



WHEN I GET OLD

- NEW KNOWLEDGE ABOUT AUTISM AND AGING

THE KNOWLEDGE-CREATING NETWORK ON GERONTOLOGY AND AUTISM (GAU)



The GAU network consists of five autism support groups in Denmark, who has created a knowledge-creating network on gerontology and autism. (GAU):

- Specialist Area Autism, department Senior House Hinnerup, Central Denmark Region (residential services)
- Children and Autism Center in Ringe, Region of Southern Denmark (residential and activity services)
- Højtoft in Bagsværd, run by the Højtoft Fund (residential services)
- The SOVI Fund in Gladsaxe (employment services, social economy enterprise company)
- Spurvetoften in Brejning, Vejle Municipality (residential services)

Who is GAU, and what is the project about?

As part of a three-year project that ran from 2014-2017, the network has collected new, practical knowledge about autism and aging. Autism specialist consultant Jannik Beyer is part of the network, and The National Board of Social Services is following the network's progress. The project is financed by the VELUX FONDEN and managed by DEFACTUM in Region Central Denmark Region.

Need for new knowledge about autism and aging

The first generation of people who were diagnosed with autism in the 1980s is getting older. These people are experiencing age-related changes. The changes are a challenge for both the people with autism themselves and the support staff at the autism organizations that work with them on a daily basis. The need to know more about the aging of precisely this group was the reason that five autism support groups in Denmark created a knowledge-creating network on gerontology and autism (GAU).

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The network's goal is to shed light on how people with autism over age 50 experience the life changes that are part of aging. In the network we have researched new and practical knowledge about how we as professionals can support people with autism to age with the best possible life quality.

The network has worked with three themes which have been the focus of the project

- Changes in daily life
- Changes in health
- Changes in relationships

Our method: Practice-based research

Through methodic and systematic investigations of our own practices, the service providers in the network have each worked with specific cases that relate to the project's three themes. The network has worked with both in-depth studies of phenomena and method development as it relates to helping people with autism handle their challenges and maintain their quality of life.

Through courses, supervision, and network creation, the employees who work every day with people with autism are being trained to be able to make systematic and qualitative analyses of their own visions about the people they care for. The network structure does not only have a research goal. It has created room for knowledge sharing, the exchange of experiences, and mutual inspiration, which has allowed for quicker implementation of methods and results.

We believe that the GAU project shows the value of integrating systematic analysis tools in the pedagogic field and of testing the durability of the preconceptions and the routines we as professionals bring into our interaction with the citizens. Through GAU, we have discovered new and sometimes surprising knowledge about the target group, the services we offer, and the interaction between people with autism and professional caregivers.



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What we learned: Changes in daily life

- It is important to distinguish between social aging, psychological and mental aging, and biological aging. As professionals, we should be aware that we can't always use age as the only explanation for the changes people with autism are experiencing.
- It requires careful research to find out the good hours for individual people with autism, and this knowledge is necessary in order to make changes to daily life. It's important that any look into the quality and values of daily life for the individual focus on so-far unseen possibilities for involvement and self-determination and create options for flexibility. They create solutions that help create improved life quality for the individual.
- We show that special frameworks have major significance for the well-being of people with autism. That said, it can be hard to determine if the changed physical frameworks are creating an environment that is particularly well-suited to older people with autism or is just generally well-suited for people with autism as a whole.

What we learned: Changes to health

- There is a need for regular health checks, and we as professional methodologists should actively engage with them. It's important that basic knowledge of aging is available for autism service providers,

and that staff members are able to identify health changes among people with autism.

- It is essential that we as professionals can read the signals of people with autism when it comes to stress load because of a mismatch between demands and the individual's resources. There is a need for us to cooperate more closely with the public health services in order to determine whether it is sickness or other factors that explains the changes we have noticed in the people with autism.
- As a professional, it is important to keep an eye on the assumptions that can, for example, arise in an employee group. These assumptions can affect the educational initiatives that will be undertaken by the group, and they can turn out to be incorrect.
- The professionals at service organizations for people with autism have a central role as translators and communicators of important information to health personnel. This requires that the employees of these service organizations are ready to carry out this task. A possible solution might be that the person with autism takes along a "hospital passport" when visiting doctors and specialists to explain how the people with autism communicates and experiences pain. The idea is that the hospital passport would be filled out by the person with autism along with someone that knows that person well.

What we learned: Changes to relationships

- As professionals, we have underestimated the meaning of relationships for quality of life when it comes to people with autism. It is important that we remember that a lack of initiative to initiate social relationships should not be confused with a lack of interest.
- It is possible to map people with autism's relationship skills and work with a focus on Social Thinking. Professionals have a central role when it comes to facilitating horizontal relations between people with autism, and they must be careful not to get in the way of the creation of relationships. These relationships can have significant and long-term meaning for the individual's quality of life.
- Our surveys show how vulnerable people with autism really are when it comes to relationship skills. Professionals often aren't sufficiently aware of how much the relationships between the people with autism and employees consists of helping and support.

- Our project shows that it is actually possible to create greater interaction between people with autism by focusing, for example, on a common third. That way we as professionals create an increased social understanding and capability.
- We recommend that professionals begin much early to support the development of social capabilities. This focus should also be highly weighted in cooperation with authorities when we work out goals.

