, p. 21).

"Anton loves water. One of the important skills to learn for kayaking is how to fall out & get back in. For Anton however, the bigger challenge is learning to remain in the kayak. Anton sat for his kayaking test at Lake Webster in the summer & passed" (Obs Scout pp. 10-11).

Expressing Choices: having & expressing preferences about one's own or another's participation in an occupation, & others' responses to that expression. Anton had limited spoken communication to express choice. When his choice was expressed, others had control over whether that choice was realized. Anton was offered choices between a limited number of activities, and, in the school setting, along with other students, was required to use cards to convey his preferences. However this meant choice was then restricted to that offered.

"Liam [another child in Anton's class] ... is refusing to pass his symbol [about his lunch]. Esther, his teacher, later explains to me that they are teaching him to be more independent of his teacher aide, to initiate activities & choices himself. He is reminded that he will sit there all morning hungry if he doesn't pass the symbol" (Obs SV, p. 17).

"Anton gets restless & gets up from the computer, walking unsteadily to the door out to the deck outside. 'Anton wants to go on the tramp?' asks Benny [carer]. You can't. It's wet' ... 'What do you want to do?' 'Nemo?' Anton indicates he still wants to go out, crying & shrieking. Benny lets him open the door & accompanies him out" (Obs HV, p. 5).

Important Aspects of Anton's Participation - People

Driving Participation: Anton's participation was actively pushed in certain directions by Kathleen, his mother & by Pete, his carer. They highly valued participation in community activities. Driving involved risk-taking, persistence, visioning, sourcing opportunities, problem solving, & resilience.

"I'm saying, just let him have a go you know.... And, and X is saying 'what if ... Pete's saying 'X, why don't you start thinking about, what we can do, not what we can't do. Let's just start thinking about the positives, what can be achieved & what we're aiming for' & I tend to feel a bit that way. Um I think I'm not quite as um, concerned about um, negative eventualities because I think we will get past them. In fact I'm determined that we will get past them you see" (Kathleen, MI, pp. 21-22).

Regulating Participation: Anton's involvement in shared occupations was managed using a variety of strategies. These included preparing him, restricting occupations, times, & places for participation, enforcing boundaries for his actions & body positions, & monitoring his safety, wellbeing & progress. Anton's participation was tightly regulated, but Steve, his teacher aide, & Pete, his caregiver delivered strategies in a more relaxed way.

"[Esther] stands at the front with a tambourine. 'We are finishing in five. Five, four, three, two, one. Right. Everyone to the mat. Good boy Anton. You went to the mat first. We're all going down for a story. Two rugby cards for you for working so beautifully & finishing off. Beautiful behavior & you get rewarded. Work time is now FINISHED!" (Esther,

TI, pp. 21-22).

Networking: communicating information about & planning for occupations in which people share. Networking supported Anton's participation by sharing experiences, providing opportunities for participation, & ensuring his needs were met. It occurred formally at meetings, assessments, & through documentation. Kathleen networked informally when participating in Anton's occupations. Albert regularly made time for a brief "update" (MI, p. 27) with Kathleen via the phone when at work, but had less time for networking.

"I take him to school & obviously that, the day ends for me there. And then I'll come back.... Between 5:30 and 7:30.... Other than Saturdays & Sundays I don't know much of what he's doing" (Albert, FI, pp. 3-4).

"Do you give Anton food first [after school]?" [researcher] "We, we did used to but we've compared notes with Pete & the respite people & they say no, they let him flake out a little bit & play with the toys" (Kathleen, MI, p. 34).

Important Aspects of Anton's Participation - People

Engaging: connecting with an occupation & the people who share in it. This was sometimes signified by the words “took to” (TAI, p. 7), “zones in” (TI, pp. 5, 20), or “hooked in” (FI, pp. 5-6) but was also indicated by the interest shown, the effort applied, & the degree of absorption. Where the occupation was very simple, such as running, Anton was able to engage with people, but where the occupation was complex, or of high interest, he tended to focus on the task.

“We have one guy comes in, Eugene [a peer from the mainstream school]. And he’s really good. You know he understands Anton & Anton sort of, took to Eugene” (Pete, TAI, p. 7).

“He [Anton] is the sort of person who gets absorbed in what he’s doing & you have to put a bomb under him to get him to move” (Kathleen, MI, p. 11).

“Anton continues to play [with cars] for another minute or so, then sits, pulling at his finger. He gets up & goes to the table. Now he is ready to play with the computer train game again.... He lies down & picks up a puzzle piece, but sticks at this momentarily only” (Obs, HV, pp. 6-7).

