

# Appendix 5.1:

## Case Study Report 1 Anna

Anna is 10 years old. She lives in Kingsville a rapidly growing semi-rural township with her mother Jan, her younger brother Ben, & her older-half brother. Anna & her family are New Zealand European.

Anna sustained a severe traumatic brain injury in a car accident at age 1 year 2 months. Her injuries included bilateral frontal contusions, diffuse axonal injury, & a left fronto-parietal fracture. She was hospitalized for 22 days, then received in-patient rehabilitation for 6 ½ months. She has reduced vision to the right, dysphasia, & wears hand & foot splints.

Anna has regular surgery & rehabilitation to address orthopaedic issues resulting from her injury. She attends regular hospital appointments for hormone injections.

Anna attends Kingsville primary school full-time, & is in a year 5-6 class. Anna has an after-school carer, Mary. She walks to & from school with Ben supervised by her mother or Mary. Anna & Ben stay with their father one night a week & some holidays. They also attend a school holiday program.

Anna is skilled at writing poetry. She enjoys sports. She has a cat called Smudge.

### Wild One

Have you seen the breeze on the fur  
Have you heard the slap slap slap of  
her tail  
Have you seen the big waves licking up  
the sand  
Have you felt the soft pads on her paws  
Have you seen the sand flicking the in  
air when she digs  
Have you heard the howl of the wind  
Have you seen her chasing the birds on  
the shore  
All the howling & the slap slap slap  
I tell you the sea will be wild forever  
(Poem, Anna, age 11 years)



### Being in a Team

*"What's nice about doing  
soccer?" (Researcher)  
"Then well like I can be in like a  
team" (Anna, ChI, p.168).*

## Case One: Anna

## Contents of Case Study One

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- Introduction to Anna. The poster Anna made about her occupations.....  
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 & Anna.....
- Anna's recent occupations. ....
- Diagram: important aspects of Anna's participation.....
- Discussion: important aspects of Anna's participation: The concepts in the diagram are explained & illustrated.....  
Diagram: overall characterization of Anna's participation.....  
Qualifying the problematic situation.....
- Solutions to the problematic situation.....

### Key: Abbreviations used in citations of data sources for Anna's case study

MI	Mother Interview number	Obs SV1	Observations School Visit 1 – Art - 2007
ChI	Child Interview	Obs SV2	Observations School Visit 2 – 2008
TI	Teacher Interview 2007	Obs SV3	Observations School Visit 3 – Maths. Power Walk 2008
TAI	Teacher Aide Interview	Obs HV	Observations Home Visit
SENCOI	Special Education Needs Coordinator	R -SRA	Rehabilitation document - Social Rehabilitation Assessment Report
	Interview	R - TIMP	Rehabilitation document – Training for Independence Module Plan
		R - TIPCR	Rehabilitation document – Training for Independence Program
			Completion Report

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 & Abbreviations

## Contents of Case Study One

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### Key to Colors for Participation

	Family
	Community
	School
	Rehabilitation (medical)

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### Key: Abbreviations used in citations of data sources for Anna's case study

MI	Mother Interview (Jan)	Obs SV1	Observations School Visit 1 – Art - 2007
ChI	Child Interview (Anna)	Obs SV2	Observations School Visit 2 – 2008
TI	Teacher Interview 2007 (Natalie, Miss J)	Obs SV3	Observations School Visit 3 – Maths. Power Walk 2008
TAI	Teacher Aide Interview (Joanne K)	Obs HV	Observations Home Visit
SENCOI	Special Education Needs Coordinator Interview (Leslie)	R -SRA	Rehabilitation document - Social Rehabilitation Assessment Report
		R - TIMP	Rehabilitation document – Training for Independence Module Plan
		R - TIPCR	Rehabilitation document – Training for Independence Program Completion Report

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## Contents & Key to Abbreviations & Colors

**Jan: Anna's mother.**

Sustained fractures in the car accident. Has a chronic health condition. She has separated from Tony, Anna & Ben's dad. Regularly visits her parents who are 3 hours drive away & in poor health. Works 5 days/week in a local hardware store, & built a new deck & play area onto the family home. Keen gardener. Home was recently purchased by the council for demolition. Jan may need a mortgage to purchase another home.

**Scrimping and Scraping**

*"I've been poor for so long ... The thought of adding another 10 years of scrimping & scraping.... I have to work full time.... I don't really have any choice... It's made it really hard. Probably just because I'm on my own, more than the fact that Anna is disabled"* (MI, p. 4).

**Good Stuff to Look Back on**

*"I want to keep it as good a childhood [for Anna] as I can possibly make it, so when she looks back, & when she's feeling excluded, she's got good stuff, to look back on"* (MI, p. 145).

Anna: Interview & Poster-making session

**Researcher Visit to Family Home at Weekend**

*"We planted all the sunflowers.... If you go & have a look, some are popping up"* (Jan, Obs HV, p. 1).

*"I'm always very conscious of where they [Anna & Ben] are & what they are doing, but they pretty much have to entertain themselves while you try & get that stuff [lawn-mowing] done.... So I usually sort them out with something inside to do"* (Jan, Obs HV, p. 14).

*"You eat your cheese & your cracks [crackers] please" [Jan to Anna]....*

*"I, I want another go [at PlayStation].... Oh I hate my bricks & my cheese" [Anna].... "Alright well if you've had enough, but you've had an hour on the PlayStation already. Maybe after tea" [Jan].* (Obs HV, p. 49)

**Natalie (Miss J.) : Anna's Teacher 2007**

Second year of teaching. First year of teaching in P. township. Class of 30 Year 5 & 6 students. Keen interest in drama & music productions.

**Learning on the Job**

*"So much of what is valuable I learned on the job realistically.... The balance, the juggling act of catering for so many different needs.... There is a diverse range. The logistics, the getting organized for so many different groups ... Experience helps"* (TI, p. 15).

**A Bonus to Have Her**

*"She really fits in to, the mainstream routines.... She would be horrified to be not included, even though she's you know obviously restricted & limited she gives 110%. The kids have been really supportive with that too, we just adapt all of our games to suit her ... I think it's a bonus to have her ... it has made them a lot more sensitive to others' needs ... They really strive to help her"* (TI, pp. 1-2).

