


This is what we want to do



The Policy Programme of the Swedish National Association Attention. The Swedish National Association Attention is a interest group for people with neurodevelopmental disorders (NPD).

RIKSFÖRBUNDET
Attention

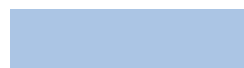
A photograph of a woman and a young girl sitting outdoors in a park. The woman, on the left, has reddish-brown hair and is wearing a white jacket. She is smiling and looking towards the girl. The girl, on the right, has long reddish-brown hair and is wearing a brown jacket over a red and white striped shirt. She is also smiling and looking down. They are sitting on a wooden bench. The background is a lush green forest with many trees and sunlight filtering through the leaves.

The policy programme of the Swedish National Association is based on the UN Convention on the Rights of Persons with Disabilities (ICRPD) and the UN Convention on the Rights of the Child.

© Riksförbundet Attention
Programme approved by the Association's AGM 2015
Graphical form/illustrations: Lovisa Schiller
Photographs: Scandinav

Contents

Human Rights	4
Living with Neurodevelopmental Disorders	6
Support and Treatment	8
Early Provision of Services	10
Technical Aids and Adjustments.....	12
A School for Everybody	14
Work and Making a Living.....	16
Influence and Participation	18
Research and Development	20
Leisure Time and Culture.....	22
Facts about Neurodevelopmental Disorders	24
About the Swedish National Association Attention	26





Human Rights

Attention's work is based on the UN Convention on the human Rights of Persons with Disabilities. The convention clarifies the rights that people with disabilities have. It entails a clear marker that society is to be suited to people and not the opposite.

Knowledge makes a difference

We believe that negative attitudes, prejudice and discrimination are often founded on a lack of knowledge. We thus work to increase knowledge about the needs of our members. Understanding changes attitudes.



Attention works for:

- Every human being to be seen as equally valuable and to be respected irrespective of gender, gender identity or gender expression, ethnic affiliation, religion or other belief, disability, sexual orientation or age.
- Society to embrace differences in humans and see differences as a possibility and not a hindrance.
- Society to be accessible for people with Neurodevelopmental Disorders (NPD).
- Everybody having the possibility of developing based on their own pre-conditions. Services in the form of healthcare, social care and support are to be arranged based on individual needs.

Living with Neurodevelopmental Disorders (NPD)

The UN convention recognizes that all people are equal before and according to the law and are without any discrimination entitled to the same protection and the same benefits.

NPD is not visible and it can be difficult for others to understand what it is like to live with these disabilities. Since about 7% of the population have NPD everyone who works in healthcare, support and education needs to have knowledge about what NPD is. Knowledge provides understanding that leads to an individually adjusted approach and better services.



Attention works for:

- ➔ Increasing knowledge about NPD for everyone who works with people by disseminating information and offering education.
- ➔ Everyone living in Sweden to have access to information about NPD in a language they understand.
- ➔ Girls/women with NPD to be given particular attention so that everybody with NPD has the same rights to support and healthcare.
- ➔ People with NPD who are in prison, in institutions or treatment units to have the right to health examinations, treatment, support and aids that contribute to strengthening their opportunities to manage their future lives.
- ➔ Society being accessible to people with NPD.



Support and Treatment

Every human being has the right to receive equal healthcare, health promotion measures and rehabilitation according to the UN Convention.

NPD has mainly genetic roots that entail a lifelong disability. There are several ways of reducing symptoms. So-called multimodal services have shown



to be most effective. This entails a combination of services, for example, psychosocial and educational support measures, psychological treatment and if necessary medication.

Since everybody is different it is important that the treatment is based on each individual's pre-conditions, needs and desires.

Different people need different types of support

Children often have good use from training impulse control and aggression, concentration and memory. Technical aids and practical education in creating structured everyday life is also effective.

Many adults with NPD are on sick-leave or have activity compensation or sickness compensation due to sensitivity for stress and society's failings in providing the right support. Everyday life for people with NPD can be made easier by increased understanding, adapted rehabilitation, housing support and other services.



