

Siblings of individuals with autism or Down syndrome: effects on adult lives

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Abstract

Background In this study, we examine instrumental and affective involvement in the sibling relationship for adults who have a brother or sister with an autism spectrum disorder (ASD) or Down syndrome (DS). We ask three research questions: (1) How do adult siblings of individuals with ASD differ from siblings of individuals with DS in their assessment of the quality of the sibling relationship and their experience of growing up with a brother or sister with a disability? (2) Are there gender effects on the sibling relationship and sibling experience in these two groups? (3) Which factors are predictive of variation in the sibling relationship for siblings of adults with ASD or DS?

Methods Data from 154 siblings who participated in two linked longitudinal studies were used. Seventy-seven siblings with a brother or sister with ASD were matched by age and gender to 77 siblings with a brother or sister with DS. The siblings in each group were between 21 and 56 years of age and over half were sisters. Siblings completed questionnaires on instrumental and affective involvement with their brother or sister with ASD or DS, the impact of growing up with a brother or sister with a

disability on their lives, and their coping skills and feelings of pessimism.

Results Compared with the siblings of adults with DS, siblings of adults with ASD had less contact with their brother or sister, reported lower levels of positive affect in the relationship, felt more pessimistic about their brother or sister's future, and were more likely to report that their relationships with their parents had been affected. For siblings of adults with ASD, a closer sibling relationship was observed when the sibling had lower educational levels, lived closer to the brother or sister with ASD, used more problem-focused coping strategies, and when his or her brother or sister with ASD had higher levels of functional independence. In contrast, for siblings of adults with DS, a closer sibling relationship was observed when the sibling did not have children, had lower levels of education, lived closer to the brother or sister with DS, when he or she used more problem-focused coping, was less pessimistic about the brother or sister's future, and when his or her life had been impacted to a greater extent by growing up with a brother or sister with DS.

Conclusions We discuss the implications of these findings for future caregiving roles for siblings. Siblings of individuals with ASD may face difficulty when their parents are no longer able to be the primary caregivers for their brother or sister with

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ASD, as they tend to have less emotional closeness and are more pessimistic about their brother or sister's future than siblings of individuals with DS. Moreover, in both groups, a closer sibling relationship was observed when the sibling used more problem-focused coping strategies, which may have implications for intervention.

Keywords adulthood, autism, Down syndrome, siblings

Introduction

Adults who have a brother or sister with autism spectrum disorder (ASD) or Down syndrome (DS) are often expected to be responsible for the well-being of their brother or sister once their parents are no longer able to do so. They face the challenge of remaining involved in their brother or sister's life while they juggle their own life responsibilities and families. ASD and DS syndrome differ, however, in behavioural phenotype (Fisman *et al.* 2000). All individuals with DS have some degree of cognitive impairment, whereas ASDs show considerable variability in cognitive functioning (American Psychological Association 2002). Also, ASD is characterized by social impairment and the presence of repetitive and unusual behaviours, whereas individuals with DS are frequently reported to be sociable and to have few repetitive behaviours. On the other hand, the early onset of Alzheimer's disease in some individuals with DS may pose an additional challenge to siblings at the stage of life when they may anticipate increased involvement in caregiving.

Our first aim of the study therefore was to examine the extent to which, during adulthood, siblings of individuals with ASD differed from siblings of individuals with DS in their assessment of the quality of the sibling relationship and their experience of growing up with a brother or sister with a disability. Although there has been virtually no research on siblings of adults with ASD and only limited study of siblings of adults with DS, more research has been conducted on siblings of young children with these disabilities. When compared with young siblings who have a brother or sister with DS, young siblings who have a brother or sister with ASD spend less time with their brother or sister (Knott *et al.* 1995), report having a less

close sibling relationship (Bagenholm & Gillberg 1991; Kaminsky & Dewey 2001), and are more concerned about their brother or sister's future (Bagenholm & Gillberg 1991).

Our second research question addressed gender effects on the sibling relationship and sibling experience in these two groups. Research on siblings of adults with intellectual disability (ID) and other disabilities has shown that sisters tend to be seen as being primary caregivers and are more involved in the lives of their sibling with ID than brothers (Zetlin 1986; Begun 1989; Greenberg *et al.* 1999; Orsmond & Seltzer 2000). The gender of the sibling with the disability also may condition the sibling experience and relationship, although the results are inconsistent. Begun (1989) found that non-disabled sisters reported more sibling contact if they had a brother with ID than if they had a sister with that disability. In contrast, Orsmond & Seltzer (2000) found that sisters were equally close to brothers and sisters with ID, but that brothers who had a sister with ID felt less positively about their sibling relationship. Wilson *et al.* (1992) found that the gender of the sibling with the disability did not influence ratings of the sibling relationship. Based on our prior research (Orsmond & Seltzer 2000), we expected that, for both groups, the gender of the sibling with disability would be important for non-disabled brothers, but not for non-disabled sisters. Given the limited research, we did not pose a directional hypothesis (i.e. that the gender effects would be stronger in one diagnostic group over the other).

Our third research question examined the factors that are predictive of variation in the sibling relationship for siblings of adults with ASD or DS. We drew upon elements of McCubbin & Patterson's (1983) Double ABCX model, focusing on two aspects of the sibling relationship as dependent variables (xX): affective involvement (positive affect in the relationship) and instrumental involvement (amount of contact and frequency of shared activities).

