IC 38: FITNESS – FUN – FRIENDS – THE POTENTIAL OF ADAPTED PHYSICAL ACTIVITY (APA)

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This handout materials consist of two files; the first one, a more textual one, presents Beitostølen Healthsport Center (BHC), a summary of the two latest PhD dissertations at BHC with the themes: “Physical Activity and Motivation in young adults with a physical disability” (Saebu 2011) and “I can participate! Children with disabilities and participation in physical activity – a mixed methods study in a habilitation context” (Nyquist, A. 2012).

Further we focus on implications for research and practice. This is follow-up based on A. Nyquist’s dissertation.

Then; “I became a bad girl”. Physiotherapy and physical activity – the stories of adults with cerebral palsy – with implications for children, an introduction, and “Physiotherapy and Physical Activity – Experiences of Adults with Cerebral Palsy, with Implications for Children”, a summary, by Reidun Jahnsen.

The second file is a Power Point presentation of activities from BHC included pictures, descriptions of the APA work at BHC, “Education, Research and Developmental activities at BHC”, and a short version of the Program: “The Local Environment Model” (Nyquist, A. 2007).
Beitostølen Healthsports Center

- **A pioneer institution within rehabilitation**
- **Focus on the potential by means of adapted physical activities**

The objectives of the center is, by means of physical, social and cultural activities, to help persons with mainly physical disabilities to achieve optimal functional independence and ability to be active and participating in daily life. A stay at the center serves as one important of a total rehabilitation "chain", most common at the latter part of rehabilitation. Main focus is on provision of a wide spectrum of activities, in spite of a disability, more than because of a disability - «focus on the potential». The activities offered are to some extent reflecting the Norwegian activity culture, with great emphasis on outdoor activities.

**Historical background**

Beitostølen Healthsports Center (BHC), located at Beitostølen, 830 meters above sea level, was opened Nov 7. 1970. It was to a great extent founded upon ideas and personal experiences of the blind visionary Erling Stordahl (1923-1994). Erling Stordahl served as the director of the center from the beginning in 1970 and till 1994. The program concept was established in cooperation with national health authorities. The building of the center was made possible by means of a national fundraising campaign of the Lions organization.

**Basic information about the operation of the center and facilities**

The center is recognized as an official part of the national specialist health service system in physical medicine and rehabilitation. There is also close relations to voluntary organizations within sports and environmental activities as part of the follow up strategies of the activities at the center. The users of the center are admitted to the center by applications from a medical doctor, also with recommendations and information from other relevant professionals.

**BHC has three main functions;**

1. **Delivery of Adapted Physical Activities (APA) to clients with mainly physical disabilities**
   A stay at the center, usually 4 weeks for adults and 2 ½ weeks for children, is paid for by the Norwegian Social Security System. This also includes guides, helpers or parents that are needed for successful participation in the programs. The short term stay at the center is one part of a rehabilitation process - one link in a "rehabilitation chain".

2. **Research and developmental activities**
   Encompasses cross professional R&D done by staff in cooperation with external scientific professionals. The purpose is to document existing experiences and develop new knowledge in the field of rehabilitation where APA is used to achieve personal rehabilitation goals.

3. **Education and information**
   Encompasses courses and educational programs for APA-students and health service personnel at all educational levels. The center receives national as well as foreign students for practice at the center. In cooperation with Norwegian School of Sports Sciences (NSS) LINK BHC is hosting parts of formal studies in APA at bachelor, master and doctoral level. Such a role also encompasses hosting a number of foreign students from the Erasmus Mundus Master in APA (EMMAPA) LINK
The center has a capacity of 60 residential clients at a time. During a year, about 700 clients, children and adults in the age range from 6-70+ with different disabilities, are staying at the center. There are a good number of students of different relevant professions in practice as part of education at all times. The center has 200 acres of land at its disposal. Besides living facilities, BHC consists of several buildings including a large sports hall, a gymnasium, a therapy pool and a swimming pool, a fitness training room, testing laboratories, indoor riding hall, horse stable, and rooms for different hobby activities. There is a sports stadium, a lake for water sports and fishing, paths in the nature, campfires, cabins, varied XC-tracks and an alpine ski hill.

