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# Preliminary Findings From a Nationwide, Multicenter Mental Health Service for Adults and Older Adolescents With Autism Spectrum Disorder and ID

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## Abstract

**Background:** The identification and treatment of psychiatric disorders in individuals with autism spectrum disorders (ASD) and ID presents many challenges. We describe the development of a professional network, together with a standardized protocol for clinical assessment, designed to promote clinical competence and professional development in eight clinical centers responsible for providing mental health services to autistic individuals with ID across all four health regions of Norway. Specific aims to describe: (1) patterns of psychiatric and behavior problems in patients treated by the network, (2) patterns of change over time, and (3) the relationship between psychiatric disorders and behavior problems.

**Method:** A standardized protocol was used to assess individual progress in 132 patients (inpatients and outpatients) with autism and ID over 2 years (at referral (T1), after 1 year (T2), and after 2 years (T3)). Changes in psychiatric symptoms and behavior problems were assessed with the Psychopathology in Autism Checklist (PAC) and Aberrant Behavior Checklist (ABC).

**Results:** Patients showed significant ( $p < .001$ ) improvements from T1 to T2 on the psychosis, depression and anxiety subscales of the PAC, but no significant improvement on the obsessive compulsive disorder (OCD) subscale. Improvements were maintained from T2 to T3. Patients showed significant ( $p < .01$ ) improvements on the ABC total score and on all ABC subscales except inappropriate speech from T1 to T2; these improvements were maintained from T2 to T3.

**Discussion:** The combination of a professional network and a standardized protocol for clinical assessment has promise as a strategy for improving professional competence and facilitating specialized mental health services for autistic individuals with ID and psychiatric disorders across an extensive geographical area.

**Keywords:** autism spectrum disorders, ID, intervention, psychiatric disorders

## Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by difficulties in social interaction and communication together with a restricted or repetitive

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repertoire of activities and interests (ICD-10, World Health Organization, 1992; DSM- 5, American Psychiatric Association, 2013). ID is estimated to co-occur in approximately 45% of individuals with ASD (Lai, Lombardo, & Baron-Cohen, 2014). People with ASD and ID represent a very heterogeneous group with respect to etiology and cognitive, language, motor, and social abilities (ICD-10, World Health Organization, 1992). The prevalence and burden of co-occurring psychiatric disorder is being increasingly recognized in individuals with ASD and ID (Dunn, Rydzewska, Fleming, & Cooper, 2020; Hollocks, Lerh, Magiati, Meiser-Stedman, & Brugha, 2018; Lugo-Marin et al., 2019; McCarthy et al., 2010; Rosen, Mazefsky, Vasa, & Lerner, 2018), and this group is particularly vulnerable to mental health problems even when compared to individuals with ASD or ID alone (Bakken, Helverschou, Høidal, & Martinsen, 2016; Dunn et al., 2020; Helverschou, Bakken, & Martinsen, 2011; Hove, 2004; Hove & Havik, 2010).

Identification and treatment of psychiatric disorder in individuals with ASD and ID present several challenges. For example, while it is well established that depression and anxiety are among the most frequent psychiatric disorders associated with ASD (Bakken et al., 2010; Helverschou et al., 2011; Hollocks et al., 2018; Moss, Howlin, Savage, Bolton, & Rutter, 2015; Lugo-Marin et al., 2019; Simonoff et al., 2012; Skokauskas & Gallagher, 2010; Steensel, Bögels, & Perrin, 2011) most data on mental health problems are derived from cohorts of individuals with ASD without co-occurring ID (Hollocks et al., 2018; Lugo-Marin et al., 2019; Matson & Cervantes, 2014). Furthermore, there is no consensus about how to adapt standard diagnostic criteria for identifying mental illness in people with ASD and ID, and few specialist diagnostic instruments are available (Helverschou, Kildahl, & Bakken, 2020; Lugo-Marin et al., 2019; Underwood, McCarthy, & Tsakanikos, 2011).

The development of mental health interventions for individuals with ASD is also a neglected area, and evidence on best clinical practice for this group is limited (Bakken et al., 2016; Helverschou et al., 2011). There have been some positive attempts to adapt treatment methods from general psychiatry to individuals with ASD (e.g., modifications to cognitive-behavioral therapies and adaptations of pharmacological studies; Kerns et al., 2016; Mohiuddin, Bobak, Gih, & Ghaziuddin, 2011; Vasa et al., 2014). There have also been efforts to implement evidence-based interventions within regular clinical services (i.e., Wood, McLeod, Klebanoff, & Brookman-Frazee, 2015), and practice pathway developments (Rosen et al., 2018). However, these studies have mainly involved younger individuals with ASD without ID (Kannabiran & McCarthy, 2009; Weston, Hodgskins, & Langdon, 2016; White, Ollendick, & Albanmo, 2013). Individuals with co-occurring ASD and ID often need more complex treatment plans (Dunn et al., 2020) and almost no high quality, randomized control trials of psychosocial interventions for this group of adults exist. Among adults with ID without ASD, studies on cognitive-behavioral therapies remain primarily at a descriptive stage (Dragan, Jackson, & Eastlake, 2018). Appropriate outcome measures to assess the impact of intervention are also lacking (Brugha, Doos, Temper, Einfeld, & Howlin, 2015). Thus, adults with ASD and ID may frequently fail to receive adequate treatment. Services are variable and often poorly integrated and therapeutic methods

are rarely adapted to their specific needs (Lunsky, Gracey, & Bradley, 2009).