We expected that in both groups, functional limitations and behaviour problems in the sibling with ASD or DS would act as stressors (aA) to the sibling relationship, but that adults with ASD would have greater functional limitations and more severe behaviour problems than adults with DS. For both groups of siblings, we expected more affective and

instrumental involvement in the sibling relationship when the brother or sister with the disability had fewer maladaptive behaviours and better functional abilities (Pruchno *et al.* 1996; Greenberg *et al.* 1999).

We also examined the sibling resources (bB; coping skills) and siblings' appraisal of their experience (cC; pessimism and the ratings of the extent to which their brother or sister had affected their life) that might influence the sibling relationship. With respect to sibling resources, we investigated two types of coping skills: problem-focused coping and emotion-focused coping. Problem-focused coping refers to behaviours that directly address the problem and are generally adaptive, whereas emotion-focused coping refers to strategies wherein the individual either avoids or emotionalizes the experience, and are generally maladaptive (Folkman & Lazarus 1980). We predicted that for both groups, greater use of problem-focused coping and less use of emotion-focused coping would be associated with closer sibling relationships (McHale *et al.* 1986).

Regarding appraisals, we expected that siblings' feelings of pessimism about the brother or sister's future would be associated with less affective and instrumental involvement. We also assessed the sibling's appraisal of the extent to which he or she perceived that his or her life was affected by the brother or sister with a disability. For both groups, we expected that siblings who felt their life had been more strongly affected would report higher levels of affective and instrumental involvement. We had data about whether this effect was positive or negative for the ASD group only; thus, we did not know whether the effect was positive or negative for the DS group.

Finally, we examined several background factors that in prior research have been shown to be related to the sibling relationship. Notably, we expected that siblings who had children themselves would be less involved in the sibling relationship (Greenberg *et al.* 1999), and that further distance from the brother or sister's residence would be associated with less contact and closeness in the sibling relationship (Zetlin 1986; Greenberg *et al.* 1999).

This is the first study to examine sibling relationships in adulthood when the brother or sister has ASD. Thus, in this paper we aim to extend the current research on sibling relationships when a family member has a developmental disability. We

examine whether the type of disability (ASD or DS) has a differential effect on the sibling relationship during adulthood, and we explore whether the same factors are associated with positive as well as negative aspects of the sibling relationship for adults with a brother or sister with ASD and DS.

Methods

Participants

The sample for this analysis included 154 adults who had a brother or sister with an ASD ($n = 77$) or DS ($n = 77$). These two groups of siblings participated in separate, but linked, longitudinal studies of family caregiving (Krauss & Seltzer 1999; Seltzer *et al.* 2003).

Siblings with a brother or sister with ASD completed a mailed questionnaire during the second round of data collection of a longitudinal study of 406 families that involved four rounds of data collection (Seltzer *et al.* 2003). The individuals with ASD were age 10 years or older at the start of the study and a diagnosis of ASD was confirmed through administration of the Autism Diagnostic Interview – Revised (Lord *et al.* 1994). Data were collected from 244 of 351 available siblings at the second round of data collection, with a response rate of 69.5%. Including only one sibling per family resulted in a sample of 145 siblings. Our selection criteria included the following: (1) if only a single sibling was available his or her data were included; (2) if more than one sibling participated, the data from the one designated as 'most involved' with their brother or sister with ASD by the mother were included; and (3) in the two families in which the mother declined to designate a most involved sibling, data from the middle sibling were included.

Siblings of individuals with DS participated in the third wave of an eight-wave longitudinal study of 461 ageing families of adults with ID, of whom 30% had DS (Krauss & Seltzer 1999). At the first round of data collection, all mothers were 55 years or older and the son or daughter with ID was living at home. Of the 431 mothers who participated during the third round of data collection, 31 had no other children. The 'most involved' sibling as nominated by the mother was recruited to participate in

the sibling study. A total of 329 siblings participated (with a response rate of 82%), of whom 132 had a brother or sister with DS.

A matched-pairs sample was created by matching each sibling who had a brother or sister with DS with a sibling whose brother or sister had ASD on gender and age (within 3 years). Each sibling with a brother or sister with DS was sequentially matched in order of identification number with a sibling with a brother or sister with ASD, until the point when the maximum number of matches could be made. Prior research on siblings of children with ASD vs. DS has matched sibling groups on age, among other factors (Rodrigue *et al.* 1993; Kaminsky & Dewey 2001, 2002; Yirmiya *et al.* 2006). Shaked & Yirmiya (2004) suggest that in conducting research on families of individuals with autism, matching sibling groups on chronological age will highlight the developmental milestones that are important to that age group. Similarly, Stoneman (1989) suggests matching on a case-by-case basis to limit group differences in demographic characteristics. As the age distributions of our samples were skewed in opposite directions, the only possible way for us to create comparable groups on age was by creating matched pairs. Thus, data from 68 of the 145 siblings of adults with ASD were not used because these siblings could not be matched with a sibling with a brother or sister with DS. A large majority of these 68 siblings were young adults aged 19–25 years, and there were few siblings of adults with DS in this age range.

Table 1 presents descriptive information on the background characteristics of the 77 matched pairs. The siblings in each group were between 21 and 56 years of age, and over half of each group (58.4%) were sisters. The siblings differed significantly only on two variables: siblings of adults with ASD were significantly less likely to have children and they had higher levels of education than siblings with a brother or sister with DS. There were trend level differences on birth order, marital status and distance to their brother or sister's house. Their brothers and sisters with the disability differed in several respects. Those with ASD were significantly older (by about 3 years), less likely to reside in the parental home, had lower levels of functional independence, had more severe behaviour problems, and were less likely to have an ID diagnosis than those with DS.

