

Participation in meaningful occupation: How do young adults living with cerebral palsy experience the quality of their participation?

Giselé Shaline Pieterse

“Research Assignment presented in partial fulfilment of the requirements for the degree of Master of Occupational Therapy at the Stellenbosch University”



Study supervisor: Mrs. ED Vlok

March 2013

Study co-supervisor: Ms. J Bester

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APPENDIX A: Approval letter from the Western Cape Department of Education

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Navrae
Enquiries **Dr A.T Wyngaard**
IMibuzo
Telephone
Telephone **021 467 9272**
IFoni
Faks
Fax
IFeksi



Wes-Kaap Onderwysdepartement

Western Cape Education Department

ISEBE leMfundo leNtshona Koloni

Verwysing
Reference **20110119-0055**
ISalathiso

Mrs Gisele Pieterse
Tarentaal Road
Bridgetown
Athlone
7764

Dear Mrs Gisele Pieterse

RESEARCH PROPOSAL: PARTICIPATION IN MEANINGFUL OCCUPATIONS: HOW DO YOUNG ADULTS LIVING WITH CEREBRAL PALSY EXPERIENCE THE QUALITY OF THEIR PARTICIPATION?

Your application to conduct the above-mentioned research in schools in the Western Cape has been approved subject to the following conditions:

1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Educators' programmes are not to be interrupted.
5. The Study is to be conducted from **01 February 2011 till 30 September 2011**
6. No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December).
Should you wish to extend the period of your survey, please contact Dr A.T Wyngaard at the contact numbers above quoting the reference number.
7. A photocopy of this letter is submitted to the principal where the intended research is to be conducted.
8. Your research will be limited to the list of schools as forwarded to the Western Cape Education Department.
9. A brief summary of the content, findings and recommendations is provided to the Director: Research Services.
10. The Department receives a copy of the completed report/dissertation/thesis addressed to:
**The Director: Research Services
Western Cape Education Department
Private Bag X9114
CAPE TOWN
8000**

We wish you success in your research.

Kind regards.
Signed: Audrey T Wyngaard
for: **HEAD: EDUCATION**
DATE: 19 January 2011

MELD ASSEBLIEF VERWYSINGSNOMMERS IN ALLE KORRESPONDENSIE / PLEASE QUOTE REFERENCE NUMBERS IN ALL CORRESPONDENCE /
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GRAND CENTRAL TOWERS, LOWER PARLIAMENT STREET, PRIVATE BAG X9114, CAPE TOWN 8000

WEB: <http://wced.wcape.gov.za>

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APPENDIX B-1: TELEPHONE SCRIPT FOR INITIAL CONTACT:

Hi, my name is Gisele Pieterse and I work as an occupational therapist (OT) at the school you attended. Is it possible for me to talk to you now for a few minutes? I'm calling to invite you to take part in a research study I'm doing for my Masters Degree through Stellenbosch University. I want you to know that your participation will be entirely voluntary and that you are free to decline to participate. You can also withdraw from the study at any point, even if you have agreed to take part. You will participate in one interview at a place that is convenient for you. There will be no cost involved to you. My study is about gaining information and insight into your experiences as a young adult living with cerebral palsy, in regards to your participation in meaningful occupations or daily activities. This includes activities like: work, self-care, leisure, relationships and involvement in the community. I would also like to find out which of these activities are most meaningful to you and how you feel about your quality of participation. I will audio taped the interview. The information collected will be treated as confidential and protected. If it is used in a publication or presentation, your identity will remain anonymous. I will also ask you to sign a written consent form at our first meeting. Where would be the most convenient place for you to meet? What day and time would suit you best? I would like to ask you a few questions now, before saying good-bye. Good-bye (Confirm date, time and place of next meeting)