Few studies have specifically examined patient profiles in different services in order to identify which types of provision or treatment best meet individual needs (Lake, McMorris, & Lunsky, 2016). It is unclear, too, which patients are more likely to be admitted to inpatient units, or how effective inpatient treatment actually is (Bakken & Martinsen, 2013). Staff training is limited and specialist education programs for professionals in mental health services for individuals with ID, with or without ASD, are scarce (Bakken et al., 2018).

It is evident that more research on effective psychosocial interventions for adults with ASD, ID and psychiatric disorders is critical (Helverschou et al., 2011; Rosen et al., 2018). Even systematic information about the demographic and clinical profiles of adults with ASD and ID referred to specialist mental health treatment is often lacking, although such knowledge may help to develop better adapted, personalized interventions. It is also essential to monitor patient outcomes and to collect information on individual changes in behavior, thinking, and mood over time (Helverschou, 2010; Helverschou et al., 2011; Hollocks et al., 2018; Kildahl, Bakken, Holm, & Helverschou, 2017).

In order to improve the quality of and access to individually tailored mental health services for individuals with ASD, the need for professional training, better liaison between specialists and the development of specialist and tertiary services are indicated (Royal College of Psychiatrists, 2020). Current trends toward dehospitalization and deinstitutionalization of services for individuals with disabilities and mental health problems also indicate a need to develop community treatment approaches and models for educating and supervising care staff who are providing supportive living and adult residential care services (e.g., Costello, Bouras, & Davis, 2007; McDonnel et al., 2019; Mohiuddin et al., 2011).

Strategies to improve the quality of, and access to, specialist mental health services for adults with ASD and ID are particularly needed in countries like Norway, which has a small and scattered population and covers a large geographical area. To begin to meet this need, a national network—the AUP (Autism, Intellectual Disability and Psychiatric Disorder) Network—for professionals providing specialized and supplementary mental health services to individuals with ASD and ID was established in 2007. Eight centers from across the entire country participate in the network. The network was established to improve access to, and quality of individually tailored services for adult with ASD and ID in need of specialist mental health services, and to increase knowledge of how psychiatric disorders present in these individuals. A clinical treatment study commenced in 2010 and is still in progress. The overall aims of the AUP multi-center study are to describe and evaluate: the characteristics of patients and their environment; rates of co-occurring psychiatric diagnoses; the delivery and adaptations of psychiatric interventions for these patients; differences in services between centers, and to evaluate individual patient outcomes. Although, at this stage, the study design cannot be used to compare the effectiveness of different treatment strategies, early findings may provide a basis for future research on more specific treatment strategies for individuals across the autism spectrum, including those with more limited abilities.

The present paper has two main objectives: (i) to describe the background, strategy and design of the AUP multicenter treatment study, (ii) to evaluate (a) patterns of psychiatric and behavior problems in patients treated by the network, (b) patterns of change over time and (c) the relationship between psychiatric disorders and behavior problems.

## AUP Multicenter Study

### Service Organization

Eight clinical centers in charge of providing specialist, hospital-level mental health services for individuals with ASD and ID covering all four health regions in Norway participate in the study. Most Norwegian health services are public and the healthcare system is founded on the principle of decentralization. Services are organized on three levels: primary health services in the municipalities; county level specialist health services, and regional or national level specialist health services. Care staff or other professionals in the municipalities may refer patients to specialist services when in need of diagnostic support or help in developing treatment plans. Three of the four health regions also have specialized regional mental health services for ASD/ID, where hospital-level specialists may refer patients should they need further assistance and specialist expertise (see Bakken et al., 2018 for a further description of this organization).

Outside the major cities, the country has many sparsely populated areas with long distances between them. Mental health services for individuals with ASD and ID vary in quality and are often poorly integrated. A further challenge is that mental health services provided by the eight centers are mainly delivered as peripatetic outpatient services in community-based facilities. Thus, clinical professionals at the eight AUP centers are responsible for the supervision and training of care staff who have variable knowledge of ASD and of treatment options.

The eight centers in the present study are interdisciplinary and staffed with psychologists, psychiatrists, medical doctors, pedagogues, learning disability nurses and psychiatric nurses. They differ in organizational structure and number and competence of professionals involved. Four of the centers are specialist mental health services for individuals with ID; the others are general services for individuals with ID (habilitation services). Three of the centers have regional responsibilities while the others have responsibility in one county. Two have both inpatient and out-patient services while the remainder provide out-patient services only. For details see Appendix 1.

