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

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\textbf{Article Info}

\textbf{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.

\textbf{Keywords:}
Autism spectrum disorder
Psychosis
Community integration
Adults
Stigma
Employment

\textbf{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 (McCull 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.

\textbf{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
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:
1) The publication should describe one or more of these topics: (a) degree of community integration of adolescents or young adults with ASD or a psychotic disorder (in terms of housing, employment etc.), (b) effectiveness of interventions to promote community integration, (c) subjective quality of life, or (d) degree of stigma or the effectiveness of anti-stigma programs.

2) If the publication concerns a single study, the research population should consist of at least 10 individuals with a diagnosis of ASD (e.g., autistic disorder, syndrome of Asperger, PDD-NOS) or a psychotic disorder (e.g., schizophrenia, schizoaffective disorder, first episode psychosis), a normal intellectual ability (IQ > 70), and an average age between 12 years and 0 months and 30 years and 11 months. Alternatively, if the publication concerns a single study on stigma of ASD or psychosis, the research population should consist of at least 10 individuals without psychopathology.

3) If the publication describes multiple studies (in a review or a meta-analysis), at least one of the included studies should meet criteria 1 and 2.

4) The publication is published in the period 1990–2014 (the last search was performed March 4, 2014). To prevent overlap with the literature reviewed in the recent (Dutch) multidisciplinary guidelines for schizophrenia (van Alphen et al., 2012) or adults with ASD (Kan et al., 2013; NICE, 2012), we chose a more narrow publication time frame for some topics: (a) ASD and employment (2011–2014) and (b) psychotic disorders and housing, employment, education, social contacts, leisure or stigma (2009–2014). We integrated knowledge formulated in the multidisciplinary guidelines in our systematic review.

5) The publication should be in English or Dutch.

An exclusion criterion was formulated with regard to the research population. The research population should not consist of a group with fragile X syndrome or 22q11.2 deletion syndrome. These are both genetic disorders that often coincide with an intellectual disability and autistic or psychotic features.
2.3. Paper selection and categorization

In total the research project leader selected 132 abstracts on ASD and 403 abstracts on psychotic disorders for further screening. Based on a full screening of the papers 76 eligible papers were found on community integration of individuals with ASD and 110 papers on community integration of individuals with a psychotic disorder (see also Figs. 1 and 2). For a complete overview of the included papers see Tables C.1 and C.2 in the Appendix.

We ordered the literature according to the following domains: housing, employment, education, social contacts, leisure, stigma, subjective quality of life, multiple domains, or other. In case a publication described multiple domains without a primary focus on either one, the publication was included in the category ‘multiple domains’. An example of a ‘multiple domains’ publication is a study where multiple outcome measures, such as having a paid job (employment) and college enrollment (education), are used to describe the prognosis for individuals with ASD or a psychotic disorder. If a publication did not fit any of the described categories, but still met the inclusion criteria, it was assigned to the ‘other’ category. For instance, a publication describing effective methods to improve the independent skills of individuals with ASD was assigned to the ‘other’ category. To check if publications were categorized reliably, the research project leader and a research assistant screened 90 (of 186) randomly selected publications double. They assigned 86% of the publications to the same category. In case the two coders disagreed, one coder usually assigned the publication to the ‘multiple domains’ category, whereas the other assigned it to only one of the life domains. There was, however, not a pattern of one coder consistently selecting the ‘multiple domains’ category, whereas the other selected a different category. Also, the two coders sometimes disagreed on which publication belonged to the ‘other’ category (a very limited number of studies was categorized ‘other’). For instance, a publication on the perception of children with ASD in the ultraorthodox Jewish society was labeled as ‘other’ by one coder, while the other coder labeled it as a publication in the ‘stigma’ category.
3. Results

3.1. Research focus of interest in the ASD literature

Notably, half (50%) of all selected publications on ASD addressed the social domain, that is, the social networks of adolescents and young adults with ASD or interventions to improve their social skills (see Table 1). It lies outside the scope of this manuscript to fully describe these findings, but we will briefly mention some of the main findings. Compared to typically developing peers, adolescents and young adults with ASD more often report having no friends (Friedman, Warfield, & Parish, 2013; Koning & Magill-Evans, 2001). Meta-analyses have demonstrated sufficient empirical evidence for the effectiveness of video (self) modeling on the social skills of individuals with ASD (Bellini & Akullian, 2007), some support for the effectiveness of TEACCH (Virues-Ortega, Julio, & Pastor-Barriuso, 2013) and sport programs (Sowa & Meulenbroek, 2012), but insufficient evidence for the effectiveness of social skills training based on Social Stories (Kokina & Kern, 2010) or at school (Bellini, Peters, Benner, & Hopf, 2007). Given that effectiveness varies according to type of intervention studied, it is not surprising that there is no agreement in the literature concerning the overall effectiveness of (any type of) social skills interventions for individuals with ASD. Some authors of systematic reviews conclude that sufficient evidence has been found for the effectiveness of social skills training (Cappadocia & Weiss, 2011; Maglione, Gans, Das, Timbie, & Kasari, 2012), while others state that effects are only modest (Case-Smith & Arbesman, 2008) or methodological shortcomings overshadow the studies’ impact (Rao, Beidel, & Murray, 2008).

