Regression in autism

Dr Avril V. Brereton

What is regression?

Pervasive Developmental Disorders (PDDs), also known as Autism Spectrum Disorders (ASDs), are a group of neurodevelopmental disorders that include autistic disorder, Asperger's Disorder, PDD- not otherwise specified (PDD-NOS), childhood disintegrative disorder (CDD) and Rett's syndrome. PDDs involve delay and disorder in the development of communication and language skills, social interaction with others and restricted and stereotyped patterns of play and behaviour. Regression in the developmental course ASDs is not new. In 1966, Lotter described developmental setback, including loss of speech in 31% of a group of children diagnosed with autism. This factsheet gives an overview of regression in ASDs based on some recent published articles but I would recommend further reading for a fuller understanding of this topic.

Children with an ASD who lose skills have become known as a subgroup called "regressive autism". Regressive autism usually refers to a child where parents report an early history of normal development for 12-24 months which is followed by a loss of previously acquired skills. Language regression is the most obvious form of regression but it can also be accompanied by more global regression involving loss of social skills and social interest.

Regression research – what do we know?

1. **How common is it?** Published studies have reported regression in speech, use of gesture and general development in between 22% and 50% of children with ASDs. Prevalence rates vary because of differences in the definitions used in these studies. For example, some defined language regression as loss of at least five words for a period of at least 3 months whereas others defined regression as a loss of consistent use of one word used communicatively. Lord et al., (2004) found that language regression occurs at equal rates in children diagnosed with autism or PDD-NOS. Hansen et al. (2008) found that 41% of children in their study of 333 children with ASD regressed in language and other skills.

2. **What causes regression and when does it happen?** Some researchers have looked for biological causes of regression in ASDs. Published papers have reported increased seizure activity associated with regression (epilepsy,

Giannotti et al., 2008; epileptiform EEGs, Tuchman and Rapin, 1997) but other researchers have countered these findings and found no increased seizure activity in children who regress (Baird et al., 2008; Hansen et al., 2008). Others have investigated links with general central nervous system dysfunction but found no difference between regression and non-regression groups on measures of gross motor development (reasonable proxies for CNS dysfunction) (Rogers, 2004). Another very important paper by Fombonne and Chakrabarti (2001) investigated whether regression has increased in frequency and whether it occurs at particular times. This was in response to the suggestion by some (Wakefield et al, 1998; Wakefield et al, 2000) that there may be a new type of autism they called "autistic enterocolitis" that is associated with regression and gastrointestinal symptoms as a consequence of measles-mumps-rubella immunization and that this new variant of autism is responsible for the alleged rise in autism rates. Fombonne and Chakrabarti (2001) found that there was "no evidence to support a distinct syndrome of MMR-induced autism or of "autistic enterocolitis" (p1). They also found no difference in the age at first parental concerns between parents of children exposed to MMR and those who were pre-MMR. There were also no significant differences between when parents detected first symptoms of autism in their children who had developmental regression compared to those whose children did not regress. Both groups of parents reported first signs of autism at about 19 months of age. Similarly they found that there was no association between developmental regression and gastrointestinal symptoms (p 1). Regression has also been investigated in relation to psychosocial stressors. To date, differences in socioeconomic status, ethnicity, birth order, high-risk birth events, and gender have not been found to be associated with regression. Also no difference has been found in age at diagnosis, or in the male: female sex ratios among regressive and nonregressive groups (Rogers, 2004). Ozonoff et al (2005) found that in their study most children with autism showed developmental abnormalities in their first year, but some displayed regression after mostly normal development. They developed a retrospective measure, the Early Development Questionnaire (EDQ), to collect specific, parent-reported information about development in the first 18 months. Based on their EDQ scores, 60 children with autism between the ages of 3 and 9 were divided into three groups: an early onset group, a definite regression group, and a smaller heterogeneous mixed group. Significant differences in early social development were found between the early onset and regression groups. However, over 50 percent of the children who experienced a regression demonstrated some early social deficits during the first year of life, long before regression and the apparent onset of autism. They concluded that the group they tentatively labelled 'delays-plus-regression' deserves further study (p 461). More recently, Meilleur and Fombonne (2009) examined the regression in 135 children with PDD, mean age 6.3 years. The sample was composed of 80 children diagnosed with autism, 44 with pervasive developmental disorder-not otherwise specified (PDD-NOS) and 11 with Asperger syndrome. The Autism Diagnostic Interview Revised (ADI-R) was used to evaluate the type of loss and to characterise associated factors including birth rank, gender and thimerosal exposure through vaccination. They found that a total of 30 (22%) subjects regressed: nine (30%) underwent language regression alone, 17 (57%) lost a skill other than language and four (13%) lost both language and another skill. Significantly higher levels of regression were found in autism (30%) compared

with PDD-NOS (14%) and Asperger syndrome (0%). Children who regressed in language skills spoke at a significantly earlier age (12 months) than those who did not regress in this domain (26 months). Parents and interviewers consistently reported developmental abnormalities prior to the loss. ADI-R domain mean scores indicated a more severe autistic symptomatology profile in children who regressed compared with those who did not, especially in the repetitive behaviour domain. Regression was not associated to thimerosal exposure, indirectly estimated by year of birth. They concluded that a loss of skill, present in one out of five children with PDD, is associated with a slightly more severe symptomatology as measured by the ADI-R, particularly in the repetitive behaviours domain. They also commented that although abnormalities are often noticed by the caregivers at the time of regression, the ADI-R reveals that other atypical behaviours were in fact present prior to the onset of regression in most cases. None of the secondary factors investigated were associated with regression. In children unexposed to thimerosal-containing vaccines, the rate of regression was similar to that reported in studies of samples exposed to thimerosal, suggesting that thimerosal has no specific association with regressive autism.

3. **Are there differences between children with autism who regress and those who don't?** Davidovitch et al, (2000) interviewed 39 mothers of children with autism about familial, pregnancy, perinatal, as well as medical history and developmental milestones. The study focused on mothers' perceptions of developmental regression. Mean age of regression was 24 months, and no significant differences were reported by mothers of children who did or did not regress. Davidovitch et al (2000) concluded that "developmental regression in our population appears to be a typical event in the natural course of autism. There is little difference between those children who regressed and those who did not regress in maternal perceptions and reports of development, family, and medical history" (p 113).

4. Outcome for children who regress

Goldberg et al (2004) introduced the Regression Supplement Form to the Autism Diagnosis Interview – Revised to gather information about the types and timing of regression and events concurrent with loss and regain of skills. Importantly, this study found that many of the children regained some of the lost skills when they were about 3 to 3 ½ years of age probably in response to therapy.
Clearly there is still much to be learnt about ASDs and regression. In particular there is little information yet about outcome for those children who regress compared to those who do not and whether there is any specific early intervention that may be helpful in preventing regression occurring or in response to it.

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