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The Development of Social Competence among Persons with Down Syndrome across the  
Lifespan: From Survival to Social Inclusion

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## ABSTRACT

The popular view that children with Down syndrome are socially competent has not been supported by empirical data. Conversely, the emerging evidence indicates that beginning in infancy and throughout the lifespan, individuals with DS show difficulties interpreting social and emotional cues, communicating about social and emotional experiences, understanding mental states such as desires and beliefs in self and others; and, regulating and acting on cognitions and emotions in an adaptive way (e.g., during peer interactions). These developmental skills are considered key components of social competence and may be implicated in the challenges that individuals with DS often face with regard to social adaptation regardless of their IQ status. Specifically, difficulties in social competence may be linked to several adjustment problems observed among individuals with DS later in life, including the areas of self-identity development, peer relationships, and mental health. This paper will focus on social competence in individuals with Down syndrome and the developmental implications of social ability across the lifespan. We will explore proximal and distal risk and protective factors (e.g., cognitive abilities, community resources) that may serve to promote or impede the development of social competence in individuals with Down syndrome.

Down Syndrome (DS) occurs as a result of the presence of all or a portion of an extra copy of chromosome 21 and is the most common non-inherited 'organic' cause of mental retardation. The genetic anomaly of DS has powerful and specific influences on the development of the child but also inadvertently affects significant people (i.e., parents, siblings, teachers, friends) in the child's life. The unique profile of disabilities associated with DS that includes medical, motor, social, affective, and cognitive features may interact with contextual features of the child's family, peer group, school, community, and culture to determine variability in development. Of particular interest is the wide variability in social adaptation among people with DS which cannot be accounted for by IQ status alone. The implication is that there are potential environmental sources of the developmental variation in outcome that have not been explored. One likely candidate is the construct of social competence, typically discussed with regard to an individual's success at meeting major personal and societal goals that are adaptive at the relevant developmental stages (Luthar & Burack, 2000; Luthar & Zigler, 1991; Rubin & Rose-Krasner, 1992).

Social competence is pertinent to understanding developmental adaptation throughout the lifespan and is particularly relevant in the lives of children with DS who must strive for social inclusion and participation. Moreover, the construct of social competence is well elaborated and easily amenable to empirical investigation; it integrates characteristics of individuals and their environments, defines the relation between these two sources of influence as dynamic and transactional and acknowledges both continuity over time and the possibility of discontinuity across contexts (Guralnick, 1996; Rose-Krasner, 1997; Sameroff, Seifer, & Bartko, 1997; Wyman, Sandler & Wolchik, 2000). During infancy, social competence may be evident within the parent-child relationship as consistency in engaging with, and responding to the other, establishes a secure and stable attachment that is integral to the infant's very survival. Later in development as the

child is increasingly able to control his behaviour and choose his environments, social competence appears to transform into something more akin to a personal characteristic of the child (Bronfenbrenner, 1999; Sroufe & Jacobvitz, 1989). However, variability in the availability of social resources and in the quality of the parent-child relationship jointly influence a child's ability to generate and coordinate flexible, adaptive responses to demands and capitalize on social opportunities in the environment (Waters & Sroufe, 1983). This is consistent with the social ecological model of development that proposes that the child is embedded within various socio-cultural systems that interact to either support or hamper his development (Bronfenbrenner, 1977, 1979; Bronfenbrenner, 2000). These dynamic systems are conceptualized as different spheres of influence and include those that have a distal (i.e., indirect) effect and those that have a proximal (i.e., direct) effect on the individual (Cicchetti & Toth, 1997). Indirect influences are thought to emanate from macrosystems, which encompass the patterns, beliefs and values of the culture in which the child exists, and the exosystems which comprise the various formal and informal social structures in the child's environment, including the neighbourhood, schools, and government policies on education and health (Bronfenbrenner, 1977, 1979; Cicchetti & Toth, 1997). Direct influences include the child's interaction with significant persons or events in their daily lives (e.g., parenting customs, sibling and peer relations and teaching practices). Risk and protective factors may be present in each of the socio-cultural systems (i.e., family, peer network, school, community) and may operate through distal and/or proximal effects that influence the course of the child's development in adaptive or maladaptive ways (Bronfenbrenner & Ceci, 1994).

In this paper we call into question the view that persons with DS are socially competent and achieve socially related goals in appropriate and effective ways. We argue that sociability and friendliness, often referred to as a personality trait among people with DS, is mistaken for socially

competent behaviour, and may actually reflect an absence of problematic social behaviors. We use developmental and socio-ecological perspectives to conceptualize the development of social competence among persons with DS across the lifespan. We review the evidence and integrate what is known about the development of social competence among individuals with DS. Efforts are made to identify opportunities for research and application of the available findings. We conclude with a discussion of the significance of considering risk and protective factors, multiple systems of influence and the primacy of social issues in future research with persons with DS.

#### Infancy and the Preschool Years: Parent-child Interactions

Compared to other newborn animals, the human infant could be described as ‘premature’ since it relies almost exclusively on his caregivers for sustenance and nurturance. The implication is that an infant’s survival and ultimately their social development are intricately linked to protective mechanisms that are inherent in the parent-child care-giving relationship (Barbar, 2000). For example, a healthy parent-child attachment increases the likelihood of behaviours that promote proximity between the dyad. For example, crying, smiling, grasping, or calling by the child typically result in bringing the parent close to the infant. Physical closeness between the dyad increases the likelihood that the parent will be aware of and respond to cues of distress and hunger as well as social bids from the child (Bowlby, 1969). The care-taking practices of the Kung San in Africa illustrate the effectiveness of physical proximity on parental responsiveness. The Kung San mothers constantly carry their infants and are able to respond to every distress cue the baby makes within 10 seconds (Barr, Konner, Bakeman, & Adamson, 1991). The child who has his basic needs met has a secure base (the parent-child relationship) from which to explore his environment and remains confident that his needs and social bids will not be ignored or misinterpreted (Ainsworth,

1973; Bowlby, 1969). Immediacy and compatibility of parental response may be particularly important to at risk infants (Barr et al., 1991).

Secure infants are engaged with their parent, are upset by a separation from their parent, but are easily consoled upon reunion. The essence of secure attachment behaviour is thought to occur when a balance is struck between an infant moving toward the world and toward the caregiver during times of distress (Bowlby, 1979). The caregiver is responsible for responding to the infant's cues, alleviating the infant's distress, and providing socio-emotional and cognitive growth while the child is similarly active and responsible for providing clear cues and responses to the caregiver's bids. This formative and formidable dyadic relationship creates a solid foundation for all future social relationships (Van Hooste & Maes, 2003). If either the child or the parent lacks the ability to engage with or respond to the other adequately, the quality of the relationship may deteriorate. Alternatively, compensatory strategies may be employed by either the child or the parent to establish adequate reciprocity and emotional nurturance. Thus, in infancy, social competence may be defined in terms of the quality of the parent-child relationship.