**Staff and applications at BHC**

There is a balance in staff between professionals with health education and pedagogical education. In addition to the administrative staff (Director, chief of staff, IT- and office services), the personnel is divided into three major divisions:

Clinical services' division
- Medical & social section (medical doctors, nurses, psychologist, social worker, laboratory test personnel),
- Activity therapeutic section(physiotherapists, occupational therapist and horseback riding therapists/instructors),
- Activity pedagogical section(adapted physical activity) specialists, environmental staff, teachers, students in APA and other relevant fields)

The clinical workers are divided into two major cross professional rehabilitation teams; one for adults and one for children. The daily practical activity sessions are organized mainly by the APA specialists and physiotherapists in close cooperation. There is also environmental activity staff in evenings and weekends. The programs are planned in close cooperation with the users' themselves, and organized and monitored of the total professional staff.
A summary of the PhD dissertation: “Physical Activity and Motivation in young adults with a physical disability” (Saebu 2011).

LIST OF PAPERS
The dissertation is based on the following research papers, which are referred to in the text by their Roman numerals:

Paper I:

Paper II:

Paper III:

ABSTRACT
Twenty years of experience at a rehabilitation center has left me with an impression that young adults with a physical disability generally were not very engaged in physical activity and a question whether this was a result of barriers related to the disability, the functioning, or environmental- or personal factors. An initial literature research also indicated that adults with a physical disability are on average less physically active than their able-bodied peers. However, the reason for this difference seemed to be an understudied issue. Therefore the aim of this thesis was to understand and try to find explanations for the physical activity behavior of young adults with a physical disability, and whether this behavior, motivation for it, and outcomes of it, could be influenced through an intervention.

The first study was a literature review which indicated that data on physical activity for young adults with a disability is scarce, and more knowledge about participation in physical activity for this population was needed (paper I). The main purpose for the second study was to examine a) total physical activity; and b) the relative importance of functioning and disability, environmental, and personal factors for total physical activity among young adults with a disability, through a survey (paper II). On the basis of the results from the second study an intervention was introduced, in order to study the outcomes of an autonomy supportive adapted physical activity program on physical activity and motivation variables, and the role of needs satisfaction in the process (paper III).

The literature review (study 1) was based on an electronic literature search. In the second study, 998 young adults with a disability were invited to participate in a cross-sectional study, and 327 informants responded to a questionnaire (study 2). In the last study (study 3), 44 persons participated in an autonomy supportive intervention based on adapted physical activity. The study had a longitudinal design, and repeated measures data were collected through an internet-based questionnaire.
The literature search (study 1) produced 4,189 articles; however, only 57 met all of the specified criteria. Significant correlates were identified in relation to type of disability and functioning, but also among environmental factors (e.g., costs, accessibility, built environment, information and social support) and personal factors (e.g. age, exercise, self-efficacy, depression, and mental health). Very few studies had investigated motivational issues. The sample in the cross sectional study (study 2) reported some differences in physical activity related to type and onset of disability, but analyses revealed that personal factors explained more of the variance in total physical activity than both environmental factors and factors related to functioning and disability. As for the general population, autonomous motivation and identity as an active person were the factors most strongly associated with physical activity behavior (Trost, Owen, Bauman, Sallis, & Brown, 2002). Results from the intervention study (study 3) demonstrated that perceived autonomy support positively predicted psychological needs satisfaction at the end of the intervention. Furthermore, needs satisfaction was positively linked to changes in autonomous motivation for physical activity, and was also indirectly associated with physical activity increases during the intervention period. The autonomy-supportive physical activity intervention also led to a positive change in perceived physical health over twelve months. Finally, psychological needs satisfaction was positively linked to changes in perceived mental health during the intervention.

The literature search revealed a lack of documentation on environmental, personal and functional factors which may be associated with physical activity in this population. There was also a lack of theory-based studies and studies investigating motivational issues. The importance of autonomy-support and autonomous motivation regulation should have important implications for how one motivates people with disabilities to engage in physical activity, and how rehabilitation is implemented. In order to motivate individuals with a disability, increasing perceptions of autonomy and autonomous motivation are the strategies which have the potential to make the greatest impact.

