

**SPASTIC CHILDREN'S ASSOCIATION OF SINGAPORE SCHOOLS**  
**CERAMAL PALAY COTTAGE**  
**Occupational Therapy Department**  
**Caregiver's Testimonies**  
**Feedback Form**

Date: \_\_\_\_\_

Name of the child: \_\_\_\_\_

1. Did the training meet your expectations? YES NO

2. Do you think you can practice these exercises at home? YES NO

3. Did the education provided to you seem suitable? YES NO

4. Is the home program helpful for you? YES NO

5. Were you satisfied with the overall arrangement? YES NO

6. Would you attend caregiver's training once in a year in future? YES NO

Any other comments: \_\_\_\_\_

Signature by Caregiver: \_\_\_\_\_ Signature by Therapist: \_\_\_\_\_

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### BACKGROUND AND INTEREST FOR STUDY

- "Evaluation should be ongoing and it should take a family point of view, including eliciting family perspectives and observations on goal attainment." (Naar-King, Siegal, Smyth and Simpson, 2000 as cited in Novak and Cusick, 2006, p.262)
- Families, not therapists, determine if therapy has been successful (King, Law, King and Rosenbaum, 1998).

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### AIMS AND OBJECTIVES

- Were the customised home programmes effective?
- If yes, in what ways?
- If no, why?
- Implications for therapists

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### LITERATURE REVIEW

- Definition of Home Programme
- Evolution of Home Programme
- Occupational Therapy and Home Programme
- Existing Research on Home Programme

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### DEFINITION OF HOME PROGRAMME

- "Therapeutic activities that the child performs with parental assistance in the home environment with the goal of achieving desired health outcomes." (Bazyk, 1989; Gajdosik, 1991; Hinojosa and Anderson, 1991; Law and King, 1993 as cited in Novak, 2007, p.463)

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### EVOLUTION OF HOME PROGRAMME

- Medical Model (Bazyk, 1989):
  - Therapy was based in institutions
  - Intervention was primarily child focused
  - Therapist was expert
- Gradually, therapy moved from inpatient service to the home (Appleton, 1991):
  - Intervention was partially directed towards the child and partially towards parents (Piggot et al, 2003).
  - Parents were "therapists and teachers" (Bazyk, 1989).

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### EVOLUTION OF HOME PROGRAMME

- Now:
  - Family-centred Practice (FCP)
  - Parents are recognised as central and expert caregivers (Dunst, 1991; Winton and Bailey, 1997).
  - Families prioritise, plan and direct their child's health care (Winton and Bailey, 1997).
  - Interventions are specifically designed for implementation in the home and in the context of daily routines (Novak, 2006).
  - Therapists are expert partners, their main task is not to treat but to enhance caregiver competency (Washington and Schwartz, 1996).

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### OCCUPATIONAL THERAPY AND HOME PROGRAMME

- OT intervention focuses on improving the child's functional performance to interact with his/her environments (Case-Smith, 1996).
- Children with disabilities require opportunities to practice new tasks repeatedly (Dormans and Pellegrino, 1998).
- Home programmes are used extensively to achieve these desired outcomes (Bobath, 1967; Finnie, 1975; Hinojosa and Anderson, 1991)
- Home programme also serve as an alterative to service provision because of limited access to therapy services, limited resources and waiting lists (Novak, 2006).

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### EXISTING RESEARCH ON HOME PROGRAMME

- Most research to date focus on:
  - Parental compliance with prescribed home programmes (Gajdosik, 1991; Gajdosik and Campbell, 1991; Law and King, 1993; Mayo, 1981; Molineux, 1993; Schreiber et al., 1995; Wortis et al., 1954)
  - Qualitative analysis of parent-child interactions (Hinojosa and Anderson, 1991; Hinojosa, Anderson and Strauch, 1988; Piggot, Paterson and Hocking, 2002; Thompson, 1998; Tyler and Kahn, 1976; Tyler and Kogan, 1977)

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### EXISTING RESEARCH ON HOME PROGRAMME

- Only 1 research to date evaluated the effectiveness of an OT home programme for Cerebral Palsy children using a randomised, controlled trial.
  - Results: Significant differences in function, goal attainment, quality of upper limb skill and parent satisfaction between the sample and control groups.
- (Novak, Cusick and Lannin, 2009)

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### METHODOLOGY

- Research Design
- Sample
- Procedures
- Data Analysis
- Reliability and Validity

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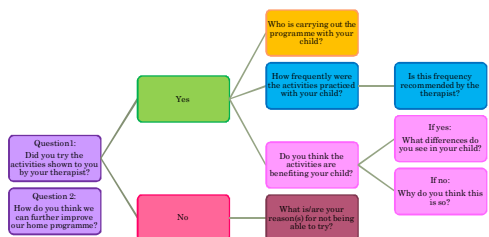
### RESEARCH DESIGN

