

The Development of a Norwegian Program of Intensified Habilitation (PIH)

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Abstract

Objective: To develop an intensified habilitation program for groups of pre-school children with cerebral palsy (CP), their parents and local professionals. In Norway the diagnostic process is provided by the specialist health care, and treatment is given by professionals in the child's home community. The PIH program should represent a supplement.

Methods: Twenty-six CP children aged 2-5 years, representing all Gross Motor Function Classification Scale levels, and their caregivers participated. They were divided into six groups following a program over 1 1/2 years, having 4 inpatient group sessions over 1-2 weeks and in-between accomplish a systematic home-program. The program focused on optimizing the children's home settings, and develop their functional activity, communication and executive functions.

Results: Participation improved the caregivers' knowledge of their child's disability and of training principles (handling). Treatment in the home setting became more goal directed. Improvements in children's functioning were described. Parents reported meeting other parents, as being positive, and the focus on coping in the families as giving them security and competence.

Conclusions: Parents are essential in a preschool child's life. They need knowledge about the different factors that are conclusive for improving their child's qualifications for participation. A multidisciplinary, family centred program organised with group sessions and home periods seems to increase the participants' competence and knowledge. The multimodal program is recommended to consist of five interacting elements: Cooperation, goal directed training, coping and stress handling in the family, improved knowledge of the child and competence in management and training.

Introduction

The diagnostic process for children with CP is in Norway usually provided by the specialized health care. The regular treatment is mainly given by professionals in the child's home community. Parents have regretted not having a specialised treatment program.

The aim of the PIH project was to form a supplementary program to the regular treatment, and within a five years period (2002-2006) to develop an intensified habilitation program for groups of pre-school children with cerebral palsy (CP), their parents and local professionals, within the Norwegian specialist health care.

The effect from participating was to be evaluated.

Methods

Twenty six CP children aged 2-5 years, representing all Gross Motor Function Classification Scale levels, and their caregivers joined 6 different groups. Each group followed a program over 1 1/2 years, having 4 inpatient group sessions over 1-2 weeks and in between accomplish a systematic home program (Fig 1).

The program was dynamic and continuously developing. It focused on optimizing the children's home settings, and developing their functional activity, communication and executive functions (Fig 2).

A pilot study with three of the groups were performed using GMFM tests, PEDI interviews, PSI, LOT, self developed questionnaires and interviews. The clinical developmental process was based on the pilot study, other studies and findings, and a continuous evaluating process with all the participants in the groups.

Acknowledgments

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The PIH Program

Fig.1 PIH A one year program
Group sessions, home program and interactive web communication

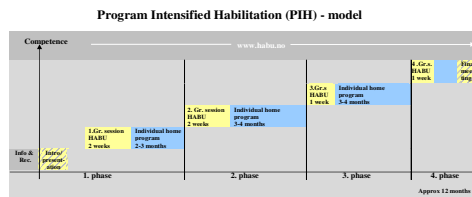
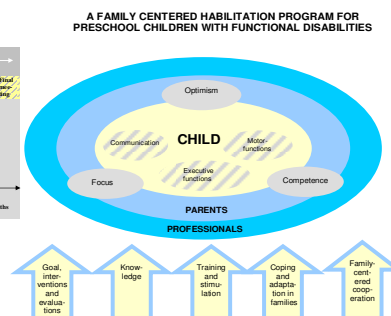


Fig 2. Illustration of the focuses in the PIH program.
The participants, the 5 aspects of intervention



Results

The pilot study and evaluation showed:

Children's PEDI & GMFM results improved (see other poster EACD 2007)

Mothers' PSI & LOT scores were reduced (oral presentation to be given EACD 2007)

Parents reported:

- Meeting other parents as being positive
- Focus on coping in the families as giving them confidence and competence
- Everyday life as being easier and participating as not exhausting
- Experiencing training as being more than physical training
- Executive functions as a central issue
- The program (PIH) as being very welcome and that PIH participation should be offered all families

Parents and caregivers said that:

- Participation improved their knowledge of their child's disability and of training and handling principles.
- Treatment in their home setting became more goal oriented

Discussion

Taking part in the program over one and a half year focusing on the child, its parents and local professionals' seems to have a positive influence on optimising the child's everyday settings, the child's function improves, but further studies needs to be done.

Parents are essential in a preschool child's life. We have assumed they need knowledge about the different factors that are conclusive for improving their children's qualifications for participation.

How to focus and combine the five interacting elements: Cooperation, goal directed training, coping and stress handling in the family, improved knowledge of the child and competence in management and training has to be further developed and studied and there needs to be a continuous evaluating process whether new elements are to be integrated.

Conclusions

Participating in the PIH program being multidisciplinary, multimodal, family centred and organised with group sessions and home periods, seems to increase the participants' competence and knowledge.

The program seems to be an alternative treatment program within the specialised health care that meet's the needs of the participating parents.

Programs will be offered preschool children, their parents and professionals from the Health South and East region of Norway. Further program development and intervention studies will be done.

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