Satisfaction: A person’s experience of enjoyment, contentment, or achievement with their participation in a shared occupation. Anton showed high levels of satisfaction with physical achievements such as the cross trainer & swimming, & with his puzzles at school. He was observed & reported to be satisfied when he used his creativity in art & crafts. Dissatisfaction was shown by Anton as frustration. It is possible some instances of his challenging behavior also reflected dissatisfaction.

The older scout brings the thick bundled-up rope [from the tug of war]

over to Anton & places it on his lap. Anton happily begins sorting the knotted rope out. Pete explains to me that Anton really likes undoing & dismantling things, so this is his job. Before the Scout master has finished talking, Anton has got the knots undone” (Obs Scout, pp. 9-10).

We have a shopping game that we play as a whole classroom & there are little pieces that need to be picked up. He [Anton] can spend up to two to three minutes trying to get one of the pieces up. They’re all turned face down & you have to flick it up to see if you’ve got that on your card & he finds it very hard to flick cards.... he does get frustrated.... When he’s focused, concentrated & he’s really trying, if he can’t do something, he does get frustrated (Esther, TI, p. 14).

Important Aspects of Anton’s Participation - People

Opportunities & Resources: aspects of an environment that offer possibilities for shared occupations.

There is a wee track to the right of that bridge, through the bush which heads up to grandad's house, we sometimes go up there for ginger beer or a biscuit or something.... There's another little bridge there too because there are two streams (Kathleen, MI, p. 14).... I let the chooks out after lunch.... He chases the chooks sometimes (pp. 22-23).... The goats ... we reared them since they were three weeks old and Anton knew them. Taught him how to pat them softly. Not to hit them on the back, you know, pat softly. He's learned to pat ... the rabbits softly" (pp. 24-25).

Anton's family came to hear of opportunities through networking. Multiple opportunities were available for participation in rehabilitation occupations.

"The music therapy was suggested to us by his psychiatrist.... And the soccer, I think I read a notice in the bulletin, & I thought soccer would be quite good & the scouts came from Pete & Lynne [caregivers], their suggestion (Kathleen, MI, p. 42).

"Anton is now under the care of a Pediatrician, Pediatric Neurologist & Pediatric Neuropsychiatrist" (Rehab IRP S1, p. 2). "Resources & Personnel [to support Anton to achieve learning goals]: Physiotherapist, Speech Language Therapist, Art Specialist, Expressive Arts Specialist, Music Specialist, PE Specialist" (Educ IEP, p. 2). Clinical Psychology report [dated] indicates that Anton's behavior was satisfactory at the time (Rehab SNA, p. 27).

Proximity: the position of a person relative to others or to aspects of the physical environment. Anton was usually in close proximity to an adult for safety. Children were separated at school to regulate behavior, but this had the effect of limiting shared occupations.

"Who wants to do some play-dough?' Anton comes over & sits at the table. The teacher aide pushes Anton's chair close in to the table, then gets a big lump of bright green play-dough out of a bag & gives some to Andrew & some to Anton.... Anton reaches over to take some of Andrew's dough, but is discouraged by the teacher aide.... The teacher aide & Andrew move away from the table, & Anton remains on his own" (Obs Hol Prog, pp. 5-6).

Terrain: gradients, surfaces, obstacles, & hazards in an outdoors environment.

"We've got a trike for him just recently, through the Variety Club, so we will try & um, we can't do it from the top obviously from the drive, but we start up at the base of the drive where it's flatter.... And the school has got the flat courts & also the flat field which is generally quite well mown. And he loves it" (Kathleen, MI, p. 31).

"He will walk away.... If you don't keep an eye on him ... he'll walk away. That's why I want the gate closed & that's why I don't allow him to walk to the waterfall.... With a big pool underneath, so we don't want him to go there. He likes sitting on that stump, but that's quite close to the drop-off, so um, we don't want him to walk around without supervision" (Albert, FI, p. 12).

Important Aspects of Anton's Participation – Place

Layout & Space: the arrangement of items & openness of a built environment. The layout of environments facilitated regulation of participation. Smaller, enclosed spaces facilitated engagement in more challenging occupations, while larger, more open spaces facilitated less structured occupations. Despite the more open space at Scouts, Anton required little regulation.

