

Appendix A

First draft of questionnaire used in Pilot study 2: (A:1)

Interim questionnaire modified as a result of Pilot study 2 and 3: (A:2)

Occupational Performance Questionnaire (OPQ): (A:3)

WILEY

A:1 First draft of questionnaire used in Pilot study 2

Pilot study in order to evaluate the Effect of Sensory Integration Therapy on the Families of children with Autistic Spectrum disorders

Kindly complete this questionnaire to the best of your ability, particularly noting changes that have been observed since your child started O.T/ S.I. Therapy.

1. SLEEPING PATTERNS	YES	NO	N/A Why?
1.1 Does your child have a sleeping problem ?			
Describe, including number of night time wakings, and what it took to get him/her back to sleep			
1.2 As a result do other family members have regular incidents of interrupted sleep? Who and how often?			
1.3 Does he/she currently sleep through the night?			
1.4 How does this impact on family harmony? Any comments			

2. TOILET TRAINING	YES	NO	N/A Why
2.1 Is your child in a nappy ?			
2.2 Is he/she currently dry in the day?			
2.3 Is he/she currently dry at night?			
2.4 Can your child inform you that he needs to use the toilet? How?			
2.5 Does toilet training impact on the family members			

3. SOCIAL FUNCTIONS AND FAMILY GATHERINGS	YES	NO	N/A Why ?
3.1 Are you currently able to take your child with you to family gatherings?			
3.2 Are you able to take your child to birthday parties?			
3.3 Do you take your child to eat at restaurants?			
3.4 Do his/her siblings regularly have friends to play at home?			
3.5 Have you always been able to include your child in social events ?			
3.6 If not, were the rest of the family also limited in their social interactions? How?			

4. FAMILY STRESS	YES	NO	N/A Why
4.1 Did having a child with an ASD result in stress on any of the family members? Mother? Father? Siblings? What direct consequences were there for any family member?			
4.3 Does your child exhibit aggressive behaviour? Towards himself? Directed at others? Biting? Pinching? Hitting?			
4.4 Does your child experience a low frustration tolerance? How was this expressed?			
4.6 Does your child use "stimming" to deal with sensory overload? Hand flapping? Visual fixing? Masturbation?			
4.7 Are transitions between activities and environments stressful for the family? Give examples			
4.8 Is there much yelling and screaming by other family members?			
4.9 Is your child dependent on his/her parents and/or clingy?			

5. FREE TIME / PLAYTIME	YES	NO	N/A Comments
5.1 Is your child destructive towards toys/other objects? Describe			
5.2 Can your child play independently? For how long?			
5.3 Does the family socialize with family friends?			
5.4 Has the family managed to sustain relationships with other families during this period?			
5.5 Is your child able to make friends?			
5.6 Does your child attend a school?			

Thank you for your Co-operation
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Kerry Wallace and Charlene Scheepers

A:3 Interim questionnaire modified as a result of Pilot study 2 and 3

Questionnaire

A study to evaluate the Effect of Sensory Integration Therapy on the Families of children with Autistic Spectrum disorders

Kindly complete this questionnaire to the best of your ability, particularly noting changes that have been observed since your child started O.T/ S.I. Therapy.

PART 1. GENERAL INFORMATION

1. Questionnaire No.				
2. Has your child ever had Occupational Therapy?	YES		NO	
3. Was the Occupational Therapist trained in Sensory Integration therapy?	YES		NO	
4. Age when child started O.T.	Years		Months	
5. Duration of O.T. in months	Years		Months	
6. Did your child have Sensory Integration Therapy ?	YES		NO	
7. Indicate the frequency of O.T. per week with an X?	30 mins	45 mins	60 mins	MORE
8. Indicate your child's diagnosis with a X	Autistic disorder		Aspergers syndrome	
9. Is your child currently on any prescribed medication ?	YES		NO	
10. If yes -Specify which medication ? Or other medication that is not prescribed				
11. Did he/she have concurrent interventions ?	Speech Therapy		Physiotherapy	
	Applied behaviour analysis (ABA)		Other? Specify	
12. How old was your child when he/she slept through the night ?	Years		Months	
13. How old was your child when he/she was toilet trained in the day?	Years		Months	
14. How old was your child when he no longer needed to wear a nappy at night?	Years		Months	
15. At what age did your child stop having tantrums?	Years		Months	

PART 2: OCCUPATIONAL PERFORMANCE AREAS – BEFORE OCCUPATIONAL THERAPY											
BIOLOGICAL RHYTHMS											
1	SLEEPING										
1.1	Did your child have a sleeping problem before he/she had O.T?	YES		NO		Comments					
1.2	How many number times per night did he/she wake?	Almost never		1-2		3- 4		5 - 6		more	
1.3	What did it take to get him/her back to sleep?	Rocking		Humming		Singing		Feeding		Holding	
		YES	NO	YES	NO	YES	NO	YES	NO	YES	NO
1.4	As a result did other family members have regular incidents of interrupted sleep?	YES		NO		Specify					
1.5	Did your child's sleeping difficulty impact on family harmony?	YES		NO		Specify					
2	TOILET TRAINING										
2.1	Was your child in a day nappy when he/she started O.T?	YES		NO		OCCASIONALLY Specify					
2.2	Was your child still in a nappy at night when he/she started O.T.?	YES		NO		N/A					
2.3	Were there incidents of bedwetting?	YES		NO		N/A					
2.3.1	How often did accidents occur?	Never		Infrequently		Once a week		Once a month		More	
3	FEEDING										
3.1	Were there feeding issues when your child started O.T.?	YES		NO		Comments					
3.1.1	Was the variety of food tastes limited?	YES		NO		Specify					
3.1.2	Was the variety of food textures limited?	YES		NO		Specify					

3.1.3	Did this cause disruption in family routine?	YES	NO	Specify	
3.2	Were there difficulties with chewing?	YES	NO	Specify	
3.2.1	Were there difficulties with sucking ?	YES	NO	Specify	
3.2.2	Were there difficulties with swallowing ?	YES	NO	Specify	
3.2.3	Did your child used to gag?	YES	NO	Specify	
3.3	Was your child's limited attention span an issue at meal times?	YES	NO	Specify	
3.3.1	Did this limit the quantity of solid food ingested?	YES	NO	Specify	
3.3.2	For how long could your child sit at meals?	1-2 minutes	3-5 minutes	6-10 minutes	longer
3.3.3	Did this cause parents frustration / distress?	YES	NO	Comments	
3.3.4	Did it impact on family harmony at mealtimes?	YES	NO	Comments	
	FAMILY ADJUSTMENT				
4.	SOCIAL FUNCTIONS AND FAMILY GATHERINGS				
4.1	Were you able to take your child to family gatherings?	YES	NO	Comments	
4.2	Were you able to take your child to birthday parties?	YES	NO	Comments	
4.3	Were you able to take your child to eat at restaurants?	YES	NO	Comments	
4.4	Were his/her siblings able to have friends to play?	YES	NO	Comments	

