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## Adolescents & Adults with Autism A Study of Family Caregiving



### Report #5 Family Accommodations

- Principal Investigators -

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We are extremely grateful to the families of the 405 adolescents and adults who have given so generously of their time and shared their lives with us.

**Cover Art:** *Landscape* by Len from England. From the Harvey A. Stevens International Collection of Art by People with Developmental Disabilities, sponsored by the Friends of the Waisman Center.

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# Report #5: Family Accommodations

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## **Section I: Introduction**

In 1998, we began this study to investigate the changes and challenges faced by adolescents and adults with autism and their families. We are following the families of 407 adolescents and adults with autism spectrum disorders over a five-year period, with data collected every 18 months from mothers, fathers and adult siblings of the adolescents and adults with autism. When the study began, the individuals with autism ranged in age from 10 to 53, averaging 22 years of age. Most are male (about 75%) and two-thirds live at home with their parents.

One goal of our study is to understand better how families manage their daily lives in light of the special needs of their son or daughter with autism. This report focuses on the range of accommodations and changes that parents make to create a “sustainable daily routine” for the family. Families of individuals with autism spectrum disorders make such accommodations whether their son or daughter lives at home or lives elsewhere, and we highlight the accommodations made in both types of residential circumstances in this report.

At this point in time, we have completed our third round of interviews and we are getting ready for the fourth. The findings from this study are beginning to be published in scientific journals and are breaking new ground in our understanding of the lives of adolescents and adults with autism and their families.

We are deeply grateful to the families who have participated in this study. They have welcomed us into their homes, spent hours of their limited time with our interviewers, and provided information and insights that only the family can offer. We have learned so much in this process and are committed to using this knowledge to improve the quality of lives of individuals with autism spectrum disorders and their families.

Sincerely,

Marsha Mailick Seltzer, Ph.D.  
Director, Waisman Center  
Co-Principal Investigator

Marty Wyngaarden Krauss, Ph.D.  
John Stein Professor of Disability Research  
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## **Section II: Accommodations**

This report describes the accommodations and changes families have made in response to their son or daughter's special needs. These questions focused on accommodations in six areas of family life: household routines, participation in social activities, work, participation in religious activities, contact with extended family members, and finances. Our goal was to identify the ways in which having a child with an autism spectrum disorder (ASD) affects the everyday lives of families.

We asked:

*“Now I have a series of questions that ask about the concrete changes or trade-offs you may have made during the last 18 months to accommodate to your son or daughter's special needs. By concrete changes, we mean changes you made that were designed to achieve a goal.*

*We recognize that these types of changes may have a cost or benefit to your son or daughter, your family as a whole, and to you as an individual. I'd like to ask you about how these changes have made an impact.*

*Let's start with your son or daughter. How have these changes affected him/her? Have they been mostly beneficial or mostly costly for him/her?*

*Next, now let's focus on your family. How have these changes affected your family as a whole?*

*Finally, let's focus on you. How have these changes affected you?”*

\_\_\_\_\_ (0) mostly beneficial for him/her

\_\_\_\_\_ (1) somewhat beneficial

\_\_\_\_\_ (2) somewhat costly

\_\_\_\_\_ (3) mostly costly for him/her

\_\_\_\_\_ (4) neither beneficial nor costly

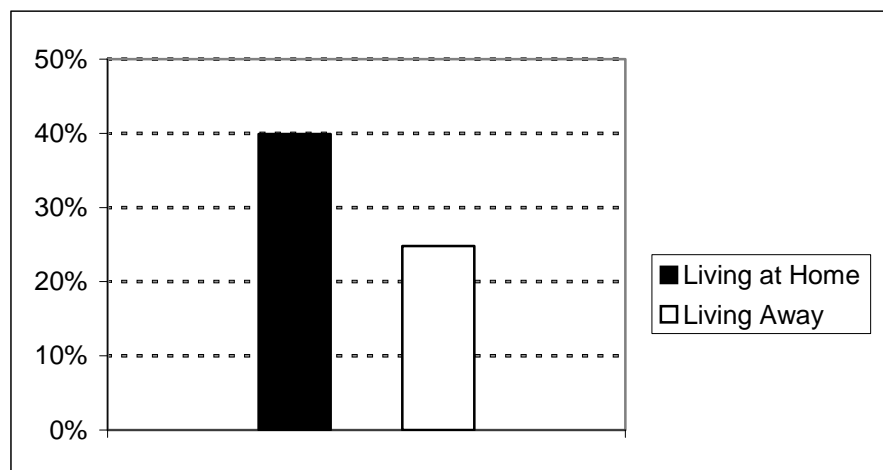
## Household Routines

First we asked about household routines. Here is the question:

*“The first question is about changes you may have made in your **household routines**. By household routines we mean any schedules or patterns you have established for doing housework, outside chores, preparing meals, and for making sure the members of your family get to the places they need to go. During the past 18 months, did you make a change in your **household routines** to accommodate to your son or daughter’s needs?”*

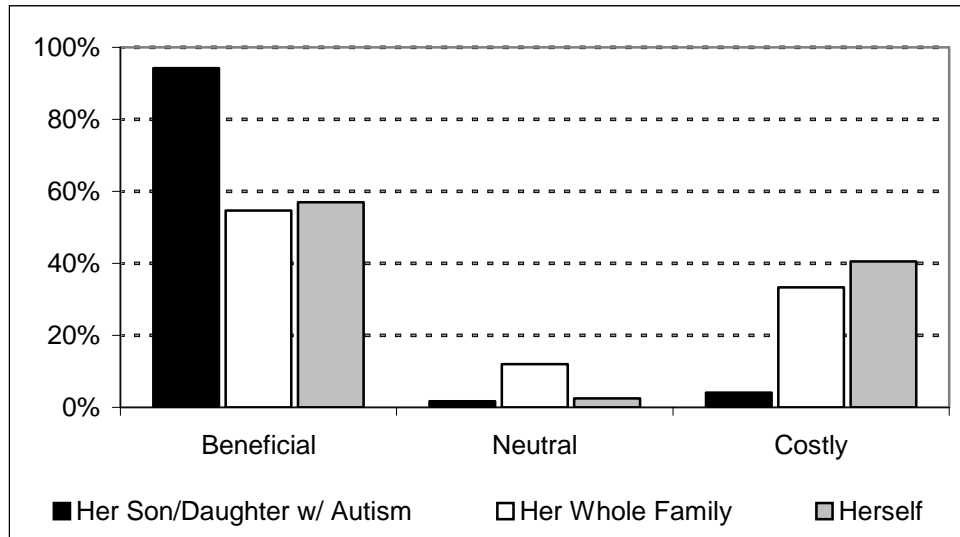
As shown in Figure 1, 40% of families whose son or daughter with an ASD lived at home had made accommodations in household routines during the past 18 months. This was in contrast to 25% of families whose son or daughter with an ASD lived away from home.

**Figure 1. Percent of Families Making Changes in Household Routines**



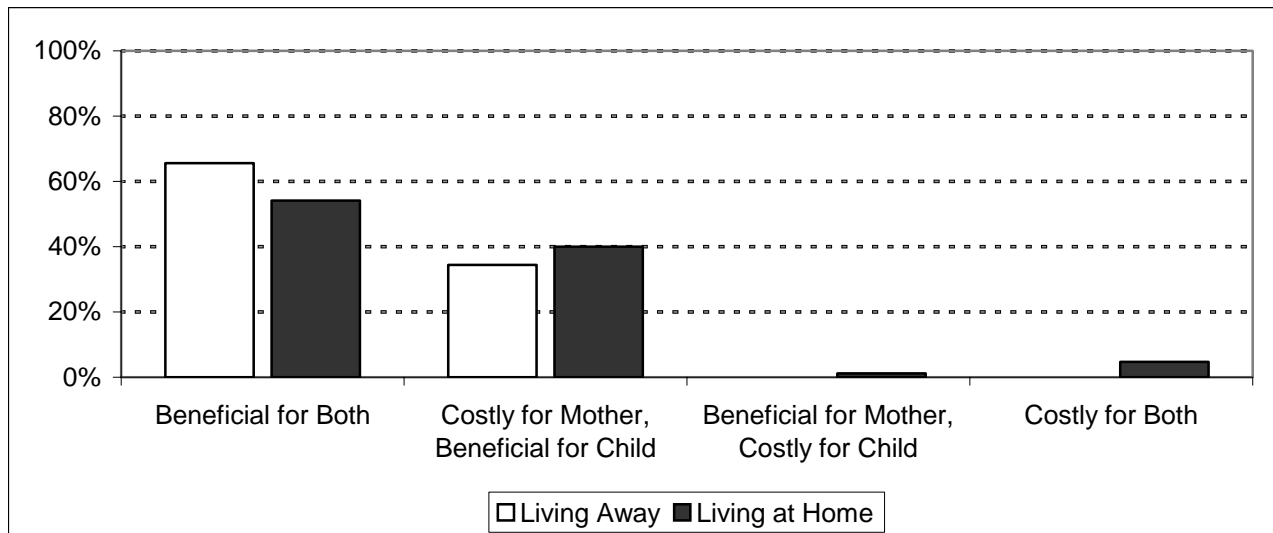
As seen in Figure 2, 92% of all household accommodations were assessed as beneficial for the person with an ASD. About one half were rated as beneficial for the whole family or for the mother herself. Very few accommodations in household routines were rated as neutral. Almost no one reported that the accommodations were costly to the son or daughter with an ASD. About one third rated their household accommodations as costly to the whole family. And about 40% responded that the changes made in household routines were costly to the mother herself.