Measures

Instrumental involvement

Frequency of sibling contact was measured with two questions that asked siblings how often they saw their brother or sister in person and spoke with them on the phone (both scored from 0 'never' to 7 'daily'). For our measure of shared activities, siblings indicated the type of activities that they shared with their brother or sister in the last year. We calculated a count of the number of different types of shared activities in the past year (from 0 to 6), and also examined the frequency of participation in each activity.

Affective involvement

Positive affect in the sibling relationship was measured with the Positive Affect Index (PAI; Bengtson & Black 1973). The PAI includes 10 items, each rated on a 6-point scale (from 1 'not at all' to 6 'extremely'). Five questions address the sibling's feelings towards his or her brother or sister with ASD or DS (e.g. 'How much affection do you have toward your brother/sister?'), and five questions represent the sibling's perception of reciprocated affect from his or her brother or sister (e.g. 'How much affection do you feel that your brother/sister has for you?'). The five questions address the dimensions of affection, understanding, trust, fairness and respect in the relationship. PAI scores ranged from 22 to 60 for siblings of individuals with DS ($\alpha = 0.94$) and from 20 to 60 for siblings of individuals with ASD ($\alpha = 0.92$).

Characteristics of the brother or sister with the disability

Functional independence in activities of daily living was measured using the Revised ADL Index (Seltzer & Krauss 1989), which includes 20 items in the domains of personal care, housekeeping, meal preparation, mobility and community interaction. For this analysis, the score for functional independence was the number of tasks the individual performed independently. Scores ranged from 0 to 17 and from 0 to 19 for individuals with DS and ASD, respectively.

Mothers completed the behaviour problems subscale of the Scales of Independent Behaviours – Revised (SIB-R; Bruininks *et al.* 1996). This

Table 1 Background characteristics of siblings and brother or sister with ASD or DS

	ASD group (n = 77)	DS group (n = 77)	Test statistic
<i>Siblings</i>			
Age (mean years)	38.17 (SD = 8.20)	38.16 (SD = 7.73)	$t(76) = 0.09$, ns
Gender (% female)	58.4	58.4	$\chi^2(1, n = 77) = 0.00$, ns
Gender of sibling pairs (%)			$\chi^2(2, n = 77) = 1.55$, ns
Brother–brother with disability	32.9	31.6	
Brother–sister with disability	9.2	10.5	
Sister–brother with disability	35.5	42.1	
Sister–sister with disability	22.4	15.8	
Birth order (% older)	66.2	80.5	$\chi^2(1, n = 77) = 3.03$, $P = 0.08$
Marital status (% married)	62.3	77.9	$\chi^2(1, n = 77) = 3.78$, $P = 0.05$
Parental status (% have children)	51.9	71.4	$\chi^2(1, n = 77) = 5.03$, $P < 0.05$
Level of education (%)			$z(76) = 2.02$, $P < 0.05$
High school	14.3	20.8	
Some college	26.0	32.5	
College graduate	22.1	26.0	
Some graduate school	10.4	6.5	
Graduate school	26.0	14.3	
Employment status (% employed)	83.1	88.3	$z(1, n = 77) = 0.67$, ns
Household income (%)			$z(76) = 0.61$, ns
<\$20 000/year	13.0	9.1	
\$20 000–39 999/year	19.5	24.7	
\$40 000–59 999/year	23.4	31.2	
≥\$60 000/year	41.6	33.8	
Distance to brother/sister's residence (%)			$z(68) = 1.85$, $P = 0.06$
<15 min	19.5	29.9	
15–30 min	15.6	24.3	
30–60 min	16.9	14.3	
>1 h	39.0	31.2	
Live with parent(s) (%)	7.8	5.2	$z(1, n = 77) = 0.00$, ns
<i>Brother or sister with ASD or DS</i>			
Age (mean years)	34.88 (SD = 9.62)	31.84 (SD = 7.21)	$t(76) = 2.68$, $P < 0.01$
Gender (% male)	72.7	67.5	$\chi^2(1, n = 77) = 0.30$, ns
Live with parent(s) (%)	33.8	89.6	$\chi^2(1, n = 75) = 37.21$, $P < 0.001$
Functional independence (mean)	8.04 (SD = 4.81)	9.47 (SD = 4.65)	$t(76) = 2.04$, $P < 0.05$
Maladaptive behaviours (mean)	109.36 (SD = 7.80)	104.32 (SD = 5.40)	$t(65) = 3.93$, $P < 0.001$
Intellectual disability (%)	89.6	100	$z(1, n = 77) = 2.83$, $P < 0.01$

ASD, autism spectrum disorder; DS, Down syndrome; ns, not significant; SD, standard deviation.

measure consists of eight behaviour problems: behaviour that is hurtful to self, unusual or repetitive, withdrawn or inattentive, socially offensive, uncooperative, hurtful to others, disruptive, and destructive of property. The mother was asked whether her son or daughter manifested each of these eight behaviour problems within the last 6 months and, if so, to rate the frequency and severity of the behaviour, each measured on a

6-point scale. Standardized algorithms (Bruininks *et al.* 1996) were used to translate frequency and severity ratings into a general summary score where higher scores indicated more severe maladaptive behaviours. Maladaptive behaviour scores ranged from 100 to 126 in the DS sample, and from 100 to 134 in the ASD sample. According to the SIB-R clinical categorizations, eight individuals with DS were categorized as having behaviour problems that

were 'marginal' and one individual had 'moderate' behaviour problems. A greater number of individuals with ASD had 'marginal' behaviour problems ($n = 21$), four had 'moderate' behaviour problems, and two had 'serious' behaviour problems.

