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Developmental regression among children with autism spectrum disorder: Onset, duration, and effects on functional outcomes



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ABSTRACT

Studies using varied methods report that developmental regression occurs in a sizeable proportion of children with autism spectrum disorder (ASD). Findings are equivocal as to whether regression is associated with poorer cognitive and adaptive functioning. This study examined retrospective parent report in 2105 Simons Simplex Collection participants with ASD. Children were classified as having "full" or "subthreshold" losses on language and/or other skills using items from the Autism Diagnostic Interview-Revised (ADI-R) and a supplemental interview to capture more subtle regressions. Overall, 36.9% of children had some type of regression (27.8% language, 27.0% other-skill loss), with the supplemental interview capturing 11.7% of losses that would have been missed using the ADI-R alone. This figure is consistent with previous parent-report studies but lower than clinician-observed rates in prospective investigations. Early language losses—either full or subthreshold—and full other-skill losses appear to be associated with more deleterious outcomes by middle childhood. Findings may signify the need for more immediate and/or intense therapies for children who have even minor skill losses, particularly in language skills. Results further demonstrate the utility of an expanded set of additional queries with slightly modified criteria to capture such early, subtle losses.

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1. Introduction

By definition, children with autism spectrum disorder (ASD) experience aberrant development in social skills, language, and restricted or repetitive behaviors/interests, typically within the first three years of life (APA, 2000, 2013). However, it is clear that the trajectory of ASD is not uniform across affected children. Some experience early onset of ASD, which is characterized by developmental delays and/or unusual patterns of development from birth or shortly thereafter. Others

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seem to develop typically during the first year or two, then reach a plateau where they fail to progress at their former pace and begin to exhibit ASD symptoms (Kalb, Law, Landa, & Law, 2010). Still others show a regressive onset, in which children experience apparently typical development, followed by a loss of previously acquired skills (Ozonoff, Williams, & Landa, 2005; Ozonoff et al., 2010). However, regression is not limited to *onset* of ASD; some children present with an early onset, then some months later experience regression (Luyster et al., 2005; Ozonoff et al., 2005). For example, in one qualitative study, 69.4% of 327 parents said that their child experienced developmental regression; 47.4% indicated the regression as the first sign of ASD in their children, while 22% noticed characteristics of ASD prior to the regression (Goin-Kochel & Myers, 2005).

Developmental regression in ASD has received increasing attention over the years, and it is possible that this trajectory represents a distinct ASD subtype. Most often, regression occurs in language and/or social skills, with some research demonstrating language regression as highly specific to ASD (Pickles et al., 2009). Most losses are reported between 1 and 3 years of age (e.g., Meilleur & Fombonne, 2009), with recent meta-analytic results noting average age of loss at 21.4 months (Barger, Campbell, & McDonough, 2013). Although many children eventually regain some or all of the skills that were lost, duration of loss varies. The primary focus of research on regression, to date, has been prevalence and types of skills lost. On average, studies using retrospective parent report have found that regression occurs in about one-third of children with ASD (e.g., Baird et al., 2008; Goldberg et al., 2003; Luyster et al., 2005; Werner, Dawson, Munson, & Osterling, 2005a), with most rates falling between 20% and 50%; however, depending on the methodology, regression rates range from as low as 17% (Fombonne & Chakrabarti, 2001) to as high as 86.4% (Ozonoff et al., 2010). Overall, studies that used parent-report questionnaires as opposed to interviews noted higher rates of regression. One reason for this may be that, during an interview, the clinician can guide the flow of conversation to clarify which behaviors truly meet criteria for a skill loss as opposed to a developmental plateau, slowing of skill gains, or fluctuations in behavior over a brief time. Thus, the interview may be a more valid method for obtaining regression data compared to survey methodologies.

However, the most recent studies suggest that parent interview may underestimate developmental regression compared to prospective clinician observation (Ozonoff et al., 2010, 2011). The key difference across these methodologies concerns definition of regression, as different rates will undoubtedly be reflected when different criteria are used to categorize skills as "lost." For example, when infants were observed longitudinally and their behaviors coded in minute-by-minute segments by trained clinicians, gradual and subtle decreases in social skills (e.g., social smiles, directed vocalizations) were observed in 87% of those who later met criteria for ASD (Ozonoff et al., 2010). Compared with retrospective parent report, where skill mastery prior to loss is often established according to strict criteria, it is easy to appreciate how these approaches can generate markedly different results. It is possible, too, that different intensities of regression exist, such that some are obvious and easy for parents to recognize, while others are more subtle and may only be detected when behavioral scores are compared over time, and that these "flavors" of regression could be experienced differentially by the ASD population. In a similar vein, Pickles et al. (2009) suggested that language delays in ASD could be masking even larger proportions of language losses that would otherwise become apparent if the children had developed words on time.

1.1. Differences in functional outcomes between children with ASD who do/do not lose skills

To date, findings are mixed in terms of the effects of regression on ASD-symptom severity and cognitive/adaptive-functioning outcomes (see Rogers, 2004; Stefanatos, 2008, for reviews). For example, Lord, Schulman, and DiLavore (2004) conducted a longitudinal examination of 110 children with ASD from ages 2 to 5, using the *Autism Diagnostic Interview-Revised* (ADI-R) to classify children as having regressed or not. Cognitive functioning and ASD-symptomatology (per the *Autism Diagnostic Observation Schedule* [ADOS] and ADI-R domain scores) were not different across groups. More recently, Schumway et al. (2011) used an ADI-R-based categorization scheme to classify young children with ASD (*M* age = 42–46 months) into four onset classes: early onset, delay + regression, plateau, and regression. Groups were not different from one another on any measures, which included ADI-R and ADOS domains, the *Vineland Adaptive Behavior Scales* (VABS), and the *Mullen Scales of Early Learning*.

Other investigators, however, have demonstrated that children with ASD and regression display more severe impairments, as measured by IQ, adaptive behaviors, language, and ASD symptomatology, than those without skill losses. Bernabei, Cerquiglini, Cortesi, and D'Ardia (2007) conducted a longitudinal study of 40 children with ASD between the ages of 2 and 6, wherein regression was captured via a semistructured parent interview and validated through home-video analyses. Children who experienced regression had significantly poorer communication skills, play skills, and lower mental ages when compared to those who had not regressed. Wiggins, Rice, and Baio (2009) reviewed records of 285 children 8-year-olds who met study criteria for ASD. Compared to those who reportedly did not exhibit regression, significantly larger proportions of those with a documented skill loss met criteria for intellectual disability (IQ score \leq 70) and were rated by clinician reviewers as being more impaired.

Findings also are mixed on whether degree of loss affects outcomes. Kalb et al. (2010) used a web-based questionnaire to collect data on 2720 children with ASD whose families were participating in the Interactive Autism Network (IAN). At the time of data collection, children's average age was 8.1 years (range = 3–17). Findings revealed significantly elevated ASD-symptom severity, as measured with the *Social Responsiveness Scale* (SRS) and *Social Communication Questionnaire* (SCQ), for children who lost skills compared to those who had not, but also that those with more severe losses scored higher (indicating more problematic functioning) relative to those who had more moderate or mild losses. However, using data from multiplex

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