#### Risk and protective factors associated with DS

Compared to typically developing infants, those affected by DS develop at a slower rate, show uneven development across domains, have motor challenges, and experience more frequent hospitalizations for health concerns (Cicchetti & Ganiban, 1990; Cooley & Graham, 1991; Dunst, 1998). Specifically, these infants are challenged by impairments in motor control, information processing, language acquisition, emotion recognition and affect regulation (Kasari, Freeman & Hughes, 2001; Knieps, Walden & Baxter, 1994; Moore, Oates, Hobson & Goodwin, 2002; Wishart & Pitcairn, 2000). Any and all of these risk factors may interfere with the infant's ability to use the parent-child relationship to meet their basic needs and desires.

Despite these problems, the parent-child relationship may be buffered by several protective factors. For example, infants with DS look at faces and may be socially engaging due to their attractive physical attributes and interest in people (Carr, 1994; Fidler, 2003; Hornby, 1995; Kasari, Freeman, Mundy & Sigman, 1995). Certain aspects of social-emotional communication may be intact among infants with DS despite cognitive impairments (Kasari et al., 1995). As compared to children with other types of developmental disorders, children with DS have fewer externalizing behaviours that might alienate or unduly stress their parents (Kasari & Hodapp, 1996). Parents of children with DS achieve similar scores on measures of parental stress as that of parents of TD children, significantly lower than that of parents of children with autism or other undiagnosed etiologies of mental retardation (Kasari & Sigman, 1997; Seltzer, Krauss, & Tsunematsu, 1993). The disability of DS is visible, not heritable and widely recognized relative to other developmental disabilities. Many families of children with DS receive support from their extended family members and wider community and report being cohesive and harmonious (Kasari & Hodapp, 1996).

#### Dyadic interactions

Between the second and third month of life there are significant developments in behavioural synchrony, turn-taking, and reciprocity between the parent and infant, precursors to a healthy attachment (Ainsworth, 1973; Fogel, 1977; Schaffer, 1977; Schore, 1994). However, infants with DS may show less predictability, clarity and frequency in social cueing and consequently, their parents are more likely to misinterpret, over-interpret and/or occasionally miss cues. For example, infants with DS displayed dampened and fewer smiles, less eye contact and excited waving of their arms and legs, signs that may indicate a decreased intensity of emotional expressiveness toward the parent (Cicchetti & Sroufe, 1978; Emde, Katz & Thorpe, 1978). At 12-

19 months, children with DS showed diminished emotionality and separation distress as compared to their CA matched peers (Thompson, Cicchetti, Lamb & Malkin, 1985). In one study, seven month old infants with DS were described as more “difficult to read” than TD infants of comparable age (Hyche, Bakeman & Adamson, 1992). In addition to diminished social-communicative behaviours with their mothers, infants with DS show fewer approach behaviors, less persistence, lower thresholds for sensory stimulation and more passivity during play (Bridges and Cicchetti, 1982; Linn, Goodman & Lender, 2000).

The difficulty in providing or responding to cues within the dyadic interaction may lead to a lack of synchrony or compatibility in the interaction. Under these conditions, parents may focus their attention to structuring, scaffolding and controlling the interaction. For example, there is evidence that mothers of infants with DS (17-44 months) exert more control and direction during naturalistic play than mothers of same-aged TD infants (Cielinski, Vaughn, Seifer, & Contreras, 1995; Mahoney, Fors & Wood, 1990; Landry & Chapieski, 1990; Mahoney & Robenalt, 1986). The increased structure and guidance improves functional use of objects (Maurer & Sherrod, 1987), compliance with requests (Landry, Garner, Pirie & Swank, 1994) and activity during play (Mahoney, 1988). Although beneficial for cognitive growth fostering (Crawley & Spiker, 1983), a focus on teaching and managing the parent child interaction may result in a tradeoff on socio-emotional growth (Ganiban, Barnett & Cicchetti, 2000). For example, infants with DS show less intense and visible distress upon separation from their parent and briefer recoveries following the return of their parent, and do not seek to maintain contact and require little to no comforting (Thompson et al., 1985; Vaughn, Goldberg, Atkinson, Marcovitch, MacGregor & Seifer, 1994). The interaction pattern between parents and children with DS during the Strange Situation Task could not be classified within the traditional attachment style framework (Vaughn et al., 1994).

Although disruptions in dyadic interactions and attachment are not evident in all parents of and children with DS (Iarocci Virji-Babul & Reebye, in press), there is evidence to suggest that certain parent-infant dyads may benefit from early intervention designed to foster a balanced style that incorporates high responsiveness and scaffolding as well as supportive praise in order to meet both the cognitive and emotional needs of infants with DS (Bornstein & Tamis-Lemonda, 1989; Roach, Barratt, Miller & Leavitt, 1998;; Spiker, Boyce & Boyce, 2002).

#### Triadic interactions

Dyadic interactions in which the child and their communicative partner share attention in face-to-face interactions are the precursors to later sharing of attention toward inanimate objects or other significant adults and peers (Carpendale & Lewis, 2004). At this stage, the child's face-to-face interactions with parents decrease as more time is devoted to attending to objects. The coordination of attention between objects and parent (or other significant adult) is an important step in a child's learning awareness of and interest in significant persons or events. For example, during joint attention episodes children learn to point to make requests and to direct others' attention, follow others' gaze or point and the emotions of others (usually their parent) to guide their interpretations of an ambiguous event (Klinnert, Campos, Sorce, Emde, Svejda, 1983; Walden & Ogan, 1988) and make connections between an object and its verbal label (Carpenter, Nagell & Tomasello, 1998). This stage of development marks the beginning of a gradual process of differentiation between the self and other that culminates in an understanding of others' thoughts and feelings as different from one's own (Carpendale & Lewis, 2004).

In contrast to TD children, children with DS may continue to fixate on an adult's emotionally expressive face rather than shifting attention between the adult and a salient play object (Kasari, Mundy, Yirmiya & Sigman, 1990; Kasari, Freeman, Mundy & Sigman, 1995;

Ruskin, Kasari, Mundy and Sigman, 1994). The sustained attention to emotional faces, may suggest to the parent that the child is similarly engaged and motivated to interact, yet prolonged attention to the caregiver's face may indicate difficulties with processing faces (Kaiser, Virji-Babul, Iarocci, McLaughlin & Tanaka, 2005, April) and has been associated with language delays in children with DS (Sigman & Ruskin, 1999). Even though these infants look at their mothers for longer amounts of time as compared to TD children of the same mental age and language ability (Kasari et al., 1995) they do not appear to fully benefit from joint attention episodes as they show fewer social referencing looks to their mothers in ambiguous situations (Kasari et al., 1995) and make fewer attempts to direct their mother's attention across social situations (Fischer, 1987; Landry et al., 1994). Language delays and, in particular, discrepancies between receptive and expressive language among children with DS may further impact triadic interactions as they may have the effect of reducing parents' use of inner state terms such as desires, beliefs, and feelings that promote the child's understanding of affective and mental states in the self and other (Dunn et al., 1991; Meins, 2002; Tingley, Gleason & Hooshyar, 1994) as well as fostering attachment security within the dyad (Meins, Fernyhough, Fradley & Tuckey, 2001). Thus, triadic interactions are likely to pose a significant challenge to young children with DS and their adult play partners as both the child's abilities and parental expectations may be incompatible (Iarocci, McLaughlin, Virji-Babul, & Reebye, 2005, March).

