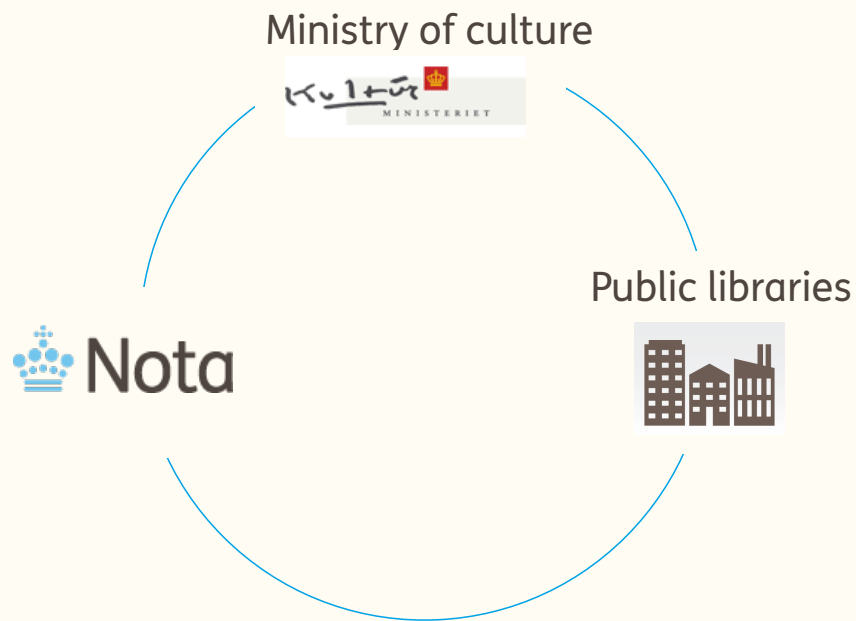


Dyslexia among the young

August 7th 2010

My name is Simon, I am a project leader at Nota - the Danish National Library for people with reading disabilities. I am going to tell you a little bit about our efforts in the area of supporting dyslectic readers. Especially we are currently conducting a research on dyslectic youth - from 12-16 years of age - and this study will be my primary subject today.

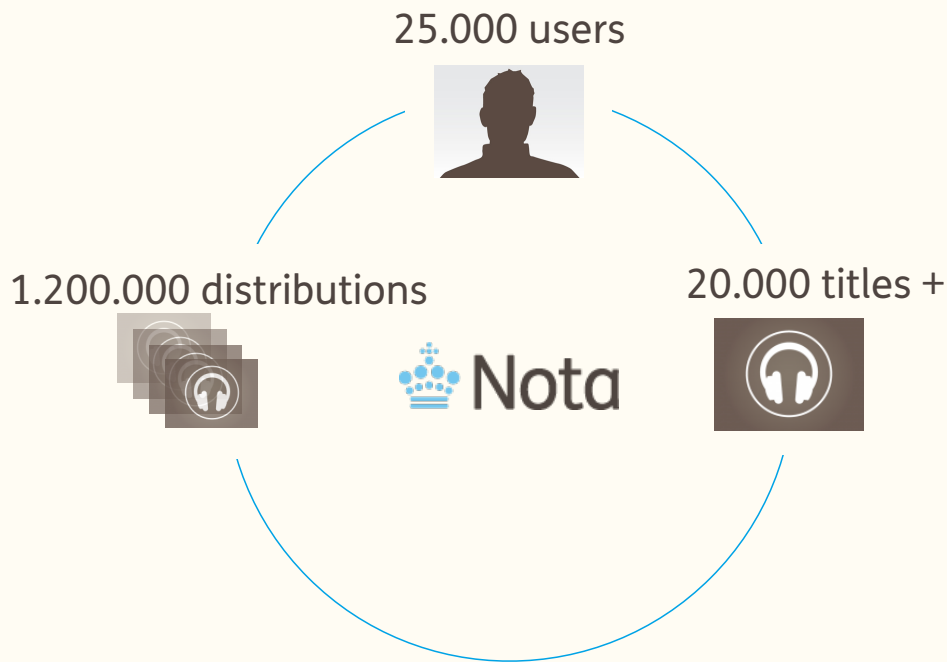
Nota



Let me just briefly introduce you to my institution, to give you a picture of the context I am speaking in. Nota is a National library with direct reference to the Ministry of Culture - they pay 99% of our income. As opposed to the public libraries that are run by the local municipalities, we are national and serve people with print disabilities all over the country.