Attention works for:

- Services in the form of healthcare, help and support to be evidence-based and a part of the healthcare guarantee.
- Knowledge guide for all NPD diagnoses to be produced.
- The National Board of Health and Welfare's handbook of current knowledge about ADHD to be used by the municipalities, health authorities, other care providers and relevant authorities in order to improve healthcare and support services.
- Support and healthcare services to be suited to meet the needs and functioning of each patient. The services are to make use of the knowledge that exists among professionals such as occupational therapists, healthcare and support coordinators etc.
- Everyone receiving the same possibilities for healthcare, home-help and technical aids, irrespective of where one lives and which doctor one has.
- The creation of coordinators who can help people with NPD and their family carers in their contact with healthcare services, schools and authorities.
- Health and municipal authorities to collaborate and provide coordinated services.
- People who have problems with alcohol/drug abuse and NPD to receive treatment and support for both the disability and the abuse.
- Complaints about deficiencies in health care and support services to be presented in a simple and easily accessible way to those who are responsible. Deficiencies are to be addressed quickly.
- Everyone to have a Coordinated Individual Care Plan (CICP) with clear information about his/her treatment.
- The healthcare guarantee to be designed so that it also includes the time for the medical examination.
- An improved right for support and knowledge for family carers.
- The right to get a second medical opinion to be extended to also include serious disabilities, not just medical conditions. A system that provides the possibility of raising one's case to the Patient Board or somewhere similar should be introduced.



Early Provision of Services

Healthcare and support are to be provided with the aim of an early detection and suitable services according to the UN Convention.

The support and approach that children receive from those around them is crucial for the development of a disability later in life. It is important to detect children who have a disability as early as possible in order to prevent problems later in life.

Services irrespective of diagnosis

Support services should be focused on helping children who show symptoms of NPD even if they do not have a diagnosis. Pre-school, school, healthcare and other services should be coordinated and waiting times shortened.

Support for parents prevents problems

An important preventive service is to provide support to parents. Appropriate parent education is needed that anyone can take part of without cost. The parents should be involved and be given the tools so that they can participate in the planning of healthcare and support.



Attention works for:

- Children who show signs of NPD to be detected and examined as early as possible. Assessments and measures that are performed to be documented and followed up.
- Habilitation services to be provided early and include everyone who needs them.
- Medical examinations and support to be given to the whole of the family when needed.

Technical Aids and Adjustments

According to the UN Convention, the government is to encourage research and the development of new technology and technical aids as well as facilitating the access to technical aids of high quality, including making them available at a reasonable cost.

Society makes great demands on our ability to deal with information, knowledge and sensory impressions – our cognitive ability. A person who has a diminished cognitive ability can need help to organize his/her impressions.

People with NPD are to receive support in their everyday lives based on their needs. Examples of such support are: technical aids, adapted software, advice from occupational therapists and education.

There are several types of technical aids that make it easier to organize, plan, remember, keep tabs on the time and find one's way in new environments. This is why we work to improve the availability of technical aids.



Attention works for:

- ➔ Increasing the use of standardized assessments for functional levels that can better capture and describe the consequences of our disabilities.
- ➔ Clear-cut information to be available about which technical aids and adaptations that are available and where to go to get them.
- ➔ Schools and workplaces to consider technical aids as a natural adaptation measure.
- ➔ Computers, cell phones and applications (apps) to be counted as technical aids and thus be subsidized.
- ➔ People are to be allowed to test technical aids already during the time for the medical examination.



A School for Everybody

According to the UN Convention, people with disabilities are to have the right to an inclusive and free education on the same conditions as others.



It is a right to receive education in all school subjects based on each student's starting point. Early services and individually adapted support in school is necessary in order for children with NPD to be able to develop their abilities and cope with adult life. The availability of cognitive aids, adapted environments and knowledgeable staff should be a matter of course.

Folk high schools, higher education and other education for adults are to be individually adapted so that more people with NPD dare to go in for further education. Without such adaptations many have to really work hard to in order to compensate for their difficulties, which leads to stress and problems in keeping up with the studies. Legislation concerning discrimination is to include all types of study.