In rehabilitation, the focus has often been on the health imperatives of physical activity, supervised by medical expertise. In terms of self-determination theory, this is a more controlled motivation with emphasis on the health benefits as opposed to autonomous motivation driven by positive experiences of the activity in itself. The present study indicates that autonomous motivation, autonomy support, and need satisfaction play a more important role in predicting physical activity and physical- and mental health among young adults with physical disabilities. This should encourage health care practitioners to emphasize autonomy supportiveness in rehabilitation settings.

**Keywords:** disability, rehabilitation, physical activity, self-determination, motivation, physical and mental health

This study contributes to increased evidence-based knowledge on children with disabilities and their participation. It is based on children’s perspective in a habilitation context with participation in adapted physical activity as the main intervention. The background of the study is the discrepancy between the importance of participating in self-initiated play and leisure activities, and the possibility of such participation for children with disabilities. Participation restrictions in children with disabilities are well documented (Grue & Rua, 2010; Imms, 2008a; King et al., 2003; Orlin et al., 2010; Tøssebro & Ytterhus, 2006). However, research in the field documents few explanations for these restrictions. And only a small part of this research takes children’s perspective.

The overall purpose of this study is to generate knowledge and to explore issues of importance about possibilities, wishes, and experiences from participation in physical activity of children with primarily physical disabilities at a rehabilitation center in Norway and in their own local community. The child-centered approach of the study is grounded on the children’s and their parents’ participation in 1) the development of the research questions, 2) the exploration and adaptation of the evaluation instruments, and in 3) the generation of empirical data.

Participation is in The International Classification of Function, Disability and Health – Children and Youth (ICF-CY, WHO 2001) defined as involvement in a life situation, and is a complex and dynamic phenomenon. The thesis is based on the framework of ICF-CY as well as on the understanding of activity and participation as subjective bodily experiences in a given context (Duesund, 1993, 2007; Merleau-Ponty, 1994). Disability is understood as a relational phenomenon (Grue & Rua, 2010), and the understanding of childhood and peer context is interactionistic (Frønes, 2007; Ytterhus & Tøssebro, 2006).

The overall purpose of the study and the wish for pluralistic empirical data requires a comprehensive theoretical perspective, which is the rationale for the use of a mixed methods design (Greene & Hogan, 2005; Tashakkori & Teddlie, 2003, 2010).

The first part of the thesis describes and discusses the children’s perceptions and wishes related to participation in physical activity during, and three months after, a three weeks stay at a rehabilitation center. A total of 149 children and their parents participated in the first part of the study. Data was gathered by means of a semi-structured interview, Canadian Occupational Performance Measure (COPM), and six children and parents participated in depth interviews. The children express a clear wish to participate in familiar activities, and there are some gender differences in the choice of activities.

Some differences between the priorities of the children and their parents are also revealed. However, there are more similarities than differences between the subgroups. Even if the perception of the performance and the satisfaction with the performance of the chosen activities is fairly good ahead of the three weeks at the rehabilitation center, both the children and their parents report improvement in performance and satisfaction with the performance during the stay and three months after.
The results indicate that some of the experiences at the rehabilitation center enhance the carry over to participation in the local community. This happens when the children 1) are given the opportunity to choose the activities, 2) to improve their activity skills, and 3) to experience mastering of joyful activities in company with peers in similar situations.

The second part of the thesis looks at children’s wishes and actual participation in physical leisure activities in their local community. This includes what they do, how often, with whom, where, and how joyful they find the activities. The results document that the subjective experiences are very positive and meaningful on one side, but unpredictable and challenging on the other side, making it difficult to participate. These data come from 149 children conducting The Children’s Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC), and from in depth interviews with five children.

By means of the analysis across the two study parts, both the children’s wishes and their actual participation in activities are clearly revealed. The actual participation in the activities gives a lot of joy, and the social dimension is crucial. The children actually do what they want to do, but they want to do more than they actually do.

Participation in physical activities for children with disabilities seems to be enhanced when the children are allowed to choose their own activities. The children use individual strategies for optimizing their own possibilities to participate. These individual strategies include the tuning in of own prerequisites and skills, and the need for adaptations in the actual situation. This may appear as unpredictable. However, it seems to be shaped by the child’s will, competence, and joy of participation. It is reason to believe that the sense of involvement is crucial for participation in physical activities, both at the rehabilitation center as well as in the local community.