TELEFOON MANUSKRIP VIR EERSTE KONTAKSESSIE

Hi, my name is Gisele Pieterse en ek werk as 'n arbeidsterapeut by die skool waar jy 'n leerder was. Het jy nou 'n paar minute om met my te praat? Die rede hoekom ek bel, is om jou te nooi om deel te neem aan 'n navorsingsprojek wat ek doen vir my Meestersgraad, deur Stellenbosch Universiteit. Ek wil hê jy moet weet dat jou deelname volkome vrywillig is en dat dit jou vry staan om deelname te weier. Jy sal op geen wyse negatief beïnvloed word indien jy sou weier om deel te neem nie. Jy mag ook ter eniger tyd aan die navorsingsprojek onttrek, selfs al het jy ingestem om deel te neem. Jy sal verwag om deel te neem in een onderhoud by 'n plek van jou keuse. Daar sal geen koste aan verbonde wees vir jou nie. My studie gaan daarvoor dat ek graag ondersoek wil instel na hoe jy as 'n jong persoon met serebraalgestremdheid jou deelname in betekenisvolle aktiwiteite (take) ervaar. Hierdie take sluit in: werk, persoonlike handhawing, vryetydsbesteding, verhoudings en betrokkenheid in die gemeenskap. Ek wil spesifiek uitvind watter take is die betekenisvolste vir jou en hoe jy voel oor die kwaliteit van jou deelname in hierdie take. Die onderhoud sal op band opgeneem word en alle informasie sal streng vertroulik en beskerm hanteer word. Jy sal anoniem bly indien dit gebruik sou word vir 'n publikasie. Ek sal jou ook vra om 'n skriftelike toestemmingvorm met ons eerste afspraak te teken. Waar sal die mees gemaklikste plek vir jou wees om die onderhoud te voer? Watter dag en tyd sal jou die beste pas? Ek wil net graag 'n paar vrae vra, voordat ek totsiens sê.

Totsiens (Bevestig plek, datum en tyd van eerste afspraak)

APPENDIX B-2: QUESTIONNAIRE TO BE COMPLETED TELEPHONICALLY:

CODE NAME: _____	KODE NAAM: _____
DATE: _____	DATUM: _____
<p>1. Where do you live? Choose from the following:</p> <p>a) With your parents</p> <p>b) With other family</p> <p>c) In a residential facility or group home</p> <p>d) On your own.</p>	<p>1. Waar bly jy? Kies uit die volgende antwoorde:</p> <p>a) By jou ouers</p> <p>b) By ander familie</p> <p>c) In 'n groePHuis of residensiël versorgings oord</p> <p>d) Op jou eie</p>
<p>2. Do you have a job now?</p> <p>a) Yes</p> <p>b) No</p>	<p>2. Werk jy op die oomblik</p> <p>a) Ja</p> <p>b) Nee</p>
<p>3. If the answer to the above question is yes – where do you work?</p> <p>a) Sheltered workshop</p> <p>b) Self-employed</p> <p>c) Open labour market</p>	<p>3. As jy “ja” op die vorige vraag geantwoord het – Waar werk jy?</p> <p>a) Beskutte werkswinkel</p> <p>b) Werk vir jou self</p> <p>c) Ope werksmark</p>
<p>4. Are you married?</p> <p>a) Yes</p> <p>b) No</p>	<p>4. Is jy getroud?</p> <p>a) Ja</p> <p>b) Nee</p>

APPENDIX C: INTERVIEW GUIDE:

These are examples of questions:

Introductory questions:

- How long ago did you finish school? Tell me about what happened in your life since then.
- Could you describe a typical day in the week? Weekend? (where you go and what you do)?
- Which days do you enjoy and why?

Self-care / Self-maintenance: What activities do you do to care for yourself? Are you satisfied with them? Are you satisfied with how you perform these activities?

Probes:

- What is most important to you in terms of your attire and grooming?
- Do you experience any difficulty in managing these tasks? What are they?
- How do you feel about your appearance after completing dressing and grooming tasks?
- What opinion do you think others might have regarding your style of dressing and grooming?
- Are you satisfied with your ability to care for yourself? In what ways?
- Which household chores do you perform regularly?
- Which ones do you enjoy? Dislike? Avoid?
- How do you feel when you cannot manage some of these chores?
- Do you shop for food? What is the experience like for you?

Societal contribution: Tell me more about what you do at work.

Probes:

- What skills do you have that are important for your present job?
- What is the most enjoyable aspect of your job?
- To what extent do you enjoy what you are doing now?
- What valuable lessons have you learned since working?
- If you could change any aspect of your job, what would it be?