**Joanne K: Anna's Teacher Aide**

A parent. Employed 15 hours/week to support Anna & other children. Has worked with Anna 4 years. Assists with reading, writing & self-care activities. Not moving to intermediate school with Anna next year.

**Part of It**

*"She can be a little bit off-putting.... abrupt when she's speaking to the other children.... We're trying to work on that"* (TAI, p. 2).

**Not Hanging Over Her**

*"Instead of just hanging over her I'll just say, well I'll just go away & look at some other children's work & you just sit there & have a little think & I'll come back & by then you know hopefully you'll have some ideas"* (TAI, p. 19).

**Leslie: Assistant Principal, Special Education Needs Coordinator.**

Has worked 10 years at T. School & recalls the accident. An advocate for Anna. Values team work, communication, & parent involvement. School values are Care, Courtesy, & Cooperation.

**The Child We Place First**

*"Out of the 600 odd children at the end of every year, [Anna] would be the child we placed first, & then we place her friendships around her.... Because she's possibly our most high need pupil"* (SENCOI, p. 6). *In so much as the fact, she has possibly up to three visitors a week (p. 8)... how do you support Anna, with that big team, without making Anna feel overwhelmed, by different people having a go at her, pulling her, prodding her, poking her, asking her questions.... I sort of look after that side of her a little... I don't want her to miss school cross country*

*because there's a specialist coming, so I'll say to them 'no, it's school cross country, I want her to be part of it'"* (SENCOI, p. 20).

**Researcher Visit to Anna's 2007 Class- Art**

*Anna goes up to [the group of children] & stands & tries to join in. They are laughing & Anna claps her hand at the joke, but they are not taking notice of her or including her into the group* (Obs SV1, pp. 8-9).

**Researcher Visit to Anna's 2008 Class:** Room 23, K. Primary School. Miss C's class.

**Needing Help**

*All are with buddies or in small groups. Anna is on her own, concentrating on her lunch. She is unable to open her tube of juice, despite gnawing at it. After a while I move over, & ask if I can help. Another little girl is watching. I ask if she could fetch a pair of scissors & she rushes off to assist* (Obs SV2, p. 10).

**Participation in Reading**

*We go a special room at the back of the classroom & the door is shut. We are in here alone.... I can hear the buzz of voices from the class next door.... Anna says she wants to sit on the floor, so Joanne [teacher aide] allows this to happen.... Anna reads slowly & haltingly. Anna is enjoying her story- she is laughing with Joanne* (Obs SV2, p. 4).

**Researcher Visit to Anna's 2008 Class:** Room 16, T. Primary School. Miss C's class. Participant observations of Maths & Power Walk in preparation for school marathon.

*Anna has opted to go with the runners [not walkers].... Ahead of me I can see Anna, moving as fast as she can. It is hot, sunny. As we go, other children comment about Anna "What's she doing?" "Why is Anna in the running group?" As we move around the course, Anna falls behind & is towards the back of the walkers.... Anna seems very much on her own- no one is making an effort to walk with her- her focus is on getting around the course. Other children are in groups of two or three. As we approach the final lap.... I notice another girl is walking beside Anna & they are chatting together (Obs SV3, pp. 3-4).*

#### **Alternative Interpretation**

The children were very aware of Anna's difference & seemed very inquisitive. However, their questions may reflect a genuine desire to know Anna if seen in the context of it being the start of a new school year. Many would not have worked with Anna before.

#### **Rehabilitation Reports & Education Plans**

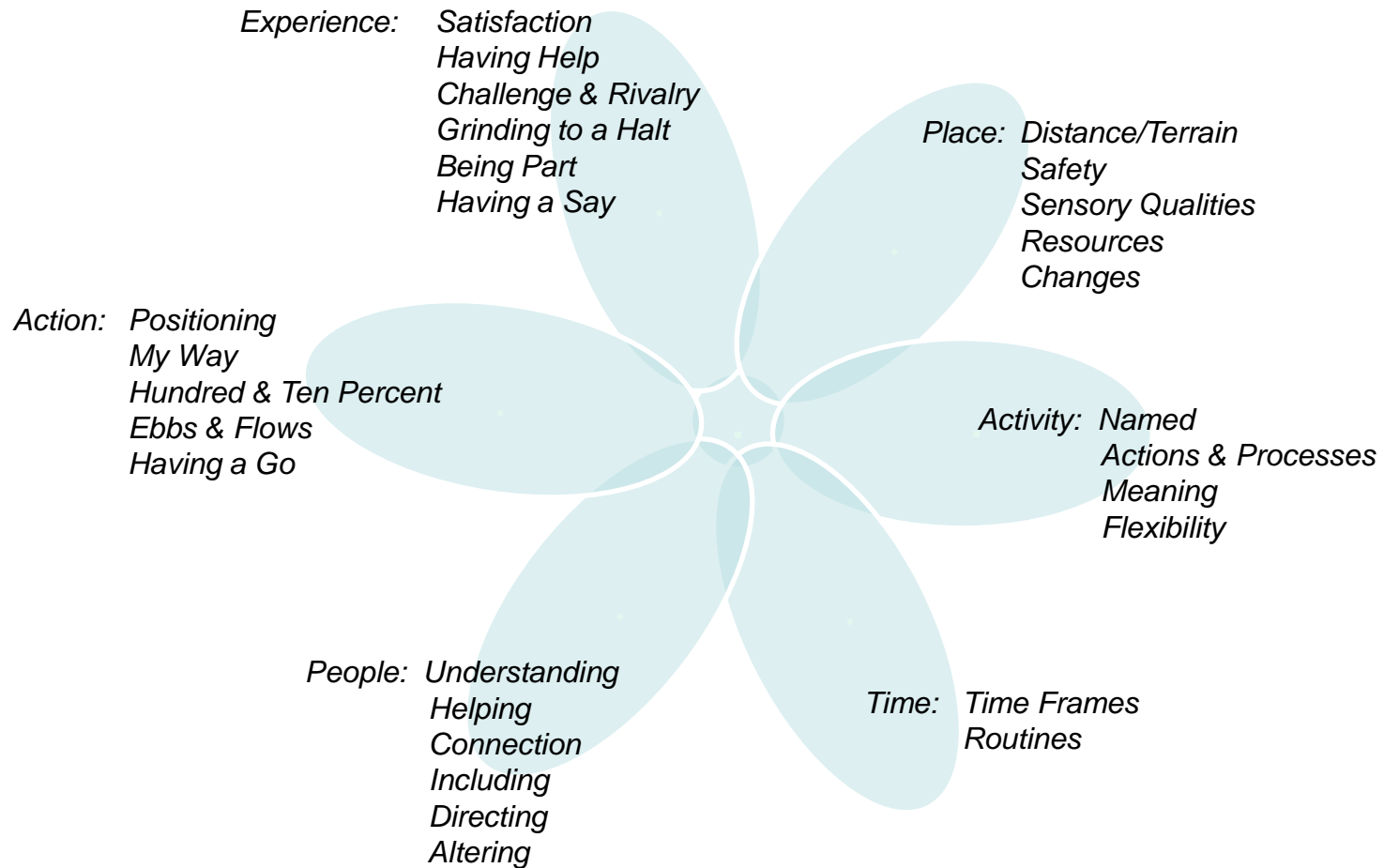
*Anna is beginning to be more aware of the differences between her & the other students at school. This is impacting on her wanting to increase her independence, & wanting less input from teacher aides & rehabilitation professionals. Jan reported she is concerned that if Anna's teacher aide hours decrease she will struggle more at school. (R – SRA, p.5).*