The generated knowledge of this study may contribute to the understanding of enhancing and restricting factors regarding participation of children with disabilities. The study reveals that the children have competence to participate actively in the choice of activities and in defining their own goals for participation. It is important that the staff in habilitation units and at rehabilitation centers use the children’s and the parents’ competence to enhance participation of children and their families by focusing on the joy of participation, and by asking which activities the children and their parents find meaningful and feasible in their local community.

**Keywords:** Children, disability, adapted physical activity, participation, habilitation, leisure activities, mixed methods
Follow-up work: Implications for research

Due to the limited number of studies in this field, it is a need for further research to strengthen the evidence base on children’s participation in meaningful activities based on a child centered perspective. It is crucial to collaborate with those concerned in the development of research questions, to ensure the relevance for the daily life of the participants, which also includes clinical professionals who can enhance research with clinical and practical relevance.

The following three challenges need to be addressed in future research:

1) Challenges related to the heterogeneity of the samples of children. Studies of different subgroups of children (age, gender, ethnicity, type of disability) would generate complementary knowledge.

2) Challenges related to transition phases. Longitudinal studies about factors that are important for remaining active during all the transition phases from childhood to adulthood, would give insight in participation as a dynamic phenomenon that is changing continuously.

3) Challenges related to the knowledge of activity characteristics and different arenas. Future research should focus on the specific potential of different physical activities, their specific content, the organization of the activities, and the possibilities of adaptation of the activities.

Future research including enjoyment in activity from the participants’ perspective, interpreted in a contextual frame, should be prioritized. The children’s participation in research projects and focus on the importance of the social dimension of participation will not only bring the rehabilitation field further and strengthen the children’s participation; it will also develop rehabilitation research further methodologically.

Implications for practice

Transfer of research results to clinical recommendations demands first of all attention on the validity and relevance of the results in specific clinical contexts.

Second, it is particularly important to emphasize to what extent the research is meaningful in the daily life for those concerned (Bredahl, 2007). If the research is oriented towards the real challenges in clinical practice and the unique experiences of the individuals living with different disabilities, the relevance and benefit will increase.

Therefore it seems relevant for the understanding of this study to start with evidence based practice built on the following model; 1) the best available research based knowledge, 2) experience based knowledge, the practitioner’s judgments of the benefit or lack of benefit, and the aim of the research, 3) user knowledge and user participation, the user’s own insight and experience (Haynes, Devereaux, & Guyatt, 2002; Hutzler, 2011; Spring, 2007). These three elements together will represent the best knowledge base for clinical decision making.

There are three recommendations that in sum may show how the results of the present study will have implications for practice:
1. Enhance the attitudes that give the children possibility to use their competence on their own situation and need for adaptation, so that they can use their own experiences.

This means to ask for the children’s opinions and strengthen aspects that make the children experience their competence on their own situation as important. The children managing their own daily situations and adaptations will in turn contribute to further use of their competence.

2. Recognize the importance of skill acquisition in meaningful activities as requirements for participation with peers.

To own sufficient skills in an activity is important, and the skill concept should be flexible regarding adaptation of the activity and its performance. To develop skills in an activity which is important in a specific context seems to be a strategy that facilitates participation in activities with peers. Peer relationships are the most important part of the social dimension of participation (Koster et al., 2009).

However, there are two central factors that modify this fact, and which are important for clinical practice. First, the children may not know about all the activity possibilities. If they are going to extend their activity repertoire, arrangements and adaptations should also be made for participation in new and unknown activities. Second, to develop sufficient skills in new activities will demand time and an appropriate arena, which the children point out as often unavailable in the local community. This will have impact on clinical practice. In the present study the rehabilitation course, where the children participate in activities with peers with similar disabilities, appears as such an arena, embedding the possibility to explore and gain skills in new activities.