- Qualitative methodology
- Semi-structured interview

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## RESEARCH DESIGN



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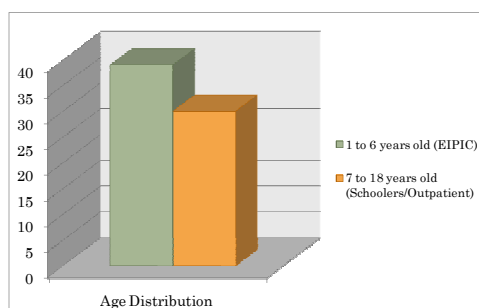
## SAMPLE

- 69 / 97 caregivers who attended the caregivers hands-on training held either in May or November 2010.
- Each participant signed a written consent form.

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## SAMPLE

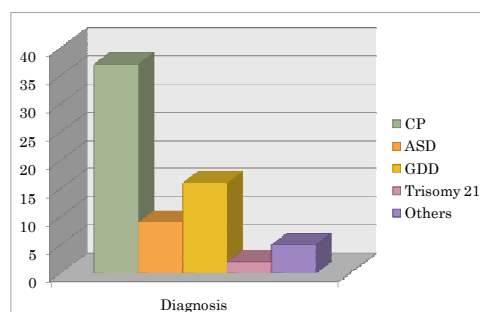


Average Age: 7.38 years old

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## SAMPLE



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## PROCEDURES

- 1 pilot study:
  - Attended the caregivers hands-on training in 2009
  - Audio tape recorded
  - Brought to attention the need for an translator when necessary

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## PROCEDURES

- Interviewing:
  - Each interviewee was randomly assigned to each researcher. No researcher interviewed the caregivers of their respective clients.
  - May training – end 2010
  - November training – early 2011
  - All 69 interviews were conducted individually either at the OT department or over the phone.
  - Each interview lasted between 10 to 30 minutes and was audio taped recorded.
  - Presence of translator when necessary.

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## DATA ANALYSIS

- Interviews were transcribed by 3 OT students on placement and checked through by 1 researcher.
- Transcripts were then coded by 1 researcher through the processes of open and systematic coding.
- All identified themes were verified with the other 2 researchers.

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## RELIABILITY AND VALIDITY

- No researcher interviewed the caregivers of their respective clients.
- Peer reviewing and member checking of data interpretations

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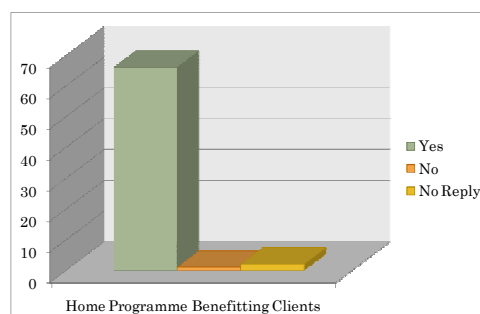
## RESULTS AND DISCUSSION

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- Were the customised home programme effective?
- If yes, in what ways?
- If no, why?
- Implications for therapists.

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## WERE THE CUSTOMISED HOME PROGRAMME EFFECTIVE?



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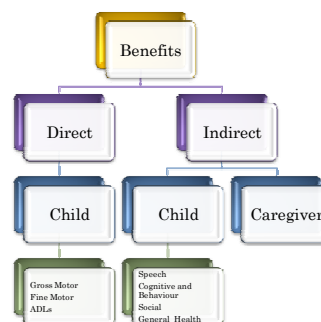
## WERE THE CUSTOMISED HOME PROGRAMME EFFECTIVE?

- Teaching materials are useful:
- *"Of course. Because the therapist actually taught us how to use it. At home, the drawing given to us reinforces what's taught in the session."*
- *"He also give me (a) CD, based on the few exercises which I can follow at home just by viewing. Because sometimes what happens is, when they teach us practically, we might forget few of them even when they give us handouts. But when they give out in CD form, it is also useful, in case I forget to use some exercise, I can always go back to (the) CD and see how the posture is and follow. Handout is also helpful. I not saying is not helpful. But then it compliments with the CD."*

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## IF YES, IN WHAT WAYS?



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## IN YES, IN WHAT WAYS?

## ○ Direct (child)

- *"He was not able to sit straight at times. He is now okay with sitting and he has started crawling"*
- *"Now I see his handwriting has improved a bit, more legible and clearer. There is spacing."*



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## IN YES, IN WHAT WAYS?