3.2. Comparison psychosis and ASD literature

As expected, we found more papers on community integration of individuals with psychotic disorders (n = 110) compared to papers on those with ASD (n = 76). Note though that the publication period criterion was stricter for the papers on psychosis, suggesting that the ratio of papers on psychotic disorders versus ASD would have been even more skewed if the same publication period had been screened. To enable a direct comparison between the foci of interest in the research fields of ASD and psychosis, we compared the relative number (proportion) of publications in each category (housing, employment, etc.), see Table 1 for an overview.

When examining the percentage of publications ordered per life domain, we noticed clear disparities in research foci and gaps in the fields of ASD and psychosis. First of all, while many publications in the psychosis field focused on the stigma of a psychotic disorder or interventions to reduce stigma (31% of all selected papers on psychotic disorder), there was much less focus on the stigma of ASD or interventions to reduce stigma of ASD (7% of all selected papers on ASD). Secondly, multiple life domains were discussed in a relatively large proportion of publications on individuals with a psychotic disorder (35%), while a smaller proportion of publications in ASD research included multiple life domains (18%). Finally, although both in the fields of ASD and psychosis, employment was a relatively frequently discussed topic (ASD: 11%; psychosis: 15%), we reckon that valuable lessons might still be learned from studies on employment of individuals with a psychotic disorder given that the absolute number of publications was twice as high (n = 16).

3.3. Findings from psychosis research

Below we discuss the main findings from psychosis research on those topics that were most prevalent in the literature: stigma, employment, and community integration in general.

3.3.1. Stigma

For persons with a diagnosis of a psychiatric disorder stigma or fear of stigma can lead to reduced seeking of help or treatment (Corrigan, 2004 in Reavley & Jorm, 2011). Stigma may also decrease their chances of finding a suitable job, house or partner and, therefore, poses a viable threat to community integration. There have been several studies on stigma of a

<table>
<thead>
<tr>
<th>Life domain</th>
<th>No. of papers on ASD</th>
<th>% of papers on ASD</th>
<th>No. of papers on psychotic disorder</th>
<th>% of papers on psychotic disorder</th>
<th>Δ%*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housing</td>
<td>1</td>
<td>1</td>
<td>5</td>
<td>5</td>
<td>-4</td>
</tr>
<tr>
<td>Employment</td>
<td>8</td>
<td>11</td>
<td>16</td>
<td>15</td>
<td>-4</td>
</tr>
<tr>
<td>Education</td>
<td>5</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>+7</td>
</tr>
<tr>
<td>Social contacts</td>
<td>38</td>
<td>50</td>
<td>6</td>
<td>5</td>
<td>+45</td>
</tr>
<tr>
<td>Leisure</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>+1</td>
</tr>
<tr>
<td>Stigma</td>
<td>5</td>
<td>7</td>
<td>34</td>
<td>31</td>
<td>-24</td>
</tr>
<tr>
<td>Subjective quality of life</td>
<td>2</td>
<td>3</td>
<td>5</td>
<td>5</td>
<td>-2</td>
</tr>
<tr>
<td>Multiple domains</td>
<td>14</td>
<td>18</td>
<td>39</td>
<td>35</td>
<td>-17</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>2</td>
<td>5</td>
<td>5</td>
<td>-3</td>
</tr>
<tr>
<td>Total</td>
<td>76</td>
<td>100</td>
<td>110</td>
<td>100</td>
<td></td>
</tr>
</tbody>
</table>

* Note: Percentage of papers on ASD minus the percentage of papers on psychotic disorder.
psychotic disorder. Stigmatization in these studies is usually operationalized as a preference for social distance (e.g., not wanting to be friends with a person with schizophrenia) or negative attitudes (e.g., people with schizophrenia are dangerous).