Nota is a virtual library, as a user you can use the services by phone or via the Internet. Using our services is free as long as you can document a print disability.

Organisation



We have approximately 25.000 enrolled members with access to our collection

The collection consists of our national collection of Danish audio books - around 20.000 titles - which we, in part, produce ourselves. Furthermore our collection has recently expanded massively through collaborations - for instance with the american non-profit organisation Bookshare providing more than 50.000 e-books in english - and the Nordic collaboration that gives cross access to the entire collections in Scandinavia. We also provide access to the primary collection of Danish study literature, and more.

We distribute just above 1.2 million titles to the users every year

Detaljer:
nordic collaboration - all titles are accessible across the Nordic countries + Royal National Inst. for the blind
- english literature + SU styrelsen (20.000 study literature)

Services

Books

- DAISY/mp3 Audio books
 - Online web-player
 - Download
 - CD - postal
- E-books
- Braille

Knowledge

- User tested design
- Collaboration
- Dissemination

Our books are primarily audio books in DAISY/mp3 format, which you can either listen to directly on our webpage, or you can download them to your computer or have them send by the danish postal system free of charge. Then we have e-books which we expect a lot from, but haven't seen so much of yet, and finally we have braille used by a steady volume of blind users.

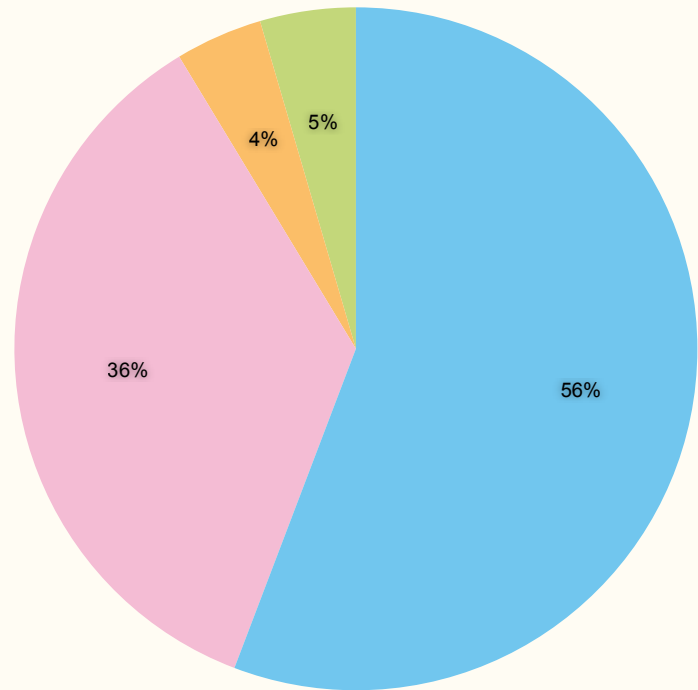
We also see ourselves as a knowledge institution, and we try to become increasingly better at knowing what our users need. We aim to cross collaborate with the body of institutions serving our users, for instance public schools and school libraries. Last we put a big effort in disseminating and sharing our knowledge primarily on the internet, but also in written media, conferences and networking.