Something to think about: A future perspective

We have come a long way in our understanding of the different ways autism can affect the course of a life. Today we adapt our autism services so the individual is guided and protected against confusion and unpredictability. But as professionals, have we created the best possible life and development conditions for the target group? This is precisely the question that we in the GAU network have tried to answer with our project.

Our hypotheses are rarely as solidly anchored as we believe

The pedagogic initiative often depends on interpretations and hypothesis about individual people with autism's behavior and needs. The greater the need for support, and the more acute the difficulties in communication, the greater role our interpretations play. That's why it's important that we as professionals remain open, humble, and analytical when it comes to our own assumptions and hypotheses.

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Our project shows that we must often revise our assumptions and hypotheses when we expose them to a thorough analysis. For example, the hypothesis that aging people with autism lose interest in social contact was refuted repeatedly throughout the entire project period. It was clear that social relationships throughout life play a decisive role for health, vitality, and life quality for the target group.

We all need to be 'disturbed' in just the right way

As professionals, we've spent many years defining autism from a perspective of diagnosis and from the capabilities that children with autism do not exhibit early in life. This has brought us a long way, but not without costs. Autism is not a static problem. Relationships, communication, and social insight are aspects we all develop throughout our lives, and in the case of people with autism, they are particularly likely to develop when people with autism live in a safe framework and are only 'disturbed' in an appropriate way.

The GAU has been an eye-opener, because it shows that a screened, structured, and predictable framework isn't in itself what leads to development. Structure and predictability can be a prerequisite for development, but structure and predictability can also lead to a feeling of powerlessness and passiveness. Understood in that way, the structured and visualized approach is not the core of the problem. But it becomes a problem when unexpected events and small interruptions in the routine are interpreted as a sign of a lack of structure and predictability. This leads to further tightening in the structure instead of communication and is the basis for people with autism looking for influence and change.



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Can Social Thinking and Understanding be learned?

Quality of life and social relationships hang tightly together in all of the cases of people with autism we have looked at. None of the people whose cases we looked at had a strong social network, but they did have some relationships. That makes it easy to get the impression that social contact isn't very interesting for people with autism, and that some people with autism might not need social relationships at all.

Our conclusion pointed to the opposite, which lead us to the new survey questions. Are we rushing to assume that people with autism don't want social relationships because they aren't able to take the initiative for contact on their own? Have we overestimated their social understanding and underestimated their social interest? Have we been misled by our own assumptions? Are we so busy with training behavior and adapting the environment that we forget to think? Are people with autism able to develop new capabilities later in life at all?

As we sought to prove our hypothesis, we put new methods and strategies into use, because the traditional autism approach the target group was familiar with focused mostly on behavior, routines, structure, and visualization of the physical, visible world. The goal was to make the world more accessible for people with autism. But what about the invisible parts of the world? The parts of the world that involve thoughts, feelings, expectations, relationships and in the last case the key to self-understanding, understanding the world around us and having influence on our own lives. Is this part of the world at all accessible for the target group, and if it is, can we work with them to help them discover it?

In the GAU network we became convinced that it is possible to change social thinking and insight no matter where people with autism find themselves in their lives, and that this type of initiative has a measurable effect on quality of life for people with autism and on their influence on their own lives. That's why it's thought-provoking that this type of initiative hasn't been prioritized in the goals and action plans for people with autism.



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Should we step back now and then to make room for social relationships between people with autism?

The GAU project shows that the target group generally has a hard time initiating and maintaining contact, and that people with autism's primary network consists of family, friends, and professionals who are able to guide and adapt contact based on the needs and preferences of people with autism. The target group often sees the professionals as their closest friends, but they are uncertain, hesitant and sometimes rejecting of other people who are also living with autism and have similar challenges.

That's why we tested an approach in which we as professionals took on more of a facilitator role than a helper role. This meant that employees worked more actively to facilitate relationships between people with autism. This change appears to have had a very positive effect but illustrates at the same time how difficult it can be for people with autism to initiate and maintain contact themselves, since they lack the very basic strategies and experience with interaction.

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New understanding and new paths

Much suggests that we are looking at a paradigm shift in the autism area at the moment. This shift has roots in the recognition that autism is a much more dynamic condition than was once believed. That means it is a grave mistake to assume that the information we have about autistic children also holds true for teenagers and adults. Autism is a development problem that can be expressed in a variety of ways over the course of a lifetime. As professionals, we need research – and to a great extent practical research – that describes the entire life process for people with autism.

The GAU project is a mirror that calls for humility. Because the mirror shows that we as professionals still have a great deal to learn, both about autism and how we can put together an initiative that can ensure people with autism's right to influence, development, and social anchoring. The mirror also shows that people with autism can develop throughout their lives if we as professionals prioritize that as an important part of our efforts. One of the ways to do that can be to ensure both practical research and Social Thinking, and by making social relationships an important part of the Danish §141 action plan and follow-up interviews that are used in Denmark to determine educational implementation.



If you would like to know more about the GAU project go to:

- Højtoft: www.hoejtoft.dk
- SOVI: www.sovi-autisme.dk
- Specialområde Autisme: www.sau.rm.dk
- AutismeCenter Region Syddanmark: www.boerneogautismecenter.rsyd.dk
- Spurveoften: www.vejle.dk/borger/mit-liv/sundhed-og-omsorg/handicap-psykiatri-og-udsatte-over-18-aar/botilbud/spurveoften