“Sometimes we have to lock the double doors to keep him outside.... There’s the DVD here & there’s food in the cupboards. I mean, I’ve got a lock, I can lock that one & I can lock the pantry to the left & that where all the food is” (Kathleen, MI, p. 38).

“The two classrooms [for the holiday program] are separated by quite a high shelf unit with items stacked on top of it. At one end of the room is a sink bench & shelving higher above it, & at the other end of the classroom is another tall unit with closed cupboard doors” (Obs Hol Prog, p. 2).

Important Aspects of Anton’s Participation – Place

Structure: the organisation of an occupation. More challenging occupations at school were tightly structured. When there was less challenge, or when he could follow others, Anton coped with loosely structured occupations.

The two different dimensions of structure were observed at Scouts. *“Usually Anton’s time is much more structured & directed. Here is free play, happy chaos. The noise levels are high, kids all different ages, all chattering, catching up, standing around in small groups. Anton & his friend chase each other (Obs Scout, p. 3).... The group begins to become more organized & stand in two long lines, each line facing the centre of the hall. Pete stands directly behind Anton, his hands on Anton’s shoulders.... Anton seems quite at ease with this [flag-raising] ritual- he has probably done this before. The scout Master speaks out- ‘Stand to attention. Bow your heads. Let us pray. The two lines of children are silent, Anton, part of them, also silent. ‘Raise the flag’.... A girl moves to the front & pulls the rope to raise the New Zealand flag ... A whistle is blown while the flag is raised. Anton is attentive, watching the flag. ‘At ease. Break off’ (p. 5).*

“Anton continues to work at his numbers activity with Esther. He is required to recognize, name, & match the numerals printed on small cards when Esther holds them up.... This is very specific, focused. It requires frequent repetition.... I note that she selects each activity, taking one activity at a time out of a basket. They do it, then she puts it all away before getting out the next activity. Each activity is small, with only a few components” (Obs, SV, pp. 7-8).

Challenge: the actions demanded by an occupation relative to a person’s capacities, & the competitiveness of that occupation.

“Anton is making very good progress in the gym. If he is concentrating well, Anton is able to remain on the treadmill at [sic] speed of 4.0 for a period of 20 minutes. Anton enjoys time on the treadmill & will quickly make his way up to the treadmill independently when told. Music is a huge motivator, with Anton preferring to complete his time on the treadmill with the radio playing” (Educ Rpt, p. 2).

“You love your puzzles don’t you. I think you should do this one. It’s harder. Take all the pieces out’.... He does seem more interested in this puzzle- there is less looking around. ‘Are you struggling a little bit here?’ [Esther] asks Anton. She helps him do the puzzle.... Esther offers encouragement & points, then Anton puts the piece into place & steadies the board.... ‘Aah, aah’ [Anton]. ‘You can do it Anton. No, no, you had it right before. That was a hard piece wasn’t it!’. I think Anton is finding this puzzle a bit challenging” (Obs SV, pp. 11-12).

Physicality: the sensory & movement experiences involved with a shared occupation. Anton enjoyed physical occupations. However participation in swimming, running & outdoor play was limited by the weather, school routines, & safety concerns.

“Anton attempts activities beyond his ability & has no understanding of danger. He climbs & will climb or jump objects that are unsafe if not closely monitored (Rehab SNA, p. 15).

“What we’re doing in PE at the moment is t-ball & he’s actually really good at it, he can run right round the posts, loves hitting the ball, yes he quite enjoys boyish physical things.... If he can give it a go, I’m like well ‘give it a go’ you know. As long as safety allows” (Steve, TAI, p. 10).

Important Aspects of Anton’s Participation - Occupation

Pace: the speed at which shared occupations occurred, or the number of occupations or steps of an occupation that were fitted into a routine. Shared occupations that were busily-paced were confusing for Anton, but were also enjoyable. Although Anton could move quickly, a slower pace fitted better with his capacities.

"I feel like sometimes we do too much yeah, & sometimes we need to slow down you know, because otherwise you kind of burn out & get tired & the kids need to sort of, take things slowly too.... And I really feel that with a class like this it's not, it's not the amount of work they're getting done it's the quality you know.... Sometimes it becomes quantity because... you've just got so much to fit in to your program, day, you just don't have time" (Esther, TI, p. 7).

Routine: the regularity & frequency of shared occupations over time. To help contain Anton's behavior, & to support his capacities, his routine was strictly managed, & even tiny details were regulated.

I asked Kathleen about Anton's morning activities.