4.5	Was the family able to sustain relationships with other families during the period prior to starting O.T.?	YES	NO	Comments							
5.	IMPACT ON INDIVIDUAL FAMILY MEMBERS										
5.1	Did having a child with an ASD result in distress in any of the family members	YES	NO	Comments							
5.1.1	Mother?	YES	NO	Comments							
5.1.2	Father?	YES	NO	Comments							
5.1.3	Siblings?	YES	NO	Comments							
5.2	Record direct consequences for any family member with an X?	Delegation of care ?		Withdrawal of one parent?		Depression		Parental separation / Divorce?		Other ?	
		YES	NO	YES	NO	YES	NO	YES	NO	YES	NO
5.3	Were you able to continue your career before your child started O.T. ?	YES	NO	Comments							
5.4	Were you able to pursue your own interests prior to your child starting O.T.?	YES	NO	Comments							
6.	SOCIAL INTERACTION										
6.1	Did your child exhibit aggressive behaviour prior to starting O.T.?	YES	NO	Comments							
6.1.1	Directed towards himself ?	YES	NO	Comments							
6.1.2	Directed at others?	YES	NO	Comments							
6.1.3	Detail using an X	Biting?		Pinching?		Hitting?		Other ?			
		YES	NO	YES	NO	YES	NO	YES	NO	YES	NO
6.2	Did your child exhibit tantrums?	YES	NO	Comments							
6.2.1	Did this cause distress to other family members?	YES	NO	Comments							

6.3	Did your child use “self stimulatory behaviour “ (stimming) to deal with sensory overload?	YES	NO	Comments							
6.3.1	Did “stimming” behaviour in public cause distress to other members of the family?	YES	NO	Comments							
6.3.2	Record with a X	Hand flapping?		Rocking ?		Masturbation?		Head banging?		Jumping?	
		YES	NO	YES	NO	YES	NO	YES	NO	YES	NO
		Smelling, sniffing ?		Breath holding, Humming?		Biting, mouthing? Sub-vocalising?		Visual fixing? Spinning objects?		Teeth grinding?	
		YES	NO	YES	NO	YES	NO	YES	NO	YES	NO
6.4	Did your child struggle to cope with transitions between activities?	YES	NO								
6.4.1	Was this distressing?	YES	NO	Comments							
6.5	Prior to starting O.T. was your child over-dependent on his/her parents or clingy?	YES	NO	Comments							
6.5.1	Was this distressing?	YES	NO	Comments							
6.6	Prior to starting O.T. was yelling and screaming by other family members a common occurrence?	YES	NO	Comments							
6.6.1	Was this distressing?	YES	NO	Comments							
6.7	Was your child able to communicate his/her needs prior to starting O.T.?	YES	NO	Comments							

6.7.1	Record with an X	Talking		Signing		Sounds		Pointing		Crying / Screaming	
		YES	NO	YES	NO	YES	NO	YES	NO	YES	NO
PLAY SKILLS / PEER INTERACTION											
7.	FREE TIME / PLAY TIME										
7.1	Was your child destructive towards toys prior to starting O.T ?	YES		NO		Comments					
7.2	Was your child able to play by him / herself prior to starting O.T? (excl. watching T.V.)	YES		NO		Comments					
7.2.1	For how long?	1 – 2 mins		2 – 5 mins		5 – 10 mins		10 – 30 mins		More ?	
7.3	Could your child play alongside another child prior to starting O.T.?	YES		NO		Comments					
7.4	Was your child able to make friends prior to starting O.T.	YES		NO		Comments					
7.5	Was your child able to participate in structured group play prior to starting O.T.?	YES		NO		Comments					
7.6	Was your child able to play in familiar settings prior to starting O.T.?	YES		NO		Comments					
7.7	Was your child able to play in unfamiliar settings prior to starting O.T.?	YES		NO		Comments					
8	SCHOOLING										
8.1	Was your child home-schooled prior to starting O.T.?			Was your child at a pre-school for children with special needs prior to starting O.T.?				Was your child able to attend a regular pre-school prior to starting O.T ?			
	YES	NO		YES		NO		YES		NO	

PART 3 : OCCUPATIONAL PERFORMANCE AREAS - AFTER OCCUPATIONAL THERAPY

BIOLOGICAL RHYTHMS

1	SLEEPING										
1.1	Does your child still have a sleeping problem?	YES		NO		N/A					
1.2	How many times per night does he/she now wake?	Almost never		1-2		3-4		5-6		more	
1.3	What does it take to get him/her back to sleep?	Rocking		Humming		Singing		Feeding		Holding	
		YES	NO	YES	NO	YES	NO	YES	NO	YES	NO
1.4	Do family members still have interrupted sleep ?	YES		NO		Specify					
1.5	Does your child's sleeping difficulty still impact on family harmony?	YES		NO		N/A					
2	TOILET TRAINING										
2.1	Is your child still in a nappy in the day ?	YES		NO		OCCASSIONALLY					
2.2	Is your child still in a nappy at night ?	YES		NO		N/A					
2.3	Are there still incidents of bedwetting?	YES		NO		Comments					
2.3.1	How often do these accidents occur?	Never		Infrequently		Once a week		Once a month		More	
3	FEEDING										
3.1	Does your child still have feeding issues?	YES		NO		Comments					
3.1.1	Is the variety of food tastes he tolerates still limited?	YES		NO		Specify					
3.1.2	Is the variety of food textures that he tolerates still limited?	YES		NO		Specify					
3.1.3	Is there still a disruption in the family routine as a result of atypical eating patterns?	YES		NO		N/A					

3.2	Does your child still struggle to chew a variety of foods?	YES	NO	Specify	
3.2.1	Does your child still struggle to suck through a straw?	YES	NO	Specify	
3.2.2	Does your child still struggle to swallow a variety of foods ?	YES	NO	Specify	
3.2.3	Does your child still gag?	YES	NO	N/A	
3.3	Does your child struggle to sit still at meal times due to limited attention span	YES	NO	Specify	
3.3.1	Does this still affect the quantity of solid food ingested?	YES	NO	Specify	
3.3.2	For how long can your child sit at meals?	1-2 minutes	3-5 minutes	6-10 minutes	longer
3.3.3	Is our child's attention span at meal times a source of frustration / distress for parents?	YES	NO	Comments	
3.3.4	Does it still impact on family harmony at mealtimes?	YES	NO	Comments	
FAMILY ADJUSTMENT					
4.	SOCIAL FUNCTIONS AND FAMILY GATHERINGS				
4.1	Are you now able to take your child to family gatherings?	YES	NO	Comments	
4.2	Are you now able to take your child to birthday parties?	YES	NO	Comments	
4.3	Are you now able to take your child to eat at restaurants?	YES	NO	Comments	
4.4	Are his/her siblings now able to have friends to play?	YES	NO	Comments	
4.5	Is the family more able to sustain relationships with other families?	YES	NO	Comments	