Systemic risk and protective factors during infancy and the preschool years

The quality of dyadic and triadic interactions may vary as a function of family and community resources and supports. For example, during the early developmental years the family system and parent-infant dyad may be more vulnerable to stressors as it accommodates a new member and renegotiations are necessary in the couple and parent-sibling relationships (Carter &

McGoldrick, 1999). The parental subsystem must also accomplish a variety of tasks simultaneously; making sense of a host of medical and other diagnostic information on DS, procuring specialized professionals and services for their child's special needs and the resources to finance them (Guralnick, 2000; Minnes, 1998). It is also a time when parents may experience negative attitudes from health professionals and others in their social networks, particularly with regard to expectations about their child's future (Virji-Babul, Eichman, & Duffield, 2004). Although social services and early intervention programs are generally accessible to children with DS and their parents, they may not be comprehensive or integrative. For example, infant development programs are designed to meet the needs of families coping with a variety of developmental disabilities and thus, are not specific to children with DS (Guralnick, 2000). They offer a variety of specialized professionals (e.g., speech and language pathologists, occupational and physical therapists) who focus on treating specific domains of function such as speech or motor development while teaching parents to adopt highly structured parenting techniques that focus on stimulating cognitive development (<http://www.idpofbc.ca/>). An alternate early intervention model that considers the reciprocal nature of the child with DS and his family's wellbeing and incorporates social competence goals that link skills from across the various domains of function may be more compatible with the goals of parents and supportive to the needs of families. Such a program would target a variety of proximal and distal protective factors and the systems that support the quality of parent-child interactions and family wellbeing (see Iarocci et al., in press).

#### Middle Childhood: Peer Interactions, Group Play and Friendships

During the school years, peer relationships play an increasingly prominent role in a child's social development. In TD children between the ages of 3 and 6 years, there is a marked decrease

in time spent in direct contact with caregivers and a concurrent increase in time spent with peers (Lewis, Feiring, & Brooks-Gunn, 1988). This trend continues throughout middle childhood as the child's social-cognitive processes mature and greater social opportunities become available. Relationships with peers are qualitatively different from those with adults and other caregivers. Peers make little or no concessions for potential deficits in others and therefore communication is truly dyadic; each partner in the relationship carries equal responsibility for the outcome of the interaction. Peer relations during unstructured exchanges on the playground as well as structured interactions in the classroom setting provide a rich environment for learning fundamental tools for social interaction (Guralnick, 1990, Hartup, 1983). For example, children learn to modulate aggressive impulses, recognize and share emotions, communicate effectively, lead an activity, and resolve moral issues (e.g. Capps, Kasari, Yirmiya & Sigman, 1993; Damon & Killen, 1982; Garvey, 1986; Serafica, 1990; Guralnick, 1995; Sigman & Ruskin, 1999). The benefits of reciprocity in friendships during middle-childhood go beyond cognitive growth and include the development of sensitivity, self-validation, and identity (Freeman & Kasari, 2002). The development of positive peer relationships may also guard against psychopathology in children and contribute to adjustment in adulthood (Nelson & Dishion, 2004).

#### Peer interactions and group play

In early and middle childhood, peer interactions consist almost exclusively of play behaviors including negotiation over toys and other desired objects, rough and tumble exchanges, social-imitative and pretend games (Sigman & Ruskin, 1999). In order to benefit from peer interactions, children must possess adequate peer-related social competence defined at this stage of development as the ability to effectively and appropriately accomplish interpersonal goals while simultaneously maintaining positive relationships with others over time and across settings

(Guralnick, 1990; Rubin & Rose-Krasnor, 1992). Examples of socially competent behaviour at this stage include but are not limited to: playing in groups, initiating play with a peer, maintaining play with a peer, requesting items, engaging in imaginative play with a peer, and forming friendships (Sigman & Ruskin, 1999; Guralnick, 1996).

Children with DS have been described as highly sociable with peers, well behaved in social situations, and active in joining a peer group (Rosner, Hodapp, Fidler, Agun & Dykens, 2004). The popular view of children with DS as socially motivated and engaged and observations that some children with DS achieve socially related goals (Hodapp, 1996) or charm their way out of difficult tasks (Pitcairn, & Wishart, 1994) have led some researchers to suggest that sociability and friendliness is a syndrome specific personality trait among people with DS (Kasari & Hodapp, 1996; Kasari, Freeman, Sigman, & Mundy, 1995). However, the term 'Down syndrome personality' is misleading as it reflects a stereotype and not a comprehensive assessment of social competence among children with DS. To date, most studies on the social behaviours of children with DS focused on a few components of SC, were based on parent reports, and compared children with DS to children with other developmental disabilities (DD) (see Capps, Kasari, Yirmiya & Sigman, 1990; Kasari et al., 1990; Landry & Chapieski, 1990; Sigman & Ruskin, 1999). In one study, children with DS showed similar incidents of smiling but their smiles were qualitatively less salient and briefer than those of TD children matched on MA (Kasari et al., 1990). Direct observations of social behavior among children with DS reveals that what appears to be sociability may actually reflect an absence of problematic or disruptive behaviors and diminished activity in the classroom and in play groups (Terry-Gage, 1999; Sinson & Wetherick, 1981; Guralnick, 1989). Thus, there is insufficient, and to some extent, contradictory evidence of socially competent behaviour among children with DS.

More sophisticated forms of play that involve interactions with several peers within a group context are particularly challenging for children with DS and, as a result, they engage in group play in a limited way (Sinson & Wetherick, 1981) and experience social isolation in school (Sigman & Ruskin, 1999). The difficulty with group play among children with DS may be due to a lack of preference for social over non-social play (Sigman & Ruskin, 1999). Alternatively, children with DS may not make sufficient bids for social interaction and need scaffolding from adults in order to effectively entice another child or group of children to play with them. The ability to initiate social bids may initially be taught through parent-child interactions as children who are more likely to initiate social interaction with adults, are also more likely to initiate social interaction with peers (Sigman & Ruskin, 1999).

Accepting social bids from others may also be challenging as children with DS were found to be considerably less receptive of social bids than their TD peers (Sigman & Ruskin, 1999). Schlottman & Anderson (1975) found that children with DS were more likely than TD peers to reject another child's bid for play by physically pushing the other child or walking away. Observations of children with DS in integrated playgroups indicate that children with DS had difficulty understanding and interpreting social situations, even when other children persisted through the use of eye contact and other common social bids. After numerous advances proved unsuccessful, the TD children gave up which would lead to progressive yet inconspicuous isolation of the child with DS (Sinson & Wetherick, 1981). Social initiations may be a key factor in the development of other aspects of social competence among children with DS (Sigman & Ruskin, 1999).