Hmm, he goes first to the toilet. Changes nappy, wash, I clean him.... Comes & cuddles in our bed. And we try & get him back to sleep because this morning it was 4 o'clock.... And then by about 6:15 he's up and he comes out here & plays with toys. I wasn't ready to get up at 6:15 which sounds very slack but I just wasn't ready to get up but I was there watching & then he says Nemo because his favorite DVD of all time is Nemo.... And he goes & bangs on that unit there sometimes if he doesn't get an answer.... And then we get up, we go & have breakfast. And he sits down with his breakfast, he eats his Mega-wheats & his um, drinks his chocolate milk or juice.... And then we go off in to the bathroom & get changed. I help him with changing. Um & he's just recently been getting quite good with, helping pull his trousers up.... Um, & so the toothbrush ... Sometimes I still have to bring the toothbrush up out & brush them here while he's sitting in the lounge which is not what we want. But generally he, we will make him go in to the bathroom ... Comb his hair, wash his face, brush his teeth. Um we try to leave it a little bit towards the end because every time he helps, he's rewarded with a raisin.... And um we sit him down on the bench ... Put his socks & shoes on ... And before I've done all this he's been sitting on the floor playing with his toys or watching Nemo or both & I've been making his lunch" (MI, pp. 6-12).

Important Aspects of Anton's Participation - Time

Time Frames: the duration of a shared occupation & the time-point at which it occurred. Albert closely monitored the time frames of Anton's seizures in an effort to identify potential contributors. Precise time frames supported accurate administration of his medications. Time frames that didn't fit with Anton's capacities influenced his participation: If something was too late & he was tired, or if the time frames were too early & Anton hadn't yet adjusted to daylight saving, his participation was precluded

"We went on, Tuesday night to the FIFA World Cup girl's soccer.... I thought we'd all go plus one of Jacque's friends but unfortunately we weren't sure whether Anton should go on a Tuesday being um, late, we thought it would be late & they were going to have the opening ceremony" (Kathleen, MI, p. 33).

"Depends on whose turn it is, goes out. Um gives him the medication at 7:00. He needs to have that at the right time" (Albert, FI, p. 2).

"It [seizures] would be once maybe every two to three weeks. In fact Albert's got records. He notes everything down. We've got a chart thing & then he, puts it on the computer & does graphs" (Kathleen, MI, p. 15).

Important Aspects of Anton's Participation – Time

Bound: Anton’s behavioral extremes, health concerns, & safety risks did not fit well with his physical & social contexts. Anton’s participation was therefore carefully contained. The range of his shared occupations was limited. When frustrated, he responded by pushing against boundaries.

Inflexible: Anton’s health, function, & behaviors were highly variable. Addressing this, routines were firmly applied.

Caught in Detail: Reflecting their intent & required frameworks, rehabilitation assessments generated intricate understandings about Anton’s capacities & needs. Kathleen spontaneously explained the tiny particulars of Anton’s daily occupations, perhaps reflecting the influence of the information requested in these assessments. With the focus inwards on details, documents miss information about the wider picture of Anton’s participation in occupations with others.

Specialized: Complex needs resulted in Anton participating in a variety of specialist assessments & interventions. At his special school he routinely participated in carefully adapted learning occupations with educational specialists & other children who had special needs. Rehabilitation documents have little information about Anton’s participation with other children in regular childhood occupations.

Over-stretched: Esther, Anton’s teacher felt that sometimes, too many things were demanded in the children’s school routines, & that these levels of busyness caused “*burnout*” (TI, p. 7). Anton felt over-stretched when the challenges misfitted with his abilities, showing agitation, or fatigue. Albert also expressed multiple demands on his time & energies. He felt stretched to the point where things began to fray.

Contained: Anton’s occupations were often contained apart from other children, & this limited their coming to know & connect with him. At his special school he was physically distanced to manage his behavior & support his learning. His own over-focus on a task tended to separate him from those around him. Moreover, the other children attending the special school had limited ability & contact time in which to learn how to share occupations with him appropriately; rather, shared occupations were carried out in parallel, with limited episodes of interaction. Interactions with peers at the holiday program were infrequent, & Anton seemed withdrawn into himself. Non-disabled peers attended a different part of the school, & visited for short periods only once a week. Information about his participation in one context was not always shared with those in other contexts.

