

Ethical aspects in research in Adapted Physical Activity¹

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Abstract:

This paper discusses some of the ethical aspects in research in Adapted Physical Activity. It indicates some of the ethical challenges related to the choice of research problem to be investigated, and the treatment of participants, not least when working with people who are in some ways in a more vulnerable life situation. Drawing also on experiences as a researcher with a disability, the challenges and potential benefits of involving people with disabilities in APA research is critically discussed.

Introduction

Adapted physical activity (APA) is a cross-disciplinary body of knowledge centred on making physical activity possible for people who experience difficulties with movement (Reid 2003: 20). It is a young and interesting area of research with many topics yet to be explored. Having worked in the area since 1993² and participated in international conferences in APA, however, I have been surprised by the apparent lack of discussion and questioning of ethical aspects of the research. With a background as a trained clinical psychologist, I have been 'brought up' in a tradition where ethical aspects should always be considered³. Now, working in the field of research and APA, I find that ethical considerations are often overlooked, or at least seldom discussed openly and in a committed way.

Ethicists of science look at science as a process, as a form of socially organised human activity. Scientific activity has assumptions, consequences and functions that demand ethical and political assessment and legitimisation (Tranøy 1986). It is this ethical assessment and legitimisation, where research carried out seen as part of a bigger picture that I want to promote here within the debate concerning APA research. As expressed by McNamee: ethics should be in the heart of sport as a practical activity, and every topic in sport necessarily has an ethical dimension, often of considerable significance (2007).

In the field of APA good and useful research is being done, where the aim and justification is obvious; in some research in APA it seems more unclear, and the same applies with regard to treatment of participants and other ethical issues. In some studies it appears as if researchers have not given these aspects the attention that I believe they deserve. Instead, ethical aspects sometimes seem to be treated more like useful technical reminders of how to conduct research and as 'having to pass an ethical committee', securing that the research is 'not harmful to the research subjects', and that the statistical significance of the results is of great importance to the study. This is a somewhat harsh stance, and I will seek to illustrate and discuss it critically through examples in this article.

Reid (2000) indicates in his article "Future directions for inquiry in APA", that there have been few philosophical papers in APA, which is unfortunate, since ideology plays an important part in APA. He finds that ethical considerations have to be one of the future's main areas for development in APA; and writes:

"A careful study of ethics will assist adapted physical activity to critically evaluate accepted rules and practices. A value system, thereby created, in

conjunction with databased experience and experiment, will guide intervention." (Reid 2000: 370)

While Reid's remarks were written in 2000, the topic has still received very little attention in *Adapted Physical Activity Quarterly* (APAQ), the main journal in the field. In fact when searching through the articles published in the journal since then, it has not been possible to find any articles that have ethical issues as their main topic.

In research in APA it has also been surprising to discover the lack of participation of researchers who themselves have a disability⁴. It is noticeable seen in the light of approaches promoted by the disability rights movement, where the necessity of involvement of people with disabilities in the research that concerns them is strongly advocated (Charlton 2000, Johnstone 2001, Barton 1996). Bridges (2001), however, indicates that it is not a matter of 'outsiders' (from the group in focus for the research) not being able to make valuable and ethical sound research, still the lack of involvement is striking as APA research and statements today often seem to promote inclusion.

I am well aware that ethics in research is a comprehensive topic, yet more than providing answers, I want to indicate some of the ethical challenges in research in APA, make some suggestions and most of all invite a debate on the matter.

Choosing topics for research in APA

Can choosing topics for research in APA research be seen as an ethical challenge? To what degree does a study need to have an obvious purpose or aim to solve a problem? It could be projects such as: "Fitness of Black African Early Adolescents With and Without Mild Mental Retardation" (Onyewadume 2006) or

"The ideal relation of extensor and flexor muscles of the knee as the target of rehabilitation programs" (Tsaklis 1998). Do we have a special obligation when researching with human participants? Of course there is a wide span ??? the types of research and I am well aware of the distinction between therapeutic and non-therapeutic research (McNamee 2007), where the first (potentially) aims directly to benefit participant(s), which is not the case or aim in the latter. Precisely how well the type and the aim of the research is communicated to potential participants, without overestimating the potential outcome of the research is also an ethical consideration. Haywood (1977) also stresses how there are types of studies that have already been researched enough, for instance studies comparing people with disability with those without. While researching developmental challenges of growing up with a visual impairment and the possible benefits of participation in physical activity (Bredahl 1997), the article with the title "The effect of regular exercise programmes for visually impaired and sighted schoolchildren" (Blessing et al. 1993) appeared. The 60 youngsters in the study (half of them with visual impairment) completed a physical test, then subsequently a 16-week training program, and finally were retested. The results were hardly surprising; the students who had trained became fitter, whether they were visually impaired or not. It might not seem fair to single out this particular project, as it is not unique in kind; nor am I criticizing the way in which this particular study was carried out. It made me wonder, however, precisely what assumptions lay behind the study. Moreover, what were the researchers actually trying to examine or test; as it has already been demonstrated numerous times that physical training makes people fitter. It is not the design of the study that I question, as the same study could have been interesting if it had been carried out with a different group of participants: people with multiple sclerosis or muscular dystrophy, for instance. These diagnoses affect people

in a way that would make it interesting to investigate whether or not participants would benefit from a particular form of physical training, or perhaps whether it actually had an opposite effect. Acknowledging my limited understanding of physiology, I do not, however, find any justification for a hypothesis that training would *not* affect muscle strength and oxygen uptake simply due to a lack of vision.

This might not seem like an ethical problem. As Haywood (1977) emphasizes, however, when researching with human participants, it is an ethical consideration for researchers to reflect upon to what degree the project is likely to be meaningful to society or to the participants, and also whether the resources we use and the effort we ask of the participants is worth it with regard to the possible results of our projects.

Mentioning projects like the ones above is not meant as examples to demonstrate that quantitative or medically based research is not meaningful or important. There are many examples of such research, but also examples of research that could benefit from a greater dialogue with practitioners and athletes. At one APA conference, for instance, a wheelchair basketball player presented the problem: "We use normal height basketball hoops when playing wheelchair basketball. The hoops used are constructed to fit two metre tall men, who are able to jump. When we sit in a wheelchair and are not able to jump, the height of the hoops excludes many players with more severe injuries from the play. He raised the question: *What hoop height is optimal for including the most players without losing the characteristics of the game?* Unfortunately the scientific committee of the conference turned down his paper, and he had to settle for a poster presentation (Mills 1998). The issue he raised, however, was a question, which researchers could look into from a biomechanical perspective in order to find answers that could make a difference by helping to solve a problem

raised by an athlete who had experienced a practical problem in his sport. This could be seen as an example where a closer dialogue between researchers and people with disabilities might benefit both the researchers in finding interesting topics for research, as well as benefit the people it aims to assist more than what might often happen today.

Treatment of participants

Another ethical concern that I wish to raise is the treatment of participants in research. It is a concern shared across medical and social research traditions, and an issue that always should concern us as researchers. This, not at least when researching with participants, like in APA, that in some ways could be seen as vulnerable.

Although the meaning of a study like the one mentioned concerning youngsters with visual impairment above could be questioned, it is not likely to have been harmful to its participants. I find, however, that in order not to do 'harm', it is important for researchers to consider not only the risk of physical injuries to the participants, but also consider the risk of psychological stress, and to make sure that the participants in the study are treated with dignity (Resnik 1998, Drowatsky 1996). By 'dignity' I mean treating participants with respect and not making them participate in anything pointless or humiliating. Although in much research, the treatment of participants in research appears to be taken seriously, I have listened to presentations of research projects at APA conferences, where participants did not seem to be treated with dignity. Frankly, this research could have been done just as well with rats.

Consider the example of researching reaction time with a Down's syndrome population (Tranda, Boikou, Batsiu 1998). The aim of the project was to test whether people with Down's syndrome could improve their reaction time. To test this,

participants were asked to practice pressing a button repeatedly over a three-week period, and their reaction times and improvements were measured. The study concluded that it could be demonstrated that the participants had improved their reaction time.

On hearing the presentation, I asked about the purpose of the study, and whether the results potentially could be of benefit for the participants, for people with Down's syndrome in general or to professionals working with people with Down's syndrome. The presenter, however, did not understand my question, and repeated that the aim was to test whether people with Down's syndrome, by practicing pressing a button for three weeks, could improve their reaction time. According to the presenter, however, this would not make any difference in the participants' everyday lives. I consider a project such as the one described above, to be ethically questionable. This, not because of the way in which the study was designed, as it could have been relevant if presented as a part of a larger complex issue, or possibly if it had been carried out with a different target group. If, for instance, the study had concerned elite-level fencers, some milliseconds might potentially have made a difference to their performances.

Some might argue that it is solely up to participants to decide whether they want to participate in any type of project. I do not discourage such arguments, I would, however, question how clear the purpose of the study was to the participants and I would also emphasize the authority of the position of being a researcher holds while recruiting participants.

The ethics of this study seem even more questionable, since the involved participants (here with Down's syndrome) might not fully understand the purpose of the study or what their participation implied. A challenge when working with a group of participants like this is to make sure that the participants understand the meaning of the project, and also understands the meaning of 'informed consent', which includes the right

to withdraw from a project one does not wish to participate in any more (Ervik 1998, Reid 1993, Bannerman 1990, Stineman, Musick 2001).

This project might not have been directly harmful to its participants, yet for both the participants themselves and for the purpose of accumulating knowledge for society, I would say that the results had a very limited use. It raises questions about the responsibilities of organisers of conferences and editors of journals: to what extent is ethics considered when selecting studies for presentations? Some might suspect that the research in a project such as the one above is more concerned with providing an opportunity to produce and present a paper at an international conference than it is with ethical issues and the treatment of its participants.

When I relate my experiences of witnessing such questionable projects to my colleagues in Norway, they find it hard to believe. Their surprise and doubt are supported by the fact that an ethical committee in Norway would not be likely to approve such projects.

One could say that the example mentioned above is just a matter of poor research; however also in research by well established researchers I find a lack of discussion of more fundamental ethical questions. One example is the highly regarded set of studies with the aim of providing training programs to enable babies with Down's syndrome to walk earlier than they normally would (Ulrich et al 2001). The research shows that participation in a daily training programme hastens the babies' ability to walk by an average of three months, which means they walk at an average age of 21 months. I do not doubt the results or the sincere effort put into the study, there is however some more fundamental questions I find it relevant to raise like; why is it important to walk earlier? An answer like 'to walk closer to what babies normally do', is not sufficient. It is not a matter of that these children would never be able to walk, so is

one perhaps just pushing a skill that would come in due time? From my point of view it would be relevant to examine questions like: what are the meanings of walking; does earlier walking provide the child with opportunities that it otherwise would not have had; and is it possible to see any difference later on in life between children who did and did not participate, a difference that possibly could be linked to the project?⁵ It could also be interesting to look at how the family as a whole was affected. Was having to train the disabled child every day, worth the effort for the family as a whole in order to speed up the child's process of learning how to walk? Ethical considerations like these might strengthen the study.

Involvement of people with disabilities in APA research

The involvement of, and influence by, the people who are the focus for studies is often a challenge in research. In the field of APA today I find that the voice of people with disabilities has been heard only to a very limited extent, and they have not often had the chance to actually influence the topics being researched. This remains the case in spite of the fact that inclusion is often stated to be central in the APA approaches.

Consider, for example, the following:

“It is about advocacy in physical activity and promoting self-advocacy in people with a disability. [...] It is an attitude about *including rather than excluding people*, but we can acknowledge a number of activity settings.”

(Reid 2003: 20, *my italics*)

Whether the lack of involvement of people with disabilities in the research can be seen as an ethical question, is open for debate. Consider, by contrast, the articulation of ethics in Aristotle's writings, as a practical discipline rather than a

theoretical one; ethics is not reducible to right statements but rather instantiated in one's actions and character. Under this description the conduct of APA research must be seen to promote inclusion not just in theory, but also in practice, I find the lack of involvement of people with disabilities in research remarkable.

At APA research conferences, for instance, very few of the participants have had a disability themselves⁶. By participants I mean being researchers or students who actively take part in the presentations and discussions at the conference. During the conferences people with disabilities typically have only got the chance to show themselves, when 'entertaining the guests' by showing their skills in practical sport, dance or music. The fact that they contribute in this way is valuable, as it reminds conference participants of central issues and helps to set a frame for the presentations and discussions. People with disabilities, however, need not only to be seen or heard but, also, to a greater extent, to be listened to in the research of APA, to be *involved* in it. By 'involvement' I mean to participate in conducting the research, or, just as importantly to provide inspiration by revealing relevant and interesting research topics.

APA, however, is not the only area dealing with issues that relate to people with disabilities that is struggling when it comes to the practical representation of the researched in research. In 2007, for instance, I participated in a Nordic conference in Special Education on 'inclusion'. Interestingly, not a single presenter in the three-day conference had personal experience with being included and being in need of special adaptation to make participation possible. Quite thought-provokingly the organisers also failed to provide an electronic version of the programme (readable to visually impaired participants); neither did they provide the requested hearing loop to the other disabled participant. Challenged on this the organisers replied that they had not imagined that any disabled person would participate. As I see it, however, 'inclusion'

is about participating and feeling welcomed, not about having to 'fight for your right' to get access and get the adaptations needed. Examples like these support the contention that there is still far to go in order to put theory and good intentions into practice.

I reconfirm the widespread view that current researchers, the research conducted, and the potential participants in research in both Special Education and APA could all benefit from a greater involvement of researchers with disabilities. So why are so few people with disabilities involved in research in APA?

Challenges in involving people with disabilities in APA research

The challenge of being biased One of the arguments that might be raised against involving people with disabilities in research could be that they could be too personally involved, and therefore have difficulties being both professional or objective in their research. When researchers research topics she or he has personal experience with, it is always relevant to consider the risk of 'going native': that is, losing one's critical or professional distance as a researcher (Kvale, Brinkmann 2008, Tregaskis, Goodley 2005). In some research traditions, biases are seen as a problem because they can affect the possibility of being 'objective' that is, being neutral and 'free from bias'. In research traditions such as German critical psychology (Holzkamp 1983???) and phenomenology (van Manen 1990), this is viewed differently: when doing research it is not a matter of being biased or not, but a question of being aware of which biases one has in order to take them into account. As emphasized by Edmund Husserl, researchers are not and cannot be objective or neutral, and, therefore, that 'objectivity' cannot be seen as a prerequisite for doing good research (Spinelli 2005).

The challenge of being biased is an issue often raised with regard to qualitative research. Yet to do quantitative or experimental studies, however, does not eliminate the fact that researchers have biases. Subjectivity is present in the topics we choose, and the methods we choose to use: both are influenced by our presuppositions. For any researcher, interest in the topic is an important prerequisite for doing good research, but also requires that we are on the guard and check our findings, no matter the method we use. To check the findings is also part of doing good and ethical research.

To be a researcher (with a disability), it is important to be aware that ones personal experiences might differ greatly from the experiences of the participants in ones research. These are challenges, however, that are shared with all other researchers, with or without disabilities, and no matter what we research.

To be biased and to be in a unique position In research concerning 'disability', being biased, by having a disability and having experiences in participating in APA, could also be seen as giving the researcher a unique position, when trying to understand the participants' situations and statements. Tregaskis (2005) emphasizes how being a researcher with a disability researching issues related to disability holds challenges, but also how it can be of help in the phase of collecting and analyzing research data.

Today, however, research in APA is carried out almost exclusively by able-bodied researchers⁷. As Bridges (2001) indicates, the fact that a person does *not* him- or herself have a disability does not mean that he or she cannot do good, valuable, and ethically sound research, and I would add the following corollary; just as being a researcher *with* a disability does not dispose him- or herself '???'to go native'⁸. I find,

however, that it is a pity that the field of APA does not make fuller use of contributions from colleagues who both have the professional background and personal experience with disability. There are parallels in this discussion with arguments raised by early feminist researchers (e.g. Bjerrum Nielsen 1995) and also in the *disability rights movement* (Johnstone 2001, Barton 1996, Charlton 2000). Both approaches challenge traditional research and question whether research about women should rather be carried out by women, and that research concerning people with disabilities should be carried out by people who themselves have disabilities.

As Bridges (2001) indicates, however, the discussion risks supporting the assumption that research by someone who is in a 'unique position' is better, and that it can only be carried out by someone who is in a similar situation to the persons the research concerns. He argues that the position is not logically tenable, let alone desirable. This might not always be practical, easy or even possible, if for example, the research concerns children, people with learning difficulties or with dementia. Involving participants like those is not impossible, but might demand that researchers need to use different methods, like, for instance, certain research being done in developmental psychology researching infants (Stern 2000, Gopnik, Meltzoff, Kuhl 2000). I would not advocate that it is *necessary* for researchers to have a disability in order to do good and relevant research concerning disability, at the same time, however, I think that researchers who themselves live with a disability (just like living a life as a woman or a man) tend to gain insights into the challenges a disability *can* create and can contribute with more perspectives on the issue. This could include, for example, experiences of being visibly different from others, or being in need of assistance more often than most others, or experiences of not being treated with

dignity. Experiences like these might be of value also during the process of finding relevant topics for research.

The importance of involving the people the research concerns and the 'nothing about us without us' approach, as emphasized by Charlton (2000), does not seem to have influenced the practice of the research in APA to any great extent yet. If we look to other fields today, there is a greater awareness of the importance of involvement of the groups the research concerns. Research concerning women is done by both men and women, as well as research concerned with ethnic minorities tends not to be carried out solely by researchers belonging to the ethnic majorities.

Although the involved researchers might be both qualified and eager to do good research, if nobody from the group under investigation is involved, however, it seems appropriate to ask: *why not?*

Practical barriers in going into research as a disabled researcher The fact that few people with disabilities are involved in research has not only to do with prejudices, lack of interest or qualifications, but also with practical hindrances in society. Hindrances for participation have been extensively explored and described in the social model of disability (Swain 1992, Hales 1996, Oliver 1996, Charlton 2000). Researchers with disabilities, not only have to overcome disabling barriers, but also to fight them constantly. This applies whenever attempting to gain access to a school or university, applying for a job, getting the necessary technical and practical support, and getting access to knowledge necessary in order to do the job. I, for instance, began my career as a staff member at university by having to wait ten months for my adapted computer to arrive so I could start to work. My sighted colleague waited for a week for his non-adapted one. As a visually impaired researcher it is a challenge to get access to literature

in a readable format, as access is being restricted by copyright protection. Quite paradoxically, even to obtain a copy of the existing electronic version of *Protection of Human Subjects with Disability: Guidelines for Research* (Stineman Musick 2001) has so far been impossible, or probably, illegal⁹. One could also ask whether to deny certain groups access to available information because of disability, might be viewed as an ethical problem. Experiences like these have, in addition to generating a great deal of frustration, provided important knowledge, and inspiration to continue the research relating disability and APA.

Inclusion in practice in APA research If the field of APA research were to make better use of the knowledge and insight provided by those who live with a disability and who have experience with participating in physical activity, some hard choices need to be made.

To what extent can those of us in the field of research in APA today say that we, for instance, encourage gifted students with disabilities to go into research; that we select students with disabilities to attend conferences; and that we make an effort to give the floor equally to researchers with disabilities? Attracting more people with disabilities to become involved in APA research does not occur only through resolutions on equal rights passed by the World Health Organization and the United Nations; it occurs mainly through the daily choices that each of us make locally. Attitudes are not the most important thing; it is *actions* that make a difference. If researchers in APA truly want to advocate inclusion, they should support the resolutions by including people with disabilities in the field to a greater extent than happens today. This would help show both people with disabilities and society at

large that people with disabilities' opinions and contributions are valued and should be taken seriously.

Involvement of people with disabilities is slowly improving No doubt, matters can improve, of which there are several encouraging examples. In 2006 the board of the *International Federation of Adapted Physical Activity's* (IFAPA) decided to appoint a person to be *Disability Community Liaison*; ensuring that there will always be at least one person at the board at any time, who besides being a professional also has a disability. At the same time, the board was made aware of the difficulties in accessing the IFAPA homepage to people with visual impairment, and an immediate decision was made and the money granted to carry out the necessary adaptations. This is an example of a barrier that wasn't made to deliberately exclude people, but was simply a lack of awareness. It can also serve as an illustration of how collaboration can help improve matters.

Just as the extent of a disability is affected by society's willingness to allow for the participation, this goes for the field of research in APA as well. The International Symposium in Adapted Physical Activity (ISAPA) in Brazil 2007 was the first ISAPA ever to also offer the conference programme in an electronic format, while none of the previous organisers had made the effort.

Prior to the ISAPA 2007 the organisers invited me as a keynote speaker at the Brazilian APA conference¹⁰. To me this was an honour, while for many of the participants it was a new experience to meet a researcher, who had a disability, was an athlete and had contributed to research in APA. In the studies, many had focused more on how to be of help to people with disabilities, and had less experience of being taught by them. To actually give the floor to researchers with disabilities at

conferences can be viewed as an ethical choice, and can be one way to change perceptions, and build bridges between professionals, and athletes, and researchers with and without disabilities.

As a researcher I was also different in the way that I presented research based on qualitative methods, while the conferences has traditionally been dominated more by medical, physiological, and sociological approaches. Studies based on qualitative methods potentially give the participants a chance to raise their voices, and to be listened to. However, I am aware that it is not the method, but just as equally the topics chosen, that might benefit from the participation of researchers with disabilities. I am also aware that this does not guarantee better research or a greater amount of research *with* and not only *on* people with disabilities, but I think that it increases the chances.

The future of ethical aspects in APA research

In this article I have indicated the apparent lack of discussion of ethical issues in research in APA, and given some examples of the challenges and its consequences. I have also called attention the ethical dilemma the lack of involvement of people with disabilities in APA research presents, and discussed some of the benefits that research in APA could gain from a greater involvement of people with disabilities.

When Loland (1992) writes about sport sciences being a young field that consists of very different approaches, from biomechanics to phenomenology, this applies to APA, as well. In fact, one could say that APA is an even younger field. Perhaps the fact that APA is a young field has meant that the emphasis has been put on its establishment and legitimization as a science, with more focus on the natural sciences

and the technicalities of research, rather than on giving attention to, and debate on, ethics in research.

APA being a relatively new field of research, like other (young) fields, continuously constructs and reconstructs itself. This means that the choices that researchers make, the conferences they hold, and the journals that publish their findings play an important part in this construction (Loland 1992). To develop good ethics in research is a joint responsibility, but researchers and organisers of research conferences have a central role in establishing good and reflected practices, which should also be reflected in the acceptance of papers for presentations at conferences.

To improve the involvement of people with disabilities, however, require choices and encouragement by people already involved in research. My claim is that a greater involvement of people with disabilities would contribute to both the internal and external validity in research in APA. If we want to change things, however, we must be willing to change practice to allow for participation, both in society and in the field of research in APA.

When I look to the future of research in APA, I am optimistic. I do not see the lack of involvement as an active, deliberate exclusion of people with disabilities by those without, but more as a bad practice based on old habits. This might be seen as an academic difference, as it results in the same practice: very few people with disabilities are involved in research in APA. Although the current researchers do not *actively* refuse involvement of people with disabilities in research, I, on the other hand, do not see many making an extra effort to involve them. I believe that those of us who do research with any minority group have an ethical obligation to make an extra effort, both in order to make a statement, and to benefit the researched and the research itself.

I have no doubt that the existence and visibility of the Paralympics has inspired new athletes to participate in physical activity. The Paralympics shows that there is a variety of ways to do sport and also what is possible for people with disabilities to participate in and to achieve. In the same way a better representation of people with disabilities in research will demonstrate that disability is not a hindrance to contributions in research. Such contributions can be varied, as it is with participation in physical activity and sport. Not everybody has the capacity, the talent, the will or the wish to become a Paralympian, nor to win a gold medal. Similarly, not everyone disabled or not, has the capacity, talent, will or wish to become a researcher. Those that do, however, ought to be encouraged and welcomed. The involvement of people with or without disabilities in research in APA, is not a matter of an "either or", but of how to develop a better "both and", through a greater collaboration and join together the efforts of researchers with a variety of qualifications, interests and experiences, which also includes having disabilities.

A greater involvement of people with disabilities might also help call attention to ethical issues in research, like ensuring that participants are being treated with dignity. This assumption is, amongst other, supported by my experiences in attending gatherings with other people with disabilities. Even at the highly competitive Paralympics, I have often experienced participants being attentive to each others' needs, like a Russian athlete with one arm who helped a French blind athlete who was lost, or an American athlete in a wheelchair who was immobilised, being pushed by a Chinese visually impaired athlete.

A greater involvement of people with disabilities in research might enhance its possibility of research looking into more important and relevant issues. As the example of the wheelchair basketball player illustrates, there are many problems out

there in the world waiting to be explored and researched, from a variety of approaches, jointly.

A greater involvement of people with disabilities into research on different levels; as formulators of topics for research, as researchers and as members of ethical committees, will, of course, not solve all ethical problems in APA, but might improve some and will be a step in the right direction. Not least of all, I think it would benefit the necessary discussion of important ethical issues in research in APA.

Notes

¹ An earlier version of this paper was published, in an earlier version, in proceedings from the conference ISAPA 2007 Rio Claro Brazil.

² As my academic journey into the area of APA is influenced by my personal experiences as a visually impaired, as a once clumsy kid and later a paralympic athlete it seems appropriate to mention in this context my multifaceted engagement with APA.

³ This is not to say that psychological intervention can not be ethically questionable, of course it can be, but at least it is open for ethical debate and expected to be so.

⁴ For the scope of this article I will use a broad definition of the term 'disability', understood as; individuals who have physical, sensory or mental challenges to a degree that it requires some adaptation to make participation in physical activity possible.

⁵ Whether it had to do with the actually walking or the interaction with an adult during the project is a further question.

⁶ Confirmed to me through personal correspondence with Claudine Sherrill, founder and former president of IFAPA (January 2008). She also confirmed that this fact has not often been questioned or documented in writing.

⁷ Confirmed through personal correspondence with Claudine Sherrill January 2008.

⁸ Uncritically surrender to the host norms.

⁹ As reported by the librarian at my university, after contacting the publisher!

¹⁰ SOBAMA 2005 Rio Claro Brazil

References

Bannerman, D.J., J. Sheldon, J.A. Sherman, and A.E. Harchik. 1990. Balancing the right to habilitation with the right to personal liberties: The rights of people with developmental disabilities to eat too many doughnuts and take a nap. *Journal of Applied Behavior Analysis* (23): 79-89.

Barton, L., ed. 1996. *Disability and society*, Addison Wetly Longman ltd.

Bjerrum Nielsen, H. 1995. Kvinneforskning som et kritisk korrektiv. *Kvinneforskning* 4: 40-48.

Blessing, D.L., D. McCrimmon, J. Stovall, and H.N. Williford. 1993. The effect of regular exercise programmes for visually impaired and sighted schoolchildren. *Journal of visual impairment & blindness* 87: 50-52.

Brantlinger, E. 2005. Qualitative Studies in Special Education. *Exceptional Children* 71(2): 195-207.

Bredahl, A-M. 1997. Kan man løbe fra problemene? Om synshandicap, idræt og fysisk aktivitet. København: Hans Reitzels Forlag.

Bridges, D. 2001. The Ethics of Outsider Research. *Journal of philosophy of Education* 35(3): 371-386.

Brinkmann, S., and S. Kvale. 2005. Confronting the ethics of qualitative research. *Journal of constructivist Psychology* 18: 157-181.

Charlton, J. 2000. *Nothing About Us Without Us: Disability Oppression and Empowerment*. University of California Press.

Drowatsky, J.N. 1996. *Ethical decision making in Physical Activity Research*, Human Kinetics, Champaign, Illinois.

Duesund, L. and F. Skårderud. 2003. Use the Body and Forget the Body: Treating Anorexia Nervosa with Adapted Physical Activity. *Clinical Child Psychology and Psychiatry* 8: 53–72.

Ervik S. N. 1998. Forskningsetikk. *Nordisk tidsskrift for spesialpedagogikk* 3: 146-154.

Fitzpatrick, D., and Watkinson. 2003. The Lived Experience of Physical Awkwardness: Adults' Retrospective Views. *APAQ* 20(3): 279-297.

Goodwin, D. L., J. Krohn, and A. Kuhnle. 2004. Beyond the Wheelchair: The Experience of Dance. *APAQ* 21(3); 229-247.

Goodwin, D. L., and K. Staples. 2005. The Meaning of Summer Camp Experiences to Youths with Disabilities. *APAQ* 22: 160-178.

Gopnik, A., A.N. Meltzoff, and P.K. Kuhl. 2000. *The scientist in the crib: What early learning tells us about the mind*. New York, HarperCollins.

Hales, G., ed. 1996. *Beyond Disability. Towards an Enabling Society*, SAGE Publ., London, UK.

- Haywood, H. C., 1977. The Ethics of Doing Research . . . and of Not Doing It. *American Journal of Mental Deficiency* 81(4): 311-317.
- Johnstone, D. 2001. *An introduction to Disability Studies*. David Fulton Publishers Ltd London.
- Kvale, S. and S. Brinkmann. 2008 (in print). *InterViews: Learning the Craft of Qualitative Research Interviewing*, Second Edition, SAGE publ., USA.
- Loland, S. 1992. The Mechanics and Meaning of Alpine Skiing. Methodological and Epistemological notes on the Study of Sport Technique. *Journal of Philosophy of Sport* XIX: 55-79.
- McNamee, M., S.P. Olivier, and P. Wainwright. 2007. *Research ethics in exercise, health and sport sciences*. London & New York, Routledge.
- Mills, A. J. 1998. Comparison of shoot styles between 8FT 10FT baskets in wheelchair basketball, Third European Conference in APA, Thessaloniki Greece.
- Oliver, M. 1996. Defining impairment and disability: Issues at stake. In *Exploring the Divide*, edited by C. Barnes. The Disability Press: 29-54.
- Onyewadume, I.U. 2006. Fitness of Black African Early Adolescents With and Without Mild Mental Retardation. *APAQ* 23: 277-292.

Resnik, D. 1981. *The Ethics of Science*. Routledge, London.

Reid, G. 2003. Defining adapted physical activity. In *Adapted physical activity*, edited by R.D. Steadward, G. Wheeler, and E. Watkinson. Edmonton, Canada: University of Alberta Press: 11-25.

Reid, G. 2000. Future directions on inquiry in Adapted Physical Activity. *Quest* 52: 369-381.

Reid, G., J.M. Dunn, and J. McClements. 1993. People With Disabilities as Subjects in Research. *APAQ* 10: 346-358.

Spinelli, E. 2005. *The Interpreted World: An Introduction to Phenomenological Psychology*. SAGE Publications, Inc.

Stern, D. N. 2000. *The interpersonal world of the infant*. Basic books.

Stineman, M.G., and D.W. Musick. 2001. Protection of human subjects with disability: guidelines for research. *Archives of physical medicine and rehabilitation* 82: 9-14.

Swain, J. et al. 1992. *Disabling Barriers – Enabling Environments*. SAGE Publications, London, UK.

Tranda, V., I. Boikou, S. Batsiu et. al. 1998. The exercises adaptation for the improvement of reaction time, as it concerns people with Down's Syndrome. The third European Conference in APA, Thessaloniki Greece.

Tranøy, K. E. 1986. Vitenskapen - samfunnsmakt og livsform. Universitetsforlaget, Oslo.

Tregaskis, C., and D. Goodley. 2005. Disability Research by Disabled and Non-Disabled People: Towards a Relational Methodology of Research Production. *International Journal of Social Research Methodology: Theory & Practice* 8(5): 363-374.

Tsaklis, P., G. Ambatzidis, K. Beis, and A. Kitsios. 1998. The ideal relation of extensor and flexor muscles of the knee as the target of rehabilitation programs. The third European Conference in APA, Thessaloniki Greece.

Ulrich, D.A., B.D. Ulrich, R.M. Angulo-Kinzler, and J. Yun. 2001. Treadmill Training of Infants with Down Syndrome: Evidence Based Developmental Outcomes. *Pediatrics* 108(5): e84.

Van Manen, M. 1990. Researching lived experience. Human science for an action sensitive pedagogy. Ontario, Canada: State University of New York Press.

Vehmas, S. 2004. Ethical Analysis of the Concept of disability. *Mental Retardation*. 42(3): 209-222.