



Long-term outcome of a cohort of adults with autism and intellectual disability: A pilot prospective study



Laura Fusar-Poli*, Natascia Brondino, Paolo Orsi, Umberto Provenzani, Andrea De Micheli, Stefania Ucelli di Nemi, Francesco Barale, Pierluigi Politi

Department of Brain and Behavioral Sciences, University of Pavia, Via Bassi 21, 27100 Pavia, Italy

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ABSTRACT

Background: Autism spectrum disorders (ASD) are a long-life condition frequently associated with intellectual disability. To date, long-term outcome has been investigated mostly in ASD people with average or above-average intelligence and there is a paucity of data about autistic adults with comorbid intellectual disability.

Aims: The aim of the present study is to assess long-term variations of adaptive abilities in a sample of autistic adults with intellectual disability and severe language impairment.

Methods and procedures: 22 adults (17 males and 5 females) affected by autism and intellectual disability were recruited and evaluated after their admission in an Italian farm-community. Vineland Adaptive Behavior Scales (VABS) were used as outcome measure for adaptive abilities. After ten years the measurement was repeated in order to study the evolution of patients' skills along time. Additionally, sociodemographic variables, changes in medication and comorbidities were recorded.

Outcomes and results: No statistically significant improvement neither deterioration was found according to VABS raw scores in the entire sample. On the contrary, a significant improvement was evident in standard scores for the Adaptive Behavior Composite Scale and for each domain.

Conclusions and implications: In general, our patients remained stable in adaptive abilities. However, our results are not generalisable to the entire autistic population, but only to inpatients with autism and comorbid intellectual disability. New measures should be developed in order to better assess changes in this particular population.

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What this paper adds?

To the best of our knowledge, this is the first study which investigates the long-term change in adaptive abilities in nonverbal adults with autism and intellectual disability (ID). In fact, previous literature studied adult outcome only in ASD patients with fluent language and average or above-average intelligence. We believe that our research might shed light on this “neglected” part of the autism spectrum. Finally, our paper critically discusses the limitations of current available assessment instruments in ASD research.

* Corresponding author.

E-mail address: laura.fusarpoli@gmail.com (L. Fusar-Poli).

1. Introduction

Autism spectrum disorders (ASD) are a complex group of neurodevelopmental conditions, characterised by two core features: impairment in social communication and reciprocity and presence of restricted and stereotyped pattern of behaviours and interests ([American Psychiatric Association, 2013](#)). They are life-long conditions generally diagnosed in early childhood; however, ASD with average or above-average intelligence are often diagnosed later ([Mazurek et al., 2014](#)). In the last few decades, the interest of the scientific community towards ASD has grown. One of the main reasons for this rising interest is the dramatic increase of ASD prevalence: in fact, the most recent data estimate ASD prevalence around 1 every 68 children in the United States ([CDC, 2014](#)). Degree of severity and symptoms characteristics may vary widely in patients in the autism spectrum: it is extremely rare to find two autistic individuals with identical clinical presentation. Additionally, parameters such as intelligence level or language development may increase phenotypic variation. Of note, intellectual disability is one of the most common comorbidities of ASD patients and may affect their clinical presentation ([Fombonne, 2009](#)).

Intellectual disability (ID) is defined by the presence of deficiencies in general mental abilities that involve both cognitive and adaptive functioning ([American Psychiatric Association, 2013](#)). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM) system, ID is arbitrarily diagnosed with an intelligence quotient (IQ) score below 70 ([American Psychiatric Association, 2013](#)). In a recent meta-analysis, ID mean prevalence is estimated to be 10.37/1000 in the general population ([Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011](#)). However, in persons affected by autism the prevalence of ID is higher: different studies estimated that almost 30% of people affected by autism are also diagnosed with ID ([Fombonne, 2009](#); [CDC, 2014](#)).