**Figure 2. Mothers' Perceptions of the Effects of Household Changes**



Next we narrowed our focus to the balance of costs and benefits (omitting the neutral ratings) to the mother and to the individual with an ASD. We examined four sets of outcomes: beneficial for both mother and son or daughter, costly for the mother but beneficial for the child, beneficial for the mother but costly for the child, and costly for both. As shown in Figure 3 below, the majority of mothers said the accommodations they made were beneficial for both themselves and the son or daughter with an ASD. However, a significant percentage viewed the changes they made as a tradeoff – beneficial for the person with an ASD, but costly for themselves. Of those making accommodations in household routines, this perceived tradeoff occurred more frequently when the child lived at home (40%) as compared to those with children living away from home (34%).

**Figure 3. Perceived Benefits and Costs.**



## **Examples of Accommodations in Household Routines (Son or Daughter Living at Home)**

### **Beneficial for Both**

- “We decided that he can do more on his own than he lets on. We determined what he needs available to him and what needs to be locked away. We started having cleaning classes once a week. He is now managing his part of the house much better. This is great for me and he seems happier.”
- “We now have a ‘chore chart’ and he knows what is expected. He can look at the schedule and the pictures and know what to do. Fewer tantrums and meltdowns because of the consistency. This has been a hard change but worth it.”
- “We have been able to find some discrete hygiene items that keep him cleaner and that make the day a lot easier.”
- “She gets up after everyone else is dressed and ready so she gets more rest and the rest of us get a more peaceful morning.”
- “We moved him from upstairs to the lower level so he can have his space. I no longer have to look at this room. We have our privacy. He has his privacy.”

### **Costly for Mother, Beneficial for Child**

- “We have a plan where the rest of us help around the house and adapt our schedules to meet his. It is easier this way because we aren’t always worrying about what he’ll do but I seem to be losing myself in the process.”
- “We have had to cut way down on household activities, like cleaning and having the TV on. We had to move the TV out of the living room because of sound problems. He needs to be alone. We gave up family sit-down meals because it was too hard. We just shut ourselves off in our bedroom.”
- “We get up earlier to accommodate him. We have to have someone watch over him during dinner preparation because that is when he melts down. The kids are separated at this time to avoid conflict. This requires a lot of management.”
- “I take him to work everyday because he sleeps so poorly. The bus that could pick him up is too early. It’s a hassle because I’m getting up earlier to get things done.”
- “We now do more preparation than ever. We have gotten after teachers to get them involved in the process and to help her anticipate changes. The housework has slipped and other things have to slide to be present with the kids. I always have to support her and this limits my social life except for other autism moms. This is extremely difficult.”



## **Examples of Accommodations in Household Routines (Son or Daughter Living away from Home)**

### **Beneficial for Both**

- “Since he is in the group home during the week it is easier to manage the household. We know that when a job gets done it will stay done because he is not home to mess things up. On the weekends it’s OK because we know that it is only short-term. We can deal with 2 days of chaos.”
- “I limit the phone calls that I take from him and I encourage his brothers to do the same. I insist that the group home attempt to resolve conflicts before calling me to intervene. I need my distance and they need to stop relying on me. It’s nice to take the backseat sometimes.”
- “We hired someone to clean for us once a week when she is at the group home. It’s a luxury, I know, but it is my one thing. It’s like a massage, but better.”
- “We set up transportation for him to get to our house and then back to his house at the end of the visit. He is getting too big for me to manage and he prefers to ride in the van. This makes visits easier.”

### **Costly for Mother, Beneficial for Child**

- “He is on a special diet now so we are cooking differently, sometimes just for him. I spend a full day shopping and cooking for him just to take food back to school.”
- “We set aside every other weekend for him. We don’t make any plans and have to decline any offers made for those weekends. We move our bedroom to the living room for those weekends so he can have his own bedroom.”
- “We are available to the group home all the time now. We always have to be ready to get into crisis mode. In many ways it isn’t much different than when she was home.”
- “Eating. Her diet is limited and so now all three meals have to be Italian. We’ve allowed more TV watching. We allow her to get up, turn on TV, and fall back asleep in the morning. This has to be done around the other kids. This is hard for all of the rest of us but it just isn’t worth the fight any longer.”
- “When he is home the whole routine is changed. The kids are no longer used to him being around so they avoid him as much as possible. They try to stay with friends on his weekends home. This makes me feel horrible as a parent.”

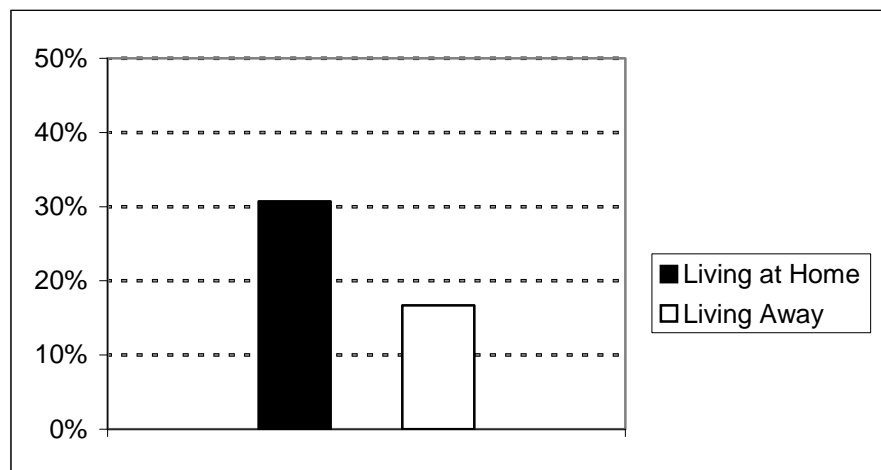
## Participation in Social & Recreational Activities

Next, we asked about participation in social and recreational activities:

*“During the past 18 months, have you made any changes or accommodations in your or your family's participation in social and recreational activities to accommodate to your son or daughter's needs?”*

As shown in Figure 4, 31% of families where the person with an ASD lived at home had made accommodations in social or recreational activities. In contrast, 17% of families where the son or daughter with an ASD lived away from home had made changes in the family's participation in social or recreational activities.

**Figure 4. Percent of Families Making Changes in Social, Recreational Activities**



As seen in Figure 5, 85% of all these accommodations were considered beneficial for the person with an ASD. Nearly two thirds were rated as beneficial for the whole family or for the mother herself. Very few accommodations were rated as neutral. Almost 10% reported that the accommodations were costly to the son or daughter with an ASD. About one third rated their social or recreational accommodations as costly to the whole family. And 36% responded that the changes made in social or recreational activities were costly to the mother herself.