5.	IMPACT ON INDIVIDUAL FAMILY MEMBERS										
5.1	Is there a noticeable improvement in the level of distress in any of the family members since your child had O.T.?	YES		NO		Comments					
5.1.1	Mother?	YES		NO		Comments					
5.1.2	Father?	YES		NO		Comments					
5.1.3	Siblings?	YES		NO		Comments					
5.2.	Has there been an improvement in the ability of family members to cope with stress ? If YES, please detail	Sharing of care		More involvement of both parents?		Resolution of depression		Resolution of marital conflict ?		Other ?	
		YES	NO	YES	NO	YES	NO	YES	NO	YES	NO
5.3	Have you been able to resume your career in any way since your child had O.T.?	YES		NO		Comments					
5.4	Have you been more able to pursue your own interests more since your child had O.T. ?	YES		NO		Comments					
6.	SOCIAL INTERACTION										
6.1	Does your child still exhibit aggressive behaviour.?	YES		NO		N/A					
6.1.1	Is it still directed towards himself ?	YES		NO		N/A					
6.1.2	Is it still directed at others?	YES		NO		N/A					
6.1.3	Is there still.....	Biting?		Pinching?		Hitting?		Other ?			
		YES	NO	YES	NO	YES	NO	YES	NO	YES	NO
6.2	Does your child still exhibit tantrums?	YES		NO		OCCASSIONALLY					
6.2.1	Are tantrums still a source of distress to other family members?	YES		NO		Comments					
6.3	Does your child still use "self stimulatory behaviour " (stimming) to deal with sensory	YES		NO		Comments					

	overload?								
6.3.1	Does "stimming" behaviour still limit your ability to take your child out to public places?	YES	NO	Comments					
6.3.2	Does your child still use the following to cope with anxiety or sensory overload?	Hand flapping?	Rocking	Masturbation	Head banging		Jumping?		
		YES NO	YES NO	YES NO	YES NO	YES NO			
		Smelling, sniffing ?	Breath holding, Humming?	Biting, mouthing? Sub-vocalising?	Visual fixing? Spinning objects?	Teeth grinding?			
		YES NO	YES NO	YES NO	YES NO	YES NO			
6.4	Does your child still struggle to cope with transitions between activities?	YES	NO	N/A					
6.4.1	Does this still cause distress to family members?	YES	NO	Comments					
6.5	Is your child still over dependent on his/her parents or clingy?	YES	NO	Comments					
6.5.1	Does this still make separations challenging?	YES	NO	Comments					
6.6	Is there still yelling and screaming by other family members in the home since your child had O.T.?	YES	NO	N/A					
6.6.1	Does this still cause distress to family members?	YES	NO	Comments					
6.7	Is your child able to communicate his/her needs since starting O.T. ?	YES	NO	Comments					
6.7.1	How does he/she communicate now? Record with an X	Talking	Signing	Sounds	Pointing		Crying/ Screaming		
		YES NO	YES NO	YES NO	YES NO	YES NO			

PLAY SKILLS / PEER INTERACTION						
7.	FREE TIME / PLAY TIME					
7.1	Is your child still destructive towards toys ?	YES	NO	Comments		
7.2	Does your child still struggle to play by him/ herself? (excl. watching T.V.)	YES	NO	N/A		
7.2.1	For how long?	1 – 2 mins	2 – 5 mins	5 – 10 mins	10 – 30 mins	More ?
7.3	Can your child play alongside another child ?	YES	NO	Comments		
7.4	Is your child able to make friends?	YES	NO	Comments		
7.5	Is your child now able to participate in structured group play ?	YES	NO	Comments		
7.6	Is your child now able to play in familiar settings?	YES	NO	Comments		
7.7	Is your child now able to play in unfamiliar settings?	YES	NO	Comments		
8	SCHOOLING					
8.1	Is your child home-schooled ?	Is your child at a pre-school for children with special needs		Is your child able to attend a regular pre-school O.T ?		
	YES NO	YES	NO	YES	NO	

9.	SUMMARY			
9.1	Do you attribute improvements in biological functions i.e. sleeping, toilet training, feeding to improved sensory regulation?	YES	NO	To what do you attribute improvements?
9.2	Do you attribute improvements in family adjustment to improvements in sensory regulation?	YES	NO	To what do you attribute improvements?
9.3	Do you attribute improvements in play skills and peer interaction to improvements in sensory regulation?	YES	NO	To what do you attribute improvements?

Comments

Please comment on any other affects OT has had in terms of the effect on your and the family's life

Thank you for your time and effort in completing this lengthy questionnaire

Kerry Wallace B.Sc (O.T.) U.C.T.

A:3 Occupational Performance Questionnaire (OPQ)

Occupational Performance Questionnaire

Kerry A. Wallace

Questionnaire Number.....MaleFemale.....

Start of Therapy.....(Date)

6 months later.....(Date completed)

1 year later.....(Date completed)

KEY TO COMPLETING THE OCCUPATIONAL PERFORMANCE QUESTIONNAIRE

Please mark the box that best describes the frequency with which your child displays the behaviours described or the affect on the family. Please answer all the questions. You may write comments at the end of each section.

Almost always	The response to the question is true 90% or more of the time
Frequently	The response to the question is true about 75% of the time
Occasionally	The response to the question is true about 50% of the time
Seldom	The response to the question is true about 25% of the time
Almost Never	The response to the question is true 10% or less of the time

Questionnaire

A longitudinal study to investigate the Occupational Performance Pre-School Children With Autistic Spectrum Disorders receiving occupational therapy using Sensory Integration theory and methods; and how this affects mothers' parenting stress.

Kindly complete this questionnaire to the best of your ability. Part 1 only required once, but you will be required to fill in Part 2 at 6 monthly intervals before and during the time your child attends SI based Occupational therapy, and Part 3 only at the end of a year.

PART 1. GENERAL INFORMATION

1. Questionnaire No.					
2. Marital status of mother		single	divorced	Living with partner	married
3. Sex of your child		Male		Female	
4. Age of your child		Years		Months	
5. Mother's Occupation					
6. Father's Occupation					
7. Family Income per month		<R2000	R5000	R10 000	>R20 000
8. Ethnic group		Caucasian	Mixed	Asian	African
9. Indicate your child's diagnosis with a X		Autistic disorder		PDD	Aspergers syndrome
10. Name of the Doctor who made the diagnosis					
11. Is your child currently on any prescribed medication ?		YES		NO	
12. If yes -Specify which medication ? Or other medication that is not prescribed					
13. Does your child have Speech Therapy ?		YES		NO	
14. Does your child have Physiotherapy?		YES		NO	
15. Does your child have ABA (Applied Behaviour Analysis)		YES		NO	
16. How old was your child when he/she slept through the night ?		Years	Months	N/A	
17. How old was your child when he/she was toilet trained in the day?		Years	Months	N/A	
18. How old was your child when he no longer needed to wear a nappy at night?		Years	Months	N/A	
19. At what age did your child stop having tantrums?		Years	Months	N/A	
20. Does your child spend the day at home with mother/caregiver?		YES		NO	
21. Is your child home-schooled?		YES		NO	
22. Is your child at a pre-school for children with special needs?		YES		NO	
23. Is your child able to attend a regular pre-school?		YES		NO	

OCCUPATIONAL PERFORMANCE AREAS

A. PERSONAL MANAGEMENT

			ALMOST ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	ALMOST NEVER
1. SLEEPING	1.1	Does your child have a sleeping problem?					
	1.2	How many times per night does he/she wake?	>6	5-6	3-4	1-2	0
	1.3.1	Do you use rocking to get him/her back to sleep?					
	1.3.2	Do you use humming?					
	1.3.3	Do you use singing?					
	1.3.4	Do you use feeding?					
	1.3.5	Do you use holding?					
	1.4	Do family members have interrupted sleep?					
	1.5	Does your child's sleeping pattern impact on family harmony?					
2. TOILET TRAINING	2.1	Is your child in a nappy in the day?					
	2.2	Is your child in a nappy at night?					
	2.3	Are there incidents of bedwetting?					
	2.3.1	How often do accidents occur during the day?					
3. FEEDING	3.1	Is the variety of food tastes your child tolerates limited?					
	3.2	Is the variety of food textures that your child eats limited?					
	3.3	Is there a disruption in the family routine as a result of atypical eating patterns?					
	3.4	Does your child struggle to chew a variety of foods?					
	3.5	Does your child struggle to suck through a straw?					
	3.6	Does your child struggle to swallow a variety of foods?					
	3.7	Does your child gag on solid food?					
	3.8	Does your child struggle to sit still at meal times due to limited attention span?					
	3.9	Does this affect the quantity of solid food eaten?					
	3.10	For how long can your child sit at meals?	longer	10-15 mins	6-10 mins	3-5 mins	1-2 mins
	3.11	Is your child's attention span at meal times a source of frustration / distress for parents?					
	3.12	Does it impact on family harmony at mealtimes?					

