

## Press release

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### Basic information

Name: Sara Højslev Avlund Email: [sara.avlund@aarhus.rm.dk](mailto:sara.avlund@aarhus.rm.dk) Phone: 26831705

Department of: Clinical Medicine

Main supervisor: Loa Clausen

Title of dissertation: Time trends, delayed diagnosis and quality of life in a cohort of children referred on suspicion of autism spectrum disorder

Date for defence: October 8, 2020 at (time of day): 14.00-16.00 Place: Auditorium A (G206-145), Entrance G, Aarhus University Hospital, Palle Juul-Jensens Boulevard, 8200 Aarhus N and virtually via Zoom. Please send an e-mail to [sara.avlund@aarhus.rm.dk](mailto:sara.avlund@aarhus.rm.dk) to receive a link for the Zoom meeting.

Press release (Danish)

**Børn og unge med autisme: ændringer i diagnostisk praksis, alder ved diagnose og livskvalitet**

I de senere årtier er der sket en markant stigning i forekomsten af diagnosticerede individer med autisme spektrum forstyrrelse (autisme), en neuroudviklingsforstyrrelse karakteriseret ved manglende social kommunikation samt stereotyp, gentagen adfærd. Tidlig diagnosticering synes afgørende for, hvordan den enkelte klarer sig, dog vanskeliggøres dette af samtidigt forekommende komorbide lidelser samt symptomlighed mellem udviklingsforstyrrelser. Herudover oplever personer, der har autisme, ofte nedsat livskvalitet, hvorfor viden om livskvalitet, og faktorer, der er forbundet hermed, potentielt vil kunne bidrage til forbedret og mere målrettet behandling.

Et nyt studie fra Aarhus Universitet, Health, har i en klinisk population af 893 børn henvist med mistanke om autisme før 8-års alderen i perioden 2000-2010 undersøgt kliniske karakteristika hos børn, der ikke blev diagnosticeret med autisme første gang, de blev undersøgt, men derimod senere. Samtidig blev ændringer i en 10-års periode i klinisk praksis og kliniske karakteristika blandt børn henvist på mistanke om autisme undersøgt, ligeom livskvaliteten i senere ungdomsår og faktorer af betydning herfor blev afdækket. Der blev brugt data fra både journaler, registre og spørgeskemaer. Projektet er gennemført af Sara Højslev Avlund, der forsvare sin afhandling den 8. oktober 2020.

Forsvaret af ph.d.-projektet er offentligt og finder sted den 8. oktober 2020 kl. 14 i auditorium A (G206-145), Indgang G, Aarhus Universitetshospital, Palle Juul-Jensens Boulevard, 8200 Aarhus N og virtuelt via Zoom. Link til zoom-mødet kan fås ved at sende en e-mail til [sara.avlund@aarhus.rm.dk](mailto:sara.avlund@aarhus.rm.dk). Titlen på projektet er ”Time trends, delayed diagnosis and quality of life in a cohort of children referred on suspicion of autism spectrum disorder”. Yderligere oplysninger: Ph.d.-studerende Sara Højslev Avlund, e-mail: [sara.avlund@aarhus.rm.dk](mailto:sara.avlund@aarhus.rm.dk)/[s.avlund@rn.dk](mailto:s.avlund@rn.dk).

Bedømmelsesudvalg:

Lektor Vibeke Fuglsang Bliksted (formand for bedømmelsesudvalget og moderator ved forsvaret)  
Institut for Klinisk Medicin, Aarhus Universitet  
Forskningsafsnittet for psykosier, Aarhus Universitetshospital, Psykiatrien.

Professor Eva Billstedt

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Lektor Mette Elmose Andersen

Psykologisk afdeling, Syddansk Universitet, Danmark.

Press release (English)

Time trends, delayed diagnosis and quality of life in a cohort of children referred on suspicion of autism spectrum disorder

Autism spectrum disorder (autism) is a neurodevelopmental disorder characterized by core deficits in social communication and stereotyped, repetitive behaviors. Early identification and intervention has been found to be important for the outcome. In recent decades, a steep rise in the prevalence of autism has been seen; however, the reasons are not yet fully understood. Symptoms are often present early in life, but co-occurring disorders and overlapping of symptoms across psychiatric disorders may overshadow autism symptoms, which may result in delay of an autism diagnosis. Individuals with autism often experience adverse effects on physical and mental development, resulting in risk of poor quality of life (QoL); nevertheless, QoL (and factors associated with QoL) is not yet fully understood in adolescents and young adults with autism.

In a clinical cohort of 893 children suspected of autism and assessed before the age of 8 in the period 2000-2010, changes in clinical practice along with clinical characteristics of children with and without a final diagnosis of autism, including characteristics of children with a delayed autism diagnosis despite early suspicion, were investigated. In addition, self-reported and parent-reported QoL, as well as factors associated with QoL, in adolescents and young adults with autism was examined in a new PhD project from Aarhus University, Health. Data sources included data from medical records, Danish registers and questionnaires.

The project was carried out by Sara Højslev Avlund, who will be defending her dissertation on October 8, 2020.

The defence is public and takes place on October 8, 2020 at 14.00 in Auditorium A (G206-145), Entrance G, Aarhus University Hospital, Palle Juul-Jensens Boulevard, 8200 Aarhus N and virtually via Zoom. For access via Zoom, please send an e-mail to [sara.avlund@aarhus.rm.dk](mailto:sara.avlund@aarhus.rm.dk). The title of the project is "Time trends, delayed diagnosis and quality of life in a cohort of children referred on suspicion of autism spectrum disorder". For more information, please contact PhD student Sara Højslev Avlund, e-mail: [sara.avlund@aarhus.rm.dk](mailto:sara.avlund@aarhus.rm.dk)/[s.avlund@rn.dk](mailto:s.avlund@rn.dk).

Assessment committee:

Associate professor Vibeke Fuglsang Bliksted (chairman and moderator of the defence)

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Psychosis Research Unit, Aarhus University Hospital, Psychiatry.

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Associate professor Mette Elmose Andersen

Department of Psychology, University of Southern Denmark.

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