Mothers reported on three other characteristics of the son or daughter with ASD or DS: date of birth, gender (0 = male, 1 = female) and whether or not they lived at home (0 = lives in parental home, 1 = lives elsewhere).

Sibling resources and appraisals

Siblings indicated the extent to which they felt their life had been impacted in eight areas as a result of growing up with a brother or sister with a disability (relationship with mother, relationship with father, relationship with spouse, thoughts about having children, feelings about self, plans for future, career, choice about where to live). We counted the number of life areas impacted for each group, and also examined the number of siblings in each group who reported that a life area was impacted. For siblings of adults with ASD, we included a follow-up question regarding the valence of the impact, asking them to indicate if the impact in each life area had been mostly positive, both positive and negative, or mostly negative. We did not have comparable valence data for siblings of adults with DS and thus do not know if the impact was positive or negative for them.

Siblings completed eight subscales of the Multidimensional Coping Inventory (Carver *et al.* 1989). Four subscales (each comprised of four items) measured problem-focused coping: active coping, planning, suppression of competing activities, and positive reinterpretation and growth. Four subscales measured emotion-focused coping: denial, focusing on and venting of emotions, behavioural disengagement and mental disengagement. Siblings rated each item on a 4-point scale according to how often they used the strategy (from 1 'not at all' to 4 'a lot'). Alpha reliabilities for problem-focused coping were 0.91 and 0.88 for siblings of individuals with ASD and DS, respectively, and for emotion-focused coping the alphas were 0.74 and 0.68, respectively.

Pessimism was measured with 10 items from the Pessimism scale of the Questionnaire on Resources and Stress (Friedrich *et al.* 1983), which assesses

worries and pessimism about the future of the family member with the disability. Siblings rated each item as 0 (false) or 1 (true) with resulting scores ranging from 0 to 10 (alpha = 0.72 for DS sample and 0.69 for ASD sample).

Sibling and family background characteristics

Siblings reported on their background characteristics, including date of birth, gender, birth order (0 = older or twins, 1 = younger than brother or sister with ASD or DS), marital status (0 = not married, 1 = married), parental status (0 = does not have children, 1 = has children), level of education (from 1 'high school or less' to 5 'graduate school'), employment status (0 = not employed, 1 = employed), household income (reported in \$20 000/year increments; adjusted 3% per year for the DS group), distance to their brother or sister's residence (either driving or how they would typically get there; 0 ≤ 15 min, 1 = 15–30 min, 2 = 30–60 min, 3 ≥ 60 min), and whether or not they lived with their parent(s) at home (0 = lives in parental home, 1 = lives elsewhere).

Results

All analyses were conducted using matched-pairs procedures (Sheskin 2004). To examine group differences on background variables and dependent variables, we used matched-pairs *t*-tests for continuous data and McNemar tests (the matched-pairs equivalent of a chi-squared test) for categorical data (Sheskin 2004). For the McNemar test, either a χ^2 statistic or a McNemar test statistic (z) (when cell sizes are small) is reported. For ordinal data, findings from Wilcoxon matched-pairs signed rank tests are presented. If at least 80% of the data were available for a particular scale, missing items were replaced by the sibling's mean rating for that scale.

Group differences in sibling relationship and resources and appraisals

As shown in Table 2, siblings with a brother or sister with DS had more frequent contact with their brother or sister than those whose sibling had ASD. They saw their brother or sister in person and spoke with him or her on the phone significantly

Table 2 Group differences in instrumental involvement

	Siblings of individuals with ASD (%)	Siblings of individuals with DS (%)	Test statistic
In person contact			$z(68) = 2.23, P < 0.05$
Never	2.6	0	
Once a year	6.5	1.3	
Several times a year	33.8	27.3	
Monthly	18.2	11.7	
Several times a month	16.9	18.2	
Weekly	9.1	19.5	
Several times a week	3.9	15.6	
Daily	5.2	0	
Phone contact			$z(76) = 3.76, P < 0.001$
Never	51.9	27.3	
Once a year	5.2	2.6	
Several times a year	24.7	19.5	
Monthly	5.2	6.5	
Several times a month	5.2	22.1	
Weekly	3.9	15.6	
Several times a week	1.3	6.5	
Daily	2.6	0	
Shared activities (mean #)	2.41 (SD = 1.76)	2.58 (SD = 1.59)	$t(75) = 0.58, ns$
Out for meal	59.7	63.6	$\chi^2(1, n = 76) = 0.02, ns$
Shopping	55.8	62.3	$\chi^2(1, n = 76) = 0.24, ns$
Movies/other rec activity	46.8	49.4	$\chi^2(1, n = 76) = 0.00, ns$
Friend or relative's home	51.9	48.1	$\chi^2(1, n = 76) = 0.21, ns$
Doctor's appointment	11.7	15.6	$z(1, n = 76) = 0.00, ns$
Vacation	11.7	20.8	$z(1, n = 76) = 0.00, ns$

ASD, autism spectrum disorder; DS, Down syndrome; ns, not significant; SD, standard deviation.

more frequently than did siblings with a brother or sister with ASD. However, there were no group differences in the total number of types of shared activities or the specific activities engaged in by sibling pairs in the past year.