Attention works for:

- ➔ Knowledge of NPD and basic remedial education to be included in all teacher training and school management courses.
- ➔ The educational aims of schools to be re-considered so that pupils with NPD will have the possibility of achieving them.
- ➔ All schools on all levels to be obligated to get updated knowledge about NPD.
- ➔ The municipality is to provide all pupils in need of special support the help they need to manage school work.
- ➔ The municipalities to establish an official function with expert knowledge to be consulted when pupils have great difficulties to achieve the aims or risk being absent for long periods of time.
- ➔ Schools to take a greater responsibility for the early detection of NPD and the introduction of necessary measures.
- ➔ Pupils with NPD to be able to feel safe and secure and included in the companionship at school.
- ➔ Schools to take a greater responsibility for preventing and counteracting mobbing.
- ➔ Adapted teaching material and technical aids to be offered to pupils in need of support.
- ➔ Compensatory technical aids to be used also for tests and examinations.
- ➔ The parents who want to have their own advocate to represent them in contacts with the school and municipality, are to be provided with one.
- ➔ School health services to be given sufficient resources in order to complete their assignment to promote the progress of the pupils towards the aims.
- ➔ Schools to cooperate more with family carers, social services, habilitation services and child and youth psychiatric services.
- ➔ The educational premises to be accessible for people with NPD.
- ➔ The government to introduce an obligation for employees to report abuse in schools (Lex Alissa).



Work and Making a Living

Every person has a right to have work and social security, irrespective of whether he/she has a disability or not, according to the UN Convention.

Different abilities can be great assets

Workplaces today miss out on many people with unique abilities that can be great assets.

Understanding and knowledge among employers and sometimes an adapted work environment can be needed in order for the positive attributes to be used. Those who have employed people with NPD should thus have training about how they can help their co-workers.

If the measures that are provided are sufficient and suited for people with psychiatric disabilities then more of our members can participate in working life.



Attention works for:

- ▶ People with NPD to have the right to have an adapted workplace, supervision and the technical aids they need in order to manage their work. The parties in the labour market should cooperate.
- ▶ Workplaces where people with NPD are employed to receive financial compensation and continual support.
- ▶ The social security to be maintained through secure, fair and easily understood social insurance with reasonable level of compensation.
- ▶ State salary subventions to be raised and made more personalized.

Influence and Participation

Every person has the right to participate in decisions that affect themselves according to the UN Convention.

We work for individuals to be able to have greater influence over their own lives and that people with disabilities are to participate in and be able to affect the decision-making processes within the municipalities, health authorities, other authorities and the parliament. The decisions will then be better and the possibility of being successful in carrying them out will be greater.

Attention is a member of the network, National Partnership for Mental Health, NPMH, where we work together with other organizations for greater influence for patients, users and family carers on all levels.



Attention works for:

- Making politicians, authorities and other decision-makers understand what it is like to live with NPD or be a family carer.
- User groups and user boards to have more influence and thereby be able to improve healthcare and social care as well as the staff approach to patients, users and family carers.
- Care forms and treatment methods are to be formed so that they strengthen each individual's influence over his/her treatment.
- Coercion only to be used when all other methods have been tested, is to benefit the individual's health and never to be used as a means of punishment. Staff are to be trained in an approach that generates low levels of affect.
- The perspectives of the patients, users and family carers to be considered in all strategic decisions and major changes in all publically financed social care and healthcare services.





Research and Development

Research and development in the last few decades has led to increased knowledge about our member groups. This includes medical, neuropsychological, psychological, social and educational knowledge.

Knowledge about the underlying causes of NPD, within the medical field, has increased. We know more about the genetic factors, about the significance of neurotransmitters and the effects of medication.

In order for even more knowledge about NPD to be gained society needs to invest more money in research – both basic research and clinical research.



Attention works for:

- More funding to research about the brain, both in general and with a focus on NPD.
- Research in psychosocial aspects for those with NPD to be strengthened.
- Increasing the dissemination of research findings and the resources for implementing these.
- Strengthening the dialogue between researchers, patients, users and family carers.
- New knowledge to be quickly introduced in course literature in educational programmes for staff in social care, social support and schools etc.
- People with their own experience and family carers to be given the prerequisites to take part in research in the medical, humanistic and social fields.