Detaljer:

1/3 of our DAISY books are provided with full text
The rest is NCC (daisy struktur i lydfil - indholdsfortegnelse)

Users

- Visually impaired
- Dyslectic
- Other
- None



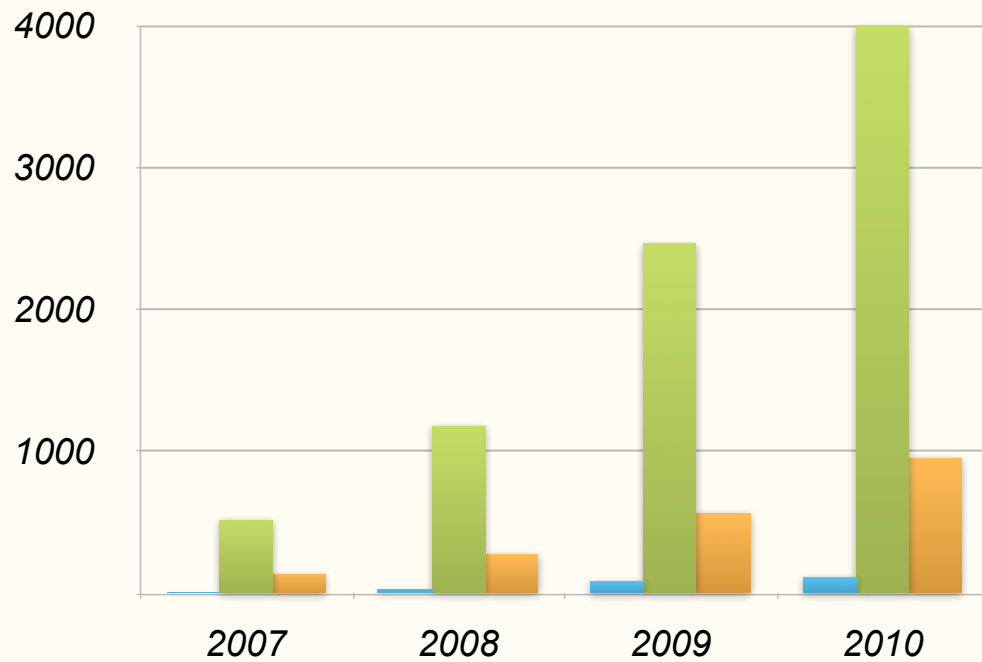
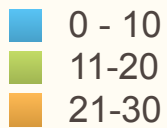
We see here the distribution of our users - as you can see there are two dominating groups, the visually impaired and the dyslectic. We still have a little overweight of visually impaired users - around 56 percent

- we have around 4 percent with a different handicap, mostly physical or neurological reading disabilities

then we have around 5 percent with no handicap - that's our own staff, teachers of print disabled and other assistants. Recently teachers of print-disabled people have been granted full access to our collection, which is a development we are very excited about

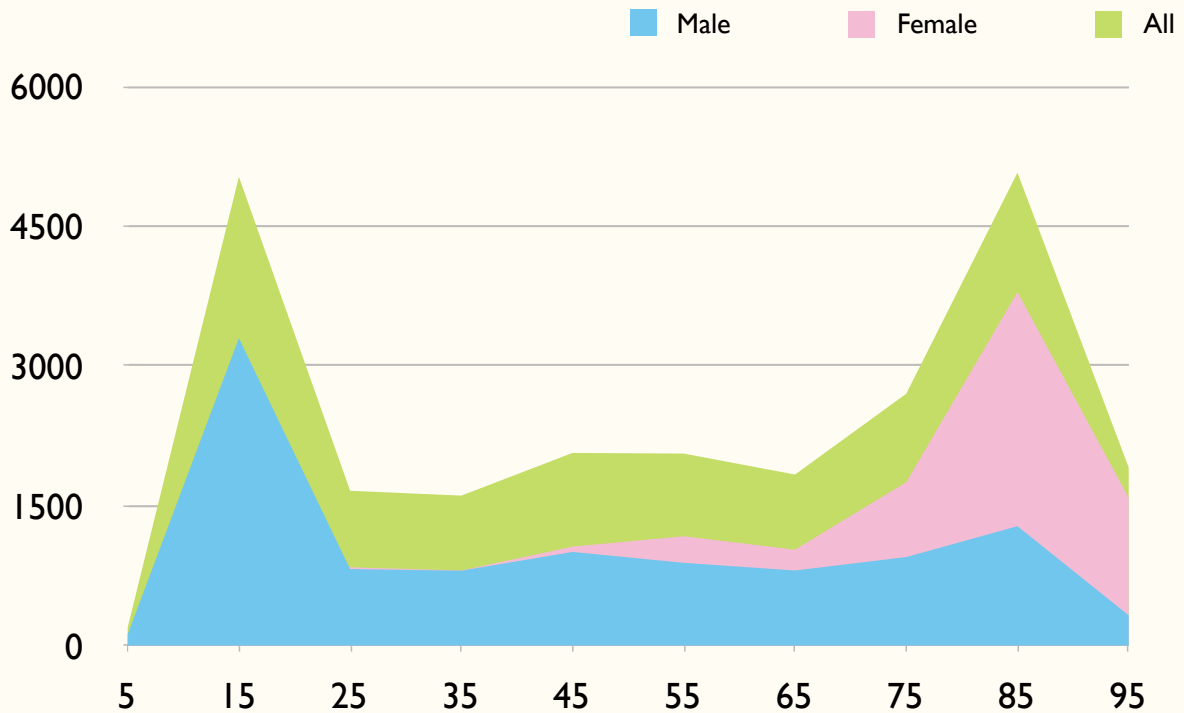
and finally we have around 36 percent dyslectic users