**SECTION TWO: FUNCTIONAL LIMITATIONS** [The] Speech Language Therapist reported that Anna's expressive language is at the level of a 6 ½ year old similar to her reading age. It was also reported that Anna has specific difficulty with word finding & planning of speech. Another area of concern is Ann's stammer which is being worked on with the Speech Language Therapist.... It was observed during the assessment that Anna had difficulty getting her message across or telling a story about what she had done at school that day (R - SRA, p. 6).

<b>Chores at Home</b>	Take wet swimming togs & towel from school bag, clear plates, homework – reading, spelling. Receives pocket money
<b>Leisure Occupations at Home</b>	PlayStation, drawing, watching TV, playing in room with dolls, teddies, making fairy soup with flowers, worm/bug hospital, sandpit – driving digger, building castles, makeup game, craft – Make it Groovy kit, Lego, building blocks, board games, reading – Dr Seuss & Geographic Magazines, trampoline, building huts in the bush, using CD player
<b>Family Occupations</b>	Gardening - planting seeds, feeding birds outside, caring for pets – cats, birds, fish, hedgehogs, cooking, shopping with mother, holiday in Australia with father, going to the movies, roller-blading, swimming at the beach, walks in the bush, accompanied by mother to occasional party with friends, going to McDonalds, self-care occupations – bathing, dressing, grooming
<b>Playground</b>	Tiggy, senior playground, chase, lunch, play with acorns
<b>Class Occupations</b>	Roll call, class news, reading with teacher aide, math, writing poetry, stories, publishing, spelling, science, art, inquiry-based learning, library, speeches, PE – jump-jam, cross country & training, swimming & sports, 2 ball soccer, golf, cricket, productions, standardized testing
<b>Extra-curricular Occupations</b>	Camp – flying fox, blindfold course, soccer, walking to & from school (previously rode special needs tricycle), self-check program after meals, swimming, riding for the disabled, school holiday program – includes arts & crafts, gardening, exploration
<b>Rehabilitation &amp; Assessment</b>	Training for Independent Rehabilitation program, Physiotherapy, Occupational Therapy, Speech Language Therapy, Stretching program, Neuropsychology assessment, Support Needs Assessment, Orthotics appointments, monthly hormone injections, Gait Laboratory assessment, Botox injection surgery, serial casting, Vision assessment & management
<b>Community Sports</b>	Swimming – Little Flippers

### Anna's Recent Occupations





### What was Important about Anna's Participation?

**Understanding:** people's awareness, expectations, & assumptions about Anna's needs, abilities, & preferences.

*"I think other parents are, um, find it a little bit difficult to have Anna because ... If they don't know her, they're not sure of her needs.... When I first met Anna I wasn't sure of her needs ... And until you get to know her"* (Joanne, TAI, p. 25).

*I ask her [a classmate] which is Anna's desk. She explains it is at the front because Anna has a di, dis, dis thing, & that the desk is positioned there for her to see easily & to help her hand"* (Obs SV1, p. 8).

*The kid's parents didn't include her ... And I kind of understand that they didn't know Anna's capabilities.... I guess these people sort of, the thought of having to change her or something like that. But she never needed it but no one ever came & asked* (Jan, MI, p. 15).

*There was an element of fear that whatever we did, we didn't want to hurt her. Like we had to get to understand that ... The leg splint, & all of the stretching had to be done correctly.... Also understanding what her capabilities were. I mean how did she get on in the swimming pool? How do we best cater for her?* (Leslie, SENCOI, p. 18).

**Helping:** Anna's mother, brother, after-school carer, & teacher aide helped her to participate in activities. Helping included preparation for activities, advocating, protecting, prompting, & physical assistance. Anna resented adult help, but struggled when help was reduced.

*"She needs a little bit of help with some of it [dressing] ... they buy her clothes that she can get on & off. But definitely her shoes ... Over the brace it's too tricky for her. So during swimming I have to dress her ,*

*help her with her brace.... By the time she gets changed ... she misses half the swimming lesson, so I take her a bit early & get her dressed & so she's all ready"* (Joanne, TAI, pp. 11-12).

**Connection:** Through taking part in activities with Anna, people formed a relationship with her & with each other. When Anna was away for medical interventions, her connections were interrupted. Jan's own ability to connect with other people at school & in the community was affected by employment demands.

*"We've got speech & language therapists that come by & occupational therapists that come by.... Generally they take her out & they have special things. Speech language therapist takes her out & does certain exercises & things with her"* (Miss J., TI, p. 4).

*"I don't think I've seen Jan since. I know she's really busy"* (Miss J., TI, p. 17).

*"He doesn't see her as disabled, he sees her as his pain in the arse sister.... The teacher decided they shouldn't be playing together, her & Ben. That they needed to be making their own friends.... I think that they are really close. And they do all the normal things, fight like cats & dogs "* (Jan, MI, p. 19).

*"She's had six speech language therapists in her time.... And she's had three physios.... There's an element of frustration around new faces. So, the team with myself & the teacher aides being consistent has been tremendously valuable, because had that changed as well ... that would be just awful"* (Leslie, SENCOI, p. 6).