### Professional Development

Representatives from the clinical centers meet 6 days each year, and a 2-day seminar is organized every other year for all professionals at the centers. The meetings and seminars are organized by the National Centre in charge of the network. Network meetings comprise a mix of case presentations and more general lectures and cover the assessment and phenomenology of psychiatric disorders in ASD and ID. Issues related to

diagnostic and treatment options are presented and discussed with the aim of providing guidance on individually tailored treatments. Because of the complexity of patients' needs, intervention planning and evaluation has to take account of many different individual and contextual factors and a standardized assessment protocol was developed to monitor the impact of treatment at an individual level. The experiences of the participating clinicians with using the standardized protocol were discussed in smaller groups during one of the seminars in order to assess the clinical feasibility of the study. (The experiences are summarized in Appendix 2.) The network is also important in promoting informal contact and direct collaboration between the participating professionals and for facilitating professional development by means of the organized meetings and seminars.

### Standardized Assessment Protocol

A standardized assessment protocol was designed as part of regular service delivery. Assessments include demographic data and information on medical status, behavior problems, psychiatric symptoms and diagnoses, environmental factors, interventions provided, and evaluations by care staff and family members. Assessments are conducted at three time points: referral to service (T1); after 12 months (T2), and after 24–27 months (T3). An overview of the protocol is presented in Table 1. For the present paper, the findings focus on changes in behavioral and psychiatric symptoms.

**Contextual factors.** These are assessed with a Norwegian checklist covering background characteristics such as living conditions and social networks (Myrbakk & von Tetzchner, 2008a). An additional checklist, specifically developed for this study, is used to assess a range of environmental factors, including whether a daily schedule is used and adjusted to the individual's interests and needs, whether individual adjustments are made in care provision such as approaches to interaction and ward atmosphere, as well as the general levels of competence of care staff. This checklist is completed by the professional in charge of assessment and treatment at each AUP center once an understanding of the patient's environmental conditions is reached, ideally during the first 3 months following referral.

**Medical assessment.** This comprises a short description of medical status and medication use.

**Intellectual disability.** All participants have received a clinical diagnosis of ID based on ICD-10 (WHO, 1992) prior to inclusion in the current study, by psychologists or psychiatrists in hospital-level services. For the current study, ID is rated as either mild/moderate or severe/profound, based on scores on the Vineland Adaptive Behavior Scales (Second edition, expanded Interview form; Sparrow, Cicchetti, & Balla, 2008) and clinical background information from hospital records. The Vineland is completed by professionals from the participating centers. More detailed cognitive data are not available due to the challenges of obtaining reliable IQ results from patients with severe cognitive, behavioral, or psychiatric difficulties.

TABLE 1  
Standardized assessment protocol AUP multicenter study

Time point	T1	T2	T3
Assessments conducted			
Contextual factors <sup>a</sup>	X	X	X
Environmental factors <sup>a,b</sup>	X	X	X
Medical assessment	X	X	X
Vineland <sup>c</sup>	X		
SCQ	X		X
ABC	X	X	X
PAC	X	X	X
Psychiatric symptoms	X	X	X
Carer evaluation <sup>a</sup>		X	
Psychiatric diagnosis	Final diagnosis and time for diagnosis registered		
Interventions	Continuous registration of interventions and professional involved		

<sup>a</sup>Norwegian developed checklists.

<sup>b</sup>Should be rated during three first months.

<sup>c</sup>Assessment is repeated at T3 for individuals with schizophrenia or those who have undergone large changes.

T1, at referral/before treatment; T2, after 12 months or at the end of treatment; T3, After 24–27 months; Vineland, The Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 2008); SCQ, Social Communication Questionnaire (Rutter et al., 2003). ABC, Aberrant Behavior Checklist (Aman & Singh, 1986); PAC, Psychopathology in Autism Checklist (Helterschou, Bakken, & Martinsen, 2008, 2009).

**ASD symptoms.** All participants have received a clinical diagnosis of ASD based on ICD-10 (WHO, 1992) by psychologists or psychiatrists in hospital-level services prior to inclusion in the current study. Level of ASD symptoms is assessed by the Social Communication Questionnaire (SCQ) (Rutter, Bailey, et al., 2003). For some participants, the ADI-R (Rutter, Lecouteur, & Lord, 2003) and ADOS (Lord et al., 2000) had been completed as part of previous assessments. However, routine use of ADI-R/ ADOS for all patients is not feasible because of the increased demands on staff time and training; the clinical validity of these instruments may also be compromised by co-occurring psychiatric disorders.

**Behavior problems.** The Aberrant Behavior Checklist (ABC; Aman & Singh, 1986) is used to assess level of problematic (“challenging”) behaviors. This assessment is completed by caregivers with good knowledge of the individual. The ABC is the most thoroughly researched checklist for behaviors that challenge, with several hundred studies investigating its psychometric properties (Aman, 2012). It is currently available in over 25 languages and is easy to administer and score. Psychometric properties vary from satisfactory to excellent (Aman, Singh, Stewart, & Field, 1985a, 1985b; Flynn et al., 2017; Ono, 1996) and its factor structure has been confirmed in numerous studies (Aman et al., 1985a; Newton & Sturme, 1988; Ono, 1996). Good psychometric properties have been demonstrated across varying levels of ID (Aman, 2012; Flynn et al., 2017), in children and adolescents with ASD (Brinkley et al., 2007; Kaat, Lecavalier, & Aman, 2014), and for its Norwegian version (Halvorsen et al., 2019). Data suggest that the ABC is sensitive to change and treatment effects and is a useful aid in the evaluation of intervention (Aman, 2012).