Users - increase in number of dyslectic users 2007-2010



But that number is increasing rather fast - this figure shows the increase during the past 4 years - which is especially remarkable on young dyslectics between ages 11 to 20. Actually this volume is growing exponentially, so we are expecting more to come. And this development is also the reason we are conducting the research, I am going to tell you about today.

User age



Nota used to be an institution serving primarily elderly women - as you can see we still have an overweight of female users aged 75 to 95 years,

But since we opened up to dyslectic users in 2006, we have seen this pattern to the left - we now have a similar overweight of male users between 15 and 25 years, most of them being dyslectic. About 3 out of 5 of these young users are boys - this is a tendency you see all the time in the area of dyslectics - but there is actually no evidence that there are factually more dyslectic boys than girls.

So, we see a vast increase in dyslectic users. This development not only reveals an improvement in the identification of dyslexia, but also a growing awareness of the necessity of being able to read.

From focus on reading...



I think every child can dream without being able to read - but in order to fulfill their dreams, danish kids must first be able to read. And this, they shall learn!

***Lars Løkke Rasmussen,
New Year, 2010***

In Denmark there's presently a strong political focus on reading - since elementary school pupils do bad in international tests, our prime-minister has declared that every kid should be able to read when they leave school. Of course this goal is maybe a little illusory, but even if the current state only has to be improved slightly, one has to take dyslexia into consideration. I was surprised to find that a general estimate of dyslexia is 5-7 percent of a given population - In a small country like Denmark with a population of 5 million people, that means more than 300.000 people in total - and up to 50.000 pupils in elementary schools right now.

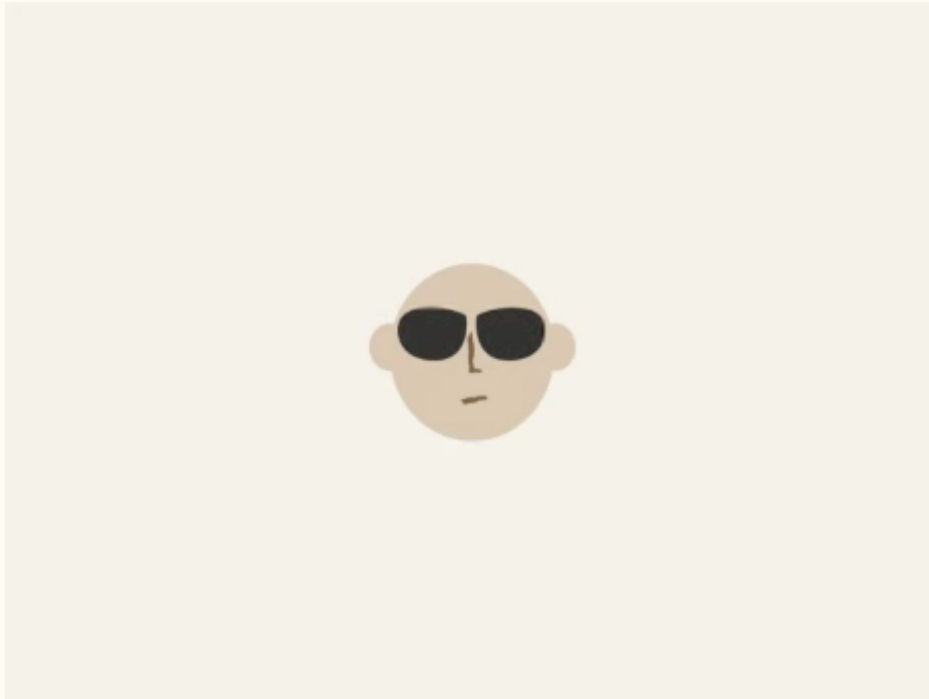
Of course the exact figure is debatable - some say 7 some say 3 percent. It's also very hard to determine - the definition of dyslexia is dynamically changing and so is the societies surrounding it. But there's reasons to believe that the problem of dyslexia is increasing.