B. SOCIAL INTERACTION			ALMOST ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	ALMOST NEVER
4. INDIVIDUAL	4.1	Does your child exhibit aggressive behaviour?					
	4.1.1	Is it directed towards himself?					
	4.1.2	Is it directed at others?					
		Is there					
	4.2.1	Biting?					
	4.2.2	Pinching?					
	4.2.3	Hitting?					
	4.2.4	Other?					
	4.3	Does your child exhibit tantrums?					
	4.3.1	Are tantrums a source of distress to other family members?					
	4.4	Does your child use “self stimulatory behaviour“ (stimming) to deal with anxiety or sensory overload?					
	4.4.1	Hand flapping?					
	4.4.2	Rocking?					
	4.4.3	Masturbation?					
	4.4.4	Head banging?					
	4.4.5	Jumping?					
	4.4.6	Smelling / Sniffing?					
	4.4.7	Breath-holding?					
	4.4.8	Biting, mouthing?					
	4.4.9	Sub-vocalising?					
	4.4.10	Visual Fixing?					
	4.4.11	Spinning objects?					
	4.4.12	Teeth grinding?					
	4.4.13	Touching vibrating objects?					
	4.4.14	Does “stimming” behaviour limit your ability to take your child out to public places?					
	4.5	Does your child struggle to cope with transitions between activities?					
	4.5.1	Does this cause distress to family members?					
	4.6	Is your child over dependent on his/her parents or clingy?					
	4.6.1	Does this make separations challenging?					

			ALMOST ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	ALMOST NEVER
5. PEER INTERACTION	5.1	Does your child ignore other children in play?					
	5.2	Does your child observe other children in play?					
	5.3	Does your child play alongside another child?					
	5.4	Does your child make eye contact during play?					
	5.5	Does your child smile in response to others?					
	5.6	Does your child respond when others ask questions or make statements?					
	5.7	Can your child take turns?					
	5.8	Can your child ask for help appropriately?					
	5.9	Can your child share toys?					
	5.10	Does your child interact with others during play?					
	5.11	Can your child imitate another child/ adult who is playing?					
	5.12	Does your child make friends?					
6. GROUP INTERACTION	6.1	Are you able to attend family gatherings with your child?					
	6.2	Are you able to take your child to birthday parties?					
	6.3	Are you able to take your child to eat at restaurants?					
	6.4	Are his/her siblings able to have friends to play?					
	6.5	Is the family able to sustain relationships with other families?					
7. COMMUNICATION		How does your child communicate?					
	7.1	Talking?					
	7.2	Signing?					
	7.3	Making sounds ?					
	7.4	Pointing ?					
	7.5	Crying/Screaming ?					

C. PLAY			ALMOST ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	ALMOST NEVER
8. LEVEL OF PLAY	8.1	Does your child run around aimlessly, visually attend to objects, and enjoy being pushed in a swing?					
	8.2	Does you child explore toys by mouthing or banging, shaking or poking one toy repetitively?					
	8.3	Does your child manipulate single objects e.g. press a button, push a car, open/shut doors?					
	8.4	Does your child like to pack and unpack, push, pull, pour, put pieces into a puzzle?					
	8.5	Does your child engage in social games e.g. tugging a blanket off his head during peek-a-boo?					
	8.6	Does your child engage in pretend play e.g. drink from an empty cup, pretend to feed a doll ?					
	8.7	Does your child substitute objects in play sequences? e.g. block for a car, claim a toy stove is hot					
9. INDIVIDUAL	9.1	Does your child choose what games to play?					
	9.1.1	Does your child seek out movement activities in play?					
	9.1.2	Does your child seek out sensory activities in play?					
	9.1.3	Does your child choose age appropriate toys to play with?					
	9.2	For how long can your child play by him/ herself in minutes? (Excluding watching T.V.)	>30	30	5-10	1 - 5	<1
	9.2.1	For how long can your child sustain attention with an adult during play in minutes?	>30	30	5-10	1 - 5	<1
	9.2.3	For how long can your child sustain attention with another child during play in minutes?	>30	30	5-10	1 - 5	<1
	9.2.4	Does your child get stuck in play themes e.g. "TV programmes"?					
	9.2.5	Can your child shift attention during play?					
10. GROUP	10.1	Can your child participate in structured group play?					
	10.1.1	Can your child play in familiar settings?					
	10.1.2	Can your child play in unfamiliar settings?					
	10.2	Does your child engage in repetitive play?					
	10.3	Is your child destructive towards toys?					
	10.4	Is your child able to cope with frustration and challenges during play?					
	10.5	Can your child imitate an adult or another child who is playing?					
	10.6	Does your child understand when others tease or joke?					
	10.7	Does your child tease or joke?					

D. IMPACT ON INDIVIDUAL FAMILY MEMBERS							
			ALMOST ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	ALMOST NEVER
11.1	Is there yelling and screaming by other family members in the home?						
11.2	Does this distress other family members?						
11.3	Does having a child with an ASD result in distress in any of the family members?						
11.3.1	Mother?						
11.3.2	Father?						
11.3.3	Siblings?						
11.4	Have you been able to pursue your chosen career since having a child with an ASD?						
11.5	Are you able to pursue your own interests?						
11.6	Have there been direct consequences for any family member?						
11.6.1	Delegation of care?						
11.6.2	Withdrawal of one parent?						
11.6.3	Marital Conflict?						
11.6.4	Parental Separation/Divorce?						
11.6.5	Depression?						

PART 3: POST-THERAPY						
		>90%	75%	50%	25%	<10%
12.	Has there been an improvement in the ability of family members to cope with stress?					
12.1	Reinstatement of marriage?					
12.2	Resolution of marital conflict?					
12.3	Resolution of depression?					
12.4	More involvement of both parents?					
12.5	Sharing of care?					
13.	PARENTAL SATISFACTION WITH INTERVENTION					
13.1	How satisfied are you with the therapist 's rapport with your child?					
13.2	How satisfied are you with the therapist 's rapport with parents?					
13.3	Is the therapeutic environment developmentally appropriate and stimulating					
13.4	Does therapy provide an appropriate level of challenge?					
14.1	To what do you attribute improvements in your child's personal management i.e. sleeping, toilet training, feeding?					
14.2	To what do you attribute improvements in family adjustment?					
14.3	To what do you attribute improvements in your child's play skills and peer interaction?					

Comments

Please comment on any other affects OT has had in terms of the effect on your child's and the family's life. Thank you for your time and effort in completing this lengthy questionnaire.

Kerry Wallace

Appendix B
Information Sheet for parents

WILEY

KERRY A. WALLACE

B.Sc (O.T.) U.C.T.
OCCUPATIONAL THERAPIST
Pr. No. 6602118

P.O.Box 3655
Cramerview
2060.
Tel: (011) 706-8280
email : kerrywallace@mweb.co.za

12 Eccleston Crescent
Bryanston
SANDTON
Fax: (011) 706-6997

Dear Mother,

A longitudinal study to explore the relationship between the occupational performance of Pre-school Children with Autistic Spectrum disorders, receiving Occupational therapy, using sensory integration theory and methods, and how this affects mothers' parenting stress.