Siblings of individuals with DS reported significantly higher levels of positive affect in their relationship with their brother or sister than siblings of individuals with ASD (see Table 3). The two groups did not differ in the number of areas they felt their life had been impacted (see Table 3), but siblings with a brother or sister with ASD were significantly more likely to report that their relationship with their mother and father had been impacted than those with a brother or sister with DS. There were also trends for siblings with a brother or sister with DS to be more likely to report that their thoughts about having children and their plans for the future

had been affected, as compared with siblings with a brother or sister with ASD (see Table 3).

Data on the valence of effects reported by siblings of individuals with ASD indicated that the majority of siblings who felt their relationship with their mother had been affected stated that it had been affected in mainly positive (42.6%) or both positive and negative (42.6%) ways. Only 14.8% of siblings felt that the impacts had been mainly negative. Similarly, of the siblings who reported that their relationship with their father had been affected, 44.7% reported mainly positive effects, 31.9% reported both positive and negative effects, and 23.4% reported mainly negative effects. Data on the valence of effects for siblings of individuals with DS were not available.

The two groups of siblings did not differ in their use of problem-focused or emotion-focused coping

Table 3 Group differences in affective involvement, resources and appraisals

	Siblings of individuals with ASD	Siblings of individuals with DS	Test statistic
Positive affect index (mean)	42.86 (SD = 9.77)	48.53 (SD = 9.46)	$t(71) = 3.59, P < 0.001$
# life areas impacted (mean)	4.58 (SD = 2.22)	4.05 (SD = 2.26)	$t(75) = 1.54, ns$
# who reported specific areas impacted (%)			
Relationship with mother	79.2	44.2	$\chi^2(1, n = 76) = 17.33, P < 0.001$
Relationship with father	77.9	36.4	$\chi^2(1, n = 75) = 25.29, P < 0.001$
Relationship with spouse or significant others	51.9	44.2	$\chi^2(1, n = 76) = 0.92, ns$
Thoughts about having children	44.2	59.7	$\chi^2(1, n = 76) = 2.86, P = 0.09$
Feelings about self	72.7	59.7	$\chi^2(1, n = 76) = 2.56, ns$
Plans for the future	59.7	75.3	$\chi^2(1, n = 76) = 3.45, P = 0.06$
Career	29.9	40.3	$\chi^2(1, n = 76) = 0.097, ns$
Choices about where to live	35.1	48.1	$\chi^2(1, n = 76) = 1.73, ns$
Coping skills (mean)			
Problem-focused coping	30.62 (SD = 8.44)	30.05 (SD = 7.14)	$t(74) = 0.45, ns$
Emotion-focused coping	12.63 (SD = 5.69)	13.51 (SD = 5.60)	$t(74) = 1.02, ns$
Pessimism (mean)	5.49 (SD = 2.28)	4.34 (SD = 2.44)	$t(74) = 3.15, P < 0.01$

ASD, autism spectrum disorder; DS, Down syndrome; ns, not significant; SD, standard deviation.

strategies (see Table 3). However, siblings with a brother or sister with ASD were significantly more pessimistic about their brother or sister's future than siblings with a brother or sister with DS.

Gender effects

Few significant gender effects were found. One-way ANOVAs conducted revealed that the following variables did not vary by the gender composition of the sibling dyad for either group: frequency of in-person contact ($F_{3,68} = 1.26, ns$ for DS group; $F_{3,69} = 0.56, ns$ for ASD group), frequency of phone contact ($F_{3,73} = 0.14, ns$ for DS group; $F_{3,72} = 0.34, ns$ for ASD group), number of shared activities ($F_{3,73} = 1.15, ns$ for DS group; $F_{3,71} = 0.43, ns$ for ASD group), positive affect in the sibling relationship ($F_{3,71} = 0.45, ns$ for DS group; $F_{3,69} = 1.16, ns$ for ASD group) or pessimism ($F_{3,72} = 2.06, ns$ for DS group; $F_{3,71} = 1.96, ns$ for ASD group).

Gender effects were found for several other variables. For siblings of individuals with DS, the perception of the number of areas of life that were impacted varied according to their gender and whether their sibling with DS was a brother or sister ($F_{3,73} = 4.08, P < 0.01$). *Post hoc* Tukey honestly significant difference analyses indicated that sisters with a sister with DS reported a significantly

greater number of life areas impacted (Mean = 5.28, SD = 2.24) than brothers with a sister with DS (Mean = 2.29, SD = 2.13). The number of life areas impacted did not vary by the gender composition of the dyad for siblings with a brother or sister with ASD ($F_{3,71} = 0.14, ns$).

Although problem-focused coping did not vary by the gender composition of the sibling dyad for either group ($F_{3,72} = 0.24, ns$ for DS group; $F_{3,71} = 1.00, ns$ for ASD group), there was a trend for variation by gender composition of the sibling dyad for the DS group with respect to emotion-focused coping ($F_{3,72} = 2.38, P = 0.08$). Again, it was the group of sisters who had a sister with DS that stood out. Sisters with a sister with DS used more emotion-focused coping (Mean = 16.18, SD = 6.43) than brothers with a sister with DS (Mean = 10.43, SD = 4.58). Emotion-focused coping did not differ by gender composition of the sibling dyad for the ASD group ($F_{3,71} = 2.13, ns$).

Factors predicting affective and instrumental involvement

Ordinary Least Squares multiple regression analyses were conducted to identify the significant predictors of positive affect in the sibling relationship, shared

activities and sibling contact. Because of the sample size constraints, we selected a parsimonious set of predictors based on bivariate correlations. These bivariate correlations are presented in Table 4, with siblings of adults with ASD presented above the diagonal and siblings of adults with DS below.

Although the two groups differed in behaviour problems, this characteristic was not significantly associated with positive affect, shared activities or sibling contact, and therefore was not included in the subsequent regression models. Level of independence, however, was significantly associated with sibling relationship variables for siblings of individuals with ASD, but not for siblings of individuals with DS, and therefore was retained for analysis in the regression models. Two sibling resources and appraisals (problem-focused coping and appraisal of life impact) were associated with sibling relationship variables for siblings of individuals with DS, but not for siblings of adults with ASD. Pessimism was significantly associated with the sibling relationship for both groups. These three variables therefore were retained in the regression analyses. Finally, a set of control variables was selected from sibling and family background characteristics that differed by group or that were significantly associated with the sibling relationship outcome variables: sibling education (significantly associated with positive affect in the relationship for siblings of adults with ASD), distance from the brother/sister's residence (significantly associated with shared activities for siblings of adults with ASD and with contact for both groups) and parental status (significantly associated with shared activities for siblings of adults with DS). Because of theoretical interest, we initially included sibling gender in our regression analyses, but this variable was never significant in the multivariate analyses, so it was not included in our final models.

The dependent variables for the regression analyses included: (1) positive affect in the sibling relationship; (2) the number of shared activities engaged in by siblings in the past year; and (3) sibling contact (a combined variable of in-person and phone contact; for example, if the sibling had *either* in-person or phone contact on a weekly basis, he or she was coded as having contact on a weekly basis). Beta weights and significance levels are presented for the final models, with R^2 change included for each variable.

The equations for the prediction of positive affect in the relationship were significant for both groups ($F_{7,60} = 2.60$, $P < 0.05$ for siblings of adults with ASD; $F_{7,66} = 6.08$, $P < 0.001$ for siblings of adults with DS) (see Table 5). For siblings of adults with ASD, greater positive affect was predicted by lower levels of sibling education and greater use of problem-focused coping by the sibling. For siblings with a brother or sister with DS, greater positive affect in the relationship was predicted by not having children themselves, having lower levels of education (at the trend level), using more problem-focused coping, and being less pessimistic about their brother or sister's future.

In predicting shared activities, the regression equation was not significant for siblings of adults with ASD ($F_{7,62} = 1.55$, ns), but was significant for siblings of adults with DS ($F_{7,67} = 4.18$, $P < 0.001$; see Table 5). For siblings of adults with ASD, engaging in more shared activities with their brother or sister was predicted by living closer to their brother or sister's residence and by their brother or sister's level of functional independence, with more shared activities when the brother or sister had higher levels of functional independence. For siblings of adults with DS, engaging in more shared activities with their brother or sister was predicted by not having children themselves, their brother or sister's level of functional independence, and perceiving that their life had been more pervasively impacted by growing up with a brother or sister with DS. As with the ASD sample, higher levels of functional independence predicted more shared activities.

Finally, the regression equations for the prediction of frequency of sibling contact were significant for both groups ($F_{7,58} = 6.90$, $P < 0.001$ for siblings of adults with ASD; $F_{7,63} = 5.75$, $P < 0.001$ for siblings of adults with DS). For siblings of adults with ASD, more contact was predicted by living closer to their brother or sister. For siblings of adults with DS, more contact was predicted by not having children themselves, living closer to their brother or sister, and reporting that their life had been impacted to a greater extent.

Discussion

The findings in this study were largely similar to the research on young children who have a brother or

Table 4 Correlations among study variables

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Sibling age		0.17	-0.17	0.18	0.76***	0.20	0.25*	-0.29*	0.04	-0.13	-0.09	-0.17	0.01	-0.19	-0.19
2. Sibling parental status	0.41***		0.06	0.18	0.06	0.09	0.01	-0.04	0.04	0.06	-0.24*	-0.04	-0.11	-0.15	-0.22
3. Sibling education	-0.09	-0.06		0.25*	-0.10	0.17	0.00	0.22	0.31**	-0.19	0.05	0.41***	-0.25*	-0.03	-0.19
4. Distance to brother/sister's residence	-0.02	0.01	0.22		0.10	0.18	0.18	-0.14	0.25*	0.05	-0.18	0.18	-0.17	-0.24*	-0.60***
5. Age of brother/sister (b/s)	0.53***	0.34**	0.09	0.06		0.24*	0.25*	-0.36***	0.03	0.03	-0.12	-0.02	-0.05	-0.24*	-0.17
6. Residence of b/s	-0.01	0.12	-0.16*	-0.09	-0.07		0.00	0.14	0.06	-0.13	-0.08	0.07	-0.04	-0.31**	-0.43***
7. Independence of b/s	0.20	0.16	-0.02	-0.09	0.11	-0.12		-0.36**	0.22	0.01	-0.19	-0.08	0.24*	0.24*	-0.09
8. Maladaptive behaviours in b/s	-0.07	-0.02	0.04	-0.02	-0.09	0.25*	-0.43***		0.00	-0.06	0.17	0.05	-0.04	-0.11	0.04
9. Sibling problem-focused coping	0.09	0.04	0.09	-0.10	-0.06	0.09	0.19	-0.10		-0.26*	-0.07	0.11	0.16	-0.02	-0.17
10. Sibling emotion-focused coping	-0.04	-0.12	-0.05	0.11	-0.01	-0.02	0.00	-0.04	-0.07		0.09	0.08	-0.15	0.12	0.09
11. Sibling pessimism	-0.15	-0.07	-0.04	0.02	0.00	-0.03	-0.30**	0.17	-0.33**	0.21		0.31**	-0.12	0.07	0.30*
12. Sibling life impacted	-0.14	0.00	0.32**	-0.01	0.11	-0.20	-0.19	0.09	0.04	0.16	0.32**		-0.18	0.02	0.00
13. Positive affect in relationship	-0.03	-0.19	-0.10	-0.02	-0.03	0.01	0.09	-0.12	0.46***	-0.08	-0.44***	-0.08		0.28*	0.20
14. Shared activities	-0.04	-0.25*	0.20	-0.01	0.09	0.01	0.08	-0.04	0.16	-0.03	-0.11	0.26*	0.32**		0.42***
15. Sibling contact	-0.10	-0.18	0.10	-0.49***	0.08	-0.23	0.05	-0.06	0.16	0.03	-0.08	0.23*	0.36**	0.43***	

* $P < 0.05$; ** $P < 0.01$; *** $P < 0.001$.

Siblings of adults with ASD above diagonal; siblings of adults with DS below.

Table 5 Prediction of affective and instrumental involvement in the sibling relationship

	Positive affect		Shared activities		Sibling contact	
	Siblings of individuals with ASD	Siblings of individuals with DS	Siblings of individuals with ASD	Siblings of individuals with DS	Siblings of individuals with ASD	Siblings of individuals with DS
Control variables: B (R ² Δ)						
Parental status	-0.137 (0.011)	-0.251* (0.038)	-0.088 (0.022)	-0.332** (0.077)	-0.163 (0.078)	-0.224* (0.036)
Sibling education	-0.317* (0.066)	-0.188*** (0.012)	-0.038 (0.004)	0.079 (0.046)	-0.143 (0.042)	0.104 (0.007)
Distance to b/s residence	-0.187 (0.008)	0.066 (0.000)	-0.276* (0.045)	0.000 (0.004)	-0.566*** (0.285)	-0.513*** (0.285)
Stress to sibling relationship: B (R ² Δ)						
Level of independence of b/s	0.164 (0.061)	-0.003(0.024)	0.282* (0.072)	0.232* (0.038)	0.130 (0.009)	0.074 (0.002)
Resources and appraisals: B (R ² Δ)						
Problem-focused coping	0.314* (0.076)	0.373** (0.216)	0.011 (0.000)	0.030 (0.010)	0.041 (0.000)	0.009 (0.002)
Pessimism	-0.081 (0.008)	-0.366** (0.097)	0.043 (0.003)	-0.183 (0.002)	0.166 (0.033)	-0.097 (0.000)
Life effects	-0.055 (0.002)	0.071 (0.004)	0.060 (0.003)	0.408*** (0.128)	0.103 (0.008)	0.277* (0.058)
R ²	0.233*	0.392**	0.149	0.304***	0.454***	0.390***

* P < 0.05, ** P < 0.01, *** P < 0.001, **** P < 0.07.
 ASD, autism spectrum disorder; b/s, brother or sister; DS, Down syndrome.

sister with ASD or DS. Past research has shown that siblings of young children with ASD spend less time with and have a less close relationship with their brother or sister than do siblings of children with DS (Bagenholm & Gillberg 1991; Knott *et al.* 1995; Kaminsky & Dewey 2001). Our findings indicate that these differences in relationship closeness and frequency of contact are also observed during adulthood. Furthermore, despite the possibility of early onset of Alzheimer's disease in the adults with DS, these siblings were still more optimistic about their brother or sister's future than were the siblings of adults with ASD. We do not know from our research, however, the extent to which the differences in these two groups of siblings are reflective of current social and behavioural characteristics of the individual with the disability, or are the result of a lifetime of shared experiences.

Siblings of adults with ASD reported significantly less contact and less positive affect in the relationship with the brother or sister with the disability than siblings of adults with DS. These findings may reflect difficulties in the behaviour of the sibling with the diagnosis (e.g. the social and communication impairments characteristic of ASD), and also difficulties faced by the non-disabled sibling. Past research has shown that family members, including siblings, may have characteristics of the 'broader autism phenotype' (BAP; subtle characteristics associated with ASDs that are thought to be genetic in nature; Piven *et al.* 1990; Smalley *et al.* 1995). The presence of BAP characteristics in siblings may be a contributing factor to the lower levels of positive affect observed in these relationships, and may also account for the lower levels of marriage and parenthood in these siblings. Regardless of the reasons for their less positive relationship, the findings of this study suggest that siblings of adults with ASD may face difficulty when their parents no longer are able to assume primary responsibility and they have to assume more of a caregiving role, as they tend to have less emotional closeness with their brother or sister, and are more pessimistic about the future, than those whose sibling has DS.

Siblings of adults with ASD were more likely than siblings of adults with DS to report that their relationships with their parents had been impacted, and counter to expectations, they reported that the effects had been more positive than negative. It is

often assumed that parents have limited availability for their non-disabled children. Our results, however, suggest that in adulthood, most of these siblings do not feel that their relationships with their parents have suffered. In contrast, siblings of adults with DS were more likely to report that their feelings about having children had been affected, although apparently not negatively.