Degree of stigma of schizophrenia varies considerably across countries (Pescosolido, Medina, Martin, & Long, 2013). Even in the least stigmatizing countries, however, the general population prefers some social distance toward individuals with schizophrenia (Pescosolido et al., 2013). Many people would not trust someone with schizophrenia with the care of their child and they are reluctant to accept someone with schizophrenia as in-law. Moreover, the general population (in several Western countries) has a less positive and more stigmatizing image of individuals with a psychotic disorder compared to individuals with another psychic disorder such as depression or panic disorder (Angermeyer, Millier, Remuzat, Refai, & Toumi, 2013; Reavley & Jorm, 2011; Yang et al., 2013). Stigmatizing attitudes toward individuals with a psychotic disorder are not only present among the general population, but have also been found among (future) professionals in health care (Petil, Petil, Pavlovic, Prolosciç, & Petric, 2011). In a cross-cultural study, medical students and doctors in Sri Lanka expressed less negative attitudes toward people with schizophrenia compared to their peers in the UK (Fernando, Deane, & McLeod, 2010). However, 18% of the respondents in Sri Lanka compared to only 1% in the UK held the belief that a patient with schizophrenia is self to blame for his/her disorder (Fernando et al., 2010).

3.3.2. Anti-stigma interventions

A way to decrease stigmatization may be to inform the general public about psychotic disorders. However, as described in the multidisciplinary guidelines for schizophrenia (van Alphen et al., 2012), an emphasis on biogenetic explanations of schizophrenia appears to stimulate negative and stigmatizing attitudes toward schizophrenia in the general population. Yet, while the social distance typically widens when the biogenetic origin is stressed, the degree of guilt attributed to the person with schizophrenia typically decreases (van Alphen et al., 2012).

Several interventions have been developed to reduce stigma of a psychotic disorder. One method is to expose individuals without psychopathology to simulated (auditory) hallucinations in order to raise their understanding of individuals with a psychotic disorder. However, based on a systematic review of studies on simulated (auditory) hallucinations, it seems that simulated hallucinations lead to increased empathy for persons with a psychotic disorder, but also to a stronger preference for social distance (Ando, Clement, Barley, & Thornicroft, 2011). Thus, a simulation of hallucinations may even have an adverse effect. Although a recent study has shown that when the simulation is embedded in an informed context stigma might still be reduced (Galletly & Burton, 2011). Another method to reduce stigma is meeting a person with a psychotic disorder or watching a video about a person with a psychotic disorder (Brown, Evans, Espenshade, & O’Connor, 2010). Anti-stigma programs at secondary schools that use this method have yielded short term positive effects, but long term effects are unclear or have not been found (Campbell, Shryane, Byrne, & Morrison, 2011; Economou et al., 2012). Finally, some studies suggest that merely imagining a positive meeting with a person with a psychotic disorder can reduce stigma (Giacobbe, Stukas, & Farhall, 2013; West, Holmes, & Hewstone, 2011).

3.3.3. Employment

In most European studies employment level of individuals with schizophrenia is estimated at 10–20%, which is considerably lower compared to that of the general population (Marwaha & Johnson, 2004). The lower employment level is not only caused by the disorder itself, but is also influenced by situational and personal factors. Factors that have been identified to predict a higher employment level among individuals with a psychotic disorder are social support, good social skills, good cognitive skills, having a paid job prior to diagnosis, education, and rehabilitation services focused on community integration (Cougnard, Goumilloux, Monello, & Verdoux, 2009; Tsang, Leung, Chung, Bell, & Cheung, 2010). Also, a shorter period of untreated first psychosis (or prodromal phase of a psychosis) is related to better job outcomes (Chang et al., 2012; Norman et al., 2012; Schimmelmann et al., 2008). Some studies also report a higher employment level of women versus men with a first psychotic episode (Chang et al., 2011; Thorup et al., 2007), but it is unclear whether this gender difference is caused by other differences such as variety in social skills.

3.3.4. Employment interventions

Supported Employment (SE) or Individual Placement and Support (IPS) are employment rehabilitation methods with the objective to help people with a psychic or physical illness gain a regular paid job as quickly as possible and to provide long term support during employment. Several studies have shown that SE/IPS is effective to increase the employment level of individuals with a psychotic disorder or a first psychotic episode (Arbess, Logsdon, 2011; Kinoshita et al., 2013; Rinaldi et al., 2010; van Alphen et al., 2012). Another method to increase employment of individuals with a psychotic disorder is to improve their neurocognitive and sociocognitive skills. Individuals with schizophrenia with better neurocognitive skills have better outcomes after a psychosocial intervention such as SE/IPS than those who perform worse on neurocognitive measures (Kurtz, 2011). Improvement of cognitive skills may, therefore, indirectly – via an increased susceptibility to the effects of other psychosocial interventions – lead to increased employment (Addington, Piskulic, & Marshall, 2010).