I am doing research on children diagnosed with Autistic Spectrum disorders (ASD). Research is just the process to learn the answer to a question. In this study we want to learn how the pre-school child's sensory profile determines their ability to carry out everyday activities in personal care, play and social interaction and how this affects their mother's stress. There will be 50 South African families included in the study.

I would appreciate you spending 30 minutes completing a questionnaire on your child's level of function in activities of daily living and family functioning, the Short Sensory Profile and the Parenting Stress Index-Short form which will each take 10 minutes of your time. This will allow me to establish how your child's abilities to do everyday activities affects the families functioning and the affect on your stress levels. You will be required to complete the same forms again after 6 months and 1 year into your child's therapy. This will allow me to establish what outcomes in terms of your child's abilities to do everyday activities most changes the families functioning and the affect on your stress levels. Short video clips of treatment are required to ensure that the therapeutic environment, therapist, and therapist/child relationship meets fidelity criteria laid down by international SI researchers. Video clips will be used purely for research purposes and will be destroyed once therapist fidelity has been established. Questionnaires will be number coded to ensure confidentiality.

Your participation is entirely voluntary, and can be assured that the information will be treated confidentially. Should you prefer not to be involved in this study or to withdraw at any time your child's therapy will not be compromised in any way and there will be no consequences to yourself.

I will endeavour to keep personal information confidential. However absolute confidentiality cannot be guaranteed. The Research Ethics Committee (Medical) (REC), may inspect or copy research records for quality assurance and data analysis. If the results are published, this may lead to individual identification. Should you have any complaints or problems, these can be reported to Prof S. Naidoo at the University of the Witwatersrand School of Public Health via The Secretary of Human Research Ethics Committee on (011) 717-1234 or by fax on 011 339-5708.

Should you be interested in the outcome of the study, once the study has been completed, feedback can be forwarded to you. Please include an e-mail address to enable me to do so. If you are happy to participate in this study, please sign and read the attached consent form. If you have any queries, more information can be obtained from Kerry Wallace at (011)706-8280. .

Thank you for your time and co-operation in this matter,

Kerry Wallace

A longitudinal study to investigate the Occupational Performance of Pre-school children with Autistic Spectrum Disorders receiving Occupational therapy using Sensory Integration theory and methods; and how this affects mothers' parenting stress.

Parent Consent form

I hereby consent to take part in the study entitled :- A longitudinal study to investigate the Occupational Performance of Pre-School Children with Autistic Spectrum Disorders receiving Occupational Therapy using Sensory Integration theory and methods; and how this affects mothers' parenting stress.

I agree to fill out the questionnaires required.

I agree that short video clips of my child's sessions, may be taken, purely for research purposes, in order to establish environmental and therapist fidelity.

I hereby consent for the information from the questionnaires to be used for research purposes,

Signed by.....Parent of (not essential?).....

Date.....Place.....

e-mail address (if applicable).....

Questionnaire No.....

Appendix C

Information letter for occupational therapists

WILEY

KERRY A. WALLACE

B.Sc (O.T.) U.C.T.
OCCUPATIONAL THERAPIST
Pr. No. 6602118

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2060.
Tel: (011) 706-8280
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12 Eccleston Crescent
Bryanston
SANDTON
Fax: (011) 706-6997

Dear Colleague,

My name is Kerry Wallace, a qualified occupational therapist with an interest in Sensory Integration therapy, and in particular its application as an early intervention strategy in the treatment of young children with Autistic Spectrum Disorders.

This research project aims to evaluate the abilities of pre- school child with ASD who is receiving occupational therapy using a sensory integration approach, to carry out everyday activities in personal care, play and social interaction. The effect of any change in this ability on family adjustment and the mothers stress levels will be determined. The study is important as in occupational therapy practice, the increase in the prevalence of ASD, is of concern, not only due to the chronic nature of the disorder, but also because research shows that it is the developmental disability that has the most profound effect on the family members.

I am requesting that you recruit any new children referred with ASD to your practice for the study. Please take particular note of the exclusion criteria, which includes children with the following co-morbidities sensory deficits (e.g deaf or blindness), cerebral palsy, mental retardation, or a child who deteriorates instead of improves Childhood disintegration disorder. Mother's who are single parents would also be excluded due to the extraneous stresses.

If you are willing for your practice to be included in the study I will need to ask that you agree to an assessment of the SI procedures used in the practice so that I can ensure the quality of therapy provided to the subjects. Please review the fidelity criteria which have been developed by Parham et al (2006) in conjunction with numerous Occupational Therapy researchers, aiming to ensure that the therapy provided adheres to the process and structure of sensory integration principles. I will contact you telephonically and discuss aspects of the fidelity criteria with you, as I need to ensure that all practices and therapists meet these criteria before their cases can be included in the study. I will need to verify the fidelity criteria, by having random sections of video-clips reviewed. Video footage of SI treatment can be submitted, or the researcher will arrange to have video footage filmed for this purpose. The video clips will be destroyed once they have been verified.

Thereafter, kindly inform me telephonically or by e-mail, when a new case with a diagnosis on the Autistic spectrum (2 – 6 yrs) is referred to you for SI therapy. I will send a numbered Occupational Performance Questionnaire, a Sensory Profile-short form (SSP) and a Parenting Stress Index (PSI-SF), for each case. They must be completed by the mother during the first month of commencing SI therapy. If necessary, you may be required to assist them in completing the questionnaire, and clarify if there are any questions. Please return the questionnaires to me in the stamped addressed envelope provided immediately.

After 6 months, and again after a year, the mother will be required to complete the same questionnaires in order for the researcher to measure the effect of SI therapy on the child's Occupational Performance, and Parenting Stress. I will send you the forms at the appropriate time. Kindly return these in the stamped addressed envelopes provided.

It will endeavour to keep personal information confidential. However absolute confidentiality cannot be guaranteed. The Research Ethics Committee (Medical) (REC), may inspect or copy research records for quality assurance and data analysis. If the results are published, this may lead to individual identification. Should you have any complaints or problems, these can be reported to Prof S. Naidoo at the University of the Witwatersrand School of Public Health via The Secretary of Human Research Ethics Committee on (011) 717-1234 or by fax on 011 339-5708.

I really do appreciate your willingness to participate in this project, which I trust will be useful in setting minimum standards for the treatment of this vulnerable population group in the pre-school years.

Regards

Kerry Wallace

Therapist Consent form

I hereby confirm the therapist for this patient is SI certified, that the fidelity criteria for SI therapy are applicable to my practice, and that my patients can be included in this study. I will submit / agree to the researcher taking video clips of treatment which will be destroyed once the researcher has verified fidelity criteria for the treating therapist and the therapeutic environment.

Signed by.....(Supervising Occupational Therapist)

.....(Date SI certified)

Date.....Place.....

Postal address.....

.....

e-mail address.....

