

AAA

Adolescents & Adults with Autism A Study of Family Caregiving



Report #19 Impact of The Great Recession on Autistic Adults and their Mothers

- Principal Investigators -

**Marsha R. Mailick, Ph.D.
Leann S. DaWalt, Ph.D.**

**Waisman Center
University of Wisconsin - Madison**

Acknowledgements

This work was supported by the National Institute on Aging (R01 AG08768) and the National Institute on Child Health and Human Development (P50 HD105353; T32 HD007489). We gratefully acknowledge support from the Waisman Center at the University of Wisconsin – Madison.

We especially acknowledge the families who have devoted their energy and time to this research. This would not be possible without your dedication. We also thank the Lifespan Family Research staff for their efforts on this project.

We credit Emily Hickey and Kate Szidon for their important contributions to this family report.

The full citation for the manuscript from which this report was prepared is: Hickey, E. J., Smith DaWalt, L., Bolt, D., Hong, J., Song, J., Lounds Taylor, J., & Mailick, M. (in press). The impact of the great recession on autistic adults and their mothers. *American Journal on Intellectual and Developmental Disability*.

Cover Art: *A Person Making Frames* by Phil Gazzolo from the Arts of Life program in Glenview, Illinois. T. 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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Section I: Introduction

Your continued participation in the Adolescents and Adults with Autism (AAA) study over the past two decades has provided valuable information on the development and experiences of people with autism spectrum disorder (ASD) and their families across the lifespan. We remain very grateful for your support, interest, and commitment to advancing knowledge about autism and family life.

In this report, we are very pleased to share with you some recent findings from the AAA study. Here we report on our work aimed at understanding the impact of the Great Recession of 2007-2009, a significant economic disruption, on individuals with autism and their family members. This particular work draws on information provided by mothers about the well-being of their son or daughter with autism and about themselves.

For this report, we analyzed eight waves of AAA data collected between 1998 and 2014 to determine how the Great Recession impacted the *physical health, problem behavior, vocational independence, and residential status* of individuals with autism, and the *physical health, depressive symptoms, and employment status* of their mothers. Results point to specific areas of vulnerability of individuals with autism and their mothers during the economic downturn, as well as a broad pattern of resilience in these families.

We hope that you will find this report to be interesting, and that these findings will inform public policy, interventions, and services to improve supports for adults with autism and their families.

Section II: Background on The Great Recession and its Broader Societal Impact

According to the US Federal government, the Great