## Important Aspects of Anna's Participation - People

**Including:** Using actions that treated Anna in a similar way to other people helped her to be included. Examples of including actions were greeting her, inviting her, rivalry, reciprocating, valuing her contribution, & sharing. Such actions were nurtured by the School Values, & were sometimes taught, & modeled for children. However there were multiple instances when Anna was treated differently, & was excluded.

*“Even the younger ones [children in the school playground] they get to know her name, & it’s ‘hi Anna, hi Anna’ & she goes ‘oh everyone knows me!’ Yeah she quite likes that”* (Joanne, TAI, p. 10).

*“Other kids [they] might say ‘you’ve got a dirty face’ to their peers but whether because Anna’s just a little bit different, they don’t say that to her, they just accept it.... I went in & it was a real mess & I said, ‘oh Anna, that’s not a good look. You ask Bridie if she thinks it’s a good look’ And Bridie said, ‘oh, not really’”* (Joanne, TAI, p. 10).

*“The pool party ... the kids just kept running away from her & she’d get close & they’d all scream & run away & that was cool the first few times. That she saw it as a game. But when it went on & on through the afternoon, they wouldn’t let her catch up or they none of them swapped to be the one they run away from.... Most of the other parents weren’t there, they all sort of left their kids & went. I stayed with Anna because of the pool.... Well had I not been there I would not have known that that was happening”* (Jan, MI, pp. 28-29).

*“I used to regularly, cry. Just, for the stuff I could see that she was missing out on ... Little comments that people would say & ‘um, oh no you can’t come you’ve got to look after Anna.’ ‘oh um Anna wouldn’t cope with that would she’.... It doesn’t change the fact that the hurt’s still there & the fact that you are being, excluded &, there’s not a lot that*

*you can do about it”* (Jan, MI, p. 17).

**Directing:** Adults required Anna to participate in certain activities. Many of these involved extra “work”.

*“Something I really think she needs to work on this year.... She hasn’t got a lot of confidence with using a computer & she needs a lot of practice this year”* (Joanne, TAI, pp. 18-19).

*“I was quite concerned at the amount of time she’d play in her room with just her little dollies, just sat on the floor by herself.... I call her out to do jobs ... Make her be a bit more interactive.... I’m not saying ‘set the table’ or things like that, but just ‘come on we’ll go & do a bit of gardening’”* (Jan, MI, pp. 21-22).

*“Stage 2 of the X [speech] program will be worked towards in order to encourage Anna to generalize the progress she has made during structured ‘treatment conversations’ during Stage 1”* (R - TIMP, p. 2).

**Altering:** People changed activities or time frames to enable Anna to participate. Not all were willing to alter things for Anna. Adequate time was sometimes required to make alterations.

*“She loved to be part of any whole class situation. So I kind of, came with that approach really ... rather than giving her something completely different, just adapt what we’re doing to suit her needs”* (Miss J., TI, p. 7).

*“They’re [others In class] so patient, if she’s a little bit slower, they wait for her, it’s really nice”* (Joanne, TAI, p. 10).

## Important Aspects of Anna’s Participation - People

**Positioning:** the physical position adopted by Anna relative to the activity & to others.

*“The bell goes- kids suddenly start coming in from the playground. Bags are being hung up, items are being put in desks, & children move up the front facing the teacher. Anna goes & sits on an adult-sized chair at the back of the class behind all the other children who sit on the floor.... I wonder why she has to sit on that chair- it singles her out as so different. However the other children don’t seem to be taking any notice. It is easier for her to see. Maybe it helps with her sitting posture” [Note: Anna later explained to me that this chair was used as a reward for good work]. (Obs SV3, pp.1-2).*

**My Way:** taking part in an activity in a unique or different way.

*“In her own way she does the cross country, in her own way she’s involved in every element of school” (Leslie, SENCOI, p. 12).*  
*“You know sitting on a mat & listening & taking on the instructions & then getting back to her desk & thinking ‘in my way I can do that’ & you know” (Leslie, SENCOI, p. 25).*

**Hundred & Ten Percent:** generating & sustaining effort to perform an activity.

*“Anna just gets in there & does her absolute, best” (Joanne, TAI, p. 10).*  
*“She’s, determined. You know when she sets her mind to something, she will achieve. Because ... she’s not a give up girl” (Leslie, SENCOI, MI, p. 24).*

*“Even though she’s you know obviously restricted & limited, she gives 110% ... She’s 110% active. It’s awesome” (Miss J., TI, p. 2).*

*“The fact that it’s going to be so much harder for her to do all the normal stuff, because only one hand works” (Jan, MI, p. 38).*

**Ebbs & Flows:** changeability in Anna’s performance of an activity.

*“She [Anna] can be a little bit short you know.... Not all the time but she can, she has her ebbs & flows” (Leslie, SENCOI, p. 22).*

*“Sometimes depending on what mood she’s in as to whether she’ll put her own toothpaste on” (Jan, MI, p. 4).*

*“Sometimes she needs a bit of....” “prompting? [researcher]” “yeah, hmmm. Or she does the old shrug, shrug the shoulders.... She does have tired days, days where she really doesn’t want to do too much” (Joanne, TAI, pp. 18-19).*

**Having a Go:** Changes in the environment provided opportunity for trying out an unfamiliar activity.

*“She gives things a go. Like if we do it for a fitness rotation, she’ll still give things a go, she knows her kind of limitations” (Miss J., TI, p. 6).*  
*When asked what activities she would do at the upcoming school camp, Anna responded “Playing on the beach. Um, um, blindfold like a confidence course, rock climbing & stuff”. “Are you going to do those things? [researcher]” “Yeah.... Yes & a flying fox.... Last year I done like everything, I done like everything a go” (Anna, CI, p. 18).*

## Important Aspects of Anna’s Participation - Action

**Satisfaction:** Anna's satisfaction with her participation in an activity reflected her comfort, enjoyment, & sometimes her achievement. Activities that emphasized difference or took her away from others created dissatisfaction.