Appendix D

Fidelity Measure

- I Physical Environment**
- II Safe Environment**
- III Therapist qualifications**
- IV Available equipment**
- V Ten core elements critical to the OT-SI intervention process**
- VI Detailed Results of Fidelity Measure of SI-OT Intervention Analysis**
Essential Characteristics of Occupational Therapy Using Sensory Integration ©

FIDELITY CRITERIA

The researcher visited all 8 sites and confirmed that in all cases the physical environments met the six criteria, the five safety criteria 92% of the Equipment stipulated was available across all sites:-

I Physical Environment

1. Adequate space to allow for flow of vigorous physical activity
2. A flexible arrangement of equipment and materials to allow for rapid change of the physical and spatial configuration of intervention environment
3. At least 3 hooks for hanging suspended equipment, with a minimum distance between the hooks of 0.75 – 1.00 m. This provides enough room to allow for full orbit on suspended equipment.
4. One or more rotational devices attached to a ceiling support to allow 360 degrees of rotation.
5. A quiet space (tent, adjacent room or partially enclosed area)
6. One or more sets of bungee cords for hanging suspended equipment.

II Safe Environment

7. Mats, cushions, pillows available to be used to pad the floor underneath all suspended equipment during intervention
8. Equipment adjustable to the child's size
9. The equipment that is accessible is monitored for safe use by the therapist
10. Equipment not being used is stored, anchored, or placed at the sides of the room, so children cannot fall or trip over it.
11. Monitoring of equipment for safety (e.g. ropes and bungee cords not frayed)

III Therapist qualifications

The credentials of therapists involved in the treatment of the subjects were verified by the researcher to ensure that they fulfilled the criteria stipulated by the research team who developed the Fidelity criteria. These included Therapist qualifications. All 7 participating therapists had completed postgraduate training in SI/SIPT through SAISI, up to Course 3 (Test Interpretation), and 5 of the therapists had completed SI/SIPT training up to Course 4(SI Treatment). Four of the therapists are considered experts in the field and provide clinical supervision and 3 of these are part of SAISI's core lecturing team in SA. The two therapists who are in the process of SI certification receive one hour per week of supervision with an expert of at least 5 yrs of experience in providing OT using SI intervention with children on the Autistic spectrum.

Therapist no.	T1	T2	T3	T4	T5	T6	T7
No. of year's experience since SCSIT/SIPT certification	20	7	19	1	SIPT Course 3	14	SIPT Course 3

IV Available equipment

		1	1a	2	3	4	5	6	7	tot
1	Bouncing equipment (trampoline)	√	√	√	√	√	√	√	√	8
2	Rubber strips or ropes for pulling	√	√	√	√	√	√	√	√	8
3	Therapy balls	√	√	√	√	√	√	√	√	8
4	Platform swing – square	√	x	x	√	x	X	√	√	4
5	Platform glider swing	√	√	x	√	√	√	x	√	6
6	Frog swing	√	√	√	√	√	√	√	√	8
7	Scooter/ramp	√	√	√	√	√	√	√	√	8
8	Flexion disc	√	√	√	√	√	√	√	√	8
9	Bolster swing	√	√	x	√	√	√	√	√	7
10	Tyre swing	√	x	x	√	√	√	x	√	5
11	Weighted objects such as balls or beanbags in a variety of sizes	√	√	√	√	√	√	√	√	8
12	Inner tubes	√	√	√	√	X	X	√	√	6
13	Spandex fabric	√	√	√	√	√	√	√	√	8
14	Crash pillow	√	√	√	√	√	√	√	√	8
15	Ball pit / snow box	√	√	√	√	√	√	√	√	8
16	Vibrating toys or massagers	√	√	√	√	√	√	√	√	8
17	Variety of tactile materials (rice brushes, carpet squares, beans)	√	√	√	√	√	√	√	√	8
18	Visual targets (e.g. balloons, Velcro darts, hanging objects)	√	√	√	√	√	√	√	√	8
19	Ramps	√	√	√	√	√	√	√	√	8
20	Climbing equipment (wooden, plastic steps, ladders or stacking tube tires, foam blocks)	√	√	√	√	√	√	√	√	8
21	Barrel for rolling	√	√	√	√	x	x	√	√	6
22	Props to support engagement in play (e.g. dress up clothes, dolls, stuffed animals, bats, balls, bikes, puppets, sports equipment)	√	√	√	√	√	√	√	√	8
23	Materials for practising daily living skills (e.g. pencils, pens and other school supplies, grooming, clothing and home related objects)	√	√	√	√	√	√	√	√	8
	Total equipment available	23	21	19	23	20	20	21	23	170
	Percentage equipment available	100	91	83	100	87	87	91	100	92

V Ten core elements critical to the OT-SI intervention process (Parham et al 2007)

1. Therapist ensures child's safety
2. Therapist presents sensory opportunities
3. Therapist helps the child to attain and maintain appropriate levels of alertness, as well as an affective state that supports engagement in activities
4. Postural, ocular, oral and or bilateral motor control are challenged.
5. Praxis and organisation of behaviour are challenged
6. Therapist collaborates with child on activity choice
7. Therapist tailors the activity to present the just-right challenge
8. Therapist ensures that activities are successful
9. Therapist supports the child's intrinsic motivation to play
10. Therapist establishes a therapeutic alliance with the child.

VI Detailed Results of Fidelity Measure of SI-OT Intervention Analysis
Essential Characteristics of Occupational Therapy Using Sensory Integration ©
Draft Summary 2007

Purpose: The purpose of this measure is to ensure for research purposes that occupational therapy using sensory integration adheres to the theory and principles developed originally by Dr. A. Jean Ayres.

Part I: Therapist Qualifications UNKNOWN

Part II: Record Review UNKNOWN

Part III: Preparation for Intervention

- A. Physical Environment **YES**
- B. Safe Environment **YES**
- C. Available Equipment **YES**
- D. Communication with Parents and Teachers Documented – Goals and Objectives Established **UNKNOWN**
- E. Family and/or Teacher Education **UNKNOWN**

Part IV: Observation of Intervention Using Sensory Integration Principles

Key to Ratings

- 4 Certainly, I think the therapist intentionally uses this strategy.
- 3 Probably, I think the therapist intentionally uses this strategy.
- 2 Doubtful, I don't think the therapist intentionally uses this strategy.
- 1 No, I don't think the therapist intentionally uses this strategy.

1. The therapist ensures physical safety by attending to the child's abilities and potential dangers.	4	3	2	1	Comments
	T6				1
	T3				2
	T4				3
	T7				4
	T2				
	T1				
	T5				
2. The therapist presents the child with at least two of the following three types of sensory opportunities a. tactile, b. vestibular, c. proprioceptive.	4	3	2	1	Comments

					1
	T6				2
	T3				3
	T4				4
	T7				
	T2				
	T1				
	T5				
3. The therapist assists child to attain and maintain appropriate levels of alertness , as well as an affective state that supports engagement in activities through changes in intensity, duration, frequency and rhythm of sensory input.	4	3	2	1	Comments
		T6			1
	T3				2
		T4			3
		T7			
		T2			
		T1			
		T5			
4. The therapist challenges postural, ocular, oral and/or bilateral motor control.	4	3	2	1	Comments
	T6				1
	T3				2
	T4				3
	T7				4
	T2				
	T1				
	T5				

5. The therapist challenges the child's praxis and organization of behavior	4	3	2	1	Comments
			T6		1

including the ability to conceptualize and plan novel motor tasks, and organize his or her own behavior in time and space.		T3			2
			T4		3
	T7				4
		T2			
	T1				
	T5				
6. The therapist collaborates in activity choice with the child. Activity choices and sequences are <u>not</u> determined solely by the therapist.	4	3	2	1	Comments
		T6			1
		T3			2
			T4		3
			T7		4
	T2				
	T1				
	T5				
7. The therapist tailors activity to present just-right challenge and suggests or supports an increase in complexity of challenge when child responds successfully.	4	3	2	1	Comments
	T6				1
	T3				2
		T4			3
	T7				4
		T2			
		T1			
		T5			
8. The therapist ensures that activities are successful by facilitating challenges in which the child can be successful in making an adaptive response.	4	3	2	1	Comments
		T6			1
	T3				2