3. Focus on enjoyment in activities

The importance of enjoyment in activity might be crucial both in a short and in a long term perspective. This is supported by former research which emphasizes the fact that participation in self-initiated, enjoyable, and variable activities with peer support is important for staying active (Erikson & Granlund, 2004; Morris, 2008). Experience of enjoyment and meaningful participation in physical activities as a child is a predictor for staying active as adult (Jahnsen, 2003). Recent research also shows that there is a clear association between internal motivation and activity level among young persons with disabilities (Sæbu & Sørensen, 2010; Sæbu, 2011). More focus on enjoyment may contribute to the prevention of the known social problems described in children and youth with disabilities (Davis, 2007).
"I became a bad girl". Physiotherapy and physical activity – the stories of adults with cerebral palsy – with implications for children

Habilitation policy in Norway:

- Before the second world war many disabled persons were hidden away, often placed on farms to work for food
- In the 1950’s NGOs started rehabilitation of children with disabilities in institutions and special schools (polio, war traumas, CP, MMC)
- Treatment optimism – focus on motor training – “to get well” – “you can if you want” – “the-be-happy-game”
- From the 1970’s the policy of integration and normalisation emerged
- Gradually transition from a “medical” to a “social model” of understanding disability
- NGOs were inspired by The Civil Rights Movement, Women’s Liberation and The Independent Living Movement.
- The Norwegian Health Directorate published: “From user to citizen” (1998) – declaring equal opportunities to participate actively in society according to your own ability and in your own way. Built on The UN Declaration of Human rights, Convention on the Rights of the Child, Anti-discrimination Act, and Universal Design

This presentation is based on two studies:


Aims: To explore self-reported expectations and experiences of function and life situation in adults with CP and contribute to a life span perspective on the follow-up of persons with CP

Method: Semi-structured interviews with 15 adults with CP, a strategic sample from the Cerebral Palsy Association in Norway. Three of the researchers had CP themselves. The interviews were transcribed and analysed according to editing analysis style

Results: The participants were 9 males and 6 females from 30 – 72 years (mean 45 years). The interviews describe that all the participants expected to live independent lives with predictable functional ability, and with an education, a job, a home, and a family like any other adult person. All the participants had their own home, seven were married or cohabitant, and four had children. However, even the youngest participant had experienced a shocking and unexpected deterioration of function, causing an existential crisis, like having a new disability. All except the oldest participant had physiotherapy during most of their childhood. However, the participants, their families and the health professionals were not aware of the possibility of early functional deterioration, with all its consequences for participation in different contexts of the society. Six participants had university education. However, only one participant was still working full-time, three had never had a job, while the others had reduced or stopped work in early age with economic and social consequences.
The story of Liv, born in 1943 with CP. Liv’s father said to her mother: “Promise me that we will never hide Liv away”. Liv trained with her mother on the kitchen table. “I was told to train to get better, but better than what? She could both walk and talk and just wanted to play! I became a bad girl. In my mind I know that I am not that bad, but I still feel like a bad girl” (57 years old) Her mother said: “How you will hate me since I didn’t force you to train!” Five years ago Liv passed away from cancer, which was diagnosed four weeks before she died.

The story of Tora, born in 1960 with CP. She was living on a small island with her family. There was no PT on the island, but now and then she went to town by boat with her mother to see a PT. “I was lucky, because I understood why I had to train, and was motivated. I trained to be able to participate with the others”. The only way to get around with the other on the island was on a bike. Tora works 50% as a consultant for Church of Norway on matters related to persons with disabilities.

**Conclusion:** There is a gap between expectations and experiences among health professionals, relatives, and persons with CP regarding: 1) CP being a stable condition and 2) Possibilities of participation in independent adult life as long as universal design is not a human right. There is a need for follow-up programs with: 1) life span perspective from early childhood to contribute to the prevention of early reduced function 2) research on causal pathways to the deterioration of function in CP 3) focus on balance between personal resources and demands in the environment 4) reducing disabling barriers in all arenas of the society


**Abstract**

**Aims:** The aims of the present thesis were:

To investigate the prevalence and time of onset of new secondary problems such as pain, fatigue, and deterioration of functional skills in adults with cerebral palsy (CP), and to identify and discuss variables potentially related to the new secondary problems.

To investigate coping potential, expressed as sense of coherence, and to identify and discuss variables potentially related to low sense of coherence in adults with CP. Norm based comparison was of special interest, both regarding coping potential and the new secondary problems. Our findings may be used in the development of life span follow-up strategies for persons with CP, and in further clinical studies on potential causal pathways.