**Psychiatric assessment.** The Psychopathology in Autism Checklist (PAC; Helterschou et al., 2008, 2009) is a caregiver-completed screening checklist for the identification of individuals with ASD and ID in need of psychiatric services. It is one of very few psychiatric instruments developed specifically for individuals with ASD (Lugo-Marin et al., 2019) and has been found to distinguish reliably between psychiatric symptoms and the core characteristics of ASD (Helterschou et al., 2008). The PAC has also been found to discriminate between adults with ASD and ID with and without psychiatric disorders, and to a certain extent between individuals with different psychiatric disorders, especially psychosis and OCD (Helterschou et al., 2009). Internal consistency and inter-rater agreement are acceptable to good (Helterschou et al., 2009). The PAC comprises 42 items distributed across 5 subscales: *psychosis* (10 items), *depression*, (7 items), *anxiety disorders* (6 items), *obsessive-compulsive disorder* (OCD) (7 items) and *general adjustment problems* (GAP) (12 items). Each item is assessed on 2 domains: “Extent of problems” (1 = no problem to 4 = severe problem) and “Change from usual behavior” (Worsened, Unchanged, and Improved). (See Helterschou et al., 2020 for further details). A two-step procedure identifies individuals with a possible psychiatric disorder. First, individuals with *severe general adjustment problems* are identified (i.e., average GAP score > cut-off). Thereafter, those individuals who obtain an average score above cut-off for any of the psychiatric subscales are classified as suspected as having a psychiatric disorder and should be referred for comprehensive psychiatric examination.

**Psychiatric symptoms.** In addition to the checklist assessment, descriptions of all psychiatric symptoms observed in the patients during the treatment period are recorded when the final psychiatric diagnosis is made.

**Final clinical psychiatric diagnostic consensus.** For many participants further assessment is necessary to reach a diagnostic conclusion, and the final diagnosis is often reached later, during the course of treatment.

**Interventions.** Details of all interventions, including type of treatment and number of hours used by professionals at the eight centers, are recorded.

**Individual evaluation.** After 1 year (T2) relevant local professionals, care staff and family members complete a feedback questionnaire about their experiences and involvement in decisions regarding assessment and intervention strategies.

### Assessment of Change Over Time in Psychiatric and Behavioral Difficulties; Preliminary Findings

#### Participants

Patients with ASD and ID referred to one of the eight centers with behavior problems or for psychiatric assessment were recruited to the study. The study includes both new referrals and re-referrals. Potential participants include all patients with ASD and ID aged 14 years or older. There are no exclusion criteria on the basis of severity of ID or presence of other disorders such as ADHD, Tourette syndrome, epilepsy, genetic syndromes, and so forth. Thus, participants include patients who are often considered as particularly challenging for services, and frequently excluded from research.

The AUP multicenter study is conducted as part of regular clinical services at the participating centers. Only patients, who are referred to one of the participating centers for assistance in psychiatric assessment and guidance in developing a treatment plan, are eligible for inclusion. The clinical centers are responsible, either individually or in cooperation with other municipal or hospital services, for diagnostic and treatment decisions.

The present paper describes 132 participants assessed at referral (T1), after 1 year (T2), and after 2 years (T3). All patients referred to the AUP with a complete assessment protocol at the time of analyses are included in the present paper. They were aged between 16–66 years ( $M = 28.6$ ,  $SD = 10.6$ ); 43 (32.6%) were female and 89 (67.4%) male; 87 (65.9%) had mild/moderate ID and 45 (34.1%) had severe/profound ID. All had SCQ scores above 15 (i.e., at/above the suggested cut-off for ASD).

#### Assessment Reported in the Present Paper

As an initial step in monitoring the potential impact of the network on patient outcomes, we conducted systematic assessments of change over 2 years in mental health and behavioral problems using the ABC and the PAC.

#### Ethical Issues

Informed consent was obtained from all the patients and / or their guardians. Data were anonymized and processed without name or other directly recognizable information. The project was approved by the Privacy Data Protection Supervisor (Local IRB, Institutional Review Board) at Oslo University Hospital, Oslo, Norway. Approval # 2010/ 19,579.

#### Statistical Analysis

Data were analyzed using the Statistical Package for the Social Sciences (SPSS, version 25). Non-normal and skewed distributions were identified by visual inspection of histograms for PAC and ABC scores. To assess change over 2 years, Cochran's Q test for nonparametric statistics was used for PAC scores (Conover, 1999) as these are calculated as binary (yes/no) responses. The Friedmans test for nonparametric statistics was used on the ABC results as these are reported as continuous responses (Zimmerman & Zumbo, 1993). Post hoc tests were used to determine whether the measures at any given time (T1, T2, T3) were significantly different from each other, based on the median rank differences. Correlations between psychiatric disorders and behavior problems were calculated using Spearman rho. Because of the number of comparisons conducted, statistical "significance" was set at  $p < .01$ .