The reason why being able to read is so critical in Denmark right now is due to the development of labor. The need for manual labor is declining while the need for skilled labour is increasing. Unskilled jobs are moving offshore, because wages and production costs are high - we lost 100.000 unskilled jobs last year. Simultaneously skilled jobs in sectors like administration, research and management are emerging. This means, that not being able to read or write is a much more severe condition than it was just a few decades ago. We simply can not afford to have so many pupils leaving school without being able to educate further. Our Prime Minister understands that - that's why he says that "in order to fulfill their dreams, danish kids must first be able to read".

(udregning: statistikbanken - elever i offentlige/private grundskoler+efterskoler per 2009 = 716.000, 7% = 50.120)

Min oversættelse af: Jeg tror, ethvert barn kan drømme uden at kunne læse – men for at opfylde sine drømme og for at udleve sine drømme, må danske børn først lære at læse. Og det skal de lære!

...to focus on acquiring knowledge



But reading may actually not be the real problem to solve when we speak of dyslexia. The real problem is rather to support the ability to acquire knowledge and information at a high level, thus being able to get a high level of education. The important thing to understand is, that educating is perfectly possible - even without being able to read or write unblemished - provided that knowledge and literature is made accessible.

Sure advanced training and pedagogics can help some of them to improve. But there's no reason to believe that contemporary school systems have the means to help the most part. The answer to their needs is to make knowledge accessible, so they can keep up with their peers at school. My hope is, that long before pedagogics in elementary schools have solved the problem of teaching disadvantaged readers how to read, accessible knowledge and literature have solved the task for them. Why? Because I think that being a disadvantaged reader in elementary school today is a daily struggle and in the worst cases a daily nightmare. There is neither the means nor the time to provide a decent support for these kids, consequently they become a buck in the school system, which eventually means that educating further is the least probable option.

Hvordan har det været
for dig at gå i skole?

How did you feel about school?

Dyslexia among youth

When we started this work, we invited about 40 pupils from special schools to a conference, and asked them how they felt about school. And from what we learned, it seems these kids generally have had a pretty bad experience - of course we can hope that this only count for some, but I wouldn't be surprised if many, if not most, feel this way. Here's what some of them are saying:

Supporting an accessible learning system

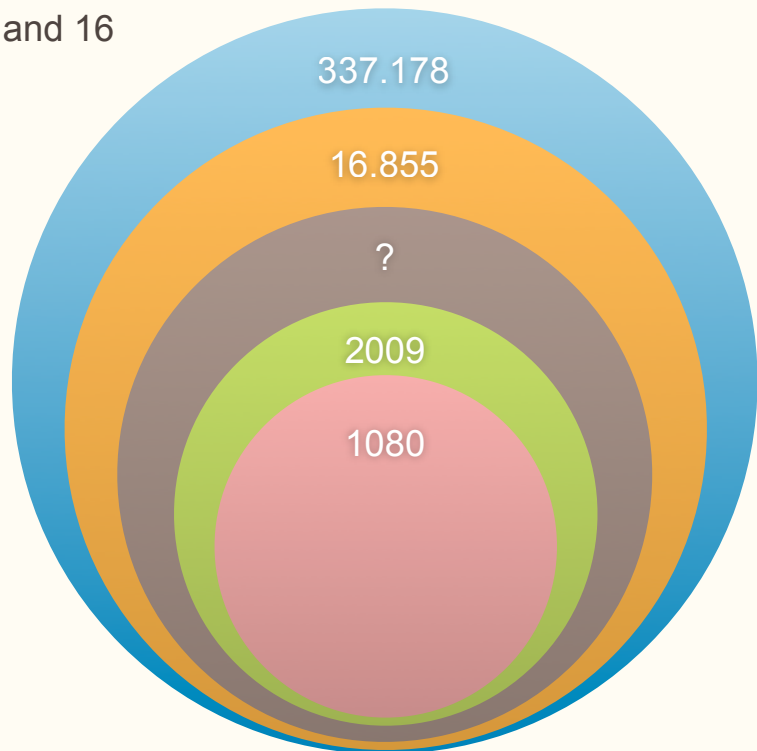


The use of speech synthesis and -recognition, audio books and e-books together form a very strong tool for people who are unable to read. And we have only seen the beginning of these technologies. Accessible knowledge does not come by itself however. The materials have to be produced in a way that will actually fit the context the user is in, and it has to be disseminated and adopted by the users and the central actors around them. In elementary schools this means teachers and pupils - and maybe most importantly - pedagogics.

This process is not an easy one, but with regards to the consequences of a rigid focus on reading, I'm sure it's the right way to go. Special libraries like Nota have big knowhow in the field of supporting disadvantaged readers with these means. We also have the ability to combine and disseminate databases both nationally and internationally - providing a central support to pupils and staff at all levels of the educational system. Our most dominant challenge is, that our services are not being used by the majority of the people who need it. A disadvantaged reader is the least likely person you would meet in a local library. We can simply see from the figures, that our services actually reach a very small amount of the potential target group.

Overview - numbers per january 1st 2010

- Young people between 12 and 16
- Est. dyslectics (5%)
- Diagnosed
- Enrolled at Nota
- Active at Nota



If we take a brief look at the specific group of young people between 12 and 16 in Denmark, there is around 340.000

A conservative estimate of dyslectics in the total volume of a population, is 5% which sums up to around 17.000.

We don't know how many of these have a diagnosis - in Denmark central registration of handicap is prohibited, so we can't say

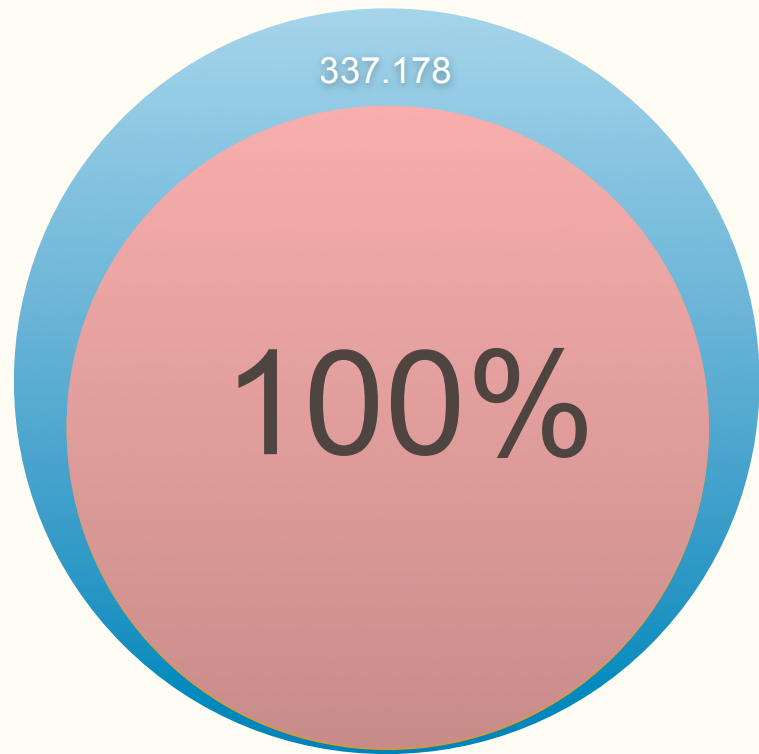
But we do know that just above 2000 are enrolled at Nota