		T4			3
	T7				4
	T2				
	T1				
	T5				
9. The therapist supports child's intrinsic motivation to play and creates a setting that supports play as a way to fully engage the child in the intervention.	4	3	2	1	Comments
	T6				1
		T3			2
		T4			3
		T7			4
	T2				
		T1			
		T5			
10. The therapist establishes a therapeutic alliance that promotes and establishes a connection with the child, working together toward one or more goals in a mutually enjoyable partnership that involves more than pleasantries.	4	3	2	1	Comments
		T6			1
		T3			2
		T4			3
	T7				4
	T2				
		T1			
	T5				

Reference: Parham, L.D., Cohn, E.S., Spitzer, S., Koomar, J.A., Miller, L.J., Burke, J.P., Brett-Green, B., Mailloux, Z., May-Benson, T.A., Smith Rol S., Schaaf, R.C., Schoen, S.A., & Summers, C.A. (2007). Fidelity in sensory integration intervention research. *American Journal of Occupational Therapy*, 61, 216-227.

The authors acknowledge the contributions of Stefanie Bodison M.A, OTR/L to the refinement of this instrument.

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Do you know the therapist in the session? (check box)	T6 (2 sessions)	<u>YES</u>	
Number of (4) Certainly ratings	5	X 10	50
Number of (3) Probably ratings	4	X 7	28
Number of (2) Doubtful ratings	1	X 3	3
Number of (1) No ratings		X 0	
Sum			81

Do you know the therapist in the session? (check box)	T3:		<u>NO</u>
Number of (4) Certainly ratings	6	X 10	60
Number of (3) Probably ratings	4	X 7	28
Number of (2) Doubtful ratings		X 3	
Number of (1) No ratings		X 0	
Sum			88

Do you know the therapist in the session? (check box)	T4		<u>NO</u>
Number of (4) Certainly ratings	3	X 10	30
Number of (3) Probably ratings	5	X 7	35
Number of (2) Doubtful ratings	2	X 3	6
Number of (1) No ratings		X 0	
Sum			71

Do you know the therapist in the session? (check box)	T7		<u>NO</u>
Number of (4) Certainly ratings	7	X 10	70
Number of (3) Probably ratings	2	X 7	14
Number of (2) Doubtful ratings	1	X 3	3

Number of (1) No ratings		X 0	
		Sum	87

Do you know the therapist in the session? (check box)	T2		<u>NO</u>
Number of (4) Certainly ratings	7	X 10	70
Number of (3) Probably ratings	3	X 7	21
Number of (2) Doubtful ratings		X 3	
Number of (1) No ratings		X 0	
		Sum	91

Do you know the therapist in the session? (check box)	T1	<u>YES</u>	
Number of (4) Certainly ratings	6	X 10	60
Number of (3) Probably ratings	4	X 7	28
Number of (2) Doubtful ratings		X 3	
Number of (1) No ratings		X 0	
		Sum	88

Do you know the therapist in the session? (check box)	T5		<u>NO</u>
Number of (4) Certainly ratings	7	X 10	70
Number of (3) Probably ratings	3	X 7	21
Number of (2) Doubtful ratings		X 3	
Number of (1) No ratings		X 0	
		Sum	91

Summary:

Using the Fidelity Measure based on Ayres Sensory Integration I rated 7 different therapists providing intervention to a single child. One therapist provided a short clip of two sessions. The rest had only one session. The ratings are based on DVD excerpts lasting approximately 5 minutes each. Prior to scoring, a panel of four world-renowned experts in sensory integration and occupational therapy reviewed the tapes of intervention for general impression. Unanimously they felt that the sessions reflected sensory integration as the method of intervention employed.

Results – 6 of the 7 therapists met the suggested criteria of 80% or above to ensure Fidelity to intervention. All therapists scored 70% or higher on the measure. Only one therapist received a score of 71, scoring low on collaborating in activity choice and addressing praxis items. The ratings were as follows: 81, 88, 71, 87, 91, 88, 91. It is therefore assumed that the interventions overall adhered to principles of occupational therapy using a sensory integration approach. In future studies, it will be important to have more than one session and video of the entire session from which to make this judgment.

Limitation – I did not have access to the entire intervention session to determine if the entire session consisted of methods consistent with Ayres Sensory Integration. I had only one session per therapist with the exception of one therapist who had brief clips of two different sessions. I had no background information on the structural aspects of the Fidelity Measure. I had limited information on which to base the rating of the process.

Appendix E

Parent Stress Index – Short Form (PSI-SF)

WILEY

Name _____ Gender _____ Date of birth _____ Ethnic group _____ Marital status _____

Child's name _____ Child's gender _____ Child's date of birth _____ Today's date _____

SA = Strongly Agree

A = Agree

NS = Not Sure

D = Disagree

SD = Strongly Disagree

- | | | | | | |
|---|----|---|----|---|----|
| 1. I often have the feeling that I cannot handle things very well. | SA | A | NS | D | SD |
| 2. I find myself giving up more of my life to meet my children's needs than I ever expected. | SA | A | NS | D | SD |
| 3. I feel trapped by my responsibilities as a parent. | SA | A | NS | D | SD |
| 4. Since having this child, I have been unable to do new and different things. | SA | A | NS | D | SD |
| 5. Since having a child, I feel that I am almost never able to do things that I like to do. | SA | A | NS | D | SD |
| 6. I am unhappy with the last purchase of clothing I made for myself. | SA | A | NS | D | SD |
| 7. There are quite a few things that bother me about my life. | SA | A | NS | D | SD |
| 8. Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend). | SA | A | NS | D | SD |
| 9. I feel alone and without friends. | SA | A | NS | D | SD |
| 10. When I go to a party, I usually expect not to enjoy myself. | SA | A | NS | D | SD |
| 11. I am not as interested in people as I used to be. | SA | A | NS | D | SD |
| 12. I don't enjoy things as I used to. | SA | A | NS | D | SD |
| 13. My child rarely does things for me that make me feel good. | SA | A | NS | D | SD |
| 14. Sometimes I feel my child doesn't like me and doesn't want to be close to me. | SA | A | NS | D | SD |
| 15. My child smiles at me much less than I expected. | SA | A | NS | D | SD |
| 16. When I do things for my child, I get the feeling that my efforts are not appreciated very much. | SA | A | NS | D | SD |
| 17. When playing, my child doesn't often giggle or laugh. | SA | A | NS | D | SD |
| 18. My child doesn't seem to learn as quickly as most children. | SA | A | NS | D | SD |
| 19. My child doesn't seem to smile as much as most children. | SA | A | NS | D | SD |
| 20. My child is not able to do as much as I expected. | SA | A | NS | D | SD |
| 21. It takes a long time and it is very hard for my child to get used to new things. | SA | A | NS | D | SD |

For the next statement, choose your response from the choices "1" to "5" below.

