

Adults with autism living at home or in non-family settings: positive and negative aspects of residential status

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Abstract

Background Very little is known about the context of caregiving by parents of adults with autism or about the perceived impacts of continued patterns of co-residence vs. out-of-family living. In the present study, maternal assessments of residential status, involvement with adult children living in a non-family setting, and the impacts on mothers of their residential arrangements were examined.

Methods Mothers from 133 families of adults (aged 22 years and older) with autism spectrum disorder (ASD) completed questionnaires as part of a longitudinal study on family caregiving. Mothers completed open-ended questions regarding the positive and negative aspects of their child's residential arrangement. Mothers also completed scaled questions regarding their satisfaction with their child's residential arrangement, the different ways in which people's lives change after a relative moves from the home, and the frequency of contact with their son or daughter.

Results Mothers found co-residing with their adult child to be of greatest positive benefit to the family while those living apart found this residential

arrangement of greatest benefit to the son or daughter with ASD. The greatest negative consequences for co-residing mothers were understood to fall on families, while mothers felt the majority of negative consequences for those that lived apart. There was a high level of contact and maternal involvement between the mother and adult child with ASD even after out-of-home placement.

Conclusions Residential status, as appraised by mothers, has varying impacts on the individual with ASD, on the family, and on mothers as individuals and caregivers. The present analysis suggests the multifaceted and highly contingent maternal experience associated with where her child with ASD lives. Among families whose children live elsewhere, there is an impressive amount of continued contact between these families and their son/daughter.

Keywords autism, caregiving, residential status

Introduction

In this paper, we compare the assessments of mothers of adults with autism or a related autism spectrum disorder (ASD) regarding the positive and negative aspects of having their son or daughter either live at home with the parent(s) or in a non-family setting. We also examine, among those whose son or daughter

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lives elsewhere, the degree of maternal involvement with their adult child and the impacts on mothers of this residential arrangement. Very little is known about the context of caregiving by parents of adults with autism or about the perceived impacts of continued patterns of co-residence vs. out-of-family living. These residential decisions are consequential for all members of the family – including the son or daughter with autism, his or her siblings, the parents individually, and the family system as a whole (Seltzer *et al.* 2000a). Obtaining parental perspectives regarding the challenges and consequences of having their adult son or daughter with autism live at home, or elsewhere, begins to address important gaps in our knowledge about the quality of life of adults with autism and their families.

According to family life cycle theory (Carter & McGoldrick 1980; Aldous 1996), there are general and predictable stages in the life cycle of the family, one of which is the 'launching stage.' This stage typically begins at the end of high school when children move out of the parental home to attend college or enter the workforce. Studies have found, however, that for parents of children with intellectual disabilities (IDs), the launching stage is often 'postponed' either because of family preferences or in recognition of the dearth of appropriate alternatives (Seltzer & Krauss 1994). Indeed, it is estimated that 60% of adults with IDs in the USA continue to live with their families (Fujiura 1998). This alteration in the 'typical' family life course has been the subject of a considerable amount of research over the last decade to understand the consequences for families and their adult children with IDs of continued co-residence with parents, although this research has not focused on distinct diagnostic groups within the population with IDs (Seltzer & Krauss 1989; Greenberg *et al.* 1993; Heller & Factor 1994). There have been no reports, however, about how families of adults with ASD in particular proceed through the launching stage. Specifically, no research has examined how such families are affected by either continued co-residence or 'launching' to a non-family setting, the degree of involvement of parents with their adult child with ASD who lives in a non-family setting, or the changes experienced by parents in their family situation and/or relationship with their adult child following relocation to a non-family setting. We examine these core issues using data from one of the

largest ongoing studies of families of adults with ASD.

Decision-making about where a child with an ID, such as autism, will live as an adult is perhaps one of the most difficult issues families confront. Thorin *et al.* (1996) note that the period of transition from USA-mandated school services (ending at age 22) under the Individuals with Disabilities Education Act (IDEA) to the adult services world is experienced as a particularly risky period for families, insofar as there is no entitlement for services for adults with IDs. They note that, in contrast to families of typically developing children who expect less involvement with their children as they are launched into the adult world, parents of children with IDs anticipate an increased level of involvement as they must work to secure needed (but not mandated) services and to confront profound decisions about where their son or daughter should (or can) live. Field & Hoffman (1999) emphasize the importance of parental involvement in developing and supporting the options available to individuals with autism as they enter adulthood, underscoring the ongoing central role of the family in helping shape the life opportunities for adults with autism. Baine *et al.* (1993) studied the areas in which parents of young adults with severe IDs report stress during the launching period and found that greatest stress was reported regarding the child's ongoing dependency, the lack of autonomy, and individual vulnerability. Fong *et al.* (1993) articulated six major parental concerns associated with the transition to adulthood among parents of children with ASD: behavioural concerns (obsessions, aggression, tantrums), social and communicative concerns (inappropriate or inadequate social skills), family related concerns (restriction in family life, need for constant supervision), education and related services (choosing integrated vs. specialized programmes, accessing behaviour management services), relationships with professionals (ineffective communication, blaming messages from professionals), and independence and future concerns (vocational, leisure, and residential services). Clearly, parental concerns about the personal welfare of their children with IDs, worries about the capacity of the adult service system to meet their children's needs, and the realization that parenting responsibilities extend beyond the time anticipated among families of typically developing children constitute a formidable burden for parents of young

adults with IDs. These issues also affect families of adults with autism but there is little in the empirical literature that addresses these basic questions.

From the broader literature on caregiving among families of adults with various IDs, three major findings can be gleaned regarding how families experience the transition of their child with an ID into the adult service system. First, parents play a major role in orchestrating this transition. Studies have consistently noted that parents of individuals with IDs are, indeed, extremely involved. Kraemer & Blacher (2001) studied parents of children with severe ID whose children were leaving the public school system and found that families occupy a central role in transition planning with school administrators and adult service providers. Second, parents stay involved with their children with ID who live in out-of-home settings. Seltzer *et al.* (2001) found that, for the 117 families in their longitudinal study of families of adults with IDs whose adult children moved from the parental to a non-family home, the mothers occupied instrumental roles in the selection of residential programmes and maintained weekly contact on average for a period of 3 years after the transition occurred. Third, there are both positive and negative evaluations of the impacts on families of the residential relocation of their son or daughter. Baker & Blacher (2002) studied the post-placement adaptation of 106 families in California and found that virtually all families (97%) reported advantages related to the services received by their child. They noted, too, both advantages and disadvantages to the family. Among the advantages to the family were increased peace of mind and/or reduced negative feelings of guilt or burden. Among the disadvantages were unease about not being able to fulfil the role of a parent as a provider of care and guidance. These studies suggest that the launching period for families of adult children with IDs is characterized by high levels of family involvement and by complex consequences that present a mixture of pluses and minuses to families and to the adult child with IDs.

How common is continued family co-residence among adults with autism? How common is relocation to a non-family setting? The extant literature sheds some light on the prominence of family co-residence over the life course for adults with autism. The generalizability of most of these studies is limited, however, by their small samples. For example,

Rumsey *et al.* (1985) followed up 14 men (average age was 28 years) and found that nine continued to live with their parents, one lived independently, and four lived in supervised residential settings. Similarly, Venter *et al.* (1992) found that 16 of the 18 high-functioning adolescents and adults they followed up lived with their parents, and the other two lived independently. Seltzer *et al.* (2000a) reported the living arrangements of adolescents and adults with autism based on data obtained from the state mental retardation/developmental disabilities (MR/DD) agencies in New York ($n = 7941$) and Massachusetts ($n = 1198$). These data suggest that most adolescents still live with their families, but the percentage drops precipitously in adulthood. They concluded that only about one-quarter to one-third of adults with autism in their 30s continue to live with their parents, a rate substantially below that of adults with other IDs, for whom it is estimated that about 60% continue to live with their parents in adulthood (Fujiura 1998). There are no US national data available on the prevalence of family-based vs. out-of-family living (either independent living, supervised community living, or other residential arrangements) of adults with autism.

The present study provides an opportunity to explore the experiences of families who vary with respect to the residential status of their adult child with autism, either co-resident or away from the family home. Specifically, we address the following questions. First, how do mothers describe the positive and negative aspects of their son or daughter's current residential setting? Second, how much contact do mothers of adults with autism living in an out-of-home setting have with their son or daughter? And third, what changes for their own lives do mothers attribute to this residential arrangement?

Method

Participants

Participants included a subsample of the families of 405 adolescents and adults with an ASD who are participating in an ongoing (four-wave) longitudinal study. Data for this analysis are from the first wave of data collection (1998–99). The 405 individuals with ASD reside in two states (201 live in Wisconsin and 204 live in Massachusetts). Families participating in the ongoing study were recruited via agencies,

schools, diagnostic clinics, and the media. Informational packets were distributed to families who were invited to participate in the research. Identical recruitment procedures were used in the two states.

The families in the larger study met three initial criteria: (1) the son or daughter was age 10 or older; (2) he or she had received a diagnosis on the autism spectrum from a medical, psychological, or educational professional, as reported by their parents; and (3) administration of the Autism Diagnostic Interview – Revised (ADI-R) (Lord *et al.* 1994) confirmed the parental report of an ASD. Of the 405 individuals in the sample, 391 (96.5%) met the full criteria for Autistic Disorder on the ADI-R based on the ‘lifetime’ algorithm score. The remaining 21 individuals (5.2%) demonstrated a pattern of impairments on the ADI-R that was consistent with their reported diagnosis of Asperger’s Disorder or Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) (Seltzer *et al.* 2003). Throughout, we use the term ‘autism spectrum disorder’ (ASD) to refer to the diagnosis of the individuals from this sample.

The sample for the present analysis consists of 133 families of adults (aged 22 years or older) with ASD. Mirroring the results of past research regarding the residential arrangements of adults with ASD, in 84 of the families in the present study (63%), the son or daughter with ASD lives in a non-family setting, whereas in the remaining 49 families, the son or daughter with ASD resides in the parents’ home.

Table 1 presents the demographic characteristics of the adults with ASD and of their mothers. There were no statistically significant differences in these characteristics between those who lived at home and those who lived elsewhere, with the exception of the child’s gender. There was a higher percentage of females (40.8%) among adults living with their parents in comparison to the percentage of adults who were females (24.4%) among those living apart from their parents ($\chi^2 = 3.97$, $P = 0.046$).

Considering the sample as a whole, the average age of the adult with autism was 31.9 years ($SD = 8.2$). The vast majority (81.5%) were said to be in good to excellent health. About a quarter (22.4%) were non-verbal, less than half (40.3%) spoke in single words or phrases, and slightly more than a third (37.3%) could speak in full sentences.

The average age of the mothers in the sample was 61.1 years ($SD = 9.2$). About two-thirds (66.7%)

Table 1 Characteristics of the sample

	Co-residing (<i>n</i> = 49)	Living apart (<i>n</i> = 86)
Characteristics of son or daughter with ASD	%	%
Age (mean/ <i>SD</i>)	30.2 (7.6)	32.9 (8.4)
Gender		
Males	59.2	75.6
Females	40.8	24.4
Health status		
Poor to fair	10.2	23.3
Good to excellent	89.8	76.7
Verbal skills		
Does not talk	24.5	21.2
Single words or phrases	38.8	41.2
Full sentences	36.7	37.6
Characteristics of mother		
Age (mean/ <i>SD</i>)	59.2 (8.6)	62.1 (9.4)
Marital status		
Married	68.8	65.5
Separated or divorced	20.9	17.9
Widowed	10.4	16.7
Education level		
High school or less	38.8	31.4
Some college	22.4	17.4
College graduate	16.3	19.8
Graduate school	22.4	31.4
Employment status		
Not employed	49.0	45.3
Works part-time	20.4	22.1
Works full-time	30.6	32.6
Health status		
Fair to poor	38.8	27.9
Good to excellent	61.2	72.1
Family income	\$44 090	\$46 923

ASD, autism spectrum disorder.

were married, almost a fifth (18.9%) were separated or divorced, and 14.4% were widows. Slightly more than half (53.5%) had not graduated from college. Less than a third (31.9%) were employed full-time, and almost half (46.7%) were not in the labour market. Almost two-thirds (68.1%) said they were in good or excellent health. Average family income was \$45 902 ($SD = 22 526$).

Procedures

Mothers completed a self-administered questionnaire before the conduct of an in-home interview.

The measures from the questionnaire used in the present analysis included the socio-demographic characteristics of the son or daughter with ASD and the mother; the residential history of the son or daughter; and for adults who lived in a non-family setting, the timing of the residential relocation and perceived changes in the family's life since the move. A variety of open-ended questions were posed in the questionnaire to which written responses were provided.

Measures

Two approaches (one qualitative, one quantitative) were taken to the measurement of the effects of the residential status of the adult child with ASD. First, mothers were asked to write responses to the following two questions: 'What are some positive things about having your son or daughter live (at home/away from home)?' and 'What are some negative things about having your son or daughter live (at home/away from home)?' As described below, these written responses were content-analysed and coded according to major themes and then according to subcategories within each major theme. Second, using a scale from 1 (very poorly) to 7 (very well), mothers also gave ratings to the following question: 'Taking things all together, how does having your son or daughter with autism live (at home/away from you) work out for you?'

Mothers of adults with ASD who lived in non-family setting provided ratings (0 = less since the move, 1 = more since the move, 2 = no change since the move) to seven items assessing different ways in which people's lives change after a relative moves from the home (i.e. the amount of free time you have, feelings of loneliness, feelings of fatigue or tiredness, worries about son or daughter's future, your financial situation, feeling emotionally involved with your son or daughter, and feeling needed by your son or daughter). Mothers also reported on the frequency of the son or daughter's visits to the family home and on parental visits to the son or daughter's residence (i.e. never, several times a year, about once or twice a month, about once a week, several times a week). They also reported on the frequency of contact by phone or in person with their child in the last month and/or contact with the group home manager or other persons responsible for the adult child in the

last month (i.e. have not talked, once, less than weekly, weekly, couple of times a week, daily).

Finally, mothers rated their level of satisfaction with the amount of contact with or about their adult child with ASD on a four-point scale from completely dissatisfied (code of 0) to completely satisfied (code of 3).

Analysis

The written comments from mothers to the questions regarding the positive and negative aspects of their son or daughter's current residential setting (either at home or in a non-family setting) were transcribed verbatim, read by the first and third authors to identify major themes and then subcategories within the major themes, and then coded by major theme and subcategory. Because there was variable length and content in the written responses, some responses contained information that was coded in more than one theme and/or subcategory. Agreement, following clarification of the themes and subcategories through deliberations, was over 90% for both the positive and negative themes for both the co-residing and non-co-residing mothers.

With respect to the positive aspects of the adult child's current residential setting, the three major themes were: benefits for the family, benefits for the son or daughter, and benefits to the parent. With respect to the negative aspects of the residential setting, the three major themes were: problems for the family (for those living at home) or problems with the programme (for those living in a non-family residential setting), negative consequences for the son/daughter, and negative consequences for the parent. Within each of these three major themes for both positive and negative aspects of the current residential setting, subcategories were developed that identified specific issues most commonly written about by the mothers. These subcategories differed depending on the residential status of the son or daughter.

To analyse the responses, we summed the total number of coded responses across all three major themes for the positive aspects of the living situation and across all three major themes for the negative aspects of the living situation. Because of the significant difference in the percentage of females who co-resided with their parents or lived elsewhere, we

Table 2 Positive and negatives aspects of child living at home ($n = 49$)

Aspects	%
Positive aspects	
Benefits for family	
Son/daughter keeps us company/is fun to be around	46.9
Shared love	14.3
Helps around the house	12.2
Family learns from son/daughter	10.2
Benefits for son/daughter	
Is getting good care at home/is secure	40.8
Benefits from interactions with family	14.3
Son/daughter is happy at home	8.2
Benefits for parent	
Peace of mind	34.7
Negative aspects	
Problems for family	
Dealing with son/daughter's behaviour	40.8
Limits family activities	14.3
Stress of daily life	12.2
Negative impact on siblings	6.1
Problems for son/daughter	
Residing at home does not challenge son/daughter	8.2
Isolation/lack of friends and social life	6.1
Not enough services	6.1
Problems for parent	
Constant caregiving/cannot leave son/daughter alone	40.8
Social isolation/limits freedom	18.4
Difficult finding respite care	8.2
Worrying about future life of son/daughter	6.1

checked whether there were gender differences in these percentages and none were significantly different. The percentage of total responses that were coded within each of the three major themes (for either positive or negative aspects) was then calculated. We also calculated the percentage of mothers whose responses were coded into each subcategory (Tables 2 and 3).

Results

We first examined mothers' descriptions of the positive and negative aspects of their adult child's current living situation, separating these descriptions from mothers who co-reside with their son or daughter from those offered by mothers who live apart from their adult child with ASD.

Table 3 Positive and negatives aspects of child living outside the home ($n = 86$)

Aspects	%
Positive aspects	
Benefits for family	
Calmer, more typical family life	26.7
Better married life	11.6
Benefits to other children	8.1
Not dealing with son/daughter's behaviour issues	8.1
Benefits for child	
Learning new skills/growing more independent/confident	54.7
Lives a structured, ordered life with better programme-based services/activities	43.0
Better social life/more friends	18.6
Age appropriate life style	11.6
Benefits for parent	
More free time/freedom	18.6
Less stress/fatigue	17.4
Able to work	5.8
Peace of mind about the future	11.6
Negative aspects	
Problems with the programme	
Staff not well trained	20.9
Concerns about quality of care and the programme	18.6
Staff turnover	11.6
Lack of communication with staff	8.1
Problems for son/daughter	
Safety concerns	12.8
Grooming/personal appearance concerns	11.6
Less integrated in family	7.0
Lonelier	2.3
Problems for parent	
Miss son/daughter	23.3
Worried/guilt	17.4
Limitation on seeing son/daughter	16.3
Loss of control/don't know details	14.0
Concerns about son/daughter's health/health care/meds	14.0
Ongoing caregiving	10.5
Missing caregiving	7.0

Mothers co-residing with their son or daughter with autism spectrum disorder

A third (36%) of the mothers in the sample currently lived with the adult son or daughter with ASD. The vast majority (81.6% or 40) of these adults had never lived outside the family home. The nine individuals who had lived elsewhere and returned home had been living at home, on average for 9.4 years ($SD = 7.1$,

range 3–26 years) since their return. Of the total number of coded positive benefits (mean = 1.82, SD = 0.86) described by mothers of adults living at home, 46.2% were family benefits, 34.7% were benefits to the son or daughter, and 19.1% were benefits to the mother.

With respect to benefits for the family, a commonly expressed benefit focused on the enhanced quality of life for the family. Almost half the mothers who co-reside with their son or daughter with ASD said that their adult child is good company for the family and is fun to have around (Table 2). Typical comments include 'she is definitely an interesting individual, fun to be with' and 'we enjoy his company'. Another positive benefit for the family was the love shared within the family. One participant stated, 'What is reinforcing and comforting to me is that he receives unconditional love and care that only a mom can give.' Some mothers noted that the adult son or daughter helps out around the house (e.g. 'Can do the heavy lifting – like putting trash out. He helps with grocery shopping.'). Others noted that they feel they have changed for the better through their non-normative parenting experiences (e.g. 'We have all learned tolerance and acceptance of others.').

With respect to benefits for the son or daughter, the most commonly expressed benefit of living at home was that he or she was getting good care and felt secure at home. Participants wrote, 'She's happier and healthier here' and 'No one else can care for him like I do.' A smaller number of mothers noted that their son or daughter benefits from interactions with the family (e.g. 'He is able to enjoy family activities, join in sports, spectating for his brother's events, be secure in the routine of family.'). Several mothers wrote of their child's happiness and preference to be living at home (e.g. 'He is content and happy.').

With respect to benefits to the mother, a third of the mothers said that co-residing with the adult child with ASD gave her peace of mind (e.g. 'I know she is safe and I have some peace of mind' and 'I don't have to worry about the quality of his care.').

Mothers were also asked about the negative aspects of co-residing with their adult child with ASD. Responses were coded within three broad categories (mean = 1.67, SD = 0.80) including problems for the family (47.9% of all negative aspects described), negative aspects for the son or daughter (11.8% of

all negative aspects described) or problems for the mother herself (40.3% of all negative benefits described).

Regarding problems for the family, mothers said having to deal with the problematic behaviour of the adult with ASD was stressful (e.g. 'When she gets aggressive she is getting a little too strong for us' and 'She has a very difficult time expressing herself when she is angry, hurt or frustrated. Usually ends up with a scream-fest.'). (Table 2). Other problems noted were limitations on the family's social activities and coping with the stress of everyday life. Participants commented, 'We are not free to go as we please' and 'She is very difficult to live with at times.' A few mothers noted that there were negative impacts on their other children resulting from living with their sibling with ASD (e.g. 'Our daughter missed some of our attention.').

Only a small number of mothers identified negative consequences of co-residing for the son or daughter. The problems that were noted included the lack of sufficient challenges provided at home (e.g. 'We are concerned that she is too content being dependent and does not want to stretch or grow'), social isolation (e.g. 'Not getting involved with others – his world is very confined'), and the lack of services for their adult child (e.g. 'No available activities or work for him during all the hours of my job.').

Mothers also noted problems for themselves resulting from living with their adult child with ASD. The most commonly cited problem was the stress of constant caregiving and not being able to leave the son or daughter alone. Participants noted, 'It is a 24 hour a day job' and 'We are somewhat tied down, as he can't be left alone.' Others wrote of their own social isolation and lack of freedom (e.g. 'Life for the parent is like being a prisoner in one's own home.'). Finally, some wrote of the difficulty of finding respite care (e.g. 'Hard to get respite care for a 28-year-old.'). and not having peace of mind about the future (e.g. 'After we are gone, he will be hopelessly lost.').

Parents who live apart from their son or daughter with autism spectrum disorder

For two-thirds of the mothers in the present study, the adult with autism lived away from the parental home. These adults were, on average, 26.7 years of

age ($SD = 9.3$) when they moved to their current residence, and had lived there, on average 6.5 years ($SD = 75.9$, range from 3 months to 27.5 years). Among the 86 individuals who live apart from their families, the majority lived in a community residential programme (73.3%) or in a semi-independent living setting (17.4%). Other types of settings in which they lived include an institutional or hospital setting ($n = 4$), independent living ($n = 2$), a foster care setting ($n = 1$) or with another family member ($n = 1$).

Mothers wrote about three main areas of benefits related to having their son or daughters live elsewhere (mean = 2.36, $SD = 1.22$): benefits to the family as a whole (20.5% of all positive benefits described), benefits to the son or daughter (56.6% of all positive benefits), or benefits to the mother (22.9% of the positive benefits described).

Regarding benefits to the family as a whole (Table 3), over a quarter of the mothers described their ability to have a calmer, more typical family life following the residential relocation (e.g. 'We are able to live a somewhat "normal" life'), including a better parent-child relationship (e.g. 'Less stress for the family and when my son with autism does come home you have more energy and patience for him.'). About a tenth noted that their marital relationship had improved since their son or daughter had moved out (e.g. 'I'm able to have some time of life for myself and my husband' and 'This is an appropriate time to enjoy with my husband.'). A smaller number of mothers noted specific benefits to siblings (e.g. 'The rest of the family can do as they please without having to abide by daughter's rules and demands. I am able to devote my time and energy to the needs of the other children.'). Others commented specifically that not having to deal with the behavioural problems or stresses of their son or daughter was a positive aspect (e.g. 'It's a great plus not to have to live with emotional and behavioural bursts daily.').

With respect to benefits to the son or daughter, over half of the mothers noted that their adult child is learning new skills and acquiring new capabilities as a result of living apart from the family. Mothers noted their child's increased confidence and independence (e.g. 'He is learning to be more independent and responsible.'). Almost half wrote that their child now has a more ordered, structured life, including access to better programme-based services and activ-

ities. One mother wrote: 'The setting is structured. He is safe. A doctor is on-call daily. He is in a room of his own. The environment is allergen free. The staff are very good with him, and it's large enough that if there's a change, he is not personally affected. They have programmes, but if he doesn't wish to join, he is allowed to be alone.' Almost a fifth said their child's social life has improved (e.g. 'He has his own friends'). A few mothers wrote that living apart was an age appropriate lifestyle (e.g. 'More age appropriate arrangement for her - i.e. living with roommates, doing own housework, etc.')

With respect to benefits to the parent, mothers wrote that they have more free time (e.g. 'We do not have to be home at 3 : 15 everyday. We have our evenings free to do what we want. We can travel.'). Others described the reduction of stress in their daily lives (e.g. 'Not having the constant stress of having to provide 24 hour care.'). Some noted that they have more peace of mind with this residential arrangement (e.g. 'First and foremost is the fear of something happening to me and what would become of my son. That has been taken care of.'). A few wrote that they are now free to resume employment (e.g. 'Allows me to work full time').

Mothers also reported on the negative aspects of their son or daughter living apart from them. Responses (mean = 1.95, $SD = 1.3$) were grouped into three domains, including problems with the son or daughter's programme or living arrangement (28.2% of all negatives cited), problems for the son or daughter (16.6% of all negatives cited), and problems for themselves (55.1% of all negatives cited).

With respect to problems with the programme, a fifth of the mothers said staff are not well trained to care for people with autism (e.g. 'I feel that staff need more training than is provided to work with people with autism.'). (Table 3). Almost as many noted specifically that they worry about the quality of care or supervision provided. One mother wrote of a lack of individualization and guidance within programmes (e.g. 'He gets a minimum of one to one time due to more needy home mates. Direct care staff has very little knowledge or interest to help him grow, learn, or reach "potential."'). They also spoke of there being not enough activities and challenges for their son or daughter (e.g. 'He seems to be actually over-supported. Staff are patronizing and don't offer him challenges that will teach him to become more inde-

pendent. The weekends at his apartment are extremely dull – lots of videos and eating; very little fun, challenging activities.’). Others complained about frequent staff turnover in the residence (e.g. ‘Having to deal with the continual shortage and turnover of staff’). Some wrote of the lack of communication between themselves and the staff (e.g. ‘We are not well informed about what goes on at the group home. There have been some service problems there and we haven’t been kept current.’).

Regarding negative aspects for the son or daughter, some mothers expressed fear that their adult child could be exploited or taken advantage of (e.g. ‘There is always the fear of someone abusing him.’ ‘He can be taken advantage of and he can display poor judgement when he is not understood by others.’). Others noted that their child appeared less well groomed than they wished (e.g. ‘Not always groomed and/or dressed as I would like her to be’). Some felt that their child is no longer as close with the family and misses out on family events (e.g. ‘We know he misses us and in some ways would like to be home. He is not fully integrated in the family as much as I would like. He does not attend many family functions’ and ‘She can no longer experience the pleasures of family life. She can no longer be part of the household.’). A few wrote that their child was lonelier living apart (e.g. ‘I also know she is lonely. She feels that I don’t love her or I would want her to live with me.’).

There were a variety of negative aspects of living apart from their adult child for the mothers themselves. The most commonly expressed negative personal impact was that the mothers miss their children (e.g. ‘I miss him terribly and am not able to give him the same level of love and attention.’). Others noted feelings of guilt about their child living away from home (e.g. ‘Guilt! I work on it a lot, but I do feel guilty that I am not “taking care” of him.’). Almost as many said that they can’t see their adult child as often as they want (e.g. ‘I don’t get to see him during the week as often as I would like.’). Others were limited by distance. One mother noted, ‘At this time, it’s 250 miles away so it is hard to commute more than 1–2 times a month especially in winter.’ A slightly smaller number regretted not knowing the details of their child’s everyday life (e.g. ‘I am not aware of all the details of her life – the funny, delightful things as well as the problems.’ and ‘One of our biggest concerns was our loss of “control” or knowledge of every

aspect of his life.’). Others worry about their child’s health and management of problematic behaviours (e.g. ‘He lives alone and his bizarre behaviours, etc. can’t be monitored. We should not have moved him until an acceptable roommate was found. He will never accept a roommate now. Unable to monitor his health (meds). What’s happening in his life. Feel he regresses being alone.’). A tenth said a negative for them is that they are still providing a lot of care (e.g. ‘We continue to be responsible for son’s health maintenance. We advocate for our son. We purchase all clothing, linens, etc. Parents do not have the energy to continue all the above responsibilities.’). On the other hand, a small number regretted that they were no longer their child’s primary caregiver (e.g. ‘Still want to pick out her clothes and comb her hair.’)

Both groups of mothers (i.e. mothers who live with their son or daughter with ASD and those living apart) were asked to rate how well the current residential situation ‘works out for you’ using a scale from 1 (very poorly) to 7 (extremely well). There was a small but significant difference between the two groups, with mothers who live with their son or daughter rating the current residential situation less favourably ($M = 5.04$) than mothers who live apart from their adult child ($M = 5.85$) ($t = -3.21$, $P = 0.002$). Both groups of mothers were asked about the degree to which their family is currently ‘socially isolated’ because of their son or daughter’s behaviours. There were no significant differences between the two groups, with about a third of the mothers living with their child (32.7%) and a little more than a third (36.0%) of those living apart reporting their family is not at all socially isolated. On the other hand, 42.9% of those living together and 37.3% of those living apart said their families are moderately or extremely socially isolated because of their son or daughter’s behaviours.

Parental contact with adult children with autism spectrum disorder living apart

Our second question addressed the degree of contact that mothers have with their son or daughter who lives apart from them. Table 4 presents the results of these analyses. There was a considerable amount of contact even though the adult lives away from home. Over half of the mothers reported that their son or daughter visits home at least weekly (39.5%) or

Table 4 Amount of contact with son or daughter who live outside the home ($n = 86$)

Item	Frequency of contact					
	Never %	Several times/year %	1–2 times/month %	Once a week %	Several times/week %	
Son or daughter visits mother at home	8.1	15.1	25.6	39.5	11.6	
Mother visits son or daughter at residence	8.1	17.4	25.6	37.2	11.6	
Item	None inlast month %	Once inlast month %	2–3 times inlast month %	Weekly %	Couple times/week %	Daily %
	Mother talked with son or daughter by phone or in person*	1.5	7.5	17.9	22.4	29.9
Mother talked with son or daughter's caregiver	2.4	14.3	29.8	22.6	21.4	9.5

* $n = 67$, only asked of mothers whose child is verbal.

several times a week (11.6%). A quarter (25.6%) reported that such visits to the family home occur a couple of times per month. The data regarding maternal visits to the son or daughter's residence are comparable, suggesting that there is a high level of in-person contact at both the family home and in the adult child's residence.

The data also indicate that mothers talk with their son or daughter with ASD on a regular basis – less than a tenth said that such communication happened only once or less in the last month (among those mothers whose child was verbal). The vast majority reported at least weekly communication with their son or daughter, with a fifth reporting at least daily communication. And, mothers appear to be in frequent communication with their son or daughter's caregivers or programme staff, with over half reporting at least weekly contact or more. Mothers were asked how satisfied they were with the amount of contact they have with or about their son or daughter, and 85.7% said they were somewhat or completely satisfied.

Maternal appraisals of changes in the family's life

The third question addressed maternal appraisals of changes in her life since her son or daughter moved out of the home. The appraisals were rated in seven areas

Table 5 Maternal ratings of changes in their lives ($n = 86$)

Item	Less since move %	More since move %	No change %
Amount of free time	4.8	90.5	4.8
Feelings of loneliness	10.8	33.7	55.4
Feelings of fatigue	44.6	12.0	43.4
Worries about son or daughter's future	24.4	43.9	31.7
Financial situation	11.0	17.1	72.0
Feeling emotionally involved with son or daughter	14.6	24.4	61.0
Feeling needed by son or daughter	30.9	18.5	50.6

and asked whether there was less change since the move, more change since the move, or no change since the move. Table 5 presents the results. The most common improvements were having more free time (90.5% of respondents) and less fatigue (44.6%). However, worries about the son or daughter's future were often greater since the move (43.9%). There was less change perceived in other areas. At least half of the mothers reported no change since the move in their feelings of loneliness, the family's financial situation,

the degree of emotional involvement with the son or daughter, or feeling needed by the son or daughter.

We examined whether maternal ratings of the seven different areas of impacts were associated with their overall ratings of how well this arrangement works out for the parent, the length of time their son or daughter has lived in the current residence, the child's age at which the move was made, the mother's age, and maternal satisfaction with the amount of contact with or about the son or daughter. Two significant differences were found. Mothers who said their worries about the future had increased since their child's move had lower overall ratings of how well this arrangement is working out ($M = 5.5$) than those who said they worried less since move ($M = 6.3$) or said there was no change since the move ($M = 6.2$) ($P = 0.027$). Second, mothers who said that they had greater feelings of being needed by their son or daughter since the move had lower overall ratings of how well this arrangement is working out for them ($M = 5.0$) than those who said they felt less needed since the move ($M = 6.3$) or those who said there was no change since the move ($M = 6.0$) ($P = 0.05$).

Discussion

There is an increasing likelihood among investigators of families caring for a child (or adult) with an ID to utilize both qualitative and quantitative data (Seltzer *et al.* 2000b; Baker & Blacher 2002; Poston *et al.* in press) and to examine both positive and negative aspects of the parenting experience (Helff & Glidden 1998). Analyses of qualitative data have yielded additional evidence for the reverberating and multiple impacts on all family members of consequential issues such as where the family member with a disability lives, the gratifications and frustrations of the parental role, and the alterations in personal and family values that often accompanies 'a difference in the family' (Featherstone 1980). The current analysis focused on three related issues: maternal descriptions of the positive and negative aspects of having her adult child with ASD live at home or live in a non-family setting, the degree of ongoing contact between mothers of individuals who live apart from the family and the family member with ASD (and his or her caregivers), and the kinds of changes that occur for mothers following the residential relocation of a family member with ASD. Analytically, these three approaches to studying the

varied impacts of residential decisions (including positive as well as problematic aspects) provide multiple perspectives on a very complex issue that has not been well described in the literature to date. The available literature is much more focused on distinct issues affecting families of young children with ASD, with far less attention given to the issues facing families of adults with ASD. Our findings provide an important and unique perspective on how mothers of adults with ASD experience the consequential decision of where their son or daughter lives.

Several major findings warrant emphasis. Residential status matters – for the individual with ASD, for the family as a whole, and for the mothers as individuals and caregivers. Specifically, among families whose son or daughter with ASD lives away from home, the preponderance of all the positive benefits noted (56.6%) were attributed to the son or daughter, in contrast to fewer positive benefits for the family (20.5%) or to the mother (22.9%). Maternal comments focused on their child's increased opportunities for personal growth, acquisition of new skills, expanded social benefits, and access to structured programmes that included a wide range of supports necessary for more independent living. In contrast, among families where the son or daughter lives at home, the ascribed benefits for the son or daughter were less common (34.7% of all positive benefits noted) and focused most typically on security rather than personal growth.

For co-residing families, a complex picture emerged whereby the largest percentage of responses of both the positive (46.2%) and the negative (47.9%) aspects of the residential status of the son or daughter with ASD were attributed to the family. The dominant theme of the positive benefits associated with co-residence focused on the enjoyment the family derives from the presence of the son or daughter with ASD (e.g. as good company, fun to be with) while concurrently, the negative aspects focused on the strain and constraints on the family caused by the controlling and problematic behaviours of the member with ASD. The juxtaposition of these joys and stressors illustrates the paradox of developmental disability described by Larson (1998) who documents the multiple and complex perspectives of parents who wish the disability could be 'cured' while acknowledging the personal growth engendered by parenting a child who presents such

basic challenges to normative concepts of human development.

For mothers as parents and individuals, the data are starkly revealing. The positive aspects associated with residential status were much less likely to benefit the mother as an individual than the family or the son or daughter with ASD. In contrast, the percentage of all negative comments associated with residential status was high for the mother as an individual as compared with the family or the son or daughter with ASD. These data suggest the multifaceted and highly contingent maternal experience associated with where her child with ASD lives. For mothers whose child lives at home, the dominant theme of the positive benefits is the peace of mind they have in ensuring the well-being of the child while the dominant theme of the negative consequences is the strain of their caregiving activities. For mothers whose child lives apart from the family, the dominant theme of the positive benefits is the freedom the mother experiences as an individual, while the dominant theme of the negative consequences is affective – missing their child. These are highly salient issues for mothers, and our data suggest that the ‘push/pull’ of child security, caregiving stress, personal independence, and affective bonds play out in a complex way for both mothers whose children with ASD live at home and those who live apart. Indeed, mothers whose son or daughter lives elsewhere reported more free time, less fatigue, but greater worries about their adult child’s future.

It is tempting to render summary judgements about the comparative benefits for families (and adults with ASD) of living either at home or living apart from their son or daughter with ASD. Our overall quantitative ratings, based on maternal report, would suggest a slight advantage to the family overall to living apart from their adult child with ASD. However, our qualitative data reveal much more nuanced and specific information about how such overall judgements are compiled and illustrate the value of focusing on the complexity, rather than the summative judgements, of families’ experiences.

Another major finding is that among families whose children live elsewhere, there is an impressive amount of continued contact between these families and their son/daughter. The vast majority of mothers report at least monthly visits to their adult child’s residence and a comparable frequency of home visit-

ing. And, there appears to be frequent and sustained communication with the son or daughter and his/her residential staff. This is important news for families, for adults with ASD, and for the service providers who assist individuals with ASD making the transition from parental to non-parental care. Living apart from the family does not translate into non-involvement among family members, a finding underscored by the qualitative data discussed above regarding the positive and negative impacts of out-of-home living. This fact has been demonstrated in multiple studies of families of children with IDs (Baker *et al.* 1993; Seltzer *et al.* 2001; Baker & Blacher 2002). It suggests, however, that the durability of family-based care is not contingent on where the son or daughter with ASD lives, as the dominant pattern of parental involvement includes frequent contact with their son or daughter, frequent contact with service providers, and an overall level of satisfaction with the amount of contact.

The results of these multiple ways of assessing the impacts on different units within the family (i.e. the family as a whole, the individual with ASD, and the mothers who are the primary caregivers) converge to underscore the central role that families of persons with ASD have in the lives of their adult children, regardless of residential setting. The durability of family caregiving over the life cycle among families affected by IDs has been noted (Fujiura & Braddock 1992; Krauss & Seltzer 1999; Marshak *et al.* 1999). While continued co-residence with parents appears to be less common among adults with ASD (in comparison to children with ASD), our data suggest that there is extensive involvement of their mothers (and presumably other family members) with their son or daughter with ASD, underscoring the importance of taking a life-span perspective to the study of families of individuals with ASD.

There are several limitations to the present study that warrant comment. First, the qualitative data analysed are based on written comments made by mothers to open-ended questions embedded in a self-administered questionnaire. Direct probing in a face-to-face interview may have yielded additional insights into the positive and negative aspects of the residential arrangement, a strategy we would recommend for future studies. Second, responses reflect the mother’s perspective of the consequences to their adult child, their families and themselves of the residential

arrangement. Other family members, such as fathers and siblings, may have quite distinct assessments that differ from maternal views. Third, we do not have the perspective of the adults with ASD on the positive and negative aspects of their living situation and this voice may provide yet more divergent and compelling perspectives to that of their mothers.

Juxtaposed to these methodological limitations are several strengths of the current study. First, the written comments by mothers reflect salient aspects of their child's living situation and thus provide vivid insight into their experiences and perceptions on issues that have rarely been explored in the current literature. Second, the sample is reasonably large (in comparison to other studies of families of individuals with ASD) and includes families co-residing and living apart from their son or daughter, permitting a comparison of the experiences. The study thus provides unique insights into an issue of critical importance to families of adults with ASD.

Understanding the 'lived experience' of families of adults with ASD constitutes a major challenge for researchers interested in the lifelong impacts on families of having a child with a developmental disability, for service providers charged with providing appropriate family support and community-based services, and for families who shoulder a tremendous lifelong responsibility. The current study offers new perspectives directly from mothers of adults with ASD on the positive and negative aspects of their child's living situation. As our data illustrate, their experiences are complex and multifaceted.

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