*"I love play cricket & swimming [Anna]." "She's a good bowler [Jan]" (Obs HV, p. 65).*

*"Anna chats with me.... Yesterday she played golf. It was a bit tricky for her to hold & use the golf-club, but she enjoyed it anyway. She says she hit a big ball, & it was easy. 'My one was bouncy. Everyone got a turn'" (Obs SV2, p. 5).*

*Anna puts a lot of effort into her school work & any thing [sic] else she attempts to complete. This can sometimes lead to frustration at not getting the desired result" (R - SRA, p. 5).*

*"She [SENCO] always gives me certificates.... I got nine of them on the fridge there. Because like I like got like heaps like five. And um like five in Term One.... And I'm trying get another one to get um to get 400 books or something else" (Anna, ChI, p. 31).*

**Having Help:** Anna's responses to being helped with an activity. People discovered that Anna preferred not to have help, but she realized help was necessary.

*I helped Anna with making a poster about her participation. "Can I snip a hole or do you want to have a go at sorting that? [researcher]" "I'll sort it out.... And, & if, & if you tell me like a million times I'll lose my concentration" (Anna, ChI, pp. 26-27).*

*"She does still need a lot of, you know one-to-one help. And, at times*

*she would rather not let, you know. I do think she still, likes her space and notices that she's different when she has that teacher-aide support, but it is necessary" (Miss J., TI, p. 9).*

*One child asks Anna for help. Anna is setting an example getting on with her work.... The others are working more together, looking at others' answers. Others continue to ask each other for help, help one another. One looks at Anna's work- seems to be helping her.... Anna has completed a very small amount of work. One answer does not seem correct. The children are struggling with this task [math worksheet]. The instructions are very small, & not written out clearly, not broken down (Obs SV3, pp. 7-8).*

**Challenge & Rivalry:** Anna's feelings about the extent to which her skills were tested or used in competition against others.

*"We had a big fight like. Rita & Josh have got a digger. And like normally it digs up like the whole sand pit.... Ben always want to dig up the whole sand pit (Anna, ChI, p. 11).*

*"She's been amazing to have in the class actually. She's taught me & the rest of the kids a lot about resilience & just getting on with the job & giving things a go & there she is with her needs & yet she, rises to the challenge continually & it's just awesome" (Miss J., TI, p. 10).*

*"Her attitude prevents anything from being too difficult because she's got such a um, an 'I can' attitude" (Miss J., TI, p. 19).*

## Important Aspects of Anna's Participation - Experience

**Grinding to a Halt:** Participation in activities involved extra effort for Anna & made her tired further limiting participation.

*“When she gets tired like this evening she started sort of moaning cause she’s like ‘oh today was bad’ &, but it’s only because she’s tired. Like when she gets home from school she’s still got a bit of oomph in her & she tells you about the good stuff, so.... Yeah it does look different when you’re worn out.... she grinds to a halt pretty quickly”* (Jan, MI, p. 1).

**Being Part:** feeling a part of an activity in which others were sharing, rather than feeling apart. Anna’s need to focus her attention on the activity, as well as her communication difficulties meant that she tended to be part in parallel as opposed to interacting.

*“The only thing I really take her out for is exercises. Yeah, stretching exercises.... She doesn’t like being taken out, you know. And she hates doing it.... She’s not very cooperative”* (Joanne, TAI, p. 4).  
*We did a music ... activity that she was involved with and then we presented a music festival as part of a community thing, she was involved in that.... We have done like an assembly for the school & she’s been part, she’s just a part of everything ... she’s insists on being part of it, she’s just as mainstream as. You know she really want to be as mainstream as possible”* (Miss J., TI, pp. 5-6).

*Nice to see Anna being involved with the group, although the group members tend to work individually rather than collaboratively. There is some quiet talking, but I feel they assume they really should be working individually, so this is at a whisper.... The children are reaching across each other for crayons, & around Anna* (Obs SV3, p. 7).

**Having a Say:** expressing preferences about participation in shared activities. Although Anna had communication difficulties, she could be quite outspoken. For many activities, it was not possible for Anna to have a say, although the SENCO supported her in this.

*She’s old enough to talk to us & tell us exactly what she does. Oh yes, she comes & sees me, hmmm. ‘Excuse me Mrs. Y. if it’s all the same with you, I am so sick & tired of going out in to the Lions Den. Why can’t I have my support, in the back room, of Room 14’. ‘Right Anna’. It’s fantastic. And then she had a go at me once because we were doing something & she missed a swimming lesson & that was really in my face. Um, & that was just bad management on timetabling, but man, she makes it quite known* (Leslie, SENCOI, pp. 21-22).

## Important Aspects of Anna’s Participation - Experience



**Distance/Terrain:** Longer distances & rugged terrain hampered Anna's participation.

*"[Anna's older siblings] wanted to go & play in the bush, it's absolutely fine, they're not going to trip over a tree &, end up flat on their face. Um, I can guarantee Anna wouldn't even get in to the bush before she fell over. You know she'd only have to pass, start getting in to a little bit of rough & that would be her gone over. Um & sometimes when she falls over & gets her one good arm trapped under her, she can't get up"* (Jan, MI, pp. 15-16).

**Safety:** Jan was concerned for Anna's safety due to her mobility difficulties. Rehabilitation reports focused on physical hazards in Anna's home environment only.

*Sometimes she falls. Especially if children are, pushing a little bit or, you know which doesn't happen very often & it's not intentional but you know how they're all rushing out of the door.... But she's pretty tough, she gets up & dusts herself down & moves on!!* (Joanne, TAI, p. 23).

*I make her aware of what's there [in an environment] ... Um the last party we went to was Guy Fawkes, & there were a couple of dogs running around. Well one of them jumped straight up on Anna & she just went straight over backwards, yeah she just doesn't have the balance to, she didn't even bend in the middle it was like neeeowwww. Yeah & she got a bang on the back of her head & was pretty upset & the owner came out & tied the dog up then* (Jan, MI, p. 16).

*"Comment on any potential hazards in the home environment that could cause further injury to the claimant" [report framework].... "Anna has had a slip getting in & out of the bath. Since the incident Jan has installed a rail that sits on the edge of the bath. The current rail being used is not secure & if used incorrectly could lead to a further slip or trip"* (R - SRA, p. 4).

**Sensory Qualities:** the amount of stimulation provided by an environment. Environments that were loud or busy were stressful for Anna.

*I asked Anna what was special about her new teacher. "She, because she's so much quieter. She used to like quiet spots. And like the other teacher move around, she would like appear a bit loud. And she said 'quiet, quiet, quiet', & when it's like really noisy, she, she said, 'quiet', & she would go like that ... Then we like all noisy again.... I got like, um, much more quieter class this year. Instead of a big loud class"* (Anna, ChI, p. 13).