#### Results

Frequencies of psychiatric disorders at T1, T2, and T3 assessed by the PAC are presented in Table 2 and Figure 1. At T1 the majority of participants ( $n = 84$ ; 63.6%) screened positive for psychiatric disorders; this proportion decreased significantly ( $p \leq .001$ ) to T2 ( $n = 59$ ; 45.0%) and continued to decrease to T3 ( $n = 44$ ; 33.3%); however, the T2 to T3 difference was not significant. Depression and anxiety were the most frequent disorders identified. On the separate PAC subscales, patients showed significant ( $p \leq .001$ ) improvements from T1 to T2 on the psychosis, depression and anxiety subscales, but the improvement was not significant on the obsessive compulsive disorder (OCD) subscale. Improvements were maintained from T2 to T3.

Frequencies of behavior problems at T1, T2, and T3 assessed with ABC are presented in Table 3 and Figure 2. Although there are no cut-off levels in the ABC, the frequency of problems at T1 was high compared to previous reports from a representative sample of individuals living in community settings (Myrbakk & Von Tetzchner, 2008b).

Patients showed significant ( $p < .001$ ) improvements from T1 to T2 on the ABC total score and on all ABC subscales, except inappropriate speech; these improvements were maintained from T2 to T3.

Correlations between ABC total score and PAC total score at each time point (T1, T2, and T3) were all significant ( $p < 0.01$ ). Most of the correlations between PAC total score and ABC total score at different times were also significant ( $p < .01$ ). The strength of the correlations was moderate to large.

TABLE 2  
Frequencies of screen positive cases of psychiatric disorder as assessed by the Psychopathology in Autism Checklist ( $n = 132$ )

	T1 (%)	T2 (%)	T3 (%)	$Q^2$	$p$	Post hoc analysis ( $p < .01$ )
Psychosis	43 (32.6)	15 (11.4)	18 (13.6)	27.8	<.001	T1 > T2, T3
Depression	67 (50.8)	46 (34.8)	30 (22.7)	28.7	<.001	T 1 > T2,T3
Anxiety	59 (44.7)	31 (23.5)	27 (20.5)	27.6	<.001	T1 > T2, T3
OCD	21 (15.9)	16 (12.2)	15 (11.4)	2.2	.331	Ns
Total <sup>a</sup>	84 (63.6)	59 (45.0)	44 (33.3)	34.7	<.001	T1 > T2, T3

<sup>a</sup>Several participants were screen positive for more than one disorder and therefore the total number of screen positive cases for any disorder are lower than the sum of screen positive cases for individual disorders.

OCD, obsessive compulsive disorder.

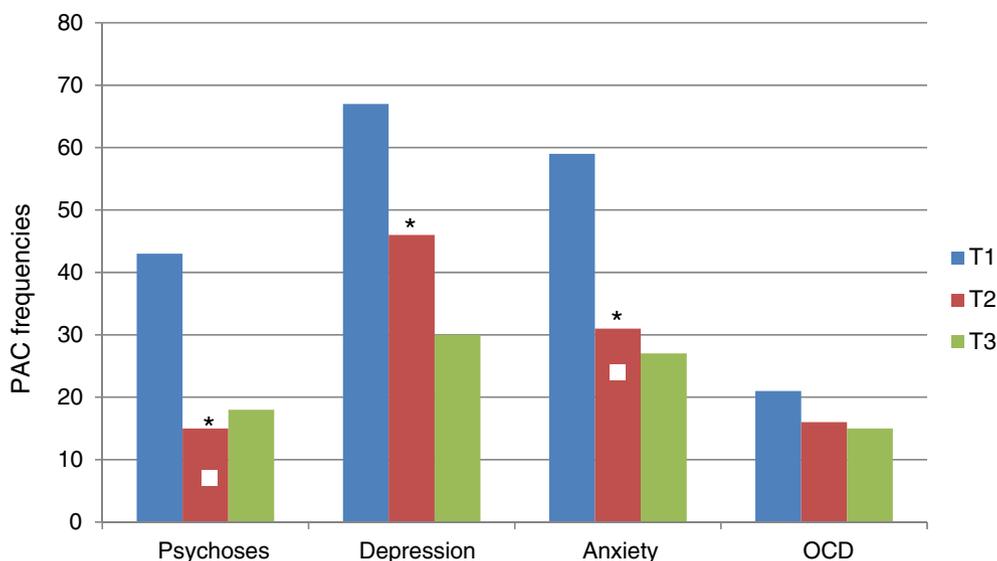


FIGURE 1

Psychiatric symptoms at T1, T2, and T3 (total number of participants with scores above cut-off on one or more disorders is lower than the sum of the different disorders due to overlap). Participants screening positive for psychoses, depression, anxiety and OCD (obsessive compulsive disorder) at T1, T2, and T3 on the Psychopathology in Autism Checklist (PAC),  $N = 132$  (1 missing OCD and total). \* $p < .001$  (Cochran’s Q-test).