- How does it make you feel to be able / not be able to earn your own money?
- Tell me more about how your relationship with your colleagues.
- What does your job mean to you?
- Are there other activities that you do to help others, like family friends, church, community?

Intrinsic gratification: What are the activities that do simply for fun and personal pleasure? Are you satisfied with how you perform them?

Probes:

- Which of these do you find especially enjoyable? What is special about them?
- How do you feel when you are engaging in one of these enjoyable activities?
- What social events are part of your life? How frequently?
- What is especially positive about them?

Reciprocal interpersonal relatedness: Who are the people that are most important in your life and why?

Probes:

- What activities do you engage in with friends? Family?
- Tell me more about your friends and how you get along with them?
- What is important to you in a relationship?
- What are some of the difficulties you've experienced in your relationships with others?
- What role do your parents / siblings or partner play in your life?

Closing questions:

- How do you view your life now?

APPENDIX D: Approval letter from the Ethics Committee

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29 November 2010

MAILED

Mrs G Pieterse
 Occupational Therapy
 2nd Floor, Teaching Block

Dear Mrs Pieterse

"Participation in Meaningful Occupations: How Do Young Adults Living With Cerebral Palsy Experience the Quality of their Participation?"

ETHICS REFERENCE NO: N10/09/315

RE : APPROVED WITH STIPULATIONS

It is a pleasure to inform you that a review panel of the Health Research Ethics Committee has approved the above-mentioned project with STIPULATIONS on 26 November 2010, including the ethical aspects involved, for a period of one year from this date.

1. Delete the word special from the first line of the English telephone consent,

This project is therefore now registered and you can proceed with the work. Please quote the above-mentioned project number in ALL future correspondence. You may start with the project. Notwithstanding this approval, the Committee can request that work on this project be halted temporarily in anticipation of more information that they might deem necessary.

Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.

Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
 Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Héliene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

29 November 2010 08:27

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Approval Date: 26 November 2010

Expiry Date: 26 November 2010

Yours faithfully

MS CARLI SAGER

RESEARCH DEVELOPMENT AND SUPPORT

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29 November 2010 08:27

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APPENDIX E: PARTICIPANT INFORMATION AND CONSENT FORM:

Research Project: Participation in meaningful occupations: How do young adults living with cerebral palsy experience the quality of their participation?

Referencenumber: N10/09/315

Principal Investigator: Gisele Pieterse

Address: Eros School, Tarentaal Rd, Bridgetown, Athlone

Contact number: 021 637 9080 (school), 072 315 8947 (cell)

You are being invited to take part in a research study. It is very important that you clearly understand what this research entails and how you could be involved. Please feel free to ask me questions about any part of the study that you do not fully understand. It is important to know that your participation is **entirely voluntary** and you are free to decline to participate. You are also free to withdraw from the study at any point, even if you do have agreed to take part. This study has been approved by the Committee for Human Research at Stellenbosch University and will be conducted according to their ethical guidelines and principles.

What is the study about and why have you been invited to participate?

I would like to gain information and insight into the experiences of young adults with CP in regards to their participation in meaningful occupations or daily activities. These occupations include: work, self-care, leisure, relationships and involvement in the community. I would also like to find out which of these occupations are most meaningful to you and how you feel about your quality of participation. I am an occupational therapist at the school you attended and that is why you have been invited to participate in this study. I have learned through informal conversations with some of our ex-learners that many of them are unemployed, unhappy and living an isolated life in the community. I hope that the results of this study will have a positive contribution to the lives of these young people.

I will at my own expense conduct interviews with you at a place that is convenient for you. Interviews will be audio taped. The information collected will be treated as confidential and protected. If it is used in a publication or presentation, your identity will remain anonymous.

Declaration by participant:

I,, hereby agree to take part in a research study entitled: "Participation in meaningful occupations: How do young adults living with cerebral palsy experience the quality of their participation?"

I have read or someone had read to me this information in a language I understand and I had a chance to ask questions and all of them have been adequately answered.

I understand that I am taking part in this study voluntary and may choose to withdraw at any time.