*"She can't stand a huge amount of movement & the bustle of you know a really busy class. She would much rather be in a calm slot"* (Leslie, SENCOI, p. 8).

*Speaking of Mary, Anna's after-school carer, Jan said "She's patient, she's quiet & gentle....They put this other woman in [Anna] couldn't cope with her ... she only did half a day"* (Jan, MI, p. 7).

## Important Aspects of Anna's Participation – Place

**Resources:** The features of an environment which supported & created opportunities for participation.

*“Trying to find clothes & things that she can manage & fit ... There’s hardly any shorts in her size now, that are made with elastic waists so she can just pull them up & down with one hand. They’ve all got domes & velcro.... Yeah, it’s about coping in a world that’s not, set up for her”* (Jan, MI, pp. 37-38).

*“She did one [school project] on posting letters so we went up to the post office & got a few pamphlets.... I think it does you good to realize that there’s other places to get information from, not just at the computer”* (Jan, MI, pp. 37-38).

*“We plant our sunflowers on the outside of the fence cause we haven’t really got room on the inside. About three or four years ago, X [a real estate business] did a promotion &.... gave everyone a packet of seeds.... People know that I plant them.... I get extra packets put in the letter box ”* (Obs HV, pp. 1-8).

**Changes:** variations in the environment. When things were familiar, they facilitated Anna’s participation. Conversely, lack of variety in activities caused Anna to complain of being bored.

*“They sort of put it on us that morning [going for the unfamiliar bush walk on camp]. That we don’t think Anna will be able to do this.... And without seeing the track or knowing what I was in for, I was forced to make that call [not to participate]”* (Jan, MI, p. 37).

*Anna’s going to have such a big thing next year [change of school]. The [rehabilitation] team will ... stay on.... Her teachers will be all new & her teacher aide will be completely different.... But then Joanne will be going from October onwards just to do the walk over & to see. We do it really early, & we do it with fun. Anna will take friends with her”* (Leslie, SENCOI, pp. 25-26).

*“I’m gonna be a whole lotta I’m bored I’m bored I’m bored”* [Anna] (Obs HV, p. 49).

## Important Aspects of Anna’s Participation – Place



**Named:** Names given to activities were not necessarily recognizable to someone who had not taken part in them, or observed the activity. Anna particularly enjoyed physical activities, but had less participation in these outside of school. A large part of her participation was in rehabilitation & assessment activities.

*“Dad & Ben & my cousin Bevan, we made up a new game ... a rugby game in the water ... In the pool, & ... you have a touch down line in the sand.... And like instead of running you float. And, & & like um, like & you don’t use your arms at all. You, you hold the ball with your um with your hands. And like, & like kick. And put it over the line”* (Anna, Chl, pp. 24-25).

*“She likes playing with her bugs & stuff” [Jan]. “What’s this bugs thing?” [researcher] “Oh she’ll go & find some slaters & make a concoction of mud & a little house for them” [Jan].... “When I grow up I’m going to be a bug doctor.... I’m going to fix bugs.... Cause some bugs are sick” [Anna] (Obs, HV, pp. 63-64).*

**Actions & Processes:** the things that were involved in an occupation. When the actions & processes were difficult, Anna’s participation was hindered. She found it hard to carry out the activity & simultaneously move around and/or interact with the other children.

*They are making individual pirate collages out of cut-up fabric scraps & textured /colored materials ... Anna is fully focused on the activity & on her interactions with her teacher aide. Other children manage to work at the activity while they chat with their neighbors & move around the room, but Anna is not chatting with the other children.... She is*

*absorbed in what she is doing & does not get up & move around like the other children* (Obs SV1, pp. 4-5).

**Meaning:** Activities gained their meaning through past experiences, challenge, learning & achievement, what they symbolised, & through the people involved.

*“The blind fold course [at camp] was cool. You have like follow a thing & you have a partner & you, have the same route, & like, roots step down, & then the people always step down ... Then the partner has to um, hold on to the rope.... And like the other group are going up. You’re going, have to take giant step”.... “So did you help somebody who was blind-folded?” [researcher] ... “Yeah, yep.... I look after them”.... “Who did you go with?” “Mrs. L. [teacher aide]. (Anna, Chl, p. 19).*

*“Anna came home, with this um, present, & it was all carefully wrapped up in a tissue, & I says, ‘What have you got Anna?’ & she says ‘Something really, really special’. She unwrapped this tissue & here’s this great lump of rock.... And she said yeah, um, ‘T. [new friend] & I were playing with this rock & we put it up really high & it, & dropped down on the ground & it broke in half so I’ve got one half & T.’s got the other half’ ... That was so cool because that was normality”* (Jan, MI, p. 19).

#### **Alternative Interpretation**

Unique activities. Many of Anna’s activities & friends were unique to her and her family. They held meaning that would not be recognized by others

### **Important Aspects of Anna’s Participation – Activity**

**Flexibility:** How readily aspects of an activity could be changed to facilitate participation. When an activity could not be changed, more help was needed, Anna's achievement was lessened, & her participation was hindered.

*"For art they've been doing, making fish ... Out of wire. Well of course you know, there's no way she could bend the wire, she couldn't cut the wire, it was all too tricky with one hand, it's hard with two hands actually! And so she really needed my help for that"* (Joanne, TAI, p. 9).

*"Have you found that there are some things that it's really difficult for her to be part of with the rest of the class? [researcher] "* *"Standardized testing. Where you can't have, really you can't have teacher aide support. We've done things like Astel testing. We've adapted them to, there's a test that you can have below level two, but those kind of things definitely need to be considered because without help, it's really, she's sinking you know & it's not good for her self esteem"* (Miss J., TI, p. 9).

*"I'm very flexible & they [therapists] will, just doesn't really matter what we're doing, kind of just come in & fit in with us.... She absolutely hated being taken out of math time.... So they've changed their time to suit with, her"* (Miss J., TI, p. 5).

### Important Aspects of Anna's Participation – Activity

**Time Frames:** the time when an activity was scheduled, and/or the duration of the activity. Activities that were long or which had an afternoon time frame posed more of a barrier to Anna as she tired. Activities that had a particularly short time frame were also problematic because Anna took longer to perform tasks. Jan also reported difficulties with time frames, finding it hard to participate in Anna's before & after school routine which didn't fit well with her own work routine.