Qualifying the Problematic Situation Misfits, Confined Connections, Contained Patterns

Tensioned: Differing views about Anton's participation resulted in underlying & unresolved tensions. Kathleen believed in providing Anton with a range of new experiences with other people. In contrast, Albert was cautious about his son's participation, & had conflicted views as to the value & his own capacity to support it. There were unvoiced disparities between people's views of classroom activities. There was also tension between ensuring Anton's engagement in occupations versus engaging with the people who shared the occupations.

Anton looks momentarily at the TV, then returns to staring at his toy.... Jeremy begins making a loud noise over by the table. 'Do you want to write?' the teacher aide asks.... Jeremy begins coloring lines on the paper. Anton is still engaged with his toy over on the couch. He sits slouched, his head over on one side. Evan, the boy with the Sesame Street toy, is sitting beside him on the other couch, still turning his toy over & over, panting audibly, periodically letting out a happy cry. Anton continues to stare. He blinks occasionally, rubs his face. Over on the table, Jeremy begins paddling his chest loudly & yells. Unexpectedly Anton looks up at me & meets my gaze (Obs Hol Prog, pp. 4-5).

Alternative Interpretation

This excerpt captures the confined & contained nature of Anton's participation seen in some settings & at some times. It contrasted with the participation seen at Scouts, at Soccer, & with his mother's descriptions of participation in kayaking, and at the playground.

An alternative explanation for Anton's participation seen in this setting could have been seizure activity & fatigue suppressing his involvement. However during the same episode, Anton made several efforts to obtain materials from the cupboards, or to engage with me in play-dough throwing, all of which were seen by staff as inappropriate, with potential for escalation, & were (understandably) stopped.

Qualifying the Problematic Situation Misfits, Confined Connections, Contained Patterns

Learning through Doing Together. As Anton shared occupations with others, he became familiar with the structure & routines, & slowly gained skills for carrying out those occupations. As others came to know Anton, they learned skills that included him into the shared occupation.

Regularizing Participation Patterns: Kathleen wished for Anton to be “*part of the landscape*” rather than “*being cosseted*” or “*separated off*” (MI, p. 16). Whilst participation in some specialized medical occupations was essential to Anton’s health, this needed to be balanced out with participation in the same occupations as other children. In busy situations where there were diverse ages & abilities, Anton fitted in with the pattern more readily. His capacity to follow others helped him to blend in with the regular pattern.

Looking to the Bigger Picture: Keeping an eye to the broader community-situated view of Anton’s participation generated awareness of imbalances in those who participated with him.

Opening Up: Kathleen & Pete actively drove Anton’s participation outwards from its confines, pushing him towards new experiences with new people. New Connections were forged.

Taking up Chances: Rather than playing it safe with familiar occupations, chances were taken with new occupations, informed by others’ & Anton’s own prior experiences & connections. This trial & error approach to new occupations risked some failures, but also resulted in some new discoveries about Anton’s capacities.

Providing Choice: Providing Anton with some choices about the occupations he would share in supported his engagement. Aligning the choices with his own interests gave him increased investment in the choice process.

Being Flexible: Consistency in medical & safety routines was essential to Anton’s participation. However, flexible attitudes in those who shared occupations with Anton facilitated his participation, by responding to variability in his capacities, needs, & preferences. Flexibility in occupations & the times & places in which they occurred enabled others to make adjustments & supported fit.

Sharing Views: Participation in planning facilitated people to share their views with each other. Different view-points were sometimes a source of opportunities & new connections.

Becoming a Part: If Anton took to a new shared occupation & to those involved, & if those others took to him, he could become a part of that occupation. He could use his capacities to achieve, & to contribute to the occupation with other people.

Determining Solutions:
Extending Connections, Easing out the Pattern, Enabling Fit: Learning through Doing Together

Dribbling [the soccer ball] from Anton to Callum, Callum to Anton, & I'm behind teaching him how to dribble.... They line up & have turns shooting at the goal.... There's parents involved & they mix in to the team. And everybody's rustling around and kicking the ball, & it comes to Anton 'Stop. Anton's turn', Anton kicks the ball to someone, then they all keep going at the normal speed.... They're very welcoming & they're helping him to be established.... One girl ... She's very encouraging 'Go Anton, Anton's turn!' ... Simon or Aaron are having a turn holding his hand, making sure he doesn't fall over the ball or run in to somebody.... [Other parents] said 'are we going to do summer soccer?' 'Yes' we are. Albert was outside helping Anton with the drills. And I think he will become more involved (Kathleen, MI, pp. 32-33).

**Determining Solutions:
Extending Connections, Easing out the Pattern, Enabling Fit: Learning through Doing Together**