

## Involvement of Adult Siblings of Persons With Developmental Disabilities in Future Planning

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### Abstract

This study examined factors influencing involvement of siblings of individuals with developmental disabilities in future planning and their expectation of future caregiving. The sample consisted of 139 adult siblings recruited from an online sibling list and a sibling conference. Results indicated that few families made plans or involved siblings in the planning. Siblings who were most involved in future planning were older, more involved in disability activities, and provided more support to their sibling with disabilities. About 38% of siblings expected to be primary caregivers and were more likely to expect this role if the sibling with a disability lived closer and was female, had more sibling contact, provided them with more support, and felt greater caregiving satisfaction. Major support needs of siblings were for support groups, workshops—training on how to assume caregiving responsibility, financial support, and printed material on making future plans.

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Planning for the future is a central task faced by families of adults with developmental disabilities. With increases in the age span of parents and their sons and daughters with disabilities, growing numbers of older parents are caring for these adults. Over 75% of adults with developmental disabilities in the United States live at home with family caregivers, and over 25% of these caregivers (711,478) are over the age of 60 years (Braddock et al., 2005; Fujiura, 1998). Hence, many of these adults with disabilities are likely to outlive their parents. Adult siblings are the most likely family members to take over care when parents can no longer provide care. Yet, many parents are reluctant to involve their children with or without disabilities in future planning (Heller & Caldwell, 2006). However, due to lifelong support needs and the changing structure of government supports, planning is particularly important for individuals with developmental disabilities and their families. In addition, to take into account the preferences and choices of the family member with a disability, planning needs to involve the person with a disability along with other family members and important people in their lives (Heller & Caldwell,

2006). Without adequate plans and supports in place, individuals with developmental disabilities have a greater chance of facing emergency placements in inappropriate settings and inadequate or inflexible financial and legal safeguards when primary caregivers can no longer provide care (Freedman, Krauss, & Seltzer, 1997; Heller & Factor, 1993). Furthermore, siblings are likely to assume future caregiving roles and may be less effective if they have not been a stakeholder in the future planning process along with their parents, sibling with disabilities, and other important people that may be involved in the planning process. This study examined the factors associated with sibling involvement in future planning and in expectations of future caregiving for a sibling with developmental disabilities. In addition, we assessed the support needs of siblings in providing care for their siblings with disabilities.

Despite the need for planning in these families, many families have not made concrete plans. Researchers have reported that between 25% and 50% of families have made plans regarding their son's or daughter's future living arrangement, and nearly half want the child to live with another

family member (Freedman, Krauss, & Seltzer, 1997; Heller & Factor, 1991). In another study, the majority of parents (78%) said that they had discussed the issue of placement with their sons or daughters without developmental disabilities; however, 64% of these children were still uncertain as to their parents' future plans for their siblings when their parents were no longer able to serve as caregivers (Griffiths & Unger, 1994). Although siblings may be likely to step in when parents can no longer provide care, they may be less likely than parents to know what those plans are or how to be involved. Siblings may not know the formal service delivery system and may be relatively unaware of the aspects of future planning that parents of people with developmental disabilities living at home have had to deal with. In addition, some siblings may want minimal or no involvement in the planning process. The extent to which siblings know about and have been involved in key aspects of future planning remains unclear. Little research has examined the factors associated with sibling involvement in future planning.

Parents most often name their other children as potential future primary caregivers (Griffiths & Unger, 1994), which may include a variety of roles, including guardian, trustee, advocate, or co-resident. Researchers examining expected future caregiving roles as reported by the siblings of adults with developmental disabilities noted that among the most involved siblings, 19% expected to co-reside with their sibling with the disability in the future (Krauss, Seltzer, Gordon, & Friedman, 1996), 44% were willing to be a future caregiver (Griffiths & Unger, 1994), and 60% expected to be a future caregiver (Greenberg, Seltzer, Orsmond, & Krauss, 1999). In a 3-year, follow-up study, 10% of siblings ended up co-residing with their sibling with a disability (Freedman et al., 1997).

Studies of factors contributing to current and future emotional and instrumental involvement of siblings have included characteristics of the person with disabilities, characteristics of the sibling without disabilities, and aspects of the current relationship (Greenberg et al., 1999; Griffiths & Unger, 1994; Krauss et al., 1996; Orsmond & Seltzer, 2000; Seltzer, Begun, Seltzer, & Krauss, 1991). Greenberg et al. (1999) described both push and pull factors that contribute to current and future involvement of siblings in each others' lives. Push factors that lead to further involvement include socialization for caregiving commonly

associated with women, reciprocity in social support, and positive caregiving appraisals. Pull factors that likely cause siblings to refrain from further involvement include severity of the disability and negative caregiving appraisal.

In general, sibling relationships are one of the longest lasting relationships that people experience, with siblings often becoming closer as other family members age and their extended family begins to shrink (Cicirelli, 1995; Goetting, 1986; White, 2001). In addition, sister and same-sex dyads tend to have stronger relationships. Geographic proximity has also been related to greater contact and involvement among siblings (White, 2001). Characteristics of the siblings with and without intellectual disabilities that have been associated with current and future involvement include gender, geographical proximity, and level of disability of the sibling with a disability (Greenberg et al., 1999; Griffiths & Unger, 1994; Krauss et al., 1996; Orsmond & Seltzer, 2000; Seltzer et al., 1991). Sisters are more likely to be the most involved siblings (Seltzer et al., 1991). However, brothers are more likely to be involved with brothers (Orsmond & Seltzer, 2000). In regard to expectations of future caregiving roles, women of both the sibling with and without disability and less severe impairment of the sibling with disabilities have been associated with greater expectation of a future primary caregiving role (Krauss et al., 1996) and greater willingness to take on the role (Griffiths & Unger, 1994). In the present study, we examined factors associated with expectations of being a primary caregiver, which may include co-residence.

The nature of the current relationship between the siblings may also impact the degree to which siblings who are not disabled are involved in future planning and the degree to which they expect to be future caregivers. Siblings are a vital part of the social network of adults with developmental disabilities. In a study of their informal support networks (Krauss, Seltzer, & Goodman, 1992), siblings constituted one quarter of the social networks of adults with developmental disabilities. The extent that these siblings have more contact and share activities has been associated with greater expectations that the siblings would co-reside in the future (Krauss et al., 1996). Other aspects of the relationship that have not been examined in relation to future issues that could facilitate involvement in future planning and caregiving

include social reciprocity among the siblings (both support provided to and support received from each other) and nondisabled-sibling involvement in disability activities (e.g., advocacy, attendance at staffings, support groups).

Furthermore, the appraisal of caregiving burden and satisfaction in relation to the sibling with a disability could affect the degree to which siblings get involved in future planning and in their expectations of future caregiving responsibilities. Griffiths and Unger (1994) reported that siblings' negative appraisals of the impact of caring for a family member with special needs (family problems and pessimism) were related to less interest in assuming future caregiving responsibilities. Little research has examined the influence of positive caregiving appraisals in future planning and expectations.

In summary, although the current literature has shown that parents often do not involve siblings in future planning, despite the fact that siblings are the persons most likely to take over caregiving in the future, the current research has not looked at the factors related to sibling involvement in future planning. Furthermore, the studies that have examined factors contributing to expectations of future caregiving among siblings have focused on the demographic characteristics of the disabled and nondisabled siblings and, to some extent, on their relationships but not on the degree to which nondisabled siblings feel satisfaction in providing care to their sibling with a disability.

In the present study, we tried to answer the following questions: (a) What factors contribute to sibling involvement in future planning and (b) what factors contribute to sibling expectations of being a primary caregiver? The factors examined include demographic characteristics of the siblings with and without disabilities, nature of sibling involvement, and caregiving appraisal. We hypothesized that pull characteristics toward future planning and caregiving would include nondisabled siblings' older age, closer geographical proximity of the siblings, greater current involvement of siblings (contact, involvement in disability activities, support to and from each other), and greater satisfaction in caregiving for the sibling with a disability. The push factors that we hypothesized would be associated with less involvement in future planning and caregiving were more severe level of disability of the sibling with a disability and greater perceived burden in providing care to the sibling with a disability.

In addition, in the present study, we sought to provide descriptive information on the extent to which siblings are involved in various aspects of future planning. Last, we assessed the support needs of siblings that could facilitate their involvement with their sibling with a disability.

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## Method

### Sample

The study sample included 139 adult siblings who identified as siblings of at least one sibling with developmental disabilities. Families were recruited from an online support list that is maintained by a sibling support project and a statewide sibling conference directed to siblings of adults with developmental disabilities. First, a notice was sent out to these siblings via a listserv. Second, a verbal notice was given in person for siblings at a sibling conference. Siblings were asked if they would like to participate in a 30–40 min survey. Originally, 485 siblings were surveyed via the listserv with separate e-mail addresses, of which 116 responded. Of those, 426 were valid e-mail addresses, making for a corrected response rate of 116 out of 426 (27%). Of those 116, 8 respondents were below the age of consent and were, thus, excluded from this analysis, reducing the sample to 108. In addition, 57 siblings were approached at a sibling conference of which 31 siblings responded for a response rate of 54%. The overall corrected sample of 483 siblings consisted of 139 siblings who completed the survey, for a response rate of 31%.

As seen in Table 1, overall, the average age for the entire sample ( $N = 139$ ) of sibling respondents was 37 years of age, with ages ranging from 18 to 62 years ( $M = 37.16$ ). The majority of the sibling respondents (92%) were sisters and half of the siblings were married. Seventy-eight percent of the siblings had graduated college. Sixty-nine percent of the siblings had family incomes over \$40,000. The sample was 87% White.

The average age of individuals with developmental disabilities was 34 years of age, with ages ranging from 10 to 72 years. Sixty percent of the siblings were brothers. About 75% of the siblings had intellectual disabilities and the remainder had other developmental disabilities. In addition, 41% of the siblings lived at home, 24% lived in a residential placement, 8% lived with the sibling respondent, 7% lived with another family member,

and the rest (11%) lived with a spouse or independently.

### Measures

The survey included questions regarding future planning activities and plans. In addition, it included demographics, measures of the current sibling relationship, and caregiving appraisal.

*Future planning activities and plans.* Siblings were asked to indicate whether their family had conducted the following 11 types of planning tasks for their sibling with developmental disabilities: created a letter of intent, located an attorney, made residential plans, established legal guardianship, established powers of attorney, applied for and are receiving appropriate government benefits, willed money or property directly to the person with a disability, established a special needs trust, identified caregiver to follow current caregiver, discussed plans with your sibling with a disability, and discussed plans with your relatives. These items were adapted from Heller and Caldwell (2006).

Future planning involvement consisted of the extent to which siblings were involved in each of the above 11 future planning activities. The scale consisted of the average of the degree of involvement across all items, which were each scored from 1 (*no involvement*) to 4 (*very involved*). The mean score for future planning involvement was 1.84, with a range from 1.00 to 3.91. Expectations of future caregiving consisted of one question asking siblings if they expected to be a future primary caregiver when parents could no longer provide care. It was coded as 0 (*no*) or 1 (*yes*).

*Demographics.* Level of education ranged from 1 (*some high school*) to 7 (*graduate degree*). Minority status was measured as anyone who indicated that they were from a minority background. The severity of disability was measured by level of adaptive functioning of the adult with developmental disabilities, which was assessed with scores on seven activities of daily living (ADLs) and eight instrumental activities of daily living (IADLs; Lawton, Moss, Fulcomer, & Kleban, 1982). Each activity was rated on needs for assistance: 1 = *total assistance*, 2 = *some assistance*, and 3 = *no assistance*. Therefore, lower scores indicate a lower level of functioning. The score was calculated by taking the average for each case across all items. The average score on the ADLs was 2.06, with a standard deviation of 0.52 (range = 1.00–2.93) and an alpha

**Table 1** Demographics

Variable	<i>n</i>	%
Sibling respondent <sup>a</sup>		
Gender		
Male	10	8
Female	120	92
Ethnic minority status		
No	128	87
Yes	19	13
Educational level		
High school or GED	8	6
Trade/vocational school	1	1
Some college	20	15
College	43	33
Some graduate school	14	11
Graduate school	45	34
Marital status		
Married	70	53
Not married	62	47
Income		
<\$20,000	15	12
\$20,001–40,000	24	19
\$40,001–60,000	31	24
\$60,001–80,000	25	20
\$80,001–100,000	12	9
>\$100,000	21	16
Sibling with disability <sup>b</sup>		
Gender		
Male	80	60
Female	54	40
Residential status		
Home with parents	55	41
In your home	11	8
Residential placement	32	24
Other family members	9	7
Living with spouse	2	2
Independently	12	9
Other	12	9

<sup>a</sup>Age:  $M = 37.16$ ,  $SD = 11.80$ . <sup>b</sup>Age:  $M = 33.9$ ,  $SD = 13.7$ .

reliability of .94. Gender of the siblings was coded 0 (*male*) and 1 (*female*). Distance from each other was coded as 0 (*live together*) to 5 (*more than a half day drive*).

*Sibling relationship.* Sibling contact consisted of three items about contact that began with the phrase, “In the past year, how often did you \_\_\_\_\_?” Siblings were then asked to rate on a scale of 1 (*none at all*) to 8 (*daily*) each of the following items: How often did you see your brother or sister, how often did you speak on the phone with your brother or sister, and how often did your brother or sister visit you at home. This scale had an alpha reliability of .68. Scores ranged from 1 to 31 ( $M = 14.67$ ,  $SD = 6.17$ ). Involvement in disability activities measured the extent to which siblings were involved in 10 self-help, advocacy activities and activities related to their brother or sister’s service agency. The items included were participation in parent–sibling training sessions–workshops, group counseling led by a professional, a parent–sibling support group (Internet groups or traditional) led by parents or siblings, a governing or advisory board of a service-provider agency, and a political advocacy group. Other items included volunteering for in-house activities (e.g., office work, classroom maintenance, working on a newsletter), visiting disability-related programs other than the ones in which my brother or sister has already participated, attending staffing meeting pertaining my brother or sister, reading materials that would help me develop more skills in working with my brother or sister, and working for pay for a program serving people with disabilities. Items were scored as 1 (*no*) or 2 (*yes*). Sums ranged from 10 to 20, with a mean of 13.41 ( $SD = 2.26$ ). Social support by nondisabled sibling consisted of items asking siblings whether they provided 8 types of support functions to the sibling with a disability

(Heller, Hsieh, & Rowitz, 1997). Support functions included gave advice, confided, took care, did household tasks, found services, gave financial aid, encouraged, and had fun and relaxed with. The items were rated 1 (*yes*) or 0 (*no*) and were averaged across the 8 items. The scores ranged from 0 to 1 ( $M = .53$ ,  $SD = .31$ ). Support by sibling with a disability was measured by asking siblings whether their siblings with a disability provided them with support for each of the above 8 support functions. The items were rated 1 (*yes*) or 0 (*no*) and were averaged across the items. The scores ranged from 0 to .75 ( $M = .14$ ,  $SD = .17$ ). Table 2 provides the number of endorsements for each of the variables listed under support for the sibling with a disability and support by the sibling with a disability.

*Caregiving appraisal.* Caregiving burden consisted of nine statements about the effects of caring for a relative with a developmental disability on job opportunities, finances, future concern, personal time, social opportunities for leisure, and caregiver’s marriage (Heller, Markwardt, Rowitz, & Farber, 1994). Each statement was rated from 1 (*strongly disagree*) to 5 (*strongly agree*). Scores were the average score of the nine items, with a range of 1.11 to 4.44 ( $SD = 0.78$ ). Alpha reliability of the scale was .86. Caregiving satisfaction consisted of five statements about satisfaction in the role of caregiver (Lawton et al., 1982). Examples of statements include, “My relative shows real appreciation for what I do for him/her” and “My relative’s pleasure over some little thing gives me pleasure.” Each statement was rated from 1 (*strongly disagree*) to 4 (*strongly agree*). Scores ranged from

**Table 2** Sibling Reciprocal Support ( $N = 139$ )

Variable	Support provided by person with disability		Support provided to person with disability by sibling	
	<i>n</i>	%	<i>n</i>	%
Fun/relaxation	70	50	103	74
Provided encouragement	29	21	95	68
Advice	16	12	70	50
Confidante	14	10	56	40
Household tasks	10	7	73	53
Provided care <sup>a</sup>	6	4	91	66
Financial aid	3	2	42	30
Found services	1	1	47	34

<sup>a</sup>Sibling with disability provided care to “me or my child” for respondent.

2.00 to 5.00 ( $M = 3.90$ ,  $SD = 0.73$ ). Alpha reliability of the scale was 0.78.

*Supports Facilitating Future Caregiving Involvement.* Supports facilitating future caregiving involvement consisted of five items starting with the question, “To what extent would the following programs and services make it easier for you to be involved with your brother/sister’s care in the future?” Each statement was rated from 1 (*not at all*) to 4 (*a great deal*). The items were as follows: printed materials for siblings on disabilities and ways to cope, support groups for siblings, workshops—training for siblings on how to assume caregiving responsibility, workshops—training for parents to make future plans, and financial support for caregivers of persons with disabilities. For the purposes of this study, we considered responses important if siblings expressed either (a) not easier at all (Option 1) or (b) at least a little easier (Options 2–4).

### Design

In this study, we used a cross-sectional design. Siblings were surveyed at one particular point in time between October and November of 2004. Hierarchical multiple and logistic regressions were used to control for variance and to test the significance of the variables. For these analyses, the variables were entered into three blocks. The first block included demographic variables, so that they could serve as controls. The second block consisted of the sibling relationship that likely influenced caregiving appraisal, which was entered as the third block. The outcome variables were sibling involvement in future planning and in expectations of future caregiving.

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## Results

### Analyses

The present study used a multiple hierarchical regression to investigate future sibling involvement and a multiple hierarchical logistic regression to investigate expectations of becoming a future primary caregiver. In the two regression models, independent variables were entered into the regression model in three blocks to control for descriptive characteristics of the sibling respondent and the sibling with a disability. The first block in both regression models consisted of four demographic variables: distance between sibling respon-

dent and sibling with a disability; ADL for the sibling with a disability; and age of sibling respondent. The second block consisted of the following sibling relationship variables: sibling involvement in disability activities, support provided by sibling respondent to sibling with a disability, support provided by sibling with a disability to respondent, and sibling contact. Last, the third block of these regression analyses consisted of the caregiving appraisal variables of satisfaction and burden.

Zero-order correlations of variables used in these analyses are summarized in Table 3.

The assumptions for both linear and logistic regressions were met. For the regressions used in this study, tolerance and variance inflation factor values suggested that multicollinearity problems were not apparent. Scale-level and dichotomous dependent variables were used for the hierarchical linear and logistic regressions respectively. Missing data on scale-level variables were deleted listwise when imputation would not be justifiable. For example, 5 participants were dropped who did not fill in the gender of the sibling with a disability. Last, missing data for the variables were analyzed to assess whether the data were missing completely at random or on the basis of minority groups, test type (written or Internet), and gender. No variables were missing in a systematic way, so imputation was justifiable.

### *Involvement in Future Planning and Expectations of Future Caregiver*

The results of the regression for predicting level of involvement in future planning are summarized in Table 4. The overall model for predicting level of involvement predicted about 36% of the variance ( $r^2 = .36$ ). In regards to level of involvement in planning for the future, only age of sibling respondent was significantly related to level of involvement in future planning in the first block ( $p < .001$ ). In block two, involvement in disability-related activities ( $p < .001$ ) and current support provided by sibling respondent ( $p < .01$ ) were significantly related to level of involvement in future planning. In the final block, neither caregiving appraisal variable (burden and satisfaction) was significantly related to level of involvement in future planning.

As shown in Table 5, in predicting expectations of the sibling as the future primary caregiver, shorter distance between siblings ( $p < .01$ ) and

**Table 3** Correlations of Variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Distance	—	-.06	-.03	-.02	.02	-.21*	.06	-.59**	-.13	-.04	.01	-.19*
2. ADL		—	.15	.05	-.02	.26**	.26**	.22*	-.11	-.08	-.04	.06
3. Age (nondisabled)			—	.00	.14	.23**	.08	.90	-.25**	.03	.37**	-.11
4. Gender of sib. with developmental disability				—	.19*	.19*	.13	.16	.07	.11	.02	.28**
5. Disability activities					—	.26**	.22*	.12	-.08	.35**	.42**	-.04
6. Support to sib. with developmental disability						—	.48**	.55**	.06	.37**	.47**	.39**
7. Support from sib. with developmental disability							—	.18*	.20*	.31**	.33**	.08
8. Sibling contact								—	.12	.25**	.19*	.45**
9. Burden									—	-.31	-.18	.15
10. Satisfaction										—	.30**	.22*
11. Involvement in future planning											—	-.03
12. Expected primary caregiver												—

Note. Sib. = sibling.

\* $p < .05$ . \*\* $p < .01$ .

female gender of the sibling with a disability ( $p < .001$ ) increased the likelihood that the sibling respondent anticipated being a primary future caregiver in Block 1. In Block 2, after controlling for the demographic variables, support provided by the sibling respondent to the sibling with a disability ( $p < .05$ ) and more contact between siblings ( $p < .01$ ) increased the likelihood that siblings expected to become primary caregivers. Last, in the final block, greater caregiving satisfaction was associated with expectations of the sibling becoming a primary caregiver ( $p < .05$ ).

Descriptive data assessed different aspects of current family future-planning task completion and sibling involvement. Table 6 summarizes the extent to which families had engaged in future-planning-related tasks according to the sibling respondents. Few families in this study made residential (32%), guardianship (39%), or special needs trust (44%) decisions or created a letter of intent, a non-legally binding planning document (44%). Only 32% of families had identified a future caregiver. In terms of involvement, siblings were most likely to be involved in making residential plans, discussing plans with other relatives, and identifying a future caregiver. Siblings were less likely to be involved in formal tasks (i.e.,

establishing a special needs trust or wills, creating a letter of intent, and establishing powers of attorney for their siblings with disabilities).

Table 7 indicates that over 70% of the siblings reported that support groups for siblings would help them care “somewhat” to “a great deal” for their sibling with a disability in the future. About 65% of the siblings felt that workshops—training for siblings on how to assume caregiving responsibility and financial support for caregivers of persons with a disability would also be helpful. Nearly 60% reported that printed material and workshops—trainings for parents on making future plans would be helpful.

## Discussion

The present study sheds light on our understanding of factors contributing to the involvement of siblings in planning for the future of their siblings with developmental disabilities and expectations of being a future caregiver. Certain demographic characteristics of the siblings and aspects of their current involvement predicted both of these aspects related to future plans. The domain of caregiving appraisal only related significantly to expectations of future caregiving. None of the push factors hypothesized (more severe level of disability, more

**Table 4** Hierarchical Regression Analysis on Involvement in Future Planning

Variable	Future planning								
	B	SE B	$\beta$	B	SE B	$\beta$	B	SE B	$\beta$
<b>Step 1:</b>									
Distance	-.03	.34	-.07	.02	.04	.03	-.01	.04	.04
ADL	-1.48	.12	-.10	-.27	.11	-.18*	-.27	.11	-.18*
Age (nondisabled)	.25	.01	.38***	.02	.01	.28***	.02	.01	.27***
Gender of Sib-DD	.03	.13	.02	-.17	.11	-.11	-.16	.11	-.10
<b>Step 2: Relationship</b>									
Disability activities				.10	.03	.29***	.10	.03	.29***
Support to Sib-DD				.75	.26	.29**	.73	.27	.28***
Support from Sib-DD				.67	.37	.15	.61	.38	.14
Sibling Contact				.00	.01	.02	.00	.01	.03
<b>Step 3: Caregiving appraisal</b>									
Burden							-.05	.08	-.05
Satisfaction							.03	.09	.03
$R^2$ Change		.15				.25			-.01
Adjusted $R^2$		.12***				.37***			.36***

Note. Sib-DD = sibling with a developmental disability.

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

caregiving burden) were significantly associated with making future plans.

Similar to findings of other studies, the majority of families in the present study had made few plans and had low involvement of the nondisabled siblings in developing the plans (Freedman et al., 1997; Griffiths & Unger, 1994; Heller & Caldwell, 2006). The only demographic predictor of involvement in future planning was older age of the sibling with a disability. It is understandable that as the adult with disabilities ages, families have a greater need to start the planning process and involve the other members of the family. In the literature on factors leading to planning, older maternal age has been associated with more planning (Heller & Factor, 1991).

Several aspects of the current sibling relationship related to more involvement in planning, including support the disabled and nondisabled siblings provide to each other and the amount of disability-related activities that the nondisabled sibling participates in. The informal support provided by the nondisabled sibling to the sibling with a disability was a significant predictor; whereas the support provided by the sibling with a disability to the nondisabled sibling approached significance

( $p = .07$ ). In a study of siblings of adults with mental illness, the degree of support reciprocity among the siblings was related to predictors of future instrumental and emotional support (Smith, Greenberg, & Seltzer, 2007). The association of sibling involvement in future planning with current involvement in disability-related activities could have been due to the information, training, and support resources provided to the nondisabled siblings who participated in such activities. Nearly 38% of the siblings in the present study expected to be primary caregivers. This figure is lower than the 60% figure reported by Greenberg et al. (1999) regarding expectations of future caregiving and similar to the 44% figure reported by Griffiths and Unger (1994) pertaining to willingness to become a primary caregiver. As predicted, key demographic characteristics related to expectations of caregiving in the present study included having a sister with a disability and closer geographical proximity. Because most of the respondents were sisters, this supports the notion that same-sex dyads tend to have stronger relationships. Unlike hypothesized, the level of disability as measured by adaptive behaviors did not have a significant impact on expectations of future caregiving. It might be a

**Table 5** Summary of Logistic Regression Analysis on Expected Primary Caregiver

Variable	Expected primary caregiver					
	OR	95% CI	OR	95% CI	OR	95% CI
<b>Step 1</b>						
Distance	0.70	(0.55–0.88)**	1.17	(0.83–1.65)	1.13	(0.79–1.62)
ADL	1.31	(0.62–2.79)	0.76	(0.31–1.87)	1.05	(0.40–2.76)
Age (Nondisabled)	0.97	(0.94–1.01)	0.95	(0.91–0.99)*	0.96	(0.92–1.00)
Gender of sib. with developmental disability	3.56	(1.64–7.74)**	3.49	(1.40–8.66)**	3.62	(1.41–9.32)**
<b>Step 2: Relationship</b>						
Disability activities			1.25	(1.004–1.56)*	1.34	(1.06–1.70)*
Support to sib. with developmental disability			18.45	(1.72–198.42)*	11.71	(1.05–130.49)*
Support from sib. with developmental disability			0.18	(0.01–3.83)	0.14	(0.006–3.19)
Sibling Contact			1.20	(1.07–1.34)**	1.18	(1.05–1.32)**
<b>Step 3: Caregiving appraisal</b>						
Burden					1.62	(0.79–3.31)
Satisfaction					2.67	(1.09–6.52)*
$R^2$ Change		.22			.03	
Nagelkerke's $R^2$	.21***		.43***		.46	

Note. OR = ordinal regression; CI = confidence interval; Sib. = sibling.

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

stronger predictor if we had asked the siblings about their expectations for co-residing with their siblings, as was asked in Krauss et al.'s (1996) study, rather than the more general expectations of future primary caregiving role. Co-residing would likely require a higher level of future demands.

As hypothesized, the current sibling relationship influenced future caregiving expectations, as siblings were more likely to expect the future role if they had more contact with their sibling with a disability and provided the sibling with more support. Greater contact with the siblings may result in more

**Table 6** Future Planning Tasks and Sibling Involvement

Families planning accomplishments	<i>n</i>	%	Siblings involved	
			Siblings involved ( <i>n</i> )	Siblings involved (%)
Willed property to person with a disability	78	56	29	21
Discussed with brother/sister with a disability	67	48	53	38
Established powers of attorney	62	45	38	27
Established special needs trust	61	44	36	26
Created a letter of intent	61	44	29	21
Established legal guardianship	54	39	53	38
Made residential plans	45	32	75	54
Identified caregiver to follow current caregiver	45	32	64	46
Located attorney	37	27	56	40
Discussed with other relatives	37	27	69	50
Applied for and receiving government benefits	16	12	57	41

**Table 7** Supports Facilitating Future Caregiving Involvement ( $N = 139$ )<sup>a</sup>

Supports	<i>n</i>	%
Support groups for siblings	85	61
Workshops/training for siblings on how to assume caregiving responsibility	84	61
Financial support for caregivers of persons with disabilities	79	57
Workshops/training for parents to make future plans	72	52
Printed materials for siblings on disabilities and ways to cope	66	48

<sup>a</sup>Participants who reported either 3 (*somewhat*) or 4 (*great deal*).

familiarity and knowledge about the needs of siblings with developmental disabilities and, hence, result in greater willingness and expectations of serving as their future primary caregiver.

In addition, the cognitive appraisal of the impact of the sibling with a disability on the life of the nondisabled sibling was an important factor associated with future caregiving expectations. Specifically, the push factor of caregiving satisfaction related to greater expectations of future caregiving, whereas the pull factor of caregiving burden was not significantly associated with lowered expectations of future caregiving. Hence, having a more positive view of the rewards of caregiving is likely to lead to greater willingness and acceptance of a primary caregiving role in regard to the sibling with a disability. This finding highlights the importance of examining not only the negative impact of siblings with a disability on their nondisabled siblings' lives but also on the positive aspect of the sibling relationship.

### Limitations

A major limitation of the present study is its reliance on a convenience sample of siblings who were either involved in an online sibling network or who attended sibling conferences and training. Hence, these findings may not generalize to less involved siblings and to siblings who have less access to computers and sibling training events. Furthermore this sample tended to be well educated and predominately female. Additional studies are needed with a wider population.

Second, the present study was limited by its use of cross-sectional data. Hence, it is not possible to assume causation. For example, greater involvement in planning could be either a result of or a cause of the nondisabled sibling's greater involvement in disability-related activities. Long-term longitudinal data can provide more information

on the influence of these factors over the life course. Intervention studies could look at the influence of different practices and policies on families' future plans. Third, expectations of future plans may be different than actual behaviors in the future. The factors leading to siblings actually taking over the responsibility from parents needs to be examined in future research.

Last, the present study is limited by its reliance on the perspectives of the nondisabled sibling. Without the view of the sibling with a disability, we do not know the extent that they want involvement with their brothers or sisters. They may want more independence from their siblings, who often have more hierarchical relations with them (Zeitlin, 1986). In addition, the siblings with a disability may have a different view than their siblings regarding the nature of their relationships. Future researchers need to also examine the views of the siblings with developmental disabilities regarding current and future relations with their siblings.

### Implications for Policy and Research

Despite the fact that the sample in this study included people who were already more involved in disability-related activities than most siblings of people with disabilities, even in these families, the majority had not made plans for the future of the sibling with a disability, as reported in other studies (e.g., Freedman et al., 1997; Heller & Factor, 1993). Only about one third of the families had made a residential plan or had identified a future caregiver. Between 40% and 46% of the families made guardianship or financial plans or developed a letter of intent (a nonlegally binding planning document). In addition, families often did not involve the siblings in developing plans. Siblings were most likely to be involved in identifying a future caregiver and in making residential plans.

They were less likely to be involved in formal tasks, such as establishing a special needs trust, creating a letter of intent, and establishing power of attorney for their siblings with a disability. Siblings can play a role in helping to encourage future planning in families. Furthermore, they need to be part of the discussions, given that they are likely to be the successors to their parents when they can no longer provide care to the family member with a disability. Even if the siblings do not plan on being primary caregivers, they may still want and need to be involved with their siblings' lives in the future. Parents may be reluctant to involve their other children out of guilt that they do not want to "burden" their other children with the additional responsibilities. Conversely, when a parent's views are more favorable to sibling involvement, the sibling tends to be more willing to take on future caregiving responsibilities (Griffiths & Unger, 1994).

With the aging of parent caregivers, professionals will be increasingly working with siblings, a constituency that to date has received less support. The present study revealed that many siblings yearn for greater involvement in the lives of their siblings with disabilities but need more information, networking opportunities, and supports. They want to be included in programs designed to help families of people with disabilities. They want more psychoeducational groups, greater use of Internet support groups for long-distance siblings, and more information on future planning to effectively transition financial, residential, and leisure responsibilities from parents to sibling caregivers.

One example of training that holds promise for promoting family future planning is the "Future Is Now" training described by Heller and Caldwell (2006). Using peer trainers (parents and people with developmental disabilities), it used a person-centered goal-planning model to facilitate discussions among family members and development of future plans. In a 1-year follow-up comparison with a control group, the families who participated in the training were more likely to develop plans, parents reported less caregiving burden, and the persons with disabilities were more likely to have more choice in their daily lives. However, very few siblings participated. Hence, training activities regarding future planning need to specifically target siblings in addition to parents and the family member with a disability.

In conclusion, the present study highlights the importance of the current relationship of siblings with and without a disability on the nondisabled siblings' involvement in future planning and on their expectations of future caregiving. Involvement in disability-related activities plays a role in providing information and support to the nondisabled sibling to better enable involvement in current and future plans. The challenge for service providers is to help families through the planning process and ensure that there are sufficient supports and options for both families and the person with a disability, whether siblings want to co-reside with their siblings in the future or opt for placements out of the home.

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