*"I want to play soccer.... And they don't let me because ... Ben always take out like with um, sporting times. Because his practice is on um, his practice is on, Wednesday. Um & if I play soccer, I'll be on Wednesday." "So you can't both go?" [Researcher] "No" (Anna, CI, p. 8).*

*"She gets very exhausted by the end of the day, & you could see her just drifting off" (Miss J., TI, p. 9).*

*"After lunch, the children have to put their things away, put on their hats & go outside. Anna rushes as fast as she can, but is the last to finish. She drops something, struggles to get her hat on. Her gait is jerky. She lurches down the steps, then back up to check on the adjacent classroom. Eventually T. [new friend] comes out & runs off. I see them both running across the field. Anna is behind" (Obs SV2, pp. 10-11).*

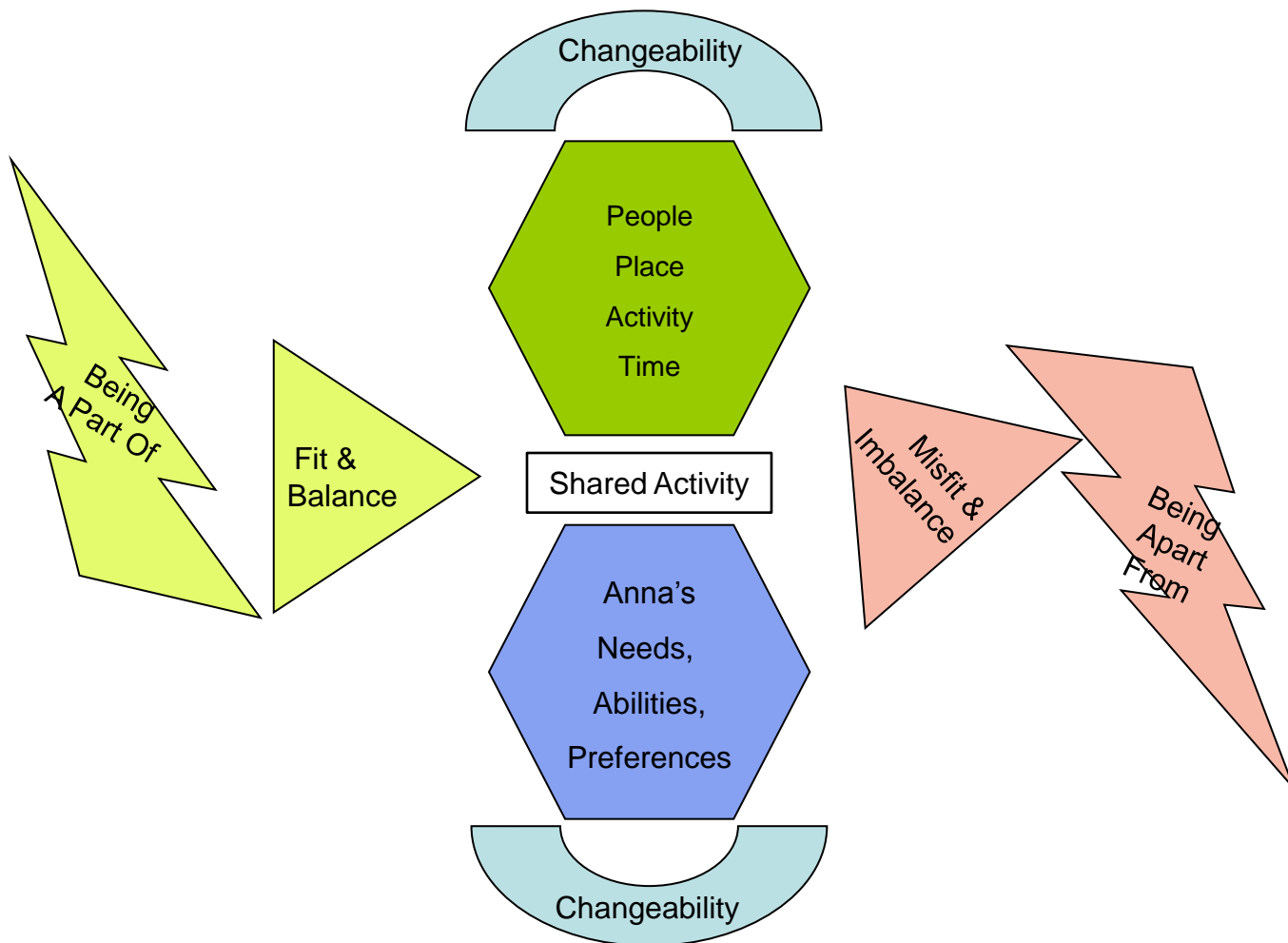
**Routines:** the way activities were patterned across days & weeks. Routines helped Anna understand activities. However very busy routines overwhelmed her. Anna's routines included rehabilitation activities.

*"I can say 'Anna' & she'll say 'I was just doing it Mum....' It's our family, the way it works, our routine ... And I'll say, I might you know Smudge will be under my feet & Anna will be standing there talking to me & I'll say 'oh can someone please ...' & she'll say 'do you want Smudge's bowl?'" (Jan, MI, p. 17).*

*"One lady was so enthusiastic, she absolutely exhausted Anna, she really did.... This lady would go home & think of ten activities to do for the next day ... She made um, fairy skirts for her & ribbons & really, really put the effort in.... But it was just too much ... Maybe, to a child with ADHD it's alright to put ten different things in, in a couple of hours in a day but to someone who really just needed that, gentleness & quietness ..." (Jan, MI p. 13).*

*Anna has been assessed over a series of sessions, both in class & on her own.... Anna's upper limb stretching program has been integrated into her activities of daily living such as dressing, swimming, & classroom paper-based activities.... Anna's lower limb stretching program has also been integrated into her activities of daily living.... Anna has attended school-based therapy appointments with her teacher aide. Further input is needed at home ... It is recommended that further 1:1 therapy is provided by an SLT targeting these areas of phonological awareness, word finding skills (expressive language) & fluency (R - TIPCR, pp. 2-3).*

### Important Aspects of Anna's Participation - Time



### Overall Characterization of Anna's Participation

**Misfits:** Anna's participation was restricted when there was a misfit between people's understandings & actions and her actual needs, abilities & preferences, (e.g. where people's actions were exclusive rather than inclusive, she was treated differently). Her participation was also restricted when there was a misfit between temporal aspects of an activity, such as time frames that were too short, or too late, or routines that were overly busy and her actual needs & preferences. Misfits were sometimes present in relation to place, such as overly challenging terrain, or inappropriate resources. Further misfits occurred when the activity was not understood by Anna as being meaningful, or the actions & processes were beyond her actual abilities.