TABLE 3  
Aberrant Behavior Checklist scores at T1, T2, and T3 ( $n = 131$ )

	T1 Median (range) <sup>a</sup>	T2 Median (range) <sup>a</sup>	T3 Median (range) <sup>a</sup>	$X^2$	$df$	$p$	Post hoc analysis ( $p < .01$ )
Irritability	16 (8–23)	9 (6–17)	10 (4–18)	18.84	2	<.001	T1 > T2, T3
Lethargy	15 (7–24)	8 (4–15)	8 (3–14)	22.02	2	<.001	T1 > T2, T3
Stereotypy	6 (3–10)	3 (1–6)	2 (0–6)	37.96	2	<.001	T1 > T2, T3
Hyperactivity	15 (9–22)	10 (4–16)	8 (3–16)	29.06	2	<.001	T1 > T2, T3
Inappropriate speech	3 (1–6)	2 (0–4)	2 (1–5)	2.76	2	.252	Ns.
Total score	53 (35–81)	38 (21–54)	34 (18–55)	40.4	2	<.001	T1 > T2, T3

<sup>a</sup>Range = 25th percentile to 75th percentile (Aman, 2012).

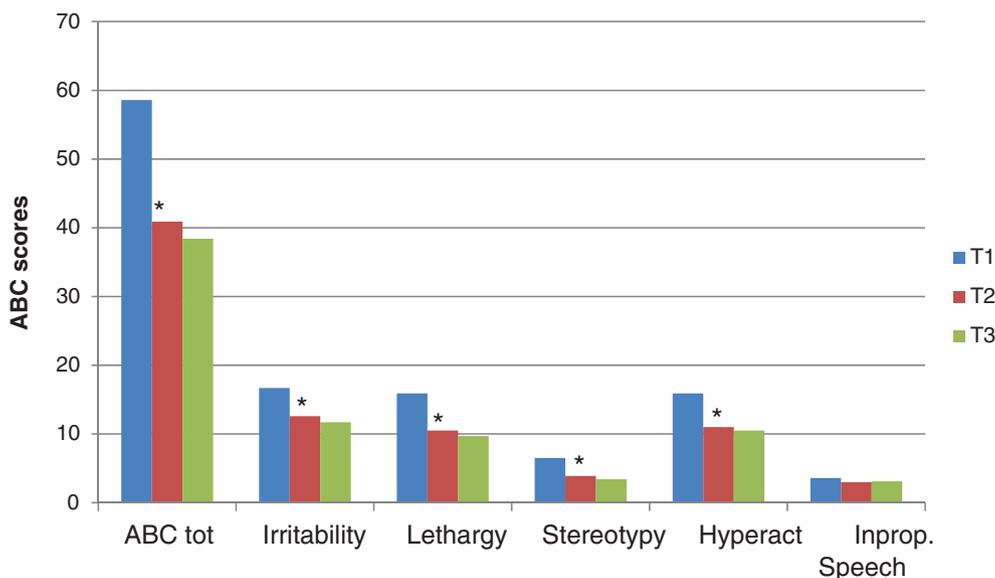


FIGURE 2

ABC-scores at T1, T2, and T3. Participants ABC total score and subscale scores T1, T2, and T3,  $N = 132$ .  $*p < .001$  (Friedmans ANOVA).

The correlation between ABC at T1 and PAC at T2 was nonsignificant. Data are presented in Table 4.

### Discussion

The AUP multicenter treatment Network study is designed to improve access to, and quality of, individually tailored services for adults and youth with ASD and ID in need of specialized mental health services in Norway. In this paper we focus on patterns of psychiatric and behavior problems in this group and how symptoms change over time. As expected, the majority of the included patients was screened, by the PAC, as having a psychiatric disorder. The most commonly identified problems were depression and anxiety, in line with previous studies of this population (Helverschou et al., 2011; Hollocks et al., 2018; Lugo-Marin et al., 2019; Rosen et al., 2018). Levels of behavior

problems at T1 were also high compared to previous reports from a representative sample of individuals with ID living in community settings (Myrbakk & Von Tetzchner, 2008b).

Unexpectedly, however, despite all participants being referred to the services because of their challenging and complex needs, almost one third did *not* screen positive on the PAC. This may be related to the strict cut-off criteria of the PAC, which were derived from a cohort of patients with ASD and ID and severe psychiatric disorders (Helverschou et al., 2009). In addition, there is some evidence that the PAC is insufficiently sensitive to identify all individuals with anxiety (Helverschou & Martinsen, 2011; Kildahl, Bakken, Iversen, & Helverschou, 2019). Thus, some participants who did not meet PAC criteria for a psychiatric disorder may, nevertheless, meet clinical criteria for an anxiety disorder. This adds to previous findings that diagnosis cannot be reliably made on the basis of standardized questionnaires or checklists alone but requires a multimodal diagnostic process, combining clinical expertise and the use of different instruments (Helverschou et al., 2020; MacNeil, Lopes, & Minnes, 2009). For diagnosis in clinical services, more detailed and in depth clinical interviews and observations are recommended (Hollocks et al., 2018) which is why the AUP study design includes both checklist assessments and a final clinical diagnosis. Systematic exploration of the relationship between diagnoses indicated by the PAC and final clinical diagnoses is planned and, hopefully, will provide greater information about the participants and on the strengths and weaknesses of the checklist.