3.3.5. Multiple domains of community integration as outcome measures

Prospective cohort studies or intervention studies of individuals with a psychotic disorder often include multiple measures of community integration such as employment and housing situation. This focus on multiple domains of
community integration may in part stem from the fact that full recovery from a disorder such as schizophrenia not only implies symptomatic remission, but also ‘the ability to function in the community, socially and vocationally’ (p. 442, Andreasen et al., 2005). It has repeatedly been shown that 14–31% of individuals with schizophrenia or a first psychotic episode shows recovery during follow-up 10–16 years later (Hegelstad et al., 2012).

4. Discussion

Both individuals with ASD and individuals with a psychotic disorder show considerable difficulties in finding a paid job, living independently, or establishing friendships and romantic relationships (Arbesman & Logsdon, 2011; Howlin & Moss, 2012). Yet, our systematic review shows important disparities in research foci on the community integration of these two groups. As anticipated, there is a much stronger focus on community integration within the psychosis literature. Below we highlight those areas of community integration that have received particularly little attention in ASD research compared to psychosis research and we formulate research recommendations for ASD researchers based on the conducted studies in the psychosis field.

4.1. Research recommendations

4.1.1. Stigma

Consistent findings of stigmatization of individuals with a psychotic disorder evoke the crucial question if and to what degree individuals with ASD are stigmatized in the 'neurotypical' society. Yet, we currently lack studies to answer this question. The few studies that have been performed on stigma of ASD have mostly focused on children's perceptions of children with ASD (Campbell, 2006). We recommend that future studies also focus on the perceptions of adolescents and adults with ASD. This research recommendation is in line with concerns expressed by researchers, clinicians, individuals with ASD and their family members about the perceptions the general public has of ASD and how these perceptions might be influenced by the media (Pellicano et al., 2014). For instance, a strong emphasis on the savant skills of some individuals with ASD or downplaying the problems observed in ASD (‘we're all a bit autistic’) may contribute to a misconception of ASD (see also Draaisma, 2009). However, we currently know little about the influence of media on the public's perception of ASD.

Furthermore, cultural differences in the perception of individuals with ASD may be considerable. For instance, in Asian countries it is more common to believe that psychiatric patients have themselves to blame for their disorder compared to Western countries (Fernando et al., 2010). In our literature search, we only found a single study on the perception of ASD and the role of culture. In the ultra-orthodox Jewish society, children with ASD may be at increased risk for social exclusion due to exemption from certain religious obligations (Shaked, 2005). Yet, at the same time, a high spiritual status is attributed to these children (Shaked, 2005).

Research recommendation 1: We recommend studies on the general public's perception of ASD and the potential role of culture and media in the formation of this perception.

4.1.2. Anti-stigma interventions

Methods that have effectively decreased stigma of psychosis may also reduce stigma of ASD. For that reason, meeting (in real life or on video) a person with ASD may be a promising way of decreasing stigma. In our systematic review we only found one publication on the effectiveness of a program specifically developed to reduce stigma of ASD. Typically developing adolescents improved in their knowledge and attitudes toward peers with ASD after participating in the program, which included both video's as well as a meeting with an adolescent with ASD (Staniland & Byrne, 2013). However, some intervention studies have also reported adverse effects of anti-stigma programs (of psychosis) and thus warn for caution. For instance, a simulation of the sensory experiences of a person with ASD might increase rather than decrease social distance. Also, a strong emphasis on the biogenetic origin of ASD might in fact worsen stigmatizing attitudes as it likely increases social distance.

Research recommendation 2: Studies on the effectiveness of anti-stigma programs of ASD are warranted and needed.

4.1.3. Employment

Both adults with ASD and parents of a child with ASD have mentioned that employment should be a research priority in ASD research (Pellicano et al., 2014). In several longitudinal studies where children with ASD were followed into adulthood, only a small minority of them gained a regular paid job (4–13%; Taylor, 2009). Moreover, the proportion of young adults with ASD and a paid job is lower compared to that of peers with other disabilities such as a learning disorder or an intellectual disability (Roux et al., 2013). They usually work in administrative functions, transport, production work, food preparation, or cleaning (Roux et al., 2013). In a systematic review, the only consistent predictor (in 15 of 18 studies) of unemployment by individuals with ASD was a low intellectual ability (Holwerda, van der Klink, Groothoff, & Brouwer, 2012). For the majority of considered predictors, including the presence of comorbid disorders or use of medication, non-significant or inconsistent findings were reported. The authors of the systematic review conclude that there is still an important gap in the literature regarding predictors of work outcomes in individuals with ASD.

