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A Rewarding Encounter - Mentally Handicapped Adults Make Acquaintance with the Easy-to-read Book and Newspaper
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ABSTRACT

The article describes mentally handicapped persons' great need of books and news and the easy-to-read publications in Sweden. The key role of the environment as a factor influencing reading is discussed as well as a project the purpose of which is to try to increase mentally handicapped persons' access to books and news through reading representatives. The project was pursued in close cooperation with the libraries.

PAPER

1. The life of mentally handicapped in Sweden today

Leave the child in a nursing home -this was the advice that most Swedish parents of mentally handicapped children received as recently as 25-30 years ago. Luckily enough, it appears selfevident to the same parents today to let the child grow up at home. The situation for mentally handicapped in Sweden has changed dramatically. For adults the completely isolated existence in giant nursing homes has been replaced by a life in a flat of one's own with home visitor support. The passivating inactivity has been replaced by work in small groups of mentally handicapped who are attending to worktasks of their own and with a special work supervisor. As best this is done at an ordinary workplace. Mentally handicapped have been given dignity, but it has been a long way and a tough fight above all for deeply involved parents who formed the joint organisation FUB. The fact that our country has undergone a fantastic economic development for a long time also had its influence. A forceful legislation today provides mentally handicapped with a multitude of special rights: personal support and assistance, a flat and service by home visitors, daily occupation, relieving staff to replace relatives, etc.

However, there are areas indicating that there is quite a distance left until the life of mentally handicapped can be compared with the life of others not burdened by handicaps. Such an area is leisure time and culture. The life of mentally handicapped in their leisure time is frequently isolated and meagre. Lacking in things which are selfevident to us -to be able to read one's morning paper, relax with a good book, listen to the radio and grammophone music, watch favourite programs in one's own TV set, go downtown to have a chat with a pal for a while, and so on. All this is impossible to most mentally handicapped. Of course the handicap is one obstacle. So very little of options is adapted to their handicap. But the most important obstacle is the lack of human support. Very often, persons in the environment of mentally handicapped do not observe these special needs and give no support to fill them. We will now take a closer look at one of these special fields, mentally handicapped persons' need of and access to books and news.

2. Is it really any point in giving mentally handicapped news and literary experiences?

Many of us would probably be inclined to answer no to that question. In any case people are questioning the use of this to those who cannot read. After having studied this subject in depth for a couple of years we would like to call out: Mentally handicapped are those of us who have a special need of reading experiences and of news! That many of them

cannot read is no obstacle -somebody else can do it for them! On the other hand, what is to be read is to be adapted to the handicap, in other words, easy-to-read.

The handicap makes the life of mentally handicapped restricted. Speech and language deficiencies obstruct the contact with others. Difficulties to make do on their own outside their home makes the world around unexplored and people and environments unknown. But books and newspapers make the world grow! The handicap also means that it proves difficult to formulate thoughts, questions and reflections and to express one's feelings and to process experiences. However, others can describe things in a way to make one recognize oneself- in the book or the newspaper. To listen to what is said in a book about love may, for instance, generate questions which would otherwise never have been put: How is it to be in love? How do I know if somebody likes me? To recognize oneself in a narrative is possible also for individuals devoid of speech. We know of a mentally handicapped man who did not speak. He had recently lost his father. His most important way to process his grief was to time and time again listen to a book on mourning.

Mentally handicapped persons need someone who reads for them. But they also need a listener, a partner in oral communication. To have a chat while the reading goes on is at least as important as it is for children when they read and chat. This makes reading impart knowledge and development at the human level. However, the access to easy-to-read information about the society, to news and books is ultimately a matter of democracy, a requirement in order for mentally handicapped to also become part of the community. This is why their joint organisation FUB has been pushing the requirement that good and easy-to-read alternatives are to be created.

3. What is the Easy-to-Read (ER) Foundation and what are we doing?

The task of the ER Foundation is to make news and literature easy to understand and easy to read for people who experience reading difficulties or are unaccustomed readers. Our activity is an investment in cultural politics and handicap support and is based on government decisions. The government appoints our Board of directors and adopts our regulations. Our operation is financed with subsidies granted by the government and also by income. Until now the subsidies have been 8 MSEK (1 MUSD). Recently the subsidies have been raised to 13 MSEK (1.7 MUSD). This reflects an obvious desire on the part of the government and parliament to improve the access to culture and information for individuals suffering from functional disturbances. The increased subsidies enable us to publish a larger number of issues of our publication and also more books.

The foundation commenced its operation in 1987 and its field of activity has been gradually extended all the time. Today there operate within the foundation:

- * One publishing company with an editorial office publishing easy-to-read (ER) books.
- * An editorial office producing an easy-to-read newspaper, 8 PAGES.
- * A marketing department operating a mailorder bookshop. The department produces i.a. a New Books publication where you can order new ER books.
- * Processing of certain community information into easy-to-read text matter is undertaken by the foundation as commissioned by certain public authorities.

Among our readers there are mentally handicapped persons, persons deaf from early childhood, aphatics, people with reading difficulties, immigrants and school-children. Our primary target group is mentally handicapped adults. Other groups we have been able to reach comparatively easily by ordinary marketing means, whereas mentally handicapped persons require special efforts.

4. The easy-to-read (ER) book and newspaper

8 PAGES is an easy-to read newspaper containing -8 PAGES. It is published weekly and contains news from Sweden and other countries, sports, cultural information, etc -just like other printed news media. But 8 PAGES tells of what happens in an easily understandable way. The text items are short and there is a lot of pictures. The newspaper is also available on cassette. The history of easy-to-read (ER) books in Sweden dates far back. In 1968 the first ER book was published. Today there are approximately 350 ER books and 15-20 new ones are being added every year. Most of the books contain pictures, drawings or photographs. It is particularly important that the pictures support the text matter. The ER books may roughly be divided into three groups:

- Adapted classics, i.e. already existing pieces of general literature which have undergone processing in order to become easier to read and to understand.
- New general literature- the authors are writing in "easy-to-read" language directly. This includes e.g. novels, tales, fiction, poetry, but also books where the picture plays a central role; some of these contain very little text matter. The ER books represent different degrees of "easy reading".
- Fact books -a very heterogenous collection of books containing everything from photographic reports on wellknown musicians and dance-bands to books with drawings of herbs and flowers.

All ER books are available on tape and can be borrowed at the libraries. Part of the new general literature books are available as cassette books, which means that you can buy them. We have also translated a picture book into a video film.

5. Traditional marketing methods do not function

Although the ER book and the ER newspaper 8 PAGES have existed for many years, only very few mentally handicapped use them. We know this from our own statistics, the borrowing rate at libraries and not least by our contacts with mentally handicapped themselves and with staff and relatives. Ordinary methods to reach a target group do not function when it comes to reaching mentally handicapped people. As we know, most of them have no ability of their own to read. One consequence of this is that these persons do not get accustomed to books and newspapers. They are taught that books are intended for those who can read and understand better than yourself. Mentally handicapped persons are in most cases dependant on others in order to carry on a reasonably normal life. They need help in order to cope with their everyday life and they need assistance to read. But they also need assistance in order to understand that what is inside a newspaper or a book may be entertaining, interesting and useful even if you are a mentally handicapped person.

Decisive for an interest to read is that the environment provides this assistance. The environment may consist of relatives, friends, personnel, teachers or others. These persons are the real gatekeepers. If they do not contribute to creating an interest in reading, the book and the newspaper will never reach the target group. Unfortunately the human environment does not always understand how important the reading of books and other publications is for mentally handicapped and this means that the persons around do not help these persons to read. To an increasing extent we are realising the necessity of informing, stimulating and influencing the human environment of mentally handicapped people. Only if this is done, mentally handicapped will be reached by news and literature.

Hopefully, the persons in their environment will discover what excellent aid the ER newspapers and books are in their own interaction with mentally handicapped persons.

6. To invest in reading representatives- the only alternative for reaching mentally handicapped readers

The Swedish organisation for mentally handicapped, FUB, has in many ways committed itself to easy-to-read publishing. Access to news, information and literature is, to mentally handicapped, as well as others, completely decisive for taking part in social life. And participation and influence are today the most important objectives to reach for mentally handicapped in Sweden. If those providing those benefits are so passive that mentally handicapped are not reached by the ER production, this is a gross injustice. Democratic rights to which all mentally handicapped are entitled such as voting rights, become meaningless if nobody assists them with information enabling them to form an opinion! For this reason FUB has started a project jointly with the ER Foundation. Within the scope of this project we will investigate if one can increase the engagement of the human environment in reading by aid of reading representatives. An important fact from which to proceed is that information only has proved completely insufficient. Printed matter has been distributed to personnel working with mentally handicapped people, the libraries have supplied information on a personal basis to the same target groups although the results have in most cases been disappointing. This has hardly made the personnel concerned more active. The unavoidable conclusion -this is no informative problem. It is a matter of attitudes! An inquiry made among staff employed in home visiting service to mentally handicapped persons has confirmed this. Their explanation why these persons did not use books and newspapers: They cannot read, they are not interested. This answer tells us two things: You do not identify yourself as an intermediary and you are not aware of the needs of mentally handicapped. In both cases this results in passivity. Within the project we are trying to process this problem by using reading representatives. In 6 municipalities each dwelling site/workplace for mentally handicapped appoints one employee to offer reading hours and library visits. This employee is also to stimulate an interest among his colleagues at work. The reading representative first participates in a study circle meeting four times. We have prepared special course literature and a video tape illustrating how a group of mentally handicapped read the newspaper 8 PAGES.

There are several different functions responsible for making mentally handicapped take part in cultural life. This is a responsibility regulated by current law and applies e.g. to those responsible for public support of mentally handicapped and the cultural administration of the municipalities, not least the libraries.

The educational associations also have a certain responsibility. Persons from these various functions collaborate in local working groups in the project. These groups have arranged "incitement days" for all welfare staff, study circles and listening-in meetings for reading representatives. The libraries have frequently played a central role for the working groups.

The reading representatives activity has been very successful. Certainly, it has been laborious for some unaccustomed staff to get going with the reading task, some have experienced it as something of a personal exposure. However, in most cases the reading hours have meant something of an inspiration, a kind of new contact with the tenants as well as more intimacy and new discussion subjects. < p> After a comparatively short time, mentally handicapped have themselves asked about the book or the newspaper. What has also been noted is that even seriously mentally handicapped who ordinarily find it very difficult to keep still have been listening with much interest. We have tried to increase their reading experience with scents, sounds and objects with linkings to the text. What is of

greatest importance now is to see to it that the reading representatives are given support in their work. The local working group, including the library, can provide a good support but the work supervisors must also clearly indicate that reading belongs to everyday doings of mentally handicapped. What we have to do is to include reading hours among the daily routines. We hope for an increase of the number of reading representatives all over the country. They help us to achieve our goal -daily reading hour- a self-evident privilege also for all mentally handicapped!