Leisure Time and Culture

Every human being has the right to participate in cultural activities, recreational activities and leisure activities on the same terms as others, according to the UN Convention.

The usual range of activities in sport, leisure and culture are to be adapted to how people with NPD are and the arrangers of these activities are to have knowledge of this.

Adapt so that everybody can participate

Individually adapted support is needed to make it possible for everybody to participate in leisure time activities. In some cases an attendant or an extra leader can be needed. In other cases individual training in a social context and in assimilating information is the answer.



Attention works for:

- ➔ Activities in sport, culture and leisure time to be made accessible for people with NPD.
- ➔ The leaders to be given education in how to adapt activities for and to approach people with various disabilities.
- ➔ Non-profit organizations to be able to receive financial support for group activities for people with NPD.



Facts about NPD

Neurodevelopmental disorders (NPD) are difficulties that are based on how the brain works. The cause is biological and has nothing to do with upbringing or intelligence. NPD is a so-called invisible disability that cannot be seen on a person.



A person with NPD can have difficulties in:

- Regulating attention
- Learning and memorizing
- Controlling impulses and activity levels
- Expressing him/herself orally and in writing
- Interaction with others
- Motor skills
- Self-reflection
- Perceiving time

Many people have these difficulties to a greater or lesser extent. When the difficulties are so great that they affect the person's development and possibilities for functioning in society then they become a disability.

The different types of NPD are closely linked and it is common that the same person has several diagnoses. Further information can be found at: www.attention.se

Examples of neurodevelopmental disorders

ADHD

ADHD means Attention Deficit Hyperactivity Disorder, which entails problems with attention and hyperactivity. Approximately 5-7% of all children suffer from it and it often persists into adult life.

ADHD is characterized by attention problems, impulsiveness and overactiveness. The symptoms vary from person to person and can be more difficult to detect in girls.

ADD is ADHD without the problems with hyperactivity and impulsiveness. Some people with ADD can instead have a lower level of activity than normal. ADD is considered to be a sub-diagnosis to ADHD. People with ADD have attention problems. Some can be thought to be day-dreaming and a bit absent-minded.

Language disorder

A language disorder entails a person's language ability being tangibly reduced. The language disorder can persist during the school years and also into adult life. People with language disorders can, despite having good hearing, need support in understanding and interpreting linguistic information. Both the understanding of language and the production of words can be affected.

Autism

Autism is characterized by socio-communicative difficulties and limited, repetitive behaviour patterns. People with autism often develop special interests. Many have difficulties in comprehending whole contexts, but are good at noting details.

Asperger's Syndrome/ASD

The diagnosis of Asperger's Syndrome has since 2014 been included in the broader diagnosis Autism Spectrum Disorder (ASD).

People with Asperger's Syndrome often have difficulties with relationships and social company. Other typical characteristics are special interests and difficulties in coping with changes.

Tourette's Syndrome

Tourette's Syndrome can be seen in repeated movements and utterances, called tics. Tourette's Syndrome is partially genetic and is often combined with ADHD or OCD.

About us ...

The Swedish National Association Attention is an interest group for people with neurodevelopmental disorders (NPD) such as ADHD, Asperger's syndrome/ASD, Tourette's Syndrome and language disorders. We work for children, young people and adults with these diagnoses so that they can be met with respect and receive the support they need in school, in the labour market and in leisure time.



We have local associations all over the country. The local associations are the core of our activities.

You can meet others in a similar situation to yourself in our local associations and take part in activities or counselling groups. It is also possible to become politically involved.



Find your nearest local association and read more about us at: www.attention.se



The Swedish National Association Attention is an interest group for people with neurodevelopmental disorders (NPD) such as ADHD, Asperger's syndrome/Autism Spectrum Disorder (ASD), Tourette's Syndrome and language disorders. We work for children, young people and adults with these diagnoses so that they can be met with respect and receive the support they need in school, in the labour market and in leisure time.

Read more about us at: www.attention.se