Once social contact is initiated, children with DS appear to maintain the interaction (Sigman & Ruskin, 1999). However, requesting items and negotiating with other children about

desired toys or objects in a non-confrontational fashion are challenging skills for children with DD (Guralnick, 1995). Neither cognitive nor language delays explain the problem of requesting in children with DS since they show both diminished verbal and non-verbal requesting (Mundy, Sigman, Kasari, Yirmiya, 1988). Requesting and negotiating are most critical when conflict arises in play and must be resolved in a manner that is judged fair by both parties. Many children with DD are reluctant or unable to engage in negotiation or compromise (Guralnick, 1990). Parents often describe their children with DS as less persistent than TD children, a quality that may hinder the ability to effectively negotiate with peers or request objects from playmates (Spiker, Boyce & Boyce, 2002).

### Friendships

Friendships represent the apex of peer related social competence and are distinguished from peer interactions with regard to their increased reciprocity, stability over time and changes across development (for a review see Kasari & Bauminger, 1998). Although the majority of children with DS can often identify at least one peer “friend”, the quantity and quality of friendships differ from those of TD children (Freeman & Kasari, 2002) and thus, contribute less to their developmental gains (Guralnick, 1995). Freeman & Kasari (2002) reported that peers whom children with DS nominated as friends were often identified as “acquaintances” by their parents thus, these friendships were likely unilateral rather than reciprocal in nature. Regardless of the nature of the friendship, children with DS may have difficulty making use of friends as resources or positively influencing the behavior of other children in a goal-directed fashion (Guralnick, 1995). Thus, reports that children with DS have friendships may not be sufficiently informative of the exact nature of those relationships and whether interventions are required to ensure that children with DS are deriving gains from playing with friends.

Whereas TD children spend more time with their peers once they enter school and are making greater gains in social competence, children with DS rely on contact with adult caregivers and teachers during the primary school years (Lewis, Feiring, & Brooks-Gunn, 1988), and are less likely to initiate social interaction with peers. Further, when they are engaged in social interaction they do so in a limited way and stand to benefit less from the experience. The limited amount and quality of social interaction with peers coupled with less contact with their caregivers may leave children with DS at greater risk for social isolation in the school context (Sinson & Wethernick, 1986).

#### Systemic risk and protective factors during middle-childhood

The development of social competence in middle-childhood involves mastering group involvement, initiating social bids and acting on the social bids of peers, resolving conflict and capitalizing on social opportunities, skills that are learned through interactions with peers, teachers and to a lesser extent parents. Thus, it is critical at this developmental stage to explore opportunities or limitations in the education system, after school care facilities, and community activity centers where primary school children spend a majority of their time. During the school years, the educational system and associated policies are particularly powerful in impacting the development of children, especially for children with DS whose education is more dependent on the system's resources and overall functioning (e.g., special education policies and practices, teaching expertise and social integration initiatives). For example, the policy of including children with DD in public schools is not only desirable for most parents and children but reflects a fundamental social value of inclusion of all children and acceptance of diversity (Rosenthal, 2001). However, research evidence suggests that simply placing children in mainstream contexts does not sufficiently benefit children with and without disabilities (Guralnick, 1996). For example, TD

children were found to speak in a derogatory manner when addressing disabled children (Beveridge & Evans, 1978) and even in situations wherein exchanges are not negative, children with DS were ignored and socially isolated in mainstreamed classrooms (Sinson & Wetherick, 1986). These negative outcomes have led certain stakeholders to examine alternatives to mainstreaming children with DS.

The proponents of special education cite research that in segregated settings, children with DS display more appropriate peer-related social interaction and receive more positive guidance from adults (Terry-Gage, 1999) and that children with DD in special education classes are generally better at playing with peers than those in mainstreamed classrooms (Freeman & Kasari, 2002). However, the variability in play and social competence may be related to the characteristics of the system (teacher scaffolding versus unstructured play) rather than the setting (special education versus mainstream) (Sigman & Ruskin, 1999). When appropriate teaching strategies are in place in the mainstream setting, children with DS are likely to seek out interactions with their TD peers (Guralnick, 1996) and, can be taught effectively to model their social behavior on that of their TD peers (Strain & Odom, 1988). Mentoring and peer-tutoring children with DS teaches leadership and compassion and thus, may also improve the social development of TD children (Beveridge, 1996; Guralnick, 1990). However, interruptions in social routines; school breaks or the introduction of new peers may be associated with a significant loss of gains made during the year (Guralnick, 1995; Sigman & Ruskin, 1999). Research is needed to explore the potential risk and protective factors that operate in other systems that impact the social lives of children during middle-childhood such as daycare facilities and community leisure centers.

Adolescence and Early Adulthood: Autonomy, Self-identity and Social Inclusion

The transition to adolescence is marked by an unprecedented convergence of significant biological, cognitive, emotional, and social changes for every child. Whereas the majority of youth are able to successfully navigate the waves of change, for some, navigating these developmental changes in the context of greater social demands, that they are not prepared to tackle, can heighten the risk for maladaptation (Jackson & Rodriguez-Tome, 1993). During this time, key social developmental tasks include the establishment of a self-identity; the renegotiation of parent-child relationships; the development of more intimate peer relationships; and the movement toward increased community involvement. The role of socio-ecological and contextual factors in the development of social competence may be most pronounced during the transition from childhood to adolescence (Weisz et al., 1997) as the adolescent period is marked by fundamental developmental changes that include experimentation with social rules and structures (Zimmerman, Ramirez, Washienko, Walter, & Dyer, 1998), adoption or rejection of cultural norms; all in an effort to understand the self in relation to others (Borysenko, 1996). Moreover, the focus on social competence during this developmental transition period permits researchers to have a unique view of developmental reorganization and mal/adaptation from the standpoint of an established developmental history of childhood and the initiation into the new developmental challenges of adolescence.

Whereas the foundation for basic social competence is typically established in childhood, adolescence and early adulthood are associated with the acquisition of more complex social repertoires and skills. Adolescents become increasingly attuned to the feelings and intentions of others (i.e., developments occur in theory of mind, emotion processing, and empathy) (Kimmel & Weiner, 1985). Adolescents become more proficient in a range of interpersonal competencies, such as initiating and maintaining conversations; appropriately disclosing personal information;

providing honest opinions; and providing emotional support to others (Buhrmester, 1990). Young people also become more skilled at managing social interactions through the use of more sophisticated interpersonal strategies (e.g., social problem-solving, interpersonal negotiation, and conflict resolution) (Zani, 1993).