And about half of them use our services actively

Overview - numbers per january 1st 2010

- Youth between 12 and 16
- Est. dyslectics (5%)
- Diagnosed
- Enrolled at Nota
- Active at Nota

100%
15%
6%



So among the total volume of ~ 17.000 kids, only ~ 2.000 are enrolled at Nota - corresponding to 15%. And yet only about 1000 - corresponding to 6% of the total volume - are actually actively using our services.

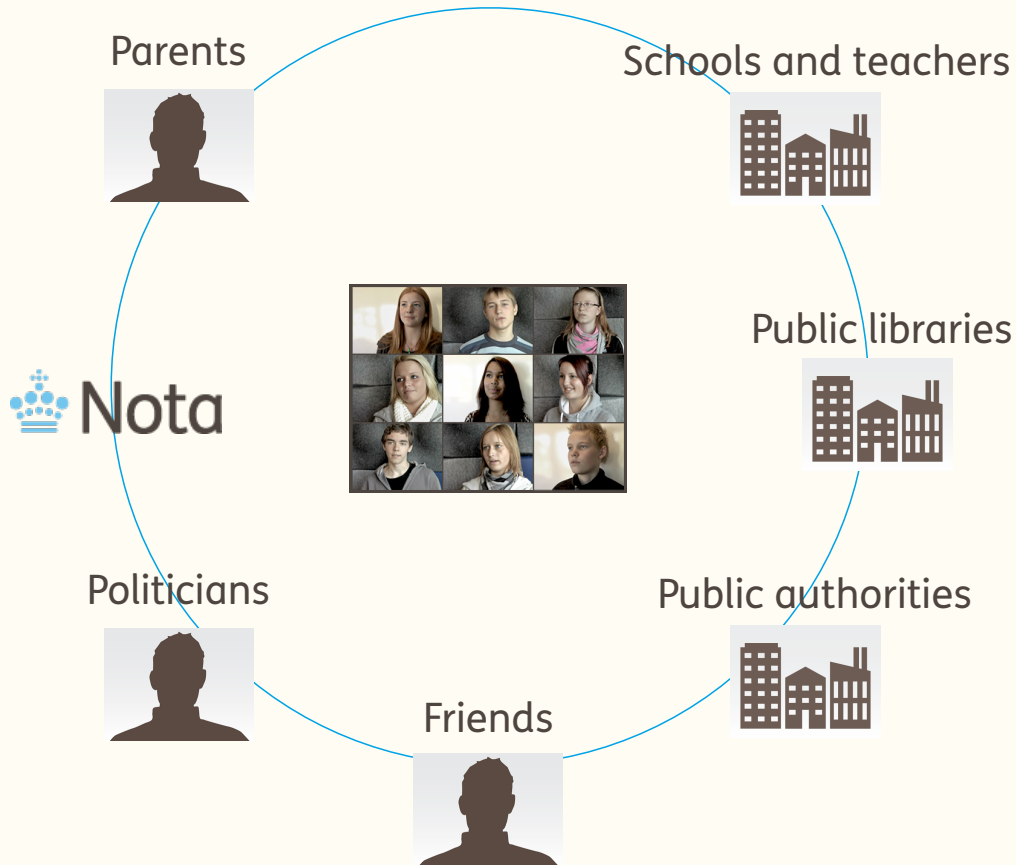
Our vision is that we should be able to help close to a hundred percent dyslectic young suffering from dyslexia. Any other criteria of success wouldn't really make sense, since we believe that the means are there to help (or can be developed), and at least in school, everyone in this group can benefit. They need to be able to aquire knowledge, otherwise their future prospects of finding a good job decreases badly.