Research recommendation 3: We advocate future longitudinal studies with work as a primary outcome measure.
4.1.4. Employment interventions

There is a widespread need for evidence-based services and interventions for individuals with ASD (Pellicano et al., 2014). Numerous methods have been proposed to support individuals with ASD in finding and keeping a job (Lee & Carter, 2012; Schall, Wehman, & McDonough, 2012), yet hardly any empirical evidence exists for the effectiveness of these methods. Despite the consistent evidence for the effectiveness of SE/IPS for individuals with psychotic disorders, there have only been few studies on the effectiveness of SE/IPS for individuals with ASD (Howlin & Moss, 2012; Taylor et al., 2012). Because these few studies do report positive effects, guideline committees in both the Netherlands (Kan et al., 2013) and the UK (NICE, 2012) have recommended SE/IPS for adults with ASD. It should be noted, however, that a paid job may not always be a possible or even a desired goal for a person with ASD (Kan et al., 2013).

Research recommendation 4: More studies should be performed on the suitability and effectiveness of SE/IPS for individuals with ASD. Furthermore, the possible interplay between the neurocognitive and sociocognitive skills of individuals with ASD and the effectiveness of psychosocial interventions deserves exploration.

4.1.5. Multiple domains of community integration as outcome measures

Compared to intervention studies in the psychosis field, it is less likely for an ASD intervention study to include multiple measures of community integration. This disparity likely stems from (a) a dominant research focus on children rather than adolescents and adults with ASD (Jang et al., 2014; Mukaetova-Ladinska et al., 2012), (b) relatively little funding of more applied ASD research (Pellicano et al., 2014), and (c) only recent inclusion of functional limitations as a diagnostic criterion for ASD (APA, 2013). Lastly, counter to research in schizophrenia, recovery from ASD is a highly controversial topic of debate and has (thus far) been operationalized as purely symptomatic, but not functional remission (Fein et al., 2013). Thus, community reintegration has not often been considered a crucial outcome measure or an essential component of recovery.

Research recommendation 5: We advocate inclusion of measures of community integration in ASD research. Also, given the DSM-5 criteria, functional remission should be a necessary component of recovery.

5. Conclusion

Rather than reinventing the wheel, existing knowledge from psychosis research can help us – researchers in the ASD field – shape and advance our future research agenda. A review of the literature on community integration of young people with a psychotic disorder confirms that the study of community integration of adolescents and young adults with ASD is still in its infancy. Research efforts regarding community integration of individuals with ASD have thus far been mostly restricted to the social domain. Even though this strong research focus makes sense given the diagnostic criteria of ASD, other indicators of community integration such as housing, employment and stigmatization have received relatively little to no attention. Despite the indisputable value of fundamental ASD research, we should also recognize the desperate need for more practical research that is of immediate use to individuals with ASD and their family members.

Acknowledgements

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Appendix A

Search terms systematic review autism spectrum disorders.

(n) = Number of publications found in 1990–2014 (unless stated otherwise).
- Autism AND employment AND intervention (20) (publications from 2011)
- Autism AND housing AND intervention (5)
- Autism AND leisure AND intervention (34)
- Autism AND social skills AND intervention AND adults (161)
- Autism AND social skills AND intervention AND adolescents (187)
- Autism AND stigma AND intervention (9)
- Autism AND supported education AND intervention AND adolescents (41)
- Autism AND academic AND intervention AND adolescents (29)
- Autism AND community integration (14)
- Autism AND employment AND quality of life (20)
- Autism AND housing AND quality of life (6)
- Autism AND leisure AND quality of life (19)
- Autism AND social network AND quality of life AND adults (8)
- Autism AND social network AND quality of life AND adolescents (6)
Appendix B

Search terms systematic review psychotic disorders.

\((n)= Number \text{ of publications found in 2009–2014 (unless stated otherwise).}

- Schizophrenia AND self-advocacy (10)
- Schizophrenia AND transition to adulthood (45)

Table C.1 and C.2.
Table C.2
Overview of the selected publications on community integration of individuals with psychotic disorders.

<table>
<thead>
<tr>
<th>Life domain</th>
<th>Single study</th>
<th>Systematic review/meta-analysis</th>
<th>Non-systematic review</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>No publications</td>
<td>No publications</td>
<td>No publications</td>
</tr>
<tr>
<td>Leisur</td>
<td>No publications</td>
<td>No publications</td>
<td>No publications</td>
</tr>
<tr>
<td>Other</td>
<td>Hastrup et al. (2013), Lora et al. (2012), Pijnenborg et al. (2010)</td>
<td>No publications</td>
<td>Drake et al. (2009), Harvey et al. (2012)</td>
</tr>
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</table>

References