Consistent with the emerging childhood literature, adolescents and young adults with DS display significant difficulties across many of the social competence domains. The evidence suggests that individuals with DS demonstrate deficits in theory of mind (particularly false belief reasoning) in comparison to MA-matched peers, including those with DD due to other etiologies (i.e., fragile X syndrome) (Abbeduto et al., 2001; Zelazo, Burack, Benedetto, & Frye, 1996). In addition to social- cognitive impairments, individuals with DS may not fully understand emotional aspects of interpersonal relationships, however, systematic examinations of emotion recognition and comprehension in adolescents or adults with DS are limited (Jobling, Moni, & Nolan, 2000). Preliminary reports suggest that emotion production may be slightly impaired in individuals with DD, as strangers appear to have more difficulty reading their emotions than “familiar others” (e.g., parents or teachers) (Maurer & Newbrough, 1987). In a study investigating the production of facial affect in adults with DS, Smith and Dodson (1996) found that adults with DS demonstrated relatively intact expression of positive affect in response to happy stimuli in comparison to TD, CA-matched peers. However, the authors also reported that the adults with DS generally displayed more “non-emotional” or “extraneous” facial movements. It was suggested that such movements could interfere with others’ interpretations of their emotional and social responses (Smith and Dodson, 1996).

Deficits in social understanding or emotion processing could potentially account for some of the socially inappropriate behaviors and interpersonal problems documented in young people

with DS (Greenspan & Shoultz, 1981). For instance, some investigators have reported abnormal behaviors in the form of overly friendly approaches towards strangers or excessive displays of affection (e.g., hugging) that are not appropriate to the situation (McGuire & Chicoine, 2002). Similarly, terms such as “hypersocial” or “excessively and intrusively cheerful” have been used to describe many adolescents or young adults with DS (Waterhouse, 2002) and suggest that these individuals may have difficulty adapting their interpersonal style to the contextual demands. Other interpersonal difficulties that have been investigated in young people within the broader Literature on DD, and which may be relevant to understanding social competence in DS, include initiating and maintaining conversations; showing interest in others; and using effective interaction strategies (Greenspan & Granfield, 1992; Zetlin, 1989).

Deficits in pragmatic language (i.e., the use of language in social interaction) have also been documented in DS. For instance, individuals with DS demonstrate difficulty taking into account the informational needs of the listener and are less likely to, or less adept at, providing “scaffolding” or speech references for listeners (Abbeduto & Murphy, 2004). Given the fundamental role that language plays in mediating most social interactions, such difficulties may compound existing social cognitive impairments and possibly lead to social misunderstandings or confusion.

Alternatively, many young people with DS demonstrate significant interpersonal strengths that may promote further social development. Although not necessarily indicative of social competence, the high levels of interest in and enjoyment of social interactions apparent among many adolescents and adults with DS (Carr, 1995) may increase social opportunities for inclusion. In addition, a high prevalence of “outerdirectedness” has been reported in persons with DD (Bybee & Zigler, 1999) and may apply to persons with DS. Outerdirectedness refers to an excessive

reliance on cues from others or the environment for feedback regarding one's performance. For instance, when presented with an unfamiliar situation or problem, individuals with DD are more likely than TD individuals to imitate others or use external cues rather than attempt to solve the problem (Bybee & Zigler, 1999). Although outerdirectedness is believed to arise when repeated failures lead to a lack of confidence in one's abilities (Turnure & Zigler, 1964), others have suggested that it may also reflect social influences (Zigler & Hodapp, 1986). More specifically, social imitation, when not excessive, may be adaptive and promote positive interactions with others. Individuals with DD may be more interested in sustaining an interaction or strengthening a bond with a supportive adult (e.g., teacher or experimenter) than solving the problem they are presented with. The potential social benefits of social interest and outerdirectedness in individuals with DS (e.g., increases in social inclusion or greater maintenance of interactions) could be explored to provide insight into using strengths to address weaknesses.

The unique profile of social competence strengths and weaknesses in young people with DS likely affects multiple aspects of their development. During the period of adolescence and early adulthood, the relationship between social competence and the achievement of key developmental tasks may be best conceptualized as reciprocal in nature. Gains in social competence likely enable individuals to better contend with issues such as developing intimate peer relationships or increasing community involvement; and, in turn, the successful negotiation of these tasks may provide more varied social opportunities for continued learning and growth.

#### Renegotiation of parent-child relationships

During adolescence, the nature of the parent-child relationship changes in order to accommodate the adolescent's move towards greater independence (Jackson & Rodriguez-Tome, 1993). This shift away from the protection and support of the immediate family necessitates a

renegotiation of parent and child roles (Honest & Robinson, 1993). Adolescents begin to assert themselves with their parents and take more responsibility for opinions, actions, and life decisions (Preto, 1989; Zani, 1993). Parents, in turn, permit more self-determination, but continue to provide the guidance and supports needed to facilitate the development of independence (Zani, 1993). During this time, parents also begin to modulate levels of authority and establish more permeable or flexible boundaries for their adolescent children – allowing them to move in and out of the family system as needed (Carter & McGoldrick, 1999). As the grown child enters adulthood, the focus within the parent-child relationship moves away from compliance and hierarchical forms of relating towards greater mutuality and, ultimately, adult-to-adult relationships are established (Carter & McGoldrick, 1999).

In DS, the normative stages of the family life cycle tend to be disrupted due to the delayed development of adaptive life skills (Jobling & Cuskelly, 2002). Many adolescents and young adults with DS continue to require high levels of management and care in their daily living, and therefore, often remain heavily reliant upon parents to provide this support (Thomson, Ward, & Wishart, 1995). Given the prolonged dependency of the child, the parent-child relationship may not be renegotiated in the same manner as with TD individuals. Parents, uncertain about how much responsibility and freedom their disabled child can manage, may find it difficult to withdraw protective supervision and control (Zetlin & Morrison, 1998).

Overprotection by parents, whether deliberate or unintentional, may impede continued social development in individuals with DS. The term “unintentional overprotection” has been used to describe parents who complete or assist with tasks (e.g., chores, personal care activities, using public transportation) that their adolescents or young adults with DS are capable of performing on their own, but perhaps with less speed or efficiency (McGuire & Chicoine, 2002). It is possible

that this pattern of parental protectiveness and child dependency is carried over from earlier years and reflects reduced flexibility in the face of changing developmental needs. Over time, parents may become hyper-vigilant to nonverbal cues signaling that the child needs help and thus, reinforce the cycle each time they readily respond. However, by overcompensating for their child's difficulties, parents may be unknowingly interfering with or limiting key social learning opportunities.

Alternatively, parenting strategies that encourage greater responsibility and freedom (with appropriate limits) may be more adaptive in facilitating their adolescent's autonomy and social growth. In a qualitative case study, Richardson, Kline, and Huber (1996) described the development of unusually strong self-management skills in an adolescent female with DS and identified various contributing factors. In particular, it was noted that the adolescent's mother had adopted a parenting style that incorporated a "practical expectation of normalcy" (i.e., age-appropriate expectations adjusted or supported as needed in light of functional limitations). For instance, when the child with DS was approaching the age at which she would be expected to do her own hair, her mother cut her hair short so that it would be easier for her to manage. Similarly, throughout her development, the child was given age-appropriate chores and responsibilities within the household (e.g., setting the table) that were accompanied by realistic expectations of achievement. In this way, the provision of appropriate challenges was believed to maximize her development.

