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Growing up with Down syndrome: Development from 6 months to 10.7 years

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ABSTRACT

Background: We analysed developmental outcomes from a clinical trial early in life and its follow-up at 10.7 years in 123 children with Down syndrome.
Aims: To determine 1) strengths and weaknesses in adaptive functioning and motor skills at 10.7 years, and 2) prognostic value of early-life characteristics (early developmental outcomes, parental and child characteristics, and comorbidity) for later intelligence, adaptive functioning and motor skills.
Methods and procedures: We used standardized assessments of mental and motor development at ages 6, 12 and 24 months, and of intelligence, adaptive functioning and motor skills at 10.7 years. We compared strengths and weaknesses in adaptive functioning and motor skills by repeated-measures ANOVAs in the total group and in children scoring above-average versus below-average. The prognostic value of demographics, comorbidity and developmental outcomes was analysed by two-step regression.
Outcomes and results: Socialisation was a stronger adaptive skill than Communication followed by Daily Living. Aiming and catching was a stronger motor skill than Manual dexterity, followed by Balance. Above-average and below-average scoring children showed different profiles of strengths and weaknesses. Gender, (the absence or presence of) infantile spasms and particularly 24-month mental functioning predicted later intelligence and adaptive functioning. Motor skills, however, appeared to be less well predicted by early life characteristics.
Conclusions and implications: These findings provide a reference for expected developmental levels and strengths and weaknesses in Down syndrome.

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What this paper adds

The current study is unique in its broad spectrum of developmental outcomes, sample size, and the homogeneous ages at each assessment point. The current findings provide an up-to-date reference for expected developmental outcomes in children with Down syndrome (DS) in terms of general level of functioning with respect to intelligence, adaptive functioning and motor skills, and the specific strengths and weaknesses that can be expected in the latter two domains. Further, our results suggest that the behavioural phenotype of DS may vary with the developmental level of the child. This study further adds important knowledge on the prognostic value of characteristics in early life for the later level of functioning. We showed that by the age of 24 months, later intelligence and adaptive functioning could already be predicted to some extent by mental developmental outcomes, male gender and (the absence or presence of) infantile spasms, the latter two predicting poorer outcomes. Motor skills, however, appeared to be less well predicted by early life characteristics.

1. Introduction

One of the most striking characteristics of Down syndrome (DS) is intellectual disability. According to criteria in the latest Diagnostic and Statistical Manual of the American Psychology Association (American Psychiatric Association, 2013), intellectual disability not only refers to intellectual deficits, but also to deficits in adaptive functioning. Further, children with DS show marked motor deficits (Vicari, 2006), which is a common finding in children with developmental disabilities (Connolly & Michael, 1986). In children with DS, these motor deficits are interwoven with their intellectual functioning (Piek, Dawson, Smith, & Gasson, 2008; Volman, Visser, & Lensvelt-Mulders, 2007), but also reflect specific DS characteristics, most notably hypotonia and poor control of muscle stiffness (Fidler, Most, & Philofsky, 2009; Lauteslager, Vermeer, & Helders, 1998). For a comprehensive overview of functioning of children with DS a description of motor skills is indispensable (Davis, 2008).

Interestingly, several syndromes causing intellectual disability are associated with characteristic patterns of strengths and weaknesses across different domains of functioning, i.e. the behavioural phenotype of a syndrome (Chapman & Hesketh, 2000; Fidler et al., 2009). In children with DS the behavioural phenotype entails markedly weak language skills, e.g. expressive language, syntactics, and verbal memory skills, while on the other hand nonverbal abilities and implicit memory tend to be relatively strong (Davis, 2008; Grieco, Pulsifer, Seligsohn, Skotko, & Schwartz, 2015; Silverman, 2007). Previously, visuospatial abilities were almost unanimously regarded as a relative strength in DS, yet this notion was challenged in a recent literature review (Yang, Conners, & Merrill, 2014). Children with DS also show specific strengths and weaknesses in adaptive functioning, where communication skills are generally found to be the weakest skill, daily living skills are somewhat stronger and socialization is the strongest adaptive skill (Coe et al., 1999; Dykens, Hodapp, & Evans, 2006; Fidler, Hepburn, & Rogers, 2006; Griffith, Hastings, Nash, & Hill, 2010; van Duijn, Dijkxhoorn, Scholte, & van Berckelaer-Onnes, 2010). Within motor skills, children with DS show relatively preserved ball skills and running speed, while balance, posture, strength, and motor planning are found to be particularly weak (Connolly, Morgan, Russell, & Fulliton, 1993; Fidler et al., 2009; Jobling, 1998; Spano et al., 1999; Vicari, 2006; Volman et al., 2007).

Although these descriptions suggest that there is only one behavioural phenotype in children with DS, it is important to consider that the phenotype emerges over time and varies with the age of the child (Chapman and Hesketh, 2001; Dykens et al., 2006; Grieco et al., 2015; Patterson, Rapsey, & Glue, 2013; Silverman, 2007; Vicari, 2006). Furthermore, it has been suggested that rather than one behavioural phenotype, there may be subgroups of children with DS showing different strengths and weaknesses (Jobling, 1998; Tsao & Kindelberger, 2009), possibly depending on the degree of intellectual disability (Laws, Buckley, MacDonald, & Broadley, 1995; Patterson et al., 2013).

Much of what we know of longitudinal development and its predictors in DS comes from a few longitudinal studies that tracked development from the crucial early years of life. However, these important studies concerned children with DS born in the 1960s (Carr, 1988; Shepperdson, 1995), 1970s (Cunningham, 1996) and 1980s (Hauser-Cram et al., 2001), who grew up in rather different circumstances in terms of health care standards and developmental ambitions as compared with children growing up today (Van Riper & Cohen, 2001). Furthermore, these studies paid only little attention to the developing motor skills. Many studies of motor skills, even quite influential ones, are limited in sample sizes and recency (Sacks & Buckley, 2003). In sum, there is a need for up to date, prospective studies that describe the developmental phenotype as a function of the child's age (Fidler et al., 2009) and as a function of the degree of intellectual disability in a wide range of developmental domains, including motor skills, and that analyse early life predictors for development. Results of such studies will offer realistic expectations with respect to developmental outcomes in children with DS growing up today, and may prove helpful in choosing optimal interventions for children at risk for suboptimal development.

With respect to early prediction of development later in life, previous studies have indicated that early developmental outcomes, particularly from around the age of two years onwards, are the best predictors for performance later in life in children with DS (Carr, 1995; Cunningham, 1996). In addition, several characteristics of the child's environment and the child itself also influence developmental outcomes, although most predictors are not consistent across studies. Concerning the child's environment, a higher parental (particularly maternal) educational level is associated with a more favourable developmental outcome (Crombie & Gunn, 1998; Cunningham, 1996), although this association was not consistently found (Carr, 1995). The same applies to early intervention programs (Crombie & Gunn, 1998; Cunningham, 1996; Hines & Bennett, 1996). Concerning child characteristics, girls with DS are generally found to show more favourably developmental outcomes