Signed at (place)on (date).....

.....

Signature of participant

.....

Signature of witness

Declaration by investigator:

I, Gisele S. Pieterse declare that I explained the above information to and encourage him/her to ask questions, which I answered. I am satisfied that he/she adequately understands all aspects of the study.

Signed at (place) on (date).....

.....

Signature of investigator

.....

Signature of witness

APPENDIX F: DEELNEMERINLIGTINGSBLAD EN – TOESTEMMINGSVORM:

Titel van navorsings studie: Deelname in betekenisvolle take: Hoe ervaar jong mense met serebraalgestemdheid die kwaliteit van hulle deelname?

Verwysingsnomer: N10/09/315

Hoofnavorser: Gisele Pieterse

Adres: Eros Skool, Tarentaal Weg, Bridgetown, Athlone.

Kontaknommer: 021 637 9080 (skool), 0723158947 (sel)

U word genooi om deel te neem aan 'n navorsingsprojek. Lees hierdie inligtingsblad op u tyd deur, omdat dit baie belangrik is dat u ten volle verstaan wat die projek behels en hoe u daarby betrokke kan wees. Indien daar enige deel van die navorsingsprojek is wat u nie verstaan nie, is u welkom om my daarvoor uit te vra. U deelname is **volkome vrywillig** en dit staan u vry om deelname te weier. U sal op geen wyse negatief beïnvloed word indien u sou weier om deel te neem nie. U mag ook te eniger tyd aan die navorsingsprojek onttrek, selfs al het u ingestem om deel te neem. Hierdie navorsingsprojek is deur die Komitee vir Mensnavorsing van die Universiteit Stellenbosch goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

Wat behels hierdie navorsingsprojek en waarom is u genooi om deel te neem?

Ek wil graag ondersoek instel na hoe jong mense met serebraalgestremdheid hul deelname in betekenisvolle aktiwiteite (take) ervaar. Hierdie take sluit in: werk, persoonlike handhawing, vryetydsbesteding, verhoudings en betrokkenheid in die gemeenskap. Ek wil spesifiek uitvind watter take is die betekenisvolste vir hulle en hoe hulle voel oor die kwaliteit van hul deelname in hierdie take. Ek is 'n arbeidsterapeut by die skool waar u 'n leerder was. U word genooi om deel te neem aan hierdie projek, omdat ek net oud leerders gekies het. Ek het deur gesprekke met ons oud leerders geleer dat baie van hulle werkloos, ongelukkig en geïsoleerd lewe in hulle gemeenskappe. Ek hoop dat die resultate van hierdie studie 'n positiewe bydrae tot die lewens van hierdie jong persone sal hê. Ek sal op my persoonlike koste'n onderhoud met u by 'n plek van u keuse voer. Onderhoude sal op band opgeneem word en alle informasie sal streng vertroulik en beskerm hanteer word. U sal anoniem bly indien dit gebruik sou word vir 'n publikasie.

Verklaring deur deelnemer:

Met die ondertekening van hierdie dokument onderneem ek,
om deel te neem aan 'n navorsingsprojek getiteld: "Deelname in betekenisvolle take: Hoe ervaar

jong mense met serebraalgestemdheid die kwaliteit van hulle deelname?” Ek het hierdie inligtings- en toestemmingsvorm gelees of aan my laat voorlees in ‘n taal wat ek verstaan. Ek het ook die geleentheid gekry om vrae te stel en al my vrae was bevredigend beantwoord. Ek verstaan dat ek vrywillig aan hierdie projek deelneem en te eniger tyd mag onttrek, sonder om op enige wyse benadeel te word.

Geteken te (plek)..... op (datum).....

.....

Handtekening van deelnemer

.....

Handtekening van getuie

Verklaring deur navorser:

Ek, Gisele S. Pieterse verklaar dat ek die inligting in hierdie dokument verduidelik het aan En hom/haar aangemeedig he tom vrae te vra en voldoende tyd gebruik het om dit te beantwoord. Ek is tevrede dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.

Geteken te (plek).....op (datum).....

.....

Handtekening van navorser

.....

Handtekening van getuie