### Self Identity

The developing sense of self undergoes its greatest transformation during adolescence (Marcia, 1980). The process of identity formation is a central task to be accomplished during this period and involves developing a clear and consistent view of the self in relation to the social

world (Suls, 1989). Other aspects of the self, related to self-identity, that continue to develop include one's self-concept (attributes the individual believes characterize him or her self) and self-esteem (overall evaluative notions about one's worth). The development of the self occurs in a social context, as it is through interactions and comparisons with others that one begins the process of constructing a sense of self (Harter, 1999).

The extent to which cognitive limitations restrict the development of self-identity in individuals with DS remains unclear. Thus far, preliminary investigations are limited to those examining self-esteem and self-understanding in DS. Cuskelly and de Jong (1996) found no group differences between adolescents with DS (MAs ranging from 4 to 7 years) and TD, MA-matched children. Both groups displayed highly positive self-evaluations, a finding that appears consistent with developmental studies suggesting that children less than 7 years old primarily view themselves as all good or all bad (with the vast majority rating themselves positively). It is believed that at this age, one is not cognitively capable of integrating contradictory evaluations of different competencies into an overall concept of global self-worth (Harter, 1983). In a study investigating self-understanding in a sample of young people with DS, Glenn and Cunningham (2004) found similar evidence of a typical developmental progression. Only those with a MA above 7 years were able to make relative comparisons to others and provide reasons for these evaluations. Furthermore, as with TD children, the majority of those capable of making comparisons made downward ones (i.e., compared themselves to less competent others). Taken together, these findings suggest that cognitive limitations affecting the ability to make social comparisons may in fact serve a protective function for young people with DS by maintaining relatively high levels of self-esteem.

Although numerous environmental factors likely influence self-identity development, the normative literature points to the key role of parenting styles. In typical development of mainstream North-American children, positive self identity formation appears to be facilitated by “democratic” parenting practices (i.e., those that provide a supportive and accepting environment and encourage the child’s responsibility and involvement in discussions relevant to his or her behavior) (Kimmel & Weiner, 1985). Similarly, in DS, parenting styles emphasizing choice and empowerment may support social growth. Brown’s (1995) quality of life model suggests that encouraging young people with DS to express their wishes and desires and to make important choices in their lives creates an atmosphere that promotes the development of a positive self-image. Families that encourage open discussions about what it means to have DS (i.e., limitations, stigma, and unique strengths) may encourage young people to inquire about, understand better and accept their condition, thus facilitating the development of positive self-esteem and self identity (Cunningham & Glenn, 2004; McGuire & Chicoine, 2002). In the same way, programs or policies that promote self-advocacy or self-determination among people with DS (i.e., encourage them to play a more active role in managing and making decisions about their lives) may help foster the development of positive self-esteem and identity.

#### Intimate relationships

As family relationships become less central in the social world of the adolescent and young adult, peer relationships assume increasing significance (Berndt, 1982). During this period of development, peer relationships also become more complex and demand greater interpersonal competence in areas such as maintaining conversation, offering emotional support to others and effectively managing conflicts (Buhrmester, 1990). Adolescent peer relationships also tend to be less based on shared play activities and involve greater collaboration, participation and enjoyment

in mutual activities, and the sharing of more intimate exchanges (Reis & Shaver, 1988). The intimate relationships that emerge during this time (i.e., friendships or dating relationships) are typically characterized by a higher degree of self-disclosure (i.e., sharing of personal thoughts and feelings), greater mutuality and increased reciprocity (Kimmel & Weiner, 1985). Intimate peer relationships provide important opportunities to learn and refine key social competence skills and serve as foundations for later social relationships (e.g., with spouses or co-workers). Conversely, negative peer influences at this stage may contribute to high-risk behaviors such as drug use or early sexual activity.

Adolescents and young adults with DS generally report a desire for friendships (Bottroff et al., 2002). However, evidence suggests that young people with DS experience significant difficulty making friends and instead spend much of their social life with their family (Bochner & Pieterse, 1996). In one study investigating the development of friendships in adolescents and young adults with DS, fifty-five percent of parents reported that their child had no “special friend” (Bottroff et al., 2002). Dating also appears to be relatively uncommon among young people with DS (Carr, 1995). Even among the youth that have established peer relationships, there is some question as to how intimate or “close” they truly are (Carr, 1995). For instance, many young people with DS appear to misinterpret helping relationships as real friendships (Turnbull, Blue-Banning, & Pereira, 2000). Within the broader literature on DD, there is evidence that adolescent friendships involve less intimacy and empathy as compared to relationships among TD individuals (Zetlin & Murtaugh, 1988), however, this issue has not been explored in persons with DS.

Jobling et al. (2000) hypothesize that a superficial understanding of the emotional aspects of relationships may limit the development and maintenance of friendships in young people with DS. They suggest that many individuals with DS learn about relationships from watching

television or the movies. However, the unrealistic and shallow models of relationships that these sources provide may lead to limited representations of friendships (or dating relationships) and the imitation of various social behaviors in the absence of true understanding. Deficits in theory of mind may make it difficult for individuals with DS to read the intentions of others and further restricts efforts to establish more intimate relationships (e.g., by leading to reduced reciprocity). In addition, such social cognitive impairments may also increase their susceptibility to negative peer group influences or exploitation.

The development of intimate peer relationships in young people with DS may also be restricted by a lack of social opportunity or a limited friendship pool (Zetlin & Morrison, 1998). The social stigma or stereotypes surrounding individuals with DS may reduce opportunities for meaningful interactions with TD peers. Intimate relationships with non-disabled peers may be further impeded by difficulties with reciprocity (i.e., TD peers may take on a caregiving role); challenges in the pursuit of shared interests due to cognitive and social limitations; or a lack of proximity (Day & Harry, 1999). Unfortunately, some individuals with DS, especially those who are higher functioning, appear reluctant to associate with their disabled peers, perhaps due to negative beliefs about their own disability (McGuire & Chicoine, 2002). Such a negative attitude may limit important opportunities for developing friendships, as most friendships occur among individuals at approximately the same cognitive level (French, 1987). In addition, given a possible history of shared experiences, friendships among individuals with disabilities have the potential to offer enhanced mutual understanding and sensitivity (Day & Harry, 1999). Individuals with DS who are not accepted by their TD peers and disregard those with disabilities may be at particular risk for social isolation.