Nevertheless, assessment of change over time indicated significant reductions in most psychiatric and behavioral symptoms from T1 to T2. These improvements were generally

TABLE 4

Spearman's rho correlations between total scores for the Aberrant Behavior Checklist and the Psychopathology in Autism Checklist ( $n = 124$ )

	ABC T1	ABC T2	ABC T3
PAC T1	.502**	.323**	.321**
PAC T2	.201*	.468**	.311**
PAC T3	.322**	.258**	.593**

\*\* $p < .01$  (two-tailed).

maintained from T2 to T3, suggesting that most patients in the eight clinical units responded positively to treatment and made good progress during the 2-year course of treatment and follow up. Although no causal assumptions regarding the impact of the network can be made on the basis of the data reported here, having a standardized protocol made it possible to monitor and document the participants' positive development over time. Further data will be needed to demonstrate that the combination of a professional network and a standardized protocol for clinical assessment helps to improve outcome and the quality of individually tailored mental health services for this group; collection of such data is currently planned.

Successful interventions require the development of services with specialist expertise both in ASD, ID and mental illness, and with sufficient resources to identify and treat mental health disorders in this group in a timely and systematic manner (Bakken et al., 2016; Helverschou et al., 2011; Simonoff et al., 2008). The aim of the network was to develop a unified, evidence-based approach to address the challenges of treating these patients, and systematic documentation of change during the course of treatment will be of importance in order to assist policy makers and further development of services. Thus, indirectly, these results may improve access to mental health services for adults with ASD and ID (Dunn et al., 2020). However, it is also evident that not all participants showed the same level of improvements and there is clearly need for further detailed analysis of factors related to the extent of change.

The significant relationship found between psychiatric disorders and behavior problems in the present study is in line with findings from previous research on individuals with ID (i.e., Emerson, Moss, & Kiernan, 1999; Minshew, 2006; Moss et al., 2000; Myers & Winters, 2002; Myrbakk & von Tetzchner, 2008a). This finding also supports suggestions that behavior problems may be indicators of psychiatric disorders in individuals with ID and ASD (Painter, Hastings, Ingham, Trevithick, & Roy, 2018). However, the inter-relationship between behaviors that challenge and psychiatric disorders is complex and poorly understood (Cooper, 2016; Painter et al., 2018) and it is unlikely that all behavior problems are underpinned by (undiagnosed) psychiatric disorders (Hemmings, 2007). Interpreting behaviors that challenge as symptoms of underlying psychiatric disorders is only justified if environmental factors (such as over- or under-stimulation), or communication, psychosocial or physical health problems, and many other variables, can be eliminated as potential causes (Helverschou, 2010; McClintock, Hall, & Oliver, 2003; Minshew, 2006). Further detailed analyses of data from the AUP study may reveal new insights into this area, including the significance of distress and emotional dysregulation associated with problem behaviour in individuals with ID (Cooper, 2016). Additionally, there may be an important relationship between psychiatric and behaviour problems in people with ASD and ID and exposure to adverse life events (Hove, Assmus & Havik, 2016; Kildahl et al., 2019a; Rittmannsberger et al., 2020). It is well established that, compared with the general population, individuals with ASD and those with ID have a heightened risk of abuse and trauma (McCarthy, Blanco, Gaus, Razza, & Tomasulo, 2017; McDonnell et al., 2019). Individuals with ASD and ID may be at even greater risk.

## Limitations and Strengths

There are several limitations in the present study that may affect the interpretation of the findings. First, it is important to emphasize that the participants are not a representative sample of adults and older adolescents with ASD and ID and mental health issues. Patients referred to the participating centers are likely to have particularly complex and challenging problems. In addition, the clinical units decide themselves which patients to include in the study. Thus, we have no control of how representative the included patients are of the total population of referred patients. The design of the study is limited to a description of the included patients and their progress during the period of study. Information on behavioral or psychiatric symptoms prior to the start of the study is not available and no comparison group was included. The strength of this paper is, however, the inclusion of participants who have often been excluded from research due to the extent and severity of their ASD and ID and comorbid psychopathology.

## Clinical Implications

Previous research (Roe, Drake, & Slade, 2015) has highlighted the importance of using a standardized schedule to monitor the efficacy of treatment intervention in clinical practice and clinical research. Despite the limitations inherent in the present study, the findings suggest that use of a standardized protocol across a wide Network, such as the AUP, may provide valuable information on clinical change that, over time, will allow for more individualized treatment planning. During one of the 2-day seminars for all professionals at the centers, their experiences were reported in the course of informal group discussions and although, at the start of the study, many feared the protocol would be too time-consuming, they subsequently reported that they found the standardized protocol useful for individual clinical work in a number of different ways and that they had started using it with more patients. The reported experiences of these clinicians support the social validity of our implementation strategy. See Appendix 2 for details.