**Figure 5. Mothers' Perceptions of the Effects of Changes in Social or Recreational Activities**

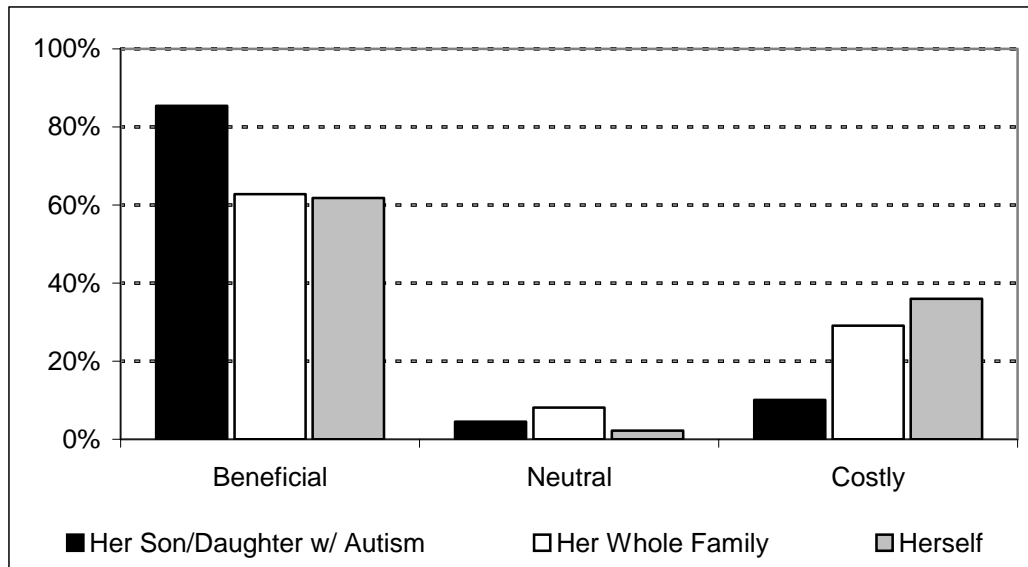
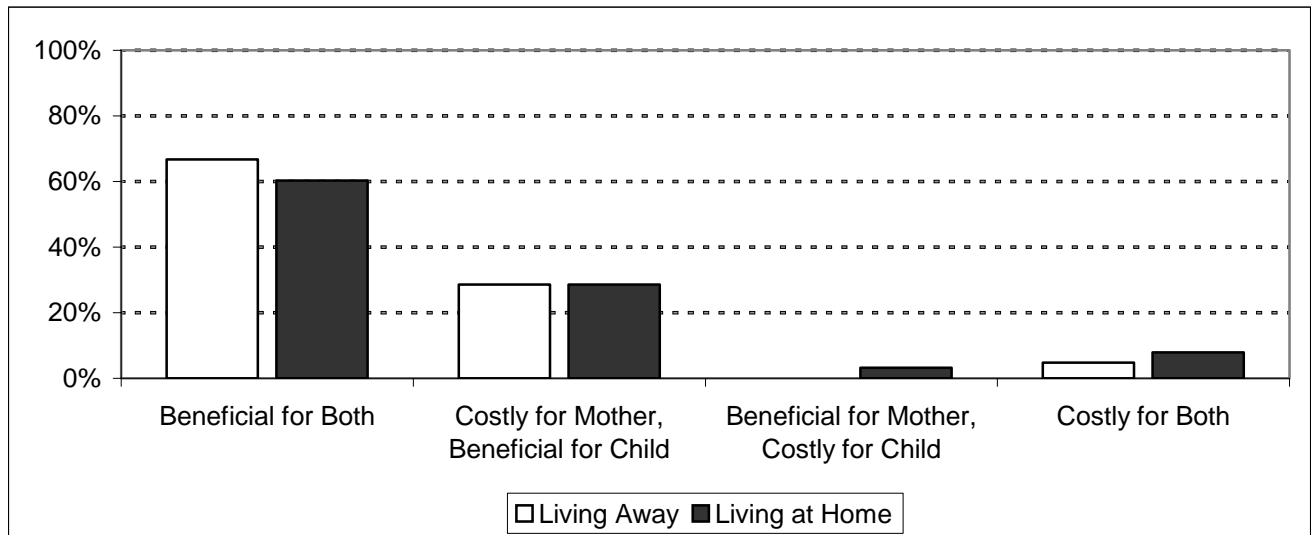


Figure 6 displays the balance of costs and benefits. About two-thirds of mothers who had made this accommodation assessed it as mutually beneficial for herself and her child with an ASD. A little more than a quarter saw the changes as beneficial for the person with an ASD but costly to herself. In very few families, the mother saw the changes as beneficial for her but costly for her child, or costly for both.

**Figure 6. Perceived Benefits and Costs.**



## **Examples of Accommodations in Social and Recreational Activities (Son or Daughter Living at Home)**

### **Beneficial for Both**

- “We’ve gone to family reunions and work picnics for the first time with him. He’s more manageable. We try to create more social opportunities. He and I practice greetings to achieve a level of sociability to go out.”
- “We’ve started taking separate vacations. I go on a trip with other autism moms and my husband goes on his own trip to visit family.”
- “We set aside 2 days a week for our other children to have play dates and to do other activities. We have a sitter to watch our son at these times. Otherwise, it is too much stress for all of us.”
- “We make more time for ourselves. Our younger son can sit with him sometimes. He likes the money and we like the time alone. It works out better now than it used to.”
- “We purchased a camper van so we can go to our son’s ballgames. She can stay in the van. We can go to the drive-thru and eat in the van and watch a movie. We can go on vacation—this is much better. We bought the van so we could start doing all of the things that we had had to curtail because of her behaviors.”

### **Costly for Mother, Beneficial for Child**

- “Our [typically developing] daughter doesn’t have friends over because of his aggressive behaviors. We are afraid of what he might do. It is hard to take our daughter to things that she enjoys because we can’t leave him alone. She is starting to prefer staying with friends. This is heart-breaking for me but he likes it when she is gone.”
- “We don’t have a social life. Our recreation with him (son with autism) is separate from our recreation with our other son. As a family we always have to consider what is good for him (son with autism) and that puts restrictions on our other son. Our other son’s activities are limited because of this strain.”
- “We just don’t go very many places anymore. She is such a homebody. We are really isolated from the rest of the world.”
- “Everything takes so much planning that I just don’t do it much anymore. He likes it because he gets to stay home and watch TV and play video games all day but I am getting cabin fever. My patience grows thin after so much time at home.”
- “We have to hire someone to sit with him when we go out because he simply refuses to go along with plans. We are getting so much less help from the county that this is hard financially. It’s getting to the point where we (my husband and I) can no longer maintain our other commitments.”

## **Examples of Accommodations in Social and Recreational Activities (Son or Daughter Living away from Home)**

### **Beneficial for Both**

- “Because we don’t bring him home anymore we visit him more often and I have been able to integrate long walks and picnics outside into our visits. He seems to enjoy these things. Also, I’ve integrated other family members and they now visit when we want to take a trip or have some other commitment.”
- “We have forced ourselves to participate more often and not be so isolated. We allow her to stay at the group home if she doesn’t want to participate whereas before we felt obligated to include her in all of our weekend activities. We have started putting ourselves in a position to participate in social activities.”
- “We foreshadow a lot and draw clear boundaries. If he acts up or won’t participate then we simply take him back to his house. He is learning that if he wants to be with us he has to behave. This has been hard and has caused many tears but it is something we must do. Now our times together are more peaceful.”
- “I’ve created some family-style social situations for her to be involved in. For the 4<sup>th</sup> of July we invited some families with children. We are working to make social situations better and easier for her. It seems to be working.”
- “We had to provide her space. This was when we had company over at Christmas. Nobody else gets their own area. I look at it so that all of us can have a nice time together and I do it by making sure her needs are taken care of first. Then the rest of us fit in around her needs.”

### **Costly for Mother, Beneficial for Child**

- “We didn’t go on a trip because he didn’t like the other people going on the trip. As a result, we decided not to go at all.”
- “My social interaction with peers has stopped. I wanted to bring him home to provide more recreational/social activities. I am required to have him out of the group home 2 weekends each month. I take him at least one more time.”
- “We hold back from doing certain social activities because we have her on Sundays. We would golf with more people on Sundays. If there are any activities, we can’t participate. This is more than we anticipated.”
- “It’s gone on forever. I miss church on weekends when I have him. If I have season tickets or whatever I have to miss when he is home. I juggle. He gets rigid so it is hard. We just do what he wants when he’s home.”
- “Since she lives away from home she doesn’t want to socialize with other friends on visits. She gets stubborn to the point that we can’t go out and do anything. The older she gets, the more inflexible she gets.”

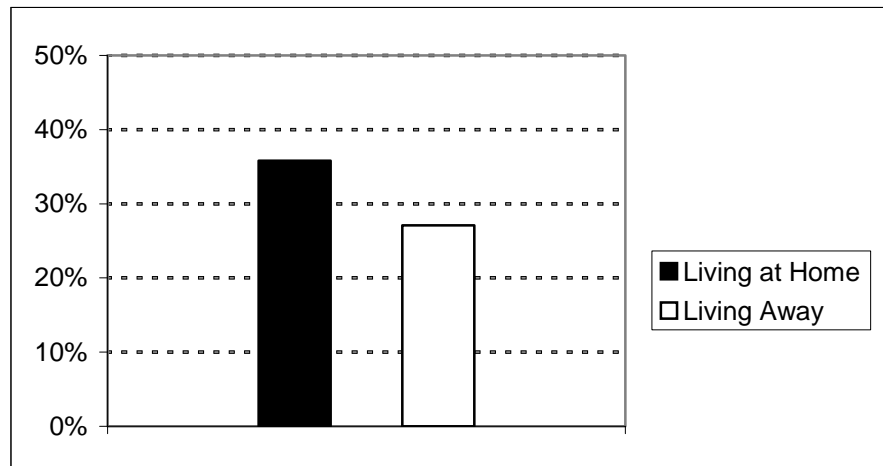
## Work

Next, we asked about changes in work:

*“During the past 18 months, have you made any changes or accommodations **in your work situation** to accommodate to your son or daughter’s needs, such as the schedule or number of hours worked?”*

As shown in Figure 7, 36% of mothers whose son or daughter with an ASD lived at home had made accommodations in their work situations. In contrast, this was true for 27% of the mothers where the son or daughter with an ASD lived away.

**Figure 7. Percent of Families Making Changes in Work**



As seen in Figure 8, 84% of all these accommodations were considered beneficial for the person with an ASD. Less than half were rated as beneficial for the whole family or for the mother herself. Almost 20% were rated as neutral in their perceived impact of the family. Eight percent reported that the accommodations were costly to the son or daughter with an ASD. About one third rated their work accommodations as costly to the whole family. And 53% responded that the changes made in their work situations were considered costly to the mother herself.

**Figure 8. Mothers' Perceptions of the Effects of Changes in Work**

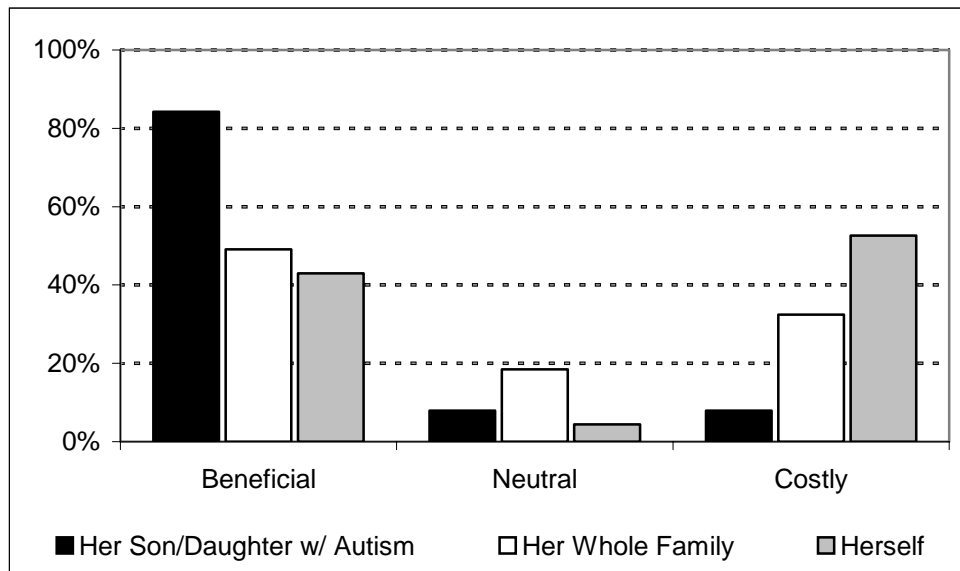
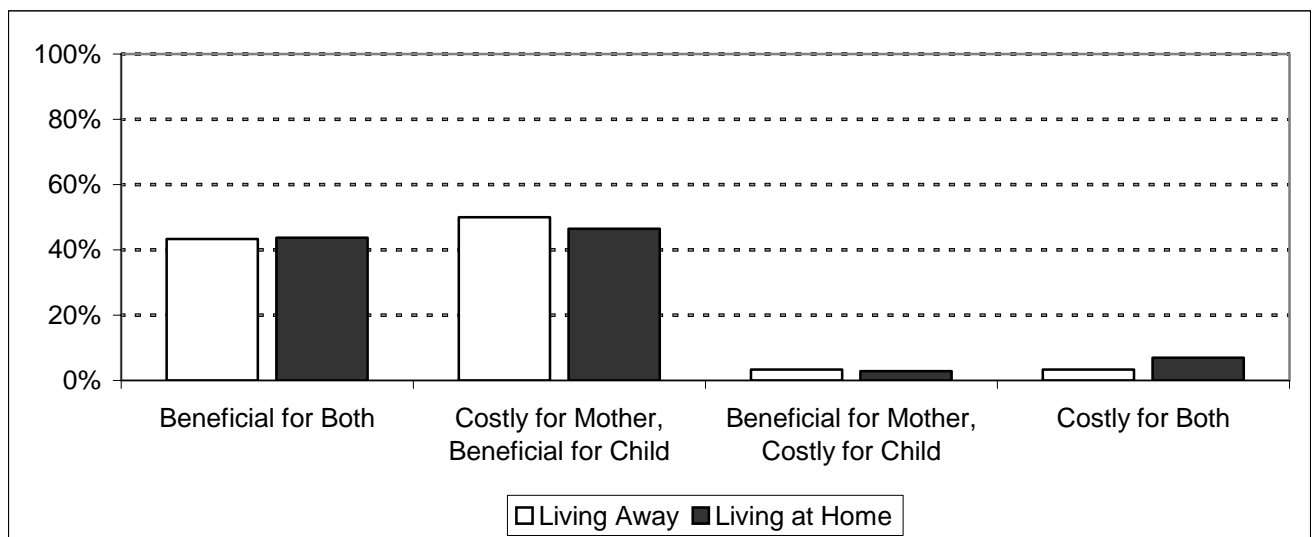


Figure 9 displays the balance of costs and benefits. About 43% of mothers who had made a work accommodation assessed it as mutually beneficial for herself and her child with an ASD. However, half saw the changes as beneficial for the son or daughter with an ASD but costly to herself. There were very few families where a work accommodation was seen as costly for the child.

**Figure 9. Perceived Benefits and Costs.**



## **Examples of Accommodations in Work Situations (Son or Daughter Living at Home)**

### **Beneficial for Both**

- “I now work evenings so that I can accommodate her schedule better. I make better money and I get a break in the evenings and I know she is being cared for.”
- “I go to work earlier and leave earlier to pick him up at school because he hates the bus.”
- “I have gone from full-time to part-time work so I can get him to jobs and appointments. I can take care of things more promptly and I’m not so stressed and rushed in the mornings.”
- “I started working because the kids are more independent. It allows them to be independent. I went to work to have a fuller life for myself.”
- “I refuse to go in and work more hours when they ask me. I don’t like to leave him alone. I am accommodating his needs by being more available to him.”
- “I switched from the day shift to the graveyard shift. This allows me to accommodate his schedule better and I am so much more relaxed now.”
- “We got a paper route so our son could have something to do and I could make a little extra money.”

### **Costly for Mother, Beneficial for Child**

- “We are both working more hours. The bills are high. We lose a lot of money to pay her medical bills so we have to work harder to have enough for the family. I had to change my hours to be with her right after school and other times when she can’t manage to be home alone.”
- “When he is having a hard day the school will call me and I have to take him home. This means I have to leave work. I often have to work on Saturdays to make up the time to accommodate his needs of getting home and having someone to stay with him.”
- “I’ve had to reduce my hours and my pay because he needs so much care. He can’t be alone with his sister anymore because of his aggression. We can’t afford for me to do this but there is no alternative.”
- “I am only able to work on school days during the academic year now. I can’t work in the summer or during school breaks. I lost my benefits because of this change.”
- “I went from working days to nights. She needs me available to her but I can’t afford to miss any work. Night shifts are hard because I am always tired. It is hard to get a break.”



## **Examples of Accommodations in Work Situations (Son or Daughter Living away from Home)**

### **Beneficial for Both**

- “Switched from full-time to part-time in order to meet the needs of my ill spouse and my son. When he visits I want to be available to him.”
- “I changed my schedule and sometimes work fewer hours to get to meetings for him. I was afraid my boss would be difficult but she understands that family comes first.”
- “I took time off from work when he was having major surgery. I was able to take family leave and didn’t lose my job.”
- “I now work from home in the evenings and on weekends. My work was reluctant at first but it has worked out so far. This is easier because if she needs me I can be there right away and I can also visit during the days.”
- “I no longer work weekends and now that is his time. He is happier when I can just be with him when he visits.”

### **Costly for Mother, Beneficial for Child**

- “Taking time off to meet with doctors, residential counselors, and vocational counselors. Taking him to more doctor appointments. Switched jobs and increased hours so it is harder to schedule appointments during non-work hours. Now have to take increased leave from work. But at least I am doing it and I have sense of what he needs.”
- “Since her services have been cut I now have to provide most of the transportation. This interferes with my work on an almost weekly basis. He gets where he needs to go but I am so stressed that I am not very pleasant when I have to transport him.”
- “I am the only person who can calm her down. The group home calls me whenever there is a problem and I am expected to talk with her or come over to resolve outbursts. My work is growing tired of these unpredictable absences.”

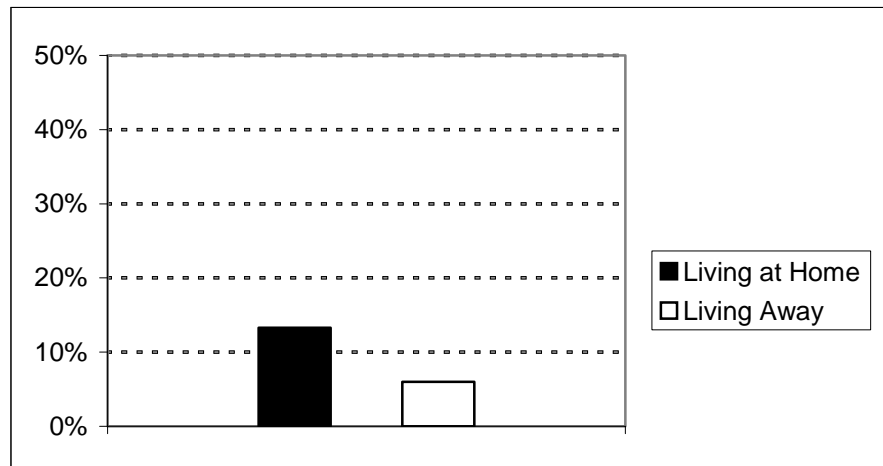
## Participation in Religious Activities

Next, we asked about changes in participation in religious activities:

*“During the past 18 months, have you made any changes or accommodations in your participation in **religious activities** to accommodate to your son or daughter’s needs?”*

Figure 10 illustrates that 13% of families where the person with an ASD lived at home had made accommodations in their religious activities. However, this was true for only 6% of the families where the son or daughter with an ASD lived away.

**Figure 10. Percent of Families Making Changes in Religious Activities**



As seen in Figure 11, 70% of accommodations in religious activities were assessed as beneficial for the person with an ASD. About one third were rated as beneficial for the whole family, and about one half for the mother herself. About 20% were rated as neutral in their perceived impact of the family. Sixteen percent reported that the accommodations were seen as costly to the son or daughter with an ASD. Nearly one half rated their religious accommodations as costly to the whole family. And 32% responded that the changes made in their religious activities were considered costly to the mother herself.

**Figure 11. Mothers' Perceptions of the Effects of Changes in Religious Activities**

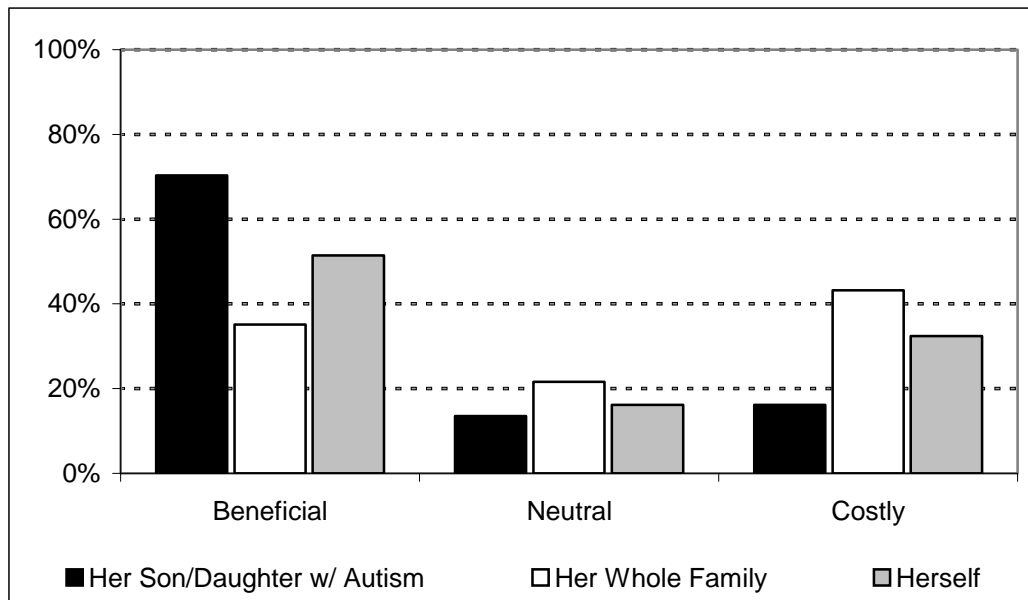
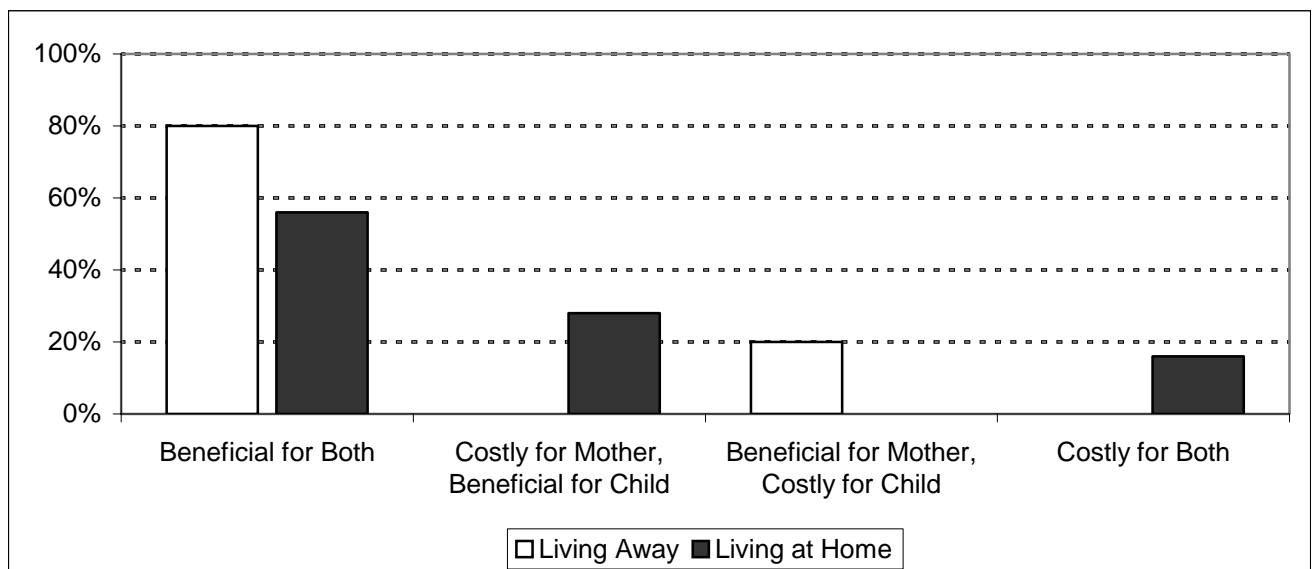


Figure 12 displays the balance of costs and benefits. Eighty percent of mothers with a child living away from home assessed their religious accommodations as mutually beneficial for herself and her child with an ASD. This was true for 56% of mothers with a child living at home. None of the families with a child living away made accommodations in religious activities that were seen as costly for the mother or for both. About one quarter of families with a child living at home had made an accommodation that was seen as costly for the mother and beneficial for the child.

**Figure 12. Perceived Benefits and Costs.**



## **Examples of Accommodations in Religious Activities (Son or Daughter Living at Home)**

### **Beneficial for Both**

- “My other kids now sit with friends at church so they don’t have to worry about what she’ll say or do. They also go with a friend to lunch after church because she always insists on going to Einstein’s after church and my other kids are sick of this same routine. It’s nice that they are older and can do things with friends now.”
- “Attending church services now because our son wants to. Since he has expressed an interest his behaviors have improved. We even have a shadow for him so that we can focus on the service and not have to worry about him.”
- “We were all going to church together but this got to be too much. Now he stays home with his dad and they rest of us go. The guys enjoy their Sunday time while the rest of us can go to services.”
- “We switched to the children’s service instead of the regular adult service. We can all get something out of it and it is a much more relaxed atmosphere.”
- “She wants to attend more functions. We have help so she can interact with others her age. Now we all go to church most days.”

### **Costly for Mother, Beneficial for Child**

- “We don’t go to church as a family anymore. I used to teach religious education classes, bell choir, Bible study, and work in the food pantry. It is just easier not to but I miss it.”
- “We quit going because of the way our children were treated. While I love going to mass, I can’t allow my children to be ridiculed.”
- “I had to go back to teaching his special needs religions education class because the teacher left. I don’t get a break from him. I no longer get to go to church and I have a lot of preparation for the class.”
- “Stopped going. Too much. Difficult to get her up and going and to maintain behavior.”
- “If he doesn’t want to go, we don’t go. Period. The consequences are too great otherwise.”

## **Examples of Accommodations in Religious Activities (Son or Daughter Living away from Home)**

### **Beneficial for Both**

- “Changes to both ourselves and our staff so staff can go to church. We go to different services so he always has supervision.”
- “When we visit now I take him to the chapel and I’ve got him making the sign of the cross. We just go to chapel now.”
- “I changed the time that I call him, which was 11am on Sundays, so that I can go to church.”
- “We’ve developed a relationship with the new minister to come over and work with her on Sunday afternoons when she is home visiting.”
- “We have to pay someone to watch her while we go to church. This adds up but it’s worth it. It makes the whole day better.”
- “Since I only have him once a month we don’t worry about going. We have our little family service that lasts about 10 minutes. It works.”

### **Costly for Mother, Beneficial for Child**

- “He has to be out of the group home on Sundays so I can’t fulfill my previous duties. The home won’t make any exceptions.”
- “I now go to services with him at the group home. He likes this but I am now completely cut off from any support for myself.”
- “We now go into the crying area and this is disruptive to the young mothers in there. I can’t find any other options other than not going.”
- “We stay home now. My husband watches it on TV and our son plays video games. It’s not the same for me on TV. I miss the social part of church.”

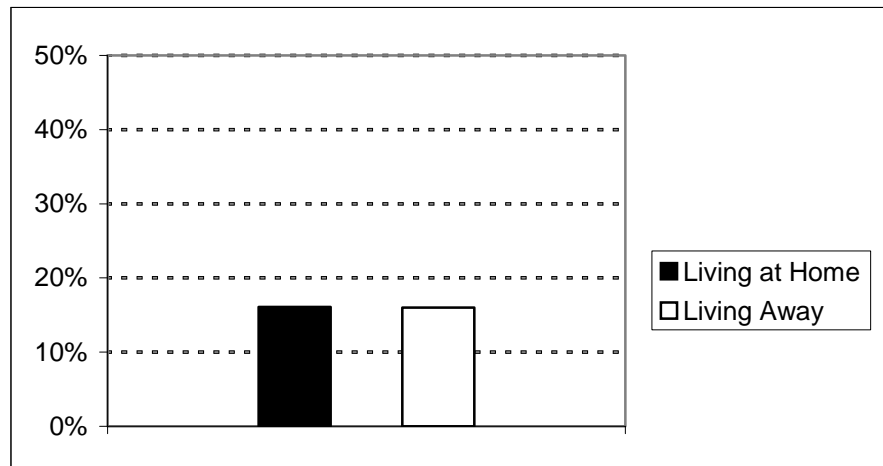
## Contact With Extended Family Members

Next, we asked about changes in contact with extended family members:

*“During the past 18 months, have you made any changes or accommodations in your contact with extended family members to accommodate to your son or daughter’s needs?”*

Figure 13 illustrates that 16% of families where the person with an ASD lived at home, and 16% those where the son or daughter lived away, had made accommodations in their contact with extended family.

**Figure 13. Percent of Families Making Changes in Contact with Family**



As seen in Figure 14, two thirds of accommodations in family contact were assessed as beneficial for the person with an ASD. About 60% were rated as beneficial for the whole family, and about one half for the mother herself. Very few were rated as neutral in their perceived impact. Eighteen percent reported that the accommodations were seen as costly to the son or daughter with an ASD. One third rated their family contact accommodations as costly to the whole family. And 46% responded that the changes made in their contact with extended family members were considered costly to the mother herself.

**Figure 14. Mothers' Perceptions of the Effects of Changes in Family Contact**

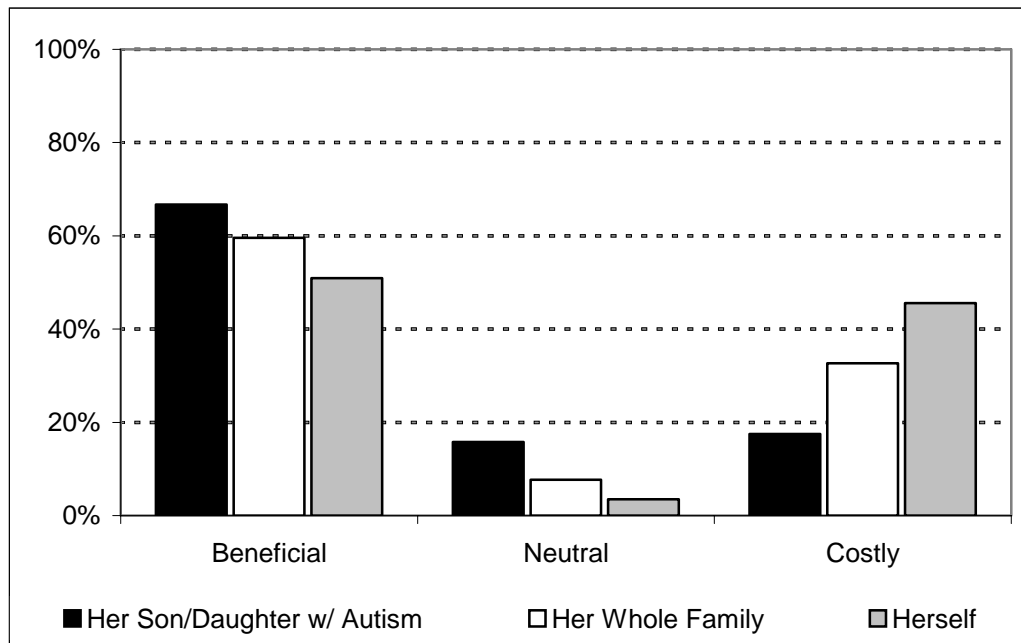
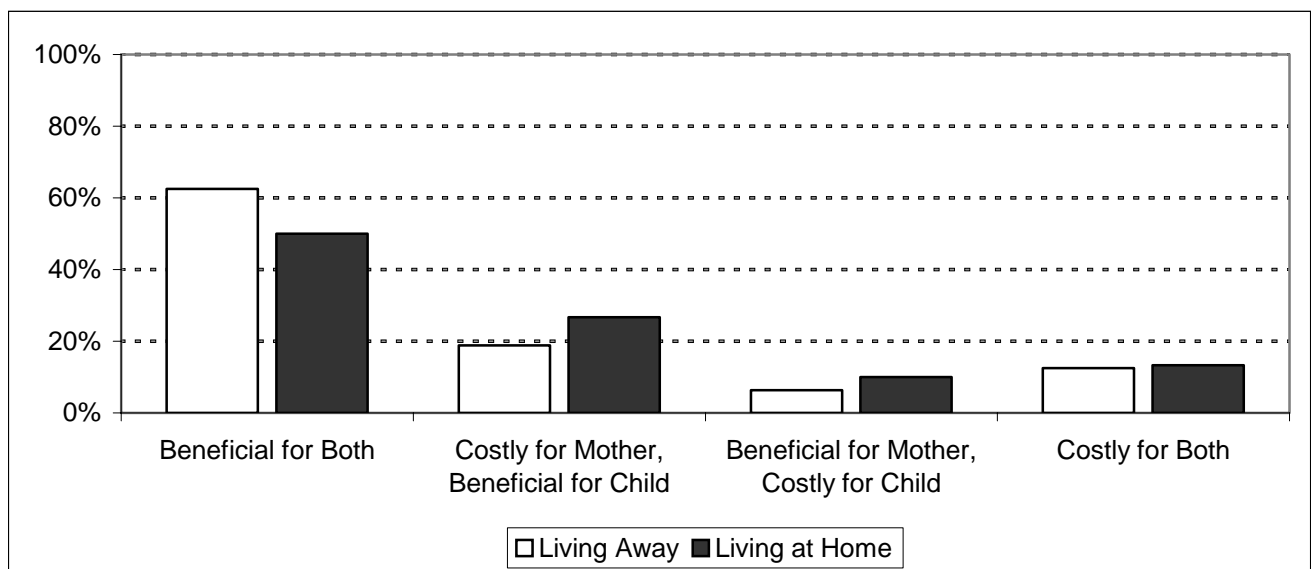


Figure 15 displays the balance of costs and benefits. Sixty three percent of mothers with a child living away from home assessed their family contact accommodations as mutually beneficial for herself and her child with an ASD. This was true for 50% of mothers with a child living at home. Between 19% and 27% of mothers saw their changes in family contact as a tradeoff – beneficial for the person with an ASD, but costly for herself.

**Figure 15. Perceived Benefits and Costs.**



## **Examples of Accommodations in Family Contact (Son or Daughter Living at Home)**

### **Beneficial for Both**

- “Trips to grandma’s and grandpa’s are different. We’ve made the trips shorter because he can’t handle it. We just go more often.”
- “I have to ask family members not to let out too much information about an event until it is set in stone. Otherwise, he worries about it and is upset if it doesn’t take place. This makes it easier for all of us.”
- “We took a vacation with just three of us. She stayed with her sitter and went to school. She stayed back so her routine wouldn’t be changed. We had a nice time being away and she liked being at home where she is most comfortable.”
- “We call her sister more often. She adores her sister and calls her a lot, even when I know she isn’t home.”
- “We have set up more trips to go to the cabin with her grandfather. It takes a great deal of time to set this up but she loves it and we all are a little more relaxed.”
- “We now have more help so we take someone along to family events and then we can all have fun.”

### **Costly for Mother, Beneficial for Child**

- “We are unable to do large family functions. I grew up in a large, close-knit family so this is hard for me.”
- “We have less contact with family since he has gotten more aggressive. We avoid them because it can be so embarrassing.”
- “I don’t feel free to leave. I would have gone to visit my brother with cancer or visit my mother but it just requires too much planning.”
- “My family likes to visit to see her but when they are here they disrupt routines and create chaos...and then they leave. It takes days for her to get back to herself and to get back into her routines.”



## **Examples of Accommodations in Family Contact (Son or Daughter Living away from Home)**

### **Beneficial for Both**

- “We try to assist him in being able to see family. We occasionally take him over to see grandparents or take grandparents to see him. With his improvement, visits are more positive.”
- “When he moved in with another family member this increased contact with the extended family.”
- “I wanted him to have contact with other family members so his sister goes to visit every weekend when we can’t.”
- “When we can’t do something with him his brother now will take him at the scheduled times so he doesn’t have to stay in the group home on the weekends. We have asked this son to be his guardian and to keep up with his life.”
- “We juggle what we do and whether or not we include him. Since we have him on alternating weekends we are able to make decisions pretty easily.”
- “I have recently sought more family support. One of our other sons, a lawyer, is helping us with ADA issues and guardianship issues. This has made a big difference.”

### **Costly for Mother, Beneficial for Child**

- “Family relationships are poor. It’s better for her (daughter with autism) but hard for me. None of us asked for this.”
- “We often choose to stay home on his weekends rather than go to family events.”
- “I don’t know what to do. He won’t go so I can’t go.”

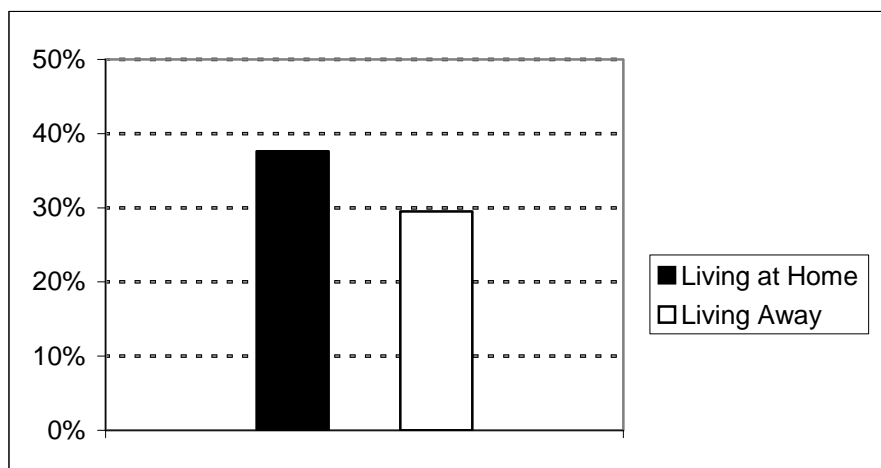
## Finances

Lastly, we asked about changes in finances:

*“During the past 18 months, have you made any changes or accommodations in your **finances or financial planning** to accommodate to your son or daughter’s needs?”*

Figure 16 illustrates that 38% of families where the person with an ASD lived at home had made accommodations in their finances. Thirty percent of families where the son or daughter lives away had made financial changes.

**Figure 16. Percent of Families Making Changes in Finances**



As seen in Figure 17, 73% of financial changes were assessed as beneficial for the person with an ASD. About half were rated as beneficial for the whole family and for the mother herself. Just over 20% were rated as neutral in their perceived impact on the person with an ASD. Eighteen percent reported that the accommodations were seen as costly to the son or daughter with an ASD. And 33% responded that the changes made in their finances were considered costly to the family, 38% to the mother herself.

**Figure 17. Mothers' Perceptions of the Effects of Changes in Finances**

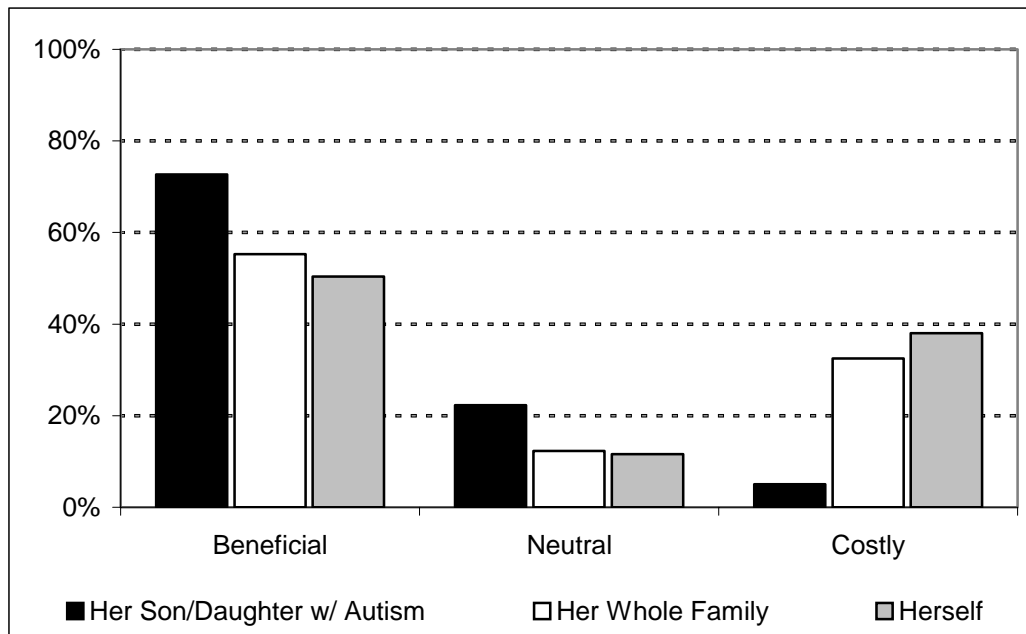
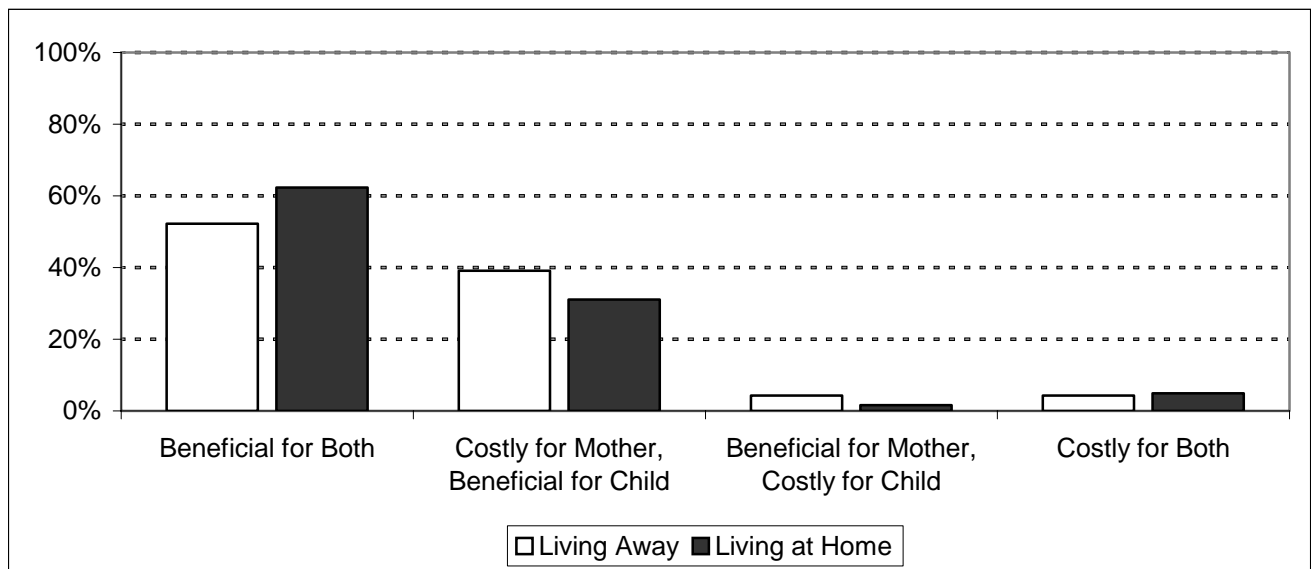


Figure 18 displays the balance of costs and benefits. One half of mothers with a child living away from home assessed their financial accommodations as mutually beneficial for herself and her child with an ASD. This was true for 62% of mothers with a child living at home. Between 31% and 39% of mothers saw their changes in family contact as a tradeoff – beneficial for the person with an ASD, but costly for herself.

**Figure 18. Perceived Benefits and Costs.**



## **Examples of Accommodations in Finances (Son or Daughter Living at Home)**

### **Beneficial for Both**

- “First of all, we are now her personal care workers. This has assisted in financial security. We can be home with her and we’re caring for her anyway, so it’s benefited her and us financially. A great deal of financial funds have gone to taking her places, meetings, interviews, cost of clothing, and gas.”
- “Zeroing in on retirement—end result is what are her long-term needs—looked at some additional investments and a trust and will so she will be cared for.”
- “We pay for more services out of pocket but at least we can get them. It’s amazing how easy it is to get respite if you can pay for it.”
- “We have applied for and received additional aid. We no longer cover his expenses because if we don’t the state will have to do so. This was hard at first but was the only way we could get any help.”
- “Our daughter started getting SSI. This has made a world of difference.”
- “We now have more life insurance for him and a retirement account for us.”

### **Costly for Mother, Beneficial for Child**

- “I pay for cranial therapy, yoga, and job coaches. The county cut back on care expenses. I paid for part of the car and the upkeep of it. This car is new. The county no longer pays for transportation services.”
- “Because of a job loss we are having to accept help from family. These are tough times with a lot of help. He still gets what he needs but we are borrowing to provide it.”
- “We are having to pay for so much more out-of-pocket. It is getting to be too much.”
- “The change in the economy has hit us pretty good. She still needs services but the wallet is tight right now. We have given up most everything for her.”

## **Examples of Accommodations in Finances (Son or Daughter Living away from Home)**

### **Beneficial for Both**

- “We bought him a house and furniture. It was the only solution we could see to facilitate transition.”
- “We changed our will and trust. His trust is now part of the AFC Community Trust. He should be well cared-for later in life.”
- “We have put money in a trust for her. We’ll have to work longer to build up this trust so she can live as she does now, but at least we are able.”
- “Increased a trust. I always update my will when I go to Europe in case I should die. Also, initially we could only put \$10,000 into a trust without penalty. Now we can do higher amounts.”
- “His caretaker is taking an extra day each month to be with him and we’re paying for it. When we took a week’s vacation, she stayed with him and we paid all the costs. It was worth it for us.”
- “We saw a lawyer. We made out wills and made arrangements for someone to oversee him. We asked his sister to be his guardian.”

### **Costly for Mother, Beneficial for Child**

- “I need to cut my hours because I just can’t do it anymore but he has too many expenses. What does the county expect families to do?”
- “We took out a second mortgage to pay for some of his expenses. The county is scaling back.”
- “We will be working much longer than we hoped. The money has to last for her so we need to keep saving.”
- “We had to accept help from our other children to pay for his expenses. This was the hardest thing I have ever had to do.”

## **Heading Off Difficulties**

Many families have told us about ways they try to head off or avoid problems by anticipating the needs of their son or daughter with an ASD. We wanted to understand this more closely so we asked the following question:

*We are interested in learning about the strategies you use to head off or avoid difficulties by anticipating the needs of your son or daughter. Could you tell us what kinds of things you do to anticipate your child's special needs in order to maintain a workable day-to-day family life?*

Here are some of the answers we received:

### **Son or Daughter Living at Home**

- “We keep the same routines every day, going in the right order. We keep close relationships with the school transportation system. We work together and wait for him. We use more detailed charts from school for foreshadowing. We allow extra time for the store. I only shop on two specific nights per week, when I know the clerks. With a couple of close friends we can foreshadow the environment and plan ahead to get together.”
- “Make sure that the things that she needs are there. I can tell when she is stressed and I can do things to calm her down and divert the others. I’m like a traffic cop! We try to get out, do something silly to blow off steam.”
- “Foreshadowing. Talk about the events to come, especially unusual ones. For example if we are going to the Y we talk about it the day before and the day of the outing. We set out the swimsuit and show pictures of where he is going. We talk about his friends who will be there. This is all for a change in routine.”
- “Talk about things. When he starts to get upset, change the subject. Smile more. The morning dictates how the day is going to go. Try to turn negative things into positive and to stop the negative spiral.”
- “We have to anticipate his needs to follow a schedule. We have to stick to the schedule. We can’t over-stimulate him. We have to watch his TV programs. We have to make food he likes. We have to leave the living room at night if he decides

to sleep on the couch. We have to watch him everywhere we go. We have to lock doors. We have to turn off lights when he wants them off.”

- “The calendar helps a great deal. Makes him aware of what is coming up. Medications have, of course, been a big help.”
- “It’s been an evolution kind of thing. We’ve learned to take subtle cues on what kind of day he’s having. So things change from day to day depending on his mood for the day.”
- “Make sure she’s not hungry. Give her a lot of warning if we need to do something. When traveling, we take her things with us. We keep her comfortable and occupied.”

### **Son or Daughter Living away from Home**

- “Foreshadow whenever possible. We explain what is expected in different situations. She doesn’t like surprises. We’re pretty much available to her to talk to us or we go over there.”
- “With her being on her own, we don’t have many accommodations to make. Most of all that has been taken away. It’s stress-free living.”
- “I watch what I buy when I know he’s coming. I put away things that may cause problems, like I lock the bathroom door and put away my purse.”
- “I have to think about what he needs. I manage his finances. I have to make sure his bills are paid and his extracurricular programs are paid for.”
- “A lot of foreshadowing—tell him what will happen in advance, what we’ll do, who we’ll see, and the like. Make sure if he’s with someone else that he has his boom box, tapes, pineapple sherbet, and extra clothes.”
- “Don’t go anywhere noisy. Stay home when he visits. Keep it calm and quiet.”
- “I do whatever he wants. I take him out to eat and I take him on walks because that’s what he likes.”
- “I always have to plan ahead.”

## **Section III: Conclusions**

This report has presented information about the kinds of changes families make in order to accommodate to the special needs of their family member with an autism spectrum disorder, and the perceived impacts of those changes.

Changes in household routines, social activities, and work were the most frequently reported types of accommodation. Changes in finances, religious activities and contact with extended family were less frequently reported.

Almost all types of accommodations were seen as mutually beneficial for the mother and the person with an ASD. The exception was changes in work. For this area of family life, a higher percentage of mothers saw their accommodations as a tradeoff – beneficial for the son or daughter with an ASD, but costly for the mother.

Every type of accommodation had some mothers reporting this type of tradeoff. This perception was most common among families making changes in work situations and household routines. It was least common in the areas of contact with extended family and participation in religious activities.

We hope the quotes from interviews capture the range of creativity and dedication families bring to the task of trying to build lives that work for them. Some families are able to find routines that work for everyone. Other families go through periods of sacrifice where the needs of one person may be met at the expense of another's.

Again, we wish to express our gratitude to all the families participating in this study. Your willingness to share your insights and experiences is helping to portray what family life is like when it includes a person on the autism spectrum.