Practical issues, such as accessibility and transportation, may cause young people with DS to depend more heavily upon family involvement to sustain friendships (Day & Harry, 1999). Individuals with DS often continue to be highly reliant upon parents or caregivers to arrange and/or facilitate socializing opportunities (e.g., provide transportation, supervision etc.) (Jobling & Cuskelly, 2002). When the required level of family support is not available, young people with DS may not be able to spend the amount of time with a friend that is normative at this stage in development. Furthermore, excessive parental involvement in social experiences may ultimately result in more highly structured or regulated social interactions (Waterhouse, 2002). That is, parents may spend more time directly regulating the interactions of young people with DS and less time encouraging more varied social behaviors or involvement in experiences that could lead to the acquisition of more diverse social skills.

Certain behavioural and personality features of young people with DS may be protective and have the potential to encourage the development of important peer relationships. In particular, research suggests that in comparison to their childhood, adolescents with DS begin to demonstrate fewer maladaptive behaviours and externalizing problems (e.g., aggressive behaviors, being argumentative or disobedient) (Dykens, Shah, Sagun, Beck, & King, 2002) and become more agreeable and cooperative (Carr, 1995). In addition, young people with DS are generally described as being socially engaging, cheerful, and friendly (Rosner, Hodapp, Fidler, Sagun, & Dykens, 2004). Thus, low rates of negative behaviours and a pleasant interpersonal style may make individuals with DS appear attractive and approachable to peers.

Large family social networks may also facilitate the development of intimate relationships in young people with DS. Larger networks can provide more opportunities for social interaction, increased exposure to social role models, and significant social rewards for the adolescent with DS

(Sloper & Turner, 1996). In addition, exposure to individuals of a variety of ages may promote the development of a wider range of social skills. For instance, the opportunity to develop friendships with younger children may allow the individual with DS to be the more competent partner in social interactions, as opposed to being at the receiving end of helping interactions (Harry, Day, & Quist, 1998). Furthermore, there may be added indirect benefits resulting from greater parental social support. Given that the parent's role as caregiver becomes non-normative as the child with DS reaches adulthood, increases in parental stress may occur, particularly as parents become older and less able to care for their adult children (Seltzer & Krauss, 1989). At this stage, parents with larger support systems may feel less burdened, and as a result, may be better able to devote time and energy to fostering their child's social development (e.g., by providing the support needed to pursue friendships outside of school or work).

Service agencies also have the potential to facilitate the development of peer relationships through the types of programs that are offered to adolescents and adults with DS. Social skills training programs, such as the one developed by Soresi and Nota (2000) have shown some promise in modifying the quality and frequency of social behaviour in individuals with DS. However, in addition to interventions that focus solely on social skills instruction, services designed to nurture the development of friendships in this population may be beneficial (Emerson & McVilly, 2004). Jobling et al. (2000) describe a program for youth with DS designed to enhance their understanding of the emotional aspects involved in friendships and report encouraging preliminary findings. Additional research among adults with DD have identified training in the use of public transportation and family support networks as key factors that promote friendships (Park, Chadsey-Rusch, & Storey, 1998). Thus, service agencies or helping professionals may play a key

role in this process by arranging family get-togethers that allow families to interact or by offering families other forms of practical assistance (Day & Harry, 1999).

#### Community involvement and social inclusion

Adolescence and early adulthood is generally a time of increasing autonomy and involvement within the wider community. Integration in the community typically involves a transition from high school to post-secondary education, the work environment, and/or leisure settings. The diverse array of social contexts available to the young adult provides multiple opportunities for social practice, success, and failure (Zetlin & Morrison, 1998).

*Post-secondary education.* In recent years, there has been a substantial increase in the number of postsecondary education centers offering opportunities for persons with disabilities; however, enrolment remains low (Morris, 2002). The opportunity to experience college or university life may be beneficial for individuals with mental retardation, even if they do not fully participate in academic programs (Hamill, 2003; Page & Chadsey-Rusch, 1995). In a qualitative case study, Hamill (2003) describes the college experience of a young woman with DS and outlines the systemic resources and supports that enabled her successful integration. Most of the factors that were identified as promoting successful integration were social in nature: small class sizes; performance-based courses emphasizing group work and interaction; involvement in non-academic aspects of campus life (e.g., eating in the cafeteria, using the library, access to email, participation in clubs); extensive academic supports (e.g., note-takers, tutoring with study buddies, and greater interaction with faculty); and modified or reduced academic expectations. In sum, a greater emphasis on facilitating the social experience of college life, as opposed to academic achievement, may create numerous opportunities to foster social growth in young people with DS.

*Employment.* Participation in employment or volunteer opportunities also has the potential to foster social integration in the lives of adults with DS. Perera (1996) outlined a number of possible social benefits of work involvement for individuals with DS. These include establishing social connections and making friends; experiencing integration; learning to coexist, sharing and relating to others; attaining social status and greater security for the future; and, increasing aspirations. Unfortunately, surveys suggest that there are high levels of unemployment among adults with DS, and those who are employed tend to be involved in “sheltered” as opposed to competitive employment (Putnam, Pueschel, & Holman, 1988).

Vocational success relies heavily upon social competence – a finding that has been demonstrated both in the general population (Mueller, 1988) and in individuals with DD (Chadsey-Rusch, 1992; Greenspan & Shoultz, 1981). For instance, to be successful, workers need to be able to follow requests and instructions, cooperate with others, and develop positive relationships with supervisors and co-workers. It has been suggested that adults with DD may contribute to their own limited job success by engaging in social behaviors that are difficult for employers or co-workers to tolerate, regardless of their good intentions (Greenspan & Shoultz, 1981). In addition, the expressive language difficulties apparent in many individuals with DS (Chapman & Hesketh, 2000) may lead to the demonstration of socially inappropriate or ineffective behaviors on the job. For instance, discontent or confusion may be communicated inappropriately by sitting down and refusing to work as opposed to effectively expressing one’s needs or feelings (McGuire & Chicoine, 2002).

Vocational training programs that consider one’s level of social competence in making decisions about work training or placement may also be associated with better work and social outcomes (Greenspan & Shoultz, 1981). Adolescents and adults with DS are likely to require

explicit assistance in developing the social skills needed to apply for, attain and keep jobs (McGuire & Chicoine, 2002). At the level of employment organizations, various systemic factors appear to promote the successful social integration of young people with DS into the work environment. For instance, suitable work settings are likely to be those that involve extensive in-service training; a highly structured training program; work stations with consistent, specific procedures; and, a clear, hierarchical order of employee positions (Contardi, 2002). Clear expectations and requirements may help to minimize the occurrence of socially inappropriate behaviors on the job.

*Leisure.* Involvement in community leisure and recreation activities may provide individuals with DS with numerous opportunities to further their social learning and social competence development. However, in general, adolescents and adults with DS do not appear to fully participate in community leisure activities. Surveys indicate that most young adults with DS engage primarily in passive or solitary activities (such as watching TV, going to a movie, or walking) as opposed to participating in sports activities, clubs, or other community organizations that would promote greater interpersonal interaction (Putnam et al., 1988). Recent findings suggest that there may actually be a decrease in the frequency and breadth of participation in active recreation that occurs in the mid to late 20's among adults with DS (Brown, 1995). Major reasons cited for decreased involvement included a lack of companions with whom to participate, poor leisure skills, and limited opportunities. As with the pursuit of friendships, there remains a significant reliance upon parent involvement for organizing, providing access to, and accompanying youth with DS to community activities (Jobling & Cuskelly, 2002). Social stigma or stereotyped perceptions may further alienate youth with DS and discourage their participation in activities with their TD peers.