## Further Research

This is the first publication from the AUP multicenter study. Further analyses and assessments are in progress and will provide the possibility of addressing a number of different research questions. There will be a particular focus on investigating in more detail the properties of the PAC; examining the relationship between psychiatric disorders, behavior problems and environmental factors; the delivery and adaptations of psychiatric interventions for these patients; differences in services between centers, and exploring patient profiles and outcomes to identify differences in outcome and which services best meet individual needs (Bakken & Martinsen, 2013; Lake et al., 2016). It is hoped that the clinical data derived from patients and staff involved in the AUP Network will contribute to a greater understanding of psychiatric disorders in ASD and ID and the development of more effective and personalized interventions for individuals

across the autism spectrum, including those with limited verbal and intellectual abilities (Rosen et al., 2018).

### Conclusion

In order to improve the quality of and access to individually tailored mental health services for individuals with ASD and ID, there is a need for professional training, better liaison between specialists, and the development of specialist and tertiary services. It is vital that the professionals involved in diagnosis and treatment have broad expertise in ASD, ID, and psychiatric disorders. The combination of ASD, ID, and psychiatric disorder, poses significant challenges to diagnosis and treatment, and specialized expertise in this area is required. In addition, dedicated training programs for professionals in mental health services for individuals with ID with or without ASD are warranted.

Preliminary data from the AUP Network study indicate reductions in psychiatric symptoms and behavioral problems during the course of treatment. The findings suggest that the combination of a professional network and a standardized protocol for routine clinical practice has the potential to improve professional competence and the quality of specialized mental health services for individuals with ASD, ID, and psychiatric disorders across a large geographical area. Further analyses and results from the study are in progress.

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## APPENDIX 1

### Participating Units in the AUP Multicenter Study



This is a map of Norway. The distance from north to south is 2,518 km. The population in Norway is approximately 5 million people. The county is divided into four health regions; north, middle, west and southeast. The southeast region is the biggest and covers almost 2/3 of the total population.

The regions are divided into 11 counties, which again are divided into 356 municipalities. The mean population size of the municipalities is 11,000. All main services are provided in the municipalities, and the municipalities get support from specialist services at county level. In addition, some specialist services which require particular expertise are established at regional level, and may support specialist services at county level and service providers in the municipalities.

*AUP network include eight clinical centers:*

One center in the northern region:

Psychiatric resource team, Nordland Hospital Trust is a specialized mental health service with regional responsibilities. Number of employees: 11.

Four centers in the middle region:

Department of Psychiatry, Section Specialized Habilitation, Nord-Trøndelag Hospital Trust. Number of employees: 13.3.

Specialized Habilitation Service, Nordmøre and Romsdal, Møre and Romsdal Hospital Trust. Number of employees: 20.5.

St. Olavs Hospital, Department of Østmarka, Habilitation Services. Number of employees: 15.

Specialized Habilitation Service, Sunnmøre, Møre and Romsdal Hospital Trust. Number of employees: 28.5.

Each center is a general service for individuals with ID and has responsibilities on county level.

One center in the western region:

Department of mental health, Regional section autism and intellectual disability mental health, Helse Fonna Hospital Trust is a specialized mental health service with regional responsibilities. Number of employees: 5.

Two centers in the south-eastern region:

Regional Section Mental Health, Intellectual Disabilities/Autism, Oslo University Hospital is a specialized mental health service with regional responsibilities and provides both in-patient and out-patient services. Number of employees: 80.

Department of Psychiatry, Section Intellectual Disability and Autism, Vestre Viken Hospital Trust is a specialized mental health service with responsibilities on county level and provides both in-patient and out-patient services. Number of employees: 24.

The AUP-network is headed by:

NevSom—Norwegian Centre of Expertise for Neurodevelopmental Disorders and Hypersomnia, Oslo University Hospital.

## APPENDIX 2

### Clinical Experiences From Using a Standardized Assessment Protocol

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The protocol is useful for individual clinical work according to diagnostic evaluations, trying to explain/understand behavior, education to care staff and family members, and provides basis for interventions and further assessment.

The protocol helps changing the understanding of care staff and family members surrounding the patient and gives increased awareness of how to provide treatment.

It is experienced as useful to assess at several times on a fixed schedule.

When the professionals get used to the protocol and have learnt the different assessment instruments it is no longer “time thieves” but good and efficient routines.

Thus, the use of the protocol has been transferred to other patients outside the project.

The total of the protocol and the systematic way of addressing challenges are highlighted as very useful.

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The appendix summarizes clinicians' experiences with using the standardized protocol of the AUP multicenter study reported during one of the 2-day seminars. Fifty clinicians participated in group discussions about benefits and challenges with following the protocol, and the experiences reported in the smaller groups were summarized in plenary.