Misfits meant that Anna's peers & others in the community **Shared Activities** infrequently with her. Their understandings & actions did not **Change**, & misfit was perpetuated. Despite a preference to be involved with her peers, Anna was often **Apart** from them.

**Imbalances:** Relative to her peers, & contrary to her own preferences, there were imbalances in the amounts of time Anna spent with others, in particular places, & in particular activities.

Due to misfits, participation in Shared Activities such as netball, classroom reading, classroom & playground games, class tramps, soccer, & out-of school social events & play was often restricted. This caused **Imbalances** in the amount of time spent with peers & people in the community, relative to time spent with family, or in occupations at home, with toys, insects & pets.

People responded to a misfit of place or activity by providing adult help

for Anna, or by directing her participation in rehabilitation "work". This arguably changed her ability to achieve the activity, but did not **Change** the imbalances in the amount of time she spent with adults rather than peers. Adult help & rehabilitation "work" also had the unintended effect of treating her differently rather than the same as her peers, reinforcing others' understandings as to her special needs, & reinforcing the misfit. Extra "work" in rehabilitation activities conceivably added extra activities to her routines, exacerbating the misfit with her energy levels & fatigue.

**Qualifying the Problematic Situation**  
**Being Apart From: Misfits and Imbalances: Lack of Shared Activity, Lack of Change**

*"She got up in the morning & she got breakfast [on a camp] & got her stuff & got her bag ready to go & they says 'we think the walk will be too far for you Anna.' And with that she burst in to tears. And I says 'well how far is it?' & they sort of says 'oh, it's a couple of k's' & they says 'but it's really, really steep in places, you know she won't be able to get up & down & we'll walk through streams & things like that & her brace &.' I really wish now we had just done it. Like bugger them. If I had to piggy back her I had to piggy-back her. But she stood there & burst into tears & I sort of thought 'oh well, they're saying we can't do it Anna.' You know it's like they all walked off & left us there.... But I hadn't even done the walk before. I didn't know what it consisted of.... Everyone was sort of back within an hour & a half. I was sort of like, well would it ... have mattered if we were half an hour late plodding along at the end? But they said 'oh they want to keep all the kids together'. So. But I'm, sure Anna, would have kept up, just from the excitement of being able to do it.... I think it is important for her to feel like she can do everything that they can do.... I think that was just, they were in a hurry. They wanted to get the walk over & done with" (Jan, MI, pp. 30-32).*

*"The whole time I've been working with Anna ... she's only had a handful of times when she's been to other people's ah children's places" (Joanne, TAI, p. 24).*

*She has possibly up to three visitors [at school] a week.... I mean B.V. [rehabilitation team] head injury people, they would visit, it's fantastic but there's three people there, there's Anna's speech language therapist, her physiotherapist & her occupational therapy are all done on school site now. Anna's not, unlike before, taken out to J.'s physio, where she used to be taken outside of school hours sometimes but you know it was always done at that site. So needs-wise she works with all If those, possibly once a week. Then there's Joanne K [teacher aide] that works with her, you know 12-15 hours per week. Then Anna was also ... going to riding for disabled, historically. Then Anna needs her stretching.... She's got the greatest need so much as understanding all the people that work with her. It's a huge amount of disruption to her day um, & the balance for that is really important, & sometimes Anna gets, really annoyed. She just wants to be left alone (Leslie, SENCOI, pp. 8-9).*

### Qualifying the Problematic Situation Being Apart From: Misfits and Imbalances

**Shared Activity:** it took people time to understand Anna's perspectives, needs, & abilities when they were not familiar with her. People came to understand better through **Sharing Activities** with her. This provided opportunities for questioning, explanation, observation, & experience. As people's understandings & actions **Changed**, there was a better **Fit** with Anna's needs, abilities & preferences. Sharing increased activity with peers better **Balanced** the amount of activity shared with adults.

**Changeability:** the degree of change that could occur in people, & in aspects of place, activity, & time. Where change occurred suddenly, shared occupation gradually supported Anna to **Fit** in again. The Balance of activities spent with peers began to change for the better. However, people were more or less willing & able to change their actions to be inclusive & to alter place, activities, & time for Anna. Alterations were also affected by the degree to which activities, place & time could be **Changed** (e.g. when people's routines were less busy change was easier). Anna's own abilities were also changeable. Whilst change was less evident in terms of her physical or cognitive abilities, gradual change had occurred in her ability to participate in activities with familiar people.

*"Yeah she just loves being in there & doing it. Anna doesn't fit in to either category. Anna's not a disabled child & Anna's not a normal child.... There's not quick fix with Anna. But it's in a sense like that she's very slow. But in the other sense, that she gets what those kids are doing. You know & she's right on to it & she's excited & it's funny.... I mean she's right up there with them. She's being part of it" (Jan, MI, pp. 35-36).*

*"With Anna, especially when she's trying to say something that's important with her, you just have to be patient &, & give her that time. Which in a classroom situation is really hard when you're trying to move things along & keep things flowing. And I find here, when I'm busy and trying to get the dinner going & seeing who's got togs & towels out of their bags & stuff like that, I'm really pushed to stop & concentrate & listen" (Jan, MI, pp. 36-37).*

*I came with that approach really, where possible, rather than giving her something completely different, just adapt what we're doing to suit her needs (p. 7).... With teacher aide help, I can incorporate her [Anna] into a group activity. A streamed group activity, she can be with my, slower learners.... They're still slightly above her but with teacher aide support she gets that group interaction, whereas ... I would be creating a whole new set of activities.... at an even lower level.... She doesn't like being individualised & here's this group, this group, this group & here's yours Anna. If I can incorporate with that, with groups, she feels so much more part of the unit. (Miss J., TI, pp. 13-14)*

## Developing Solutions: "Being a Part of" Through Shared Activity and Changeability