Focusing on the ID population, the rate of comorbid psychopathology is significantly higher compared to the general population ([Lecavalier, Gadow, DeVincenzi, & Edwards, 2009](#); [Matson & Shoemaker, 2009](#)), mostly for severe neurological or psychiatric impairments ([Arvio & Sillanpaa, 2003](#)). Among these comorbidities autism is one of the most common disorders in individuals with ID ([Turygin, Matson, & Adams, 2014](#); [McCarthy et al., 2010](#)). Researchers have estimated that nearly 40% of the ID population also meets diagnostic criteria for ASD ([Matson & Shoemaker, 2009](#)). It is evident that ASD and ID, if combined, may be more challenging for caregivers and clinicians ([Boucher, Bigham, Mayes, & Muskett, 2008](#); [Matson et al., 2009](#)). In fact, the co-presence of ASD and ID has been associated with increased social and communication impairments, higher rates of restricted and repetitive behaviours and the presence of more severe and more long-term challenging behaviours ([McCarthy et al., 2010](#); [LoVullo & Matson, 2009](#)).

Focusing on adaptive abilities, it has been reported that persons with comorbid ASD and ID displayed greater deficits in adaptive behaviour compared to individuals affected by ID alone or ID with comorbid psychiatric conditions ([Matson, Bielecki, Mayville, & Matson, 2003](#)).

In most cases children diagnosed with ASD and ID display a severe language impairment ([Wodka, Mathy, & Kalb, 2013](#)). [Tager-Flusberg et al. \(2005\)](#) estimated that around 25% of children with ASD never develops functional language, despite the intensive treatment. Absence of functional language represents the most significant predictor of negative adult outcome in ASD ([Howlin, Goode, Hutton, & Rutter, 2004](#)).

There is a paucity of literature evaluating the long-term outcome of people affected by autism, especially in adulthood ([Totsika, Felce, Kerr, & Hastings, 2010](#)). In fact, a recent review ([Magiati, Tay, & Howlin, 2014](#)) found only three studies considering patients over 30 years old at the follow-up. Additionally, the vast majority of the included papers considered only verbal subjects with normal intelligence and several studies were not specifically addressed to evaluate adaptive functioning. Overall, long-term outcomes are highly variable within each individual: the overview provided by [Magiati et al. \(2014\)](#) observed small improvements in composite or age-equivalent adaptive functioning scores, notwithstanding the aforementioned limitations. Several factors seem to be involved in determining the outcome, such as autism severity, cognitive functioning, level of language, presence of comorbidities and availability of treatment programmes and residential services ([Levy & Perry, 2011](#)).

Subjects with comorbid autism and ID could display very heterogeneous sets of abilities and deficits: for this reason, they constitute a challenge both for clinicians and researchers. In fact, psychiatrists frequently meet several difficulties in finding an appropriate treatment. Additionally, the long-term assessment of outcomes often does not rely on valid and specific instruments. Outcome measures are extremely variable among different studies, or even in a single study from baseline to follow-up evaluation. This variability does not permit a comparison between different assessments and represents an obstacle in generalising the findings. Another controversial point regards the choice of standard scores versus raw scores. In fact, the interpretation of raw scores could be very difficult while evaluating a clinical significant change; on the other hand, standard scores may not be representative of the uneven developmental profile of people with ASD ([Narzisi, Colombi, Balottin, & Muratori, 2014](#)).

Moving from the dearth of knowledge on long-term outcomes in adults with autism and comorbid ID, we aimed to investigate 10-year variation in adaptive abilities in an autistic population with ID and language impairment who had been admitted to a residential farm-community. In fact, literature data of long-term outcome are based mainly on subjects with normal intelligence and normal language development and rarely evaluate adaptive functioning ([Magiati et al., 2014](#)). According to these findings, people with autism and ID living in the general community usually experience a decline in adaptive functioning. However, it has been reported that all programmes designed for autism have some positive effects on outcomes in the short- and intermediate-term ([Nordin & Gillberg, 1998](#)). Unfortunately, the effect of interventions on long-term prognosis has not been extensively studied.

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