Few community resources are in place to facilitate the integration of individuals with DS into mainstream leisure activities. Simply creating opportunities for inclusion does not ensure that the individual with DS will be successfully integrated, just as exposure to TD peers alone does not ensure that interpersonal attraction or positive interactions will follow (Rynders & Low, 2001). However, current research suggests specific ways that community organizations can create a more inclusive atmosphere. For instance, one possibility is to structure activities so that they require cooperative interactions (Rynders & Low, 2001). This “cooperative structuring” involves creating a need for face-to-face interactions and verbal communication; positive interdependence (i.e., the necessity of working together to accomplish a goal); individual accountability for contributing to the group; and appropriate interpersonal and small-group skills. Rynders and Low (2001) argue that cooperative structuring can minimize the weaknesses of youth with DS and capitalize upon their strengths (e.g., nonverbal aptitude, pleasant personality, and earnest effort). In an empirical study, Rynders, Johnson, Johnson and Schmidt (1980) compared the effects of cooperative, competitive and individualistic goal structuring on the interpersonal outcomes of an 8-week recreational bowling program involving youth with DS and their TD peers. Results demonstrated that greater interpersonal attraction and more positive interactions occurred in the cooperative condition.

Additional suggestions are found in case studies examining instances of successful integration or unusually high peer acceptance. For instance, Harry et al. (1998) describe the nature of positive interactions occurring between an adolescent male with DS and his TD brothers and peers. The authors’ findings highlight the need for specific peers to play “advocacy” and/or “facilitatory” roles to support the adolescent with DS in participating in more complex or sophisticated group activities. In the absence of such advocates, the adolescent with DS appeared

unable to keep up with the pace of the group and would withdraw into solitary play. Given that normative peer interactions are typically based on notions of equity, they may not naturally encourage the participation of individuals with DS. Instead, the presence of individual peers to advocate for and facilitate the inclusion of young people with DS may be needed. While assigned peer buddies or “partnering” may perform this role, Harry et al. (1998) suggest that creating environments that promote the emergence of spontaneous advocates are ideal. In particular, optimal social environments may be those that encourage a sense of belongingness and respect for others and are somewhat hierarchical in structure (i.e., more capable individuals are expected to routinely help those who are younger or in need of greater supervision). In addition, the authors emphasize the importance of anticipating which activities will be appropriate for individuals with DS to take part in. Excessive expectations that they should participate in all situations may be counterproductive and unfair.

The Special Olympics is a notable example of a community organization that has led the way in providing inclusive opportunities for leisure activities for a variety of individuals with handicaps. In addition to promoting physical fitness, sports training, and athletic competition, involvement also has the potential to foster social and emotional growth in individuals with DS. For instance, the organization may provide extensive opportunities to strive for and achieve personal goals, develop friendships, engender a sense of belonging through team effort, and facilitate community involvement extending beyond the sports arena. Preliminary evidence suggests that involvement in the Special Olympics facilitates the development of social competence and positive self-esteem in individuals with DD (Dykens & Cohen, 1996).

### Social Inclusion and Mental Health

Recent evidence suggests that there may be subtle changes in sociability in DS that occur during adolescence. Dykens et al. (2002) present preliminary findings that indicate a shift toward increased withdrawal and decreased sociability during this period. Specifically, sixty-three percent of the adolescents included in their sample reported that they preferred to spend time alone. Changes in sociability may represent early phases in the cognitive and social decline common in DS (Thompson, 1999), however, they may also reflect the cumulative effects of ongoing social difficulties and limited social networks. Young people with DS may find themselves ill equipped to negotiate key social developmental tasks and progressively withdraw from the social world as it becomes increasingly complex.

Research suggests that social difficulties and/or low social support place individuals at increased risk for developing mental health problems, and particularly internalizing disorders (G. W. Brown, Andrews, Harris, Adler, & Bridge, 1986; G.W. Brown & Harris, 1978; Coyne & Downey, 1991; Turner, 1999). Thus, in DS, subtle increases in social withdrawal or isolation may set the stage for the later emergence of depressive disorders. There is evidence that rates of depression increase as individuals with DS reach adolescence and adulthood (Rowitz & Jurkowski, 1995). Furthermore, individuals with DS appear to be more vulnerable to developing depression than individuals with other developmental disabilities (by a factor of 2-3 times) (Collacott, Cooper, & McGrother, 1992). The high prevalence of depression in young people with DS is a concerning statistic that warrants more extensive research on the relation between social impairments and increased social withdrawal in persons with DS.

### Conclusion

The birth of a child with Down syndrome (DS), much like other life cycle transitions, occurs within a context of stability and change. The child enters a family system that has an established developmental history yet is adapting to changing developmental circumstances across the lifespan such as the introduction of a new child, the initiation of the child's preschool and formal schooling, increased autonomy and peer contact in adolescence, and launching the adolescent into adulthood (Carter & McGoldrick, 1999). The process of developmental reorganization, at any transitional period in the life cycle, involves both challenges to and opportunities for growth within the family system. Although children with DS and the families that care for them are sometimes referred to as 'unique' due to the added medical, psychological and systemic challenges associated with the condition of DS and, 'at risk' due to the potential for negative developmental outcomes, they can also be studied for the ways in which they successfully manage stressors and adjust to normative life cycle transitions as effectively as typical family systems do (Iarocci, Virji-Babul & Reebye, in press).

The developmental course of a child with DS is laden with potential risk and protective factors consequently, multiple pathways to adaptation or maladaptation are possible. For example, families that care for a child with DS do not have the benefit of their extended family's wisdom on raising their 'unique' child yet they may be less bound by social and cultural prescriptions on parenting. These families also often face the challenges of advocating for and acquiring resources for their parenting and child's needs, however, this very deliberate engagement in the parenting process may lead to more mindful awareness and activity in child rearing. Similarly, the social inclusion of the child with DS is not a natural process but requires commitments and concerted efforts from families, their communities and society. However, on-going societal efforts to

accommodate diversity and change within relative stability is what propels society toward more flexible and creative growth and adaptation. Accordingly, the field of mental retardation and in particular as it relates to the study and practice of rearing children with DS, needs to adapt to the changing landscape of knowledge about DS and create opportunities for continued growth.

Remarkable medical advances in the past decade have warded off the major medical conditions that previously threatened the survival of people with DS, as a result, adults with DS are living longer (Janicki, Daltonoe, Henderson & Davidson., 1999). Researchers, practitioners, parents and policy makers may now shift their focus from the survival or simple existence of persons with DS to matters that address social inclusion and the quality of their existence.

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#### **Author Notes**

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