**Methods:** A multidimensional questionnaire was sent to 766 adults with CP, 18 years or more, with no documented intellectual disabilities, living in Norway. The questionnaire included demographic and diagnostic items, items on new secondary problems and on experiences and needs for life span follow-up. In addition standardised instruments, such as, The SF 36, The Fatigue Questionnaire, The Barthel index, Life satisfaction scale, and The Sense of coherence scale (3-item version) were used.
**Results:** Totally 406 adults with CP (53%) from 18 to 72 years (mean 34 years), 51% males and 49% females, responded. The prevalence of chronic pain and chronic fatigue was 28% and 17% respectively, and 45% experienced deterioration of locomotion skills, mostly before 35 years of age. The prevalence was significantly higher, and the health problems occurred much earlier in adults with CP than in the general population. The new secondary problems were significantly associated with each other, with severity of motor impairment, low life satisfaction, and lack of adapted physical activity. They were most prevalent in persons with moderate and severe grade of CP, dependent on risk factors related to strain in specific body parts of the different types of CP. These findings may indicate association with both overuse and inactivity. Sense of coherence was significantly lower in the adults with CP than in the reference group, especially in the domain of comprehensibility.

**Conclusion:** Low sense of coherence and new secondary problems such as pain, fatigue, and deterioration of locomotion skills were significantly more pronounced in adults with CP, compared to the general population. Severity of motor impairment, overuse, and lack of adapted physical activity were important predictors regarding the experience of new secondary problems. These findings indicate a need for systematic follow-up programs for persons with CP in a life span perspective.

One of the papers in the dissertation is the following:

*Advances in Physiotherapy 2003; 5:21–32*

*Physiotherapy and Physical Activity – Experiences of Adults with Cerebral Palsy, with Implications for Children*

R. JAHNSEN 1, L. VILLIEN 2, G. AAMODT 3, J. K. STANGHELLE 1 and I. HOLM 4
Abstract
The present study is a postal survey on adults with cerebral palsy (CP) in Norway and their experiences with physiotherapy and physical activity. The respondents were 406 persons with CP, without intellectual disabilities, 49% females and 51% males between 18 and 72 years (mean 34 years). Type, amount and experience with physiotherapy and physical activity were reported addition to demographic, diagnostic and locomotion data, and data on new health problems, such as deterioration, chronic pain and fatigue. Almost all the respondents (92%) received physiotherapy as children, while 40% had physiotherapy and 46% performed physical activity regularly as adults. The study documents that physical activity may contribute to prevent deterioration, chronic pain and fatigue in adults with CP; however, grade of CP is the strongest predictive variable. The strongest predictive variable, significantly associated with regularly physical activity as an adult was having learnt how to take personal responsibility for personal health during childhood. These experiences give valuable information, which could be used to make better life span follow-up programs for the persons with CP.


CONCLUSION
The present study documents that physiotherapy and physical activity plays an important role in the life of children with CP, and that physical activity may contribute to prevent deterioration of functional skills, chronic pain and chronic fatigue in adults with CP. However, grade of CP is the strongest predictive variable in relation to deterioration and chronic pain. The study also documents that less than half of the respondents reported that they had learnt how to take personal responsibility for their own health in a life span perspective. These respondents were regularly physically active as adults. The present study supports Suzann Campbell’s study (20) on “Therapy programs for children that last a lifetime”. These therapy programs need to have contents that create inner motivation and understanding of the importance of life long active and balanced use of the body. Some indications are given as to what kind of contents these are, but further research in this field is necessary. However, active participation in goal setting and choice of meaningful activities is essential from an early age.

IC 38: FITNESS – FUN – FRIENDS – THE POTENTIAL OF ADAPTED PHYSICAL ACTIVITY (APA)
Fitness, fun and friends are the meaning of life for young people. If this is going to be gained, enjoyable activities should be introduced in social settings from an early age, to provide experiences where the impairment fades into the background and fun and friends become the dominating experience. This will hopefully develop both physical and psychological fitness, self-esteem and self-determination in addition to strength and necessary motor skills.