## ○ Indirect (child)

- *"She improves also in terms of understanding."*
- *"There is social skills with the brother, better..."*
- *"If no massage and no exercise he will get fits."*



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## IN YES, IN WHAT WAYS?

## ○ Indirect (caregivers)

- *"Yes (it) is very good...sometimes we as parents...we don't know what to do, you all are like our teachers. You teach us to teach our children..."*
- *"So at least make me pay attention to all the small details."*
- Home programmes recognise parents as experts and aim to empower them with skills to improve their child's health (Washington and Schwartz, 1996)



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## IF NO, WHY?

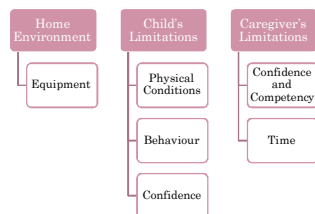
- *"Cannot really see. Cause he's very tight."*

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## IF NO, WHY?

- 9 caregivers were unable to attempt all the prescribed activities.
- 31 caregivers had difficulty adhering to the frequency recommended by the therapists whilst 28 caregivers decided their own frequency based on various factors.



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## IF NO, WHY?

## ○ Home Environment

- *"Some of the activities that are being done, like certain tools or equipment are not available at home."*
- *"I supposed things you all use here, the equipment like the putty. I was having a difficult time trying to find that and trying to get that."*



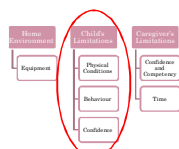
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## IF NO, WHY?

### Child's Factors

- "On a daily basis, I think it is difficult for Kendrick."
- "Sometimes she has fits, she cannot do."
- "It depends on her mood."
- "Sometimes Alvin would not want to do it. He is afraid that his parents are not capable to carry out, saying that OT would know how to do it better. He is afraid that he will fall."



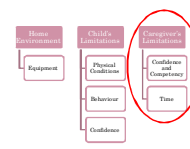
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## IF NO, WHY?

### Caregiver's Factors

- "Certain ones which I can do I will do."
- "Maybe I'm not professional enough."
- "Partly is because we are busy. Need to do housework also."
- "Because I also need to manage my older child, need guide him to do his homework."
- "If I got time I do."



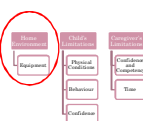
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## IMPLICATIONS FOR THERAPISTS

### Loan Equipment

- "Some of the activities that are being done, like certain tools or equipment are not available at home. So it's good to do by a process where you can loan these to us for a certain period (of time) and we have to return back."



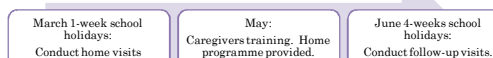
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## IMPLICATIONS FOR THERAPISTS

### Tie-up Home Visits with Caregivers Hands-on Training

- "... home visits during school holiday. Home training also takes into the consideration the environment the child is in thus making the programme more specific."
- "To come and see what we can perform at home...you all might have better idea like (how we) can use this for this purpose..."



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## IMPLICATIONS FOR THERAPISTS

### Teach 1 Technique at a Time (Hinojosa and Anderson, 1991):

- Increase sense of success and competency without feeling overwhelmed (Gajdosik and Campbell, 1991)



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## IMPLICATIONS FOR THERAPISTS

### Embed Activities within Everyday Routine (Anderson and Schoelkopf, 1996; Moersch, 1985):

- Eases caregiving strain
- Increases child's function



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## IMPLICATIONS FOR THERAPISTS

- Increase Frequency for Feedback (Bazyk, 1989; Gajdosik, 1991)
- *"(Will be) good that we can have more talks...to interact and exchange views..."*
- *"The instructions...you must follow up for 2 months then we know that we have to do. Probably we will see a more beneficial effect."*
- *"It should be made available more frequently, rather than once a year. Maybe you guys can consider having it 4 times a year, is also good because we can actually interact with the therapist."*
- *"Suggest some other things for me to teach her. Cause at times she's bored cause it's a repetition."*
- *"I want to learn new activities cause I am already very familiar with the old activities and am tired of it."*

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## IMPLICATIONS FOR THERAPISTS

- In the long run, move towards Family-centred Practice (FCP).

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## LIMITATIONS AND RECOMMENDATIONS

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## LIMITATIONS AND RECOMMENDATIONS

- Lack of randomised control group
- Varied interviewing skills of 3 researchers
- Moderate level of caregivers' compliance

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## CONCLUSION

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## CONCLUSION

- This study has established the effectiveness of SCAS OT home programme from caregivers' perspectives.
- Raised issues with the existing home programme.
- Provided suggestions and recommendations to bring about improvement.

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