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Research on community integration in autism spectrum disorder: Recommendations from research on psychosis

Anke M. Scheeren^{a,*}, Hilde M. Geurts^{a,b}^a Dutch Autism & ADHD Research Center, University of Amsterdam, Department of Psychology, Weesperplein 4, 1018 XA Amsterdam, The Netherlands^b Dr Leo Kannerhuis, Houtsnipaan 1a, 6865 XZ Doorwerth, The Netherlands

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ABSTRACT

Both individuals with an autism spectrum disorder (ASD) and individuals with a psychotic disorder have difficulties integrating in the community. By means of a systematic review of the literature on community integration of young people with ASD or psychotic disorders, we aimed to unfold research foci and gaps within the ASD literature. As anticipated, research on community integration was more advanced in the field of psychosis compared to ASD. In this paper we highlight those areas of community integration that have received particularly little attention in ASD research, such as stigmatization, and we formulate research recommendations for ASD researchers based on the research conducted in the psychosis field. The outcomes of this systematic review demonstrate a need for more practical research focused on the daily lives of adolescents and adults with ASD.

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1. Introduction

For many individuals with an autism spectrum disorder (ASD) community integration is an important challenge in their adult lives (Hendricks & Wehman, 2009; Howlin & Moss, 2012). Yet, it is only fairly recently researchers have begun to focus on adults with ASD and their integration in the community. 'Community integration' is generally understood as a multi-dimensional construct consisting of three main components: employment (or other productive activities), housing, and social and leisure activities (Sander, Clark, & Pappadis, 2010). More simply put, a person is integrated in the community when that person has something to do, somewhere to live and someone to love (McColl et al., 1998). Apart from objective measures of community integration such as a paid job, researchers also differentiate 'psychological integration', referring to a sense of belonging to the community and to others (Wong & Solomon, 2002). In this study we aim to identify potential gaps in the literature on community integration of individuals with ASD with the purpose of formulating clear research foci for the future.

1.1. Research on community integration across psychopathologies

Recently, Pellicano, Dinsmore, and Charman (2014) noted a huge disparity between ASD research that is needed according to groups of stakeholders (practitioners, researchers, individuals with ASD and their family members) and the ASD

* Corresponding author at: University of Amsterdam, Department of Brain and Cognition, Weesperplein 4, 1018 XA Amsterdam, The Netherlands. Tel.: +31 20 5256123.

E-mail address: A.M.Scheeren@uva.nl (A.M. Scheeren).

research that is actually funded in the United Kingdom (UK). While stakeholders prioritized research that is of immediate practical use, such as research on the effectiveness of services and support for people with ASD, ASD research funding in the UK goes primarily to 'basic science' such as the study of biological, neurological and cognitive systems (Pellicano et al., 2014). In line with these findings, we expect to find considerable gaps in the literature on community integration of individuals with ASD. To put the results in perspective, we will also review the literature on community integration of individuals with a psychotic disorder. Individuals with ASD and psychotic disorders share several characteristics in terms of deviations in thought, affect and behavior as well as genetic components (Barneveld et al., 2011). Both ASD and psychotic disorders are associated with substantial limitations in community integration, but there may be important differences in research foci and, therefore, differences in knowledge. Cross-pollination of knowledge between these research areas may provide new insights and boost fruitful lines of research.

There are reasons to assume that research on community integration is more evolved in the field of psychotic disorders compared to ASD. Firstly, schizophrenia usually develops in adolescence or young adulthood, while ASD often becomes manifest in (early) childhood (APA, 2013). Schizophrenia research is thus more or less restricted to the study of adolescents and adults, whereas ASD research has chiefly focused on children and much less so on adolescents and adults with ASD (Jang et al., 2014; Mukaetova-Ladinska, Perry, Baron, Povey, & Autism Ageing Writing Grp., 2012). It is, therefore, more likely that research on schizophrenia includes more mature topics such as independent living and employment compared to ASD research. Secondly, the history of research on community integration of persons with a psychotic disorder is longer considering the fact that social or vocational disfunctioning has already been included as a diagnostic criterion in the Diagnostic and Statistical Manual of Mental Disorders for schizophrenia in the 1980s (DSM-III; APA, 1980). As a comparison: functional limitations (due to core ASD characteristics) such as low vocational success were not included as a diagnostic criterion for autistic disorder until the most recent version of the DSM (DSM-5; APA, 2013). Hence, based on the presumed rich and long history of research on community integration of individuals with a psychotic disorder, we – researchers in the ASD field – may learn valuable lessons from the psychosis field.

1.2. Objectives of this review

To pinpoint gaps in our existing knowledge on community integration of individuals with ASD we compare research foci of interest between the fields of ASD and psychosis. We compare literature in the two fields by means of a selective systematic review. In our review we specifically focus on adolescence and young adulthood, because we consider this stage of life to be particularly relevant when examining community integration. During adolescence and young adulthood dramatic changes occur in all domains of life. Typically there is a shift from study to work, from living with family to independent living, and young people establish new social relationships including romantic relationships.

Summing up, this study's objectives are to answer the following research questions:

- 1) What are the potential gaps in the literature when it concerns community integration of adolescents and young adults with ASD?
- 2) How do the research foci in psychosis research compare to research foci in ASD research?
- 3) What can we – researchers in the ASD field – learn from research on community integration of individuals with a psychotic disorder?

2. Method

2.1. Search strategy

We systematically reviewed the literature on community integration of individuals with ASD or a psychotic disorder. In *Web of Science* (including *Web of Science* core collection, MEDLINE, and SciELO citation index) we entered a combination of search terms (see [Appendices A and B](#)). Note that we entered 'autism' as a search term, but we did not limit our literature selection to publications on autism (all ASDs were included). Similarly, we entered 'schizophrenia' as a search term, but we did not limit our literature selection to publications on schizophrenia (all psychotic disorders were included). Based on these search terms we found 477 publications on ASD and 988 publications on psychotic disorders (excluding duplicates; see also [Figs. 1 and 2](#)).

2.2. Inclusion and exclusion criteria

All abstracts were screened for eligibility. The research project leader (A. M. S.) and a research assistant read the same 38 abstracts and independently judged whether or not a publication should be selected for full screening (a full reading of the paper). Initially, the two raters agreed about in- or excluding the publication in 29 of 38 cases (76%). After discussion with a third researcher (H. M. G.), all cases of disagreement were resolved based on the following inclusion criteria:

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