- | | | | | | |
|---|---|---|---|---|---|
| 22. I feel that I am: | 1 | 2 | 3 | 4 | 5 |
| 1. not very good at being a parent | | | | | |
| 2. a person who has some trouble being a parent | | | | | |
| 3. an average parent | | | | | |
| 4. a better than average parent | | | | | |
| 5. a very good parent | | | | | |

23. I expected to have closer and warmer feelings for my child than I do and this bothers me.	SA	A	NS	D	SD
24. Sometimes my child does things that bother me just to be mean.	SA	A	NS	D	SD
25. My child seems to cry or fuss more often than most children.	SA	A	NS	D	SD
26. My child generally wakes up in a bad mood.	SA	A	NS	D	SD
27. I feel that my child is very moody and easily upset.	SA	A	NS	D	SD
28. My child does a few things which bother me a great deal.	SA	A	NS	D	SD
29. My child reacts very strongly when something happens that my child doesn't like.	SA	A	NS	D	SD
30. My child gets upset easily over the smallest thing.	SA	A	NS	D	SD
31. My child's sleeping or eating schedule was much harder to establish than I expected.	SA	A	NS	D	SD

For the next statement, choose your response from the choices "1" to "5" below.

32. I have found that getting my child to do something or stop doing something is:	1	2	3	4	5
1. much harder than I expected					
2. somewhat harder than I expected					
3. about as hard as I expected					
4. somewhat easier than I expected					
5. much easier than I expected					

For the next statement, choose your response from the choices "10+" to "1-3."

33. Think carefully and count the number of things which your child does that bother you. For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc.	10+	8-9	6-7	4-5	1-3
34. There are some things my child does that really bother me a lot.	SA	A	NS	D	SD
35. My child turned out to be more of a problem than I had expected.	SA	A	NS	D	SD
36. My child makes more demands on me than most children.	SA	A	NS	D	SD

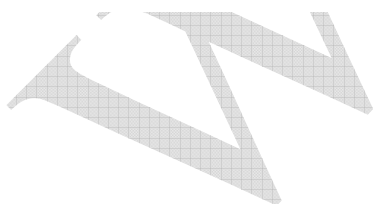
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Appendix F
Short Sensory Profile

WILEY



Short Sensory Profile

Child's Name: _____ Birth Date: _____ Date: _____

Completed by: _____ Relationship to Child: _____

Session Provider's Name: _____ Discipline: _____

INSTRUCTIONS:

Please check the box that best describes the frequency with which your child does the following behaviors. Please answer all of the statements. If you are unable to comment because you have not observed the behavior or believe that it does not apply to your child, please draw an X through the number for that item. Please do not write in the Section Raw Score Total row.

Use the following key to mark your responses:

ALWAYS

When presented with the opportunity, your child always responds in this manner, 100% of the time.

FREQUENTLY

When presented with the opportunity, your child frequently responds in this manner, about 75% of the time.

OCCASIONALLY

When presented with the opportunity, your child occasionally responds in this manner, about 50% of the time.

SELDOM

When presented with the opportunity, your child seldom responds in this manner, about 25% of the time.

NEVER

When presented with the opportunity, your child never responds in this manner, 0% of the time.

Item	Tactile Sensitivity	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
1	Expresses distress during grooming (for example, fights or cries during haircutting, nail washing, fingernail cutting)					
2	Prefers long-sleeved clothing when it is warm or short sleeves when it is cold					
3	Avoids going barefoot, especially in sand or grass					
4	Reacts emotionally or aggressively to touch					
5	Withdraws from splashing water					
6	Has difficulty standing in line or close to other people					
7	Rubs or scratches out a spot that has been touched					
Section Raw Score Total						
Item	Taste/Smell Sensitivity	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
8	Avoids certain tastes or food smells that are typically part of children's diets					
9	Eats only eat certain tastes (diet)					
10	Limits self to particular food textures/temperatures (diet)					
11	Picky eater, especially regarding food textures					
Section Raw Score Total						
Item	Movement Sensitivity	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
12	Becomes anxious or distressed when feet leave the ground					
13	Fears falling or heights					
14	Dislikes activities where head is upside down (for example, somersaults, roughhousing)					
Section Raw Score Total						
Item	Underresponsive/Seeks Sensation	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
15	Enjoys strange noises/seeks to make noise for noise's sake					
16	Seeks all kinds of movement and this interferes with daily routines (for example, can't sit still, fidgets)					
17	Becomes overly excitable during movement activity					
18	Touches people and objects					
19	Doesn't seem to notice when face or hands are messy					
20	Jumps from one activity to another so that it interferes with play					
21	Wears clothing twisted or bunched					
Section Raw Score Total						

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Item		ALWAYS	FREQUENTLY	OCCASIONALLY	NEVER
Auditory Filtering					
22	Is distracted or has trouble functioning if there is a lot of noise around				
23	Appears to not hear what you say (for example, does not "tune in" to what you say, appears to ignore you)				
24	Can't work with background noise (for example, fan, refrigerator)				
25	Has trouble completing tasks when the radio is on				
26	Doesn't respond when name is called but you know the child's hearing is OK				
27	Has difficulty paying attention				
Section Raw Score Total					
Low Energy/Weak					
28	Seems to have weak muscles				
29	Tires easily, especially when standing or holding particular body position				
30	Has a weak grip				
31	Can't lift heavy objects (for example, weak in comparison to same-age children)				
32	Preps to support self (even during activity)				
33	Poor endurance/tires easily				
Section Raw Score Total					
Visual/Auditory Sensitivity					
34	Responds negatively to unexpected or loud noises (for example, cries or hides at noise from vacuum cleaner, dog barking, hair dryer)				
35	Holds hands over ears to protect ears from sound				
36	Is bothered by bright lights after others have adapted to the light				
37	Watches everyone when they move around the room				
38	Covers eyes or squints to protect eyes from light				
Section Raw Score Total					

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Summary

Instructions: Transfer the score for each section to the Section Raw Score Total column. Put these totals by marking an X in the appropriate classification column (Typical Performance, Probable Difference, Definite Difference).*

SCORE KEY

1 = Always
2 = Frequently
3 = Occasionally
4 = Seldom
5 = Never

Section	Section Raw Score Total	Typical Performance	Probable Difference	Definite Difference
Tactile Sensitivity	/35	35 — 30	29 — 27	25 — 7
Thermal Sensitivity	/20	20 — 15	14 — 12	11 — 4
Movement Sensitivity	/15	15 — 13	12 — 11	10 — 3
Underresponsive/Seeker Sensation	/35	35 — 27	26 — 24	23 — 7
Auditory Filtering	/30	30 — 23	22 — 20	18 — 8
Low Energy/Weak	/30	30 — 26	25 — 24	23 — 8
Visual/Auditory Sensitivity	/25	25 — 19	18 — 16	15 — 8
Total	/190	190 — 133	124 — 143	143 — 38

*Classifications are based on the performance of children without disabilities (n = 1,000).

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Appendix G

Ethical clearance certificate

WILEY

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

R1449, Wallace

CLEARANCE CERTIFICATE

PROTOCOL NUMBER M968817

PROJECT

A Longitudinal Study to Explore
the Relationship between the
Occupational Performance of.....

INVESTIGATORS

Mrs KA Wallace

DEPARTMENT

Occupational Therapy

DATE CONSIDERED

06.08.25

DECISION OF THE COMMITTEE*

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE

CHAIRPERSON


(Professor M Vorster)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor: Mrs P de Win

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and ONE COPY returned to the Secretary at Room 10005, 10th Floor,
Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned
research and I/we guarantee to ensure compliance with these conditions. Should any departure to be
contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the
Committee. I agree to a completion of a yearly progress report.

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES