

Newsletter

June 2001

Special Interest Research Group 'Individuals with Profound Multiple Disabilities'



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Editorial

In September 1998 we produced a Newsletter for an (at that time) unofficial Special Interest Research Group “Individuals with profound multiple disabilities”. Our general purpose was to bring interested persons together and stimulate discussions which we had already started between colleagues from Norway, Sweden, Germany, Belgium, England and the Netherlands. In the following two years we realized several objectives.

First of all, we made an administration of possible members. Next, we asked IASSID for an official status (which was realised in 2000) and produced our first Newsletter. Most important, we co-ordinated a number of symposia on the world congress in Seattle. Five symposia on PMD were realised and we found participants from at least three other symposia to join us. After Seattle, we started with updating our list of members and informed them about the conditions of IASSID to be a member of the SIRG. With some members of the board, we discussed our plans for the future in Germany.

This newsletter will inform you about several subjects.

- We repeat in short our description of the target group: individuals with profound multiple disabilities.
- We inform you about our plans for the coming years of the SIRG. Most important, we want to inform you about the conference we are planning in October 2002 in Amsterdam.
- In this Newsletter, we offer you the official list of members of the SIRG and the members of the board. In this way we hope to stimulate communication between members of the SIRG. The list is also known by the IASSID and can facilitated contacts between members and persons outside our SIRG.
- As a special issue, we offer you a list of scientific articles and books over the last five years about PMD.

Profound multiple disabilities

To prevent misunderstandings in our SIRG, it is necessary to describe again what we mean by individuals with profound multiple disabilities (see also Vlaskamp and Nakken, 1999).

Individuals with profound multiple disabilities form a heterogeneous group, both in terms of the origin of the disability as in terms of functional and behavioural repertoires. Chromosomal abnormalities, degenerative diseases, inborn errors of metabolism, congenital brain damage and the results of serious infections can all lead to a profound multiple disability.

The 'core group' consists of individuals with such profound mental disabilities that no existing standardised tests are applicable for a valid estimation of their level of intellectual capacity and who possess profound neuromotor dysfunctions like spastic tetraplegia. Apart from profound intellectual and physical disabilities, it is presumed that they frequently have sensory impairments. The prevalence of cerebral visual disturbances in individuals with profound multiple disabilities is supposed to be very high. Individuals with profound multiple disabilities also have an overall risk of developing medical complications relating to, for example, seizure disorders and almost all require regularly administered medication. A number of profound multiple disabled people have gastrointestinal feeding tubes or suffer from physical difficulties with food ingestion. Individuals with PMD form a physically very vulnerable group of persons with a heavy or total dependence on personal assistance for every day tasks, 24 hours a day.

The described 'core group' has some overlap with two other 'groups'. The first 'group' contains individuals who are at the extreme lower end of the continuum of profound mental disabilities and who also possess physical impairments due to dysfunction of certain organs or physical inactivity. The second 'group' contains individuals with profound motor disabilities as a consequence of spasticity and skeletal deformities and 'only' severe mental disabilities.

Plans for the next three year

It is not difficult to start a SIRG, but it is not so easy to run one. First of all, you need a representative board for the SIRG. Recently, we succeeded in bringing together an international board. Fortunately, most of the time we can use the electronic highway in stead of the 'old fashioned' time consuming and expensive meetings to discuss plans for the future.

You need an up-to-date list of members, an administration and a possibility to communicate directly between board and members. To realise this, we employed a student-assistant and we intend to continue this (probably each year with a new student) for the coming years. Thirdly, you need a plan and you have to carry out such a plan. This is the most interesting but also the most difficult part of the job.

Our plan for this moment consists of three components:

1. We have to exchange information with all the members and interested parties. For this goal, we will continue to publish *Newsletters* (one or more) each year. The Newsletters are only effective if the members of our SIRG are willing to give us actual information about topics related to important issues in the discussion about the rearing, education or support of individuals with PMD. Like: examples of good practice, descriptions of research projects and publications on fundamental or applied research. We invite you to support us!
2. In Seattle, participants expressed the need to discuss good practice and research extensively. This is only possible when we meet in a conference. Therefore, we have the intention to organise a *two days conference on education and support of individuals with PMD in October 2002 in Amsterdam*. The first day will be organised for members and invited guests only and the second day will be open for public. The first day will consist mainly of discussions about statements or short presentations and of course we will discuss the initiatives of the board. The second day, members and invited guests are able to offer a lecture. We will also offer other interested guests the possibility for poster presentations. Soon we will inform you in more detail about the content of the conference, where you can sign up for a presentation, who we want to invite etc..

To organise and finance such a conference, we established the foundation OOO which stands for Foundation for Research on Education and Support for Individual with PMD (in Dutch: Stichting Onderzoek naar Opvoeding en Ondersteuning van personen met (ernstige) meervoudige beperkingen).

Make a reservation in your agenda for 2002!

3. Although June 2004 is three years from now, we must consider our contribution to *the 12th World Congress of the IASSID in Montpellier*, France. David Felce (member of programme committee) informed us about his intention to give the SIRGs the opportunity to stimulate and co-ordinate a number of coherent symposia on research related to their particular theme (as we already did in some way in Seattle on our own initiative). How we can realise this, how we have to decide about topics for symposia or even poster sessions and if we must ask for plenary sessions (with what content) is one of the items to discuss in Amsterdam. In the meantime I will inform David of our agreement with his idea to involve the SIRGs in the organisation of the World Congress.

We welcome any suggestion about activities of the SIRG. Please, write us or sent us an e-mail. You will find the (e-mail) address on the last page of this newsletter.

Scientific articles and books on ‘Individuals with profound multiple disabilities’

For members of the SIRG, it is of utmost importance to exchange information. One of the ways to do this, is by internationally published articles. This list was made by Liselot Huijsmans and Inge Smit and is up-dated by Leonard Hordijk, all master-students in the department of orthopedagogoy from the university of Groningen.

We have searched for articles in three ways:

1) Part of the list was made by scanning the following databases:

- ERIC
- PSYINDEX
- PSYCINFO
- SOCIOLOGICAL ABSTRACT
- LLBA
- MEDLINE

And we used the keywords:

- Profound multiple disabilities
- Profound multiple handicaps
- Profound mental retardation
- Profound learning disabilities

We limited the amount of articles by only searching for articles from 1997 onward.

2) Personal knowledge of board members.

3) Information mailed to us by members of the SIRG.

Criteria for selecting articles or books are:

- Publication is in English
- It is internationally published (books with ISDN-number or international journals)
- The title has to refer to persons with profound multiple disabilities

However, we must have missed important information and articles that you can send to us!

You can send it to us any time! Just mail to: sig.mult.dis@ppsw.rug.nl

The articles should preferably be in English, but you can also mail us on articles on German or French, but English abstracts would be preferred. If you have highly relevant articles in any other languages, it is necessary that you send us a translation of the title and an English abstract.

Choi, S., Meeuwssen, H. e.a. (1999). Learning and control of simple aiming movements by adults with profound mental retardation. In: *Adapted Physical Activity Quarterly*, April, 16, p. 167-177.

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List of members of the SIRG

The first informal list of participants on a not certified SIRG originated from 1996, in Helsinki. This could be called our basic list of interested members.

In 1999 the list was up-dated, based on information from the members and at the international conference in Seattle in 2000, new members were added.

In January this year, all members were mailed in order to update the list again. The persons that reacted and who were willing to become an IASSID-member (or stay one) are now on this list.

We present to you our final list and will ask you the following questions:

- Would you please check all the data in the list and keep us informed on any changes?
- Do you know people who you think would be interested in being a member of this SIRG, who aren't already? Please mail us their (e-mail) address, so we can get in touch with them.

Thank you very much.

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3. Announcement Congress Amsterdam 2002

Who will organise it?	Special Interest Group PMD
When?	October 2002
Where?	Amsterdam, The Netherlands
What subject?	Education and support of individuals with profound multiple disabilities

Further and more detailed information will follow shortly!