We found few significant gender differences, counter to our hypotheses, and those that we found were specific to sisters who had a sister with DS. These sisters reported that a greater number of their life areas had been affected (but we do not know if the effect was positive or negative) and they used more emotion-focused coping strategies (the type of coping that typically is less effective) than brothers who had a sister with DS. These findings may be reflective of the fact that sisters often grow up with the expectation that they will take on additional caregiving and household responsibilities for their sibling in the future (McHale & Gamble 1989; Wilson *et al.* 1989; Stoneman *et al.* 1991). Moreover, women in general tend to use more emotion-focused coping strategies than men (Ptacek *et al.* 1992). It is not clear, however, why the finding was particular to sisters of women with DS and not evident in sisters with a sibling with ASD. Nevertheless, the findings have implications for sisters who have a sister with DS, as their greater use of emotion-focused coping strategies may be less effective as they deal with family and caregiving transitions that will occur in the future.

We found that both overlapping and unique factors predicted the sibling relationship and sibling involvement in the two groups. For both groups, greater positive affect in the sibling relationship was found with lower educational level and greater use of problem-focused coping by the non-disabled sibling; more shared activities were reported when the brother or sister with the disability had higher levels of independence, and more sibling contact was reported when the siblings lived closer together.

The positive association between level of independence and aspects of the sibling relationship is supported by prior research on siblings of adults with ID (Wilson *et al.* 1992). Higher levels of independence in the sibling with ASD or DS and lower levels of education in the non-disabled sibling might indicate less functional divergence between the sib-

lings, which might explain the higher levels of positive affect and engagement in shared activities.

Prior research on young siblings of children with ASD has highlighted how coping skills are related to the quality of the sibling relationship (McHale *et al.* 1986), but no prior research has examined coping in adult siblings who have a brother or sister with ASD. Our findings indicate that the sibling's coping skills continue to be important in adulthood, and may be a fruitful point of intervention. Increasing siblings' use of effective coping strategies may result in more positive sibling relationships, which may become increasingly important as the parents age.

Our findings regarding the relationship between residential proximity and sibling relationship are similar to those found in prior research for sibling of adults with ID (Zetlin 1986). Greenberg *et al.* (1999) found that siblings reported both greater instrumental and affective involvement if they lived in closer proximity to their brother or sister with ID. For siblings of adults with mental illness, residential proximity was related to instrumental but not affective involvement. In the current study, residential proximity was associated with greater contact, but not with greater positive affect in the relationship, a different measure of affective involvement than was used in Greenberg *et al.*'s study.

Siblings of adults with DS (but not ASD) reported greater affective and instrumental involvement if they did not have children, if they felt less pessimistic about their brother or sister's future, and when they felt their life had been impacted to a greater extent. It is not clear why we did not observe these associations for siblings of adults with ASD. Perhaps there are other factors not measured in the present study that are important correlates of the sibling relationship and contact for those whose brother or sister has ASD. Nevertheless, the importance of the sibling's appraisals of the situation was underscored for the siblings of adults with DS. These findings have implications for service providers, as helping siblings to appraise their experiences positively may be a way to strengthen the sibling relationship in adulthood.

The Double ABCX model was useful as an organizing framework for the selection of the variables, but it proved less useful in the interpretation of our findings. Stress factors were less important in our

findings than predicted by this theoretical framework, as behaviour problems were not associated with affective or instrumental sibling involvement. Other researchers have also reported no association between behaviour problems and sibling relationships during adulthood. For example, Greenberg *et al.* (1999) found that behaviour problems were associated with emotional support for siblings of adults with ID, but not for siblings of adults with mental illness. Behaviour problems were not associated with instrumental support for either group in Greenberg *et al.*'s study.

However, we found that resources and appraisals were important factors, especially for siblings of adults with DS. Furthermore, although the Double ABCX model does not consider demographic factors, these loomed large in our findings, particularly the non-disabled sibling's level of education, parental status (in the case of DS) and residential proximity. These findings regarding demographic characteristics in part locate the sibling pair's position in the family life course and underscore the importance of a life course perspective in guiding and interpreting family research.

With respect to limitations of the current study, the cross-sectional design of our study does not allow us to make causal or directional inferences. Future longitudinal research is needed to clarify these pathways of influence. Another limitation to the current study is that data about the sibling relationship were gathered purely through the eyes of the non-disabled sibling; adding the perspective of the adult with ASD or DS would enrich our understanding of sibling relationships in these populations. Furthermore, our findings cannot be generalized to the full population of siblings of adults with ASD or DS. These findings represent the perspectives of siblings who are most involved in their brother or sister's lives (as reported by the mother), who come from families that have been willing to be part of a longitudinal research study. Our sample is largely Caucasian, although a range of income levels is represented. In addition, a larger percentage of the adults with ASD in this subsample had ID (almost 90%) than is reported in the general population of individuals with autism (75%; American Psychological Association 2002). The fact that almost all our sample members with ASD also had ID is also strength of this study, and

reduces the possibility that difference in ID status accounted for observed group differences in the sibling relationship.

Past research conducted with families of children with developmental disabilities has consistently pointed to the greater challenges parents face when raising a child with ASD compared with raising a child with another type of developmental disability (Seltzer *et al.* 2001; Abbeduto *et al.* 2004), as well as the elevated risks to sibling well-being during childhood (Bagenholm & Gillberg 1991; Gold 1993; Rodrigue *et al.* 1993; Knott *et al.* 1995; Kaminsky & Dewey 2001). The current study indicates that the stresses that affect families of children with ASD may have long-lasting, but not necessarily only negative, effects. This study represented a beginning point in attempting to describe the similarity of experiences as well as the unique challenges for siblings of individuals with ASD or DS during adulthood. Future research should investigate the complexity of these sibling relationships, including examination of ageing effects in the specific disabilities, the effects of age-related health conditions, and the presence of genetic vulnerabilities, as in the case of siblings of adults with autism.

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