Dyslexia among the young

- To create knowledge on the barriers and possibilities of young dyslectics in order to improve their educational opportunities.

To reach this goal, we must establish a dialogue with our young dyslectic users. So far this meeting has culminated in the research project we are conducting now - called dyslexia among youth. It aims to sort a number of things out. What are these kids needs in connection to reading and gaining information? What are the barriers that keep them from obtaining knowledge, and thus, participate in society at the same level as their peers?

Actors around the young



The project focuses on youth between 12 and 16, which is the most increasing group in our member volume, and whom we expect, will have a conscious stand on their own reading abilities. We also know that kids this age have a need to read since they all attend primary school.

The complexity of this task is of course, that libraries are definitely not the only player in solving this challenge. In fact the lives of these kids evolves very little around libraries or literature.

To mention a few other actors, there's parents, schools & teachers, public authorities, friends and politicians - all of which may actually affect the prospect of overcoming the disadvantages of dyslexia, much greater than the libraries can do. This does not mean that the libraries don't have an important role to play - I think they do. But it's my impression that libraries (in DK) tend to spin a little bit in circles around themselves.

So the first part of this process has been to identify some representatives of these groups and interview them to get an in depth understanding of how they view this domain - and how they see their own role in solving it. This work, which we are finalising now, have been done in collaboration with a danish innovation-company called innovation lab. We are still analysing the results at this point, but we have received pointers to the fundamental tendencies:

Findings

1. **Knowledge:** the groups have very little or no knowledge of what Nota and the public libraries has to offer
2. **Collaboration:** problematic circles in identifying and supporting dyslexia
3. **The good news:** all parts indicate that they wish to engage and solve the problem

1... the groups have very little or no knowledge of what Nota and the public libraries has to offer

2... there is some problematic circles in identifying and supporting dyslexia, where the involved actors tend to push responsibility to the others - the public authorities, who know that a diagnosis may become expensive, tend to ignore that getting a diagnosis and help is bureaucratic and difficult. Parents and the kids themselves are reluctant to recognise dyslexia, because it's related to shame and tabu - and teachers, librarians and politicians seem to know very little about the phenomenon in general. So they all have their reasons for pushing it aside

3... the good news is, there is a strong focus towards the issue, and all parts indicate that they wish to engage

So. We, as a library, of course we cannot solve this issue alone. But through this process we become more aware of how and where we can improve and do our share.

Vision

- To ensure that our services meet the users needs
- To reach 100% with our services
- To push towards a school system where accessible material is standard

1

Obviously we get to know more about our products and how we can develop them to suit the users needs better. We get to know about the situations the users are in when they need to read, and we get to know what technology they use and prefer. Our first goal is to ensure that our services are applicable to our users.

2

Next we have to make sure every potential user get to know about us - and in this domain we have to change the way we communicate. For instance we have to recognise that our communication strategy so far, have been somewhat misplaced. We have a long tradition for communicating with the public libraries. That's irrelevant. Why? Because dyslectic youth never goes to the library! If we start communicating with some of the aforementioned actors - for instance teachers, politicians and parents, there is a strong chance that the use of our services will become much more widespread.

3

Last - and this is the hard part - we have to develop how our materials become an integrated part of learning in elementary school. We might have to rethink the way accessible literature is legally supported. In Denmark there is no formal principle that ensures the presence of accessible literature in primary school - strangely, because there is such a thing at all other educational levels. Maybe this is a spot we should put more focus on? The present system creates some grey zones that hits the disadvantaged readers. Furthermore we need to collaborate with teachers, publishers and users to support and develop accessible materials and methods. We have to use the current focus and will to take a stride toward a school system where accessible material is standard.

This introductory work is obviously qualitative per definition, so to be able to make any generalised conclusions we will conduct a national quantitative survey this fall. By the end of this year we hope we will have a very strong plan for our library can contribute to the goal of making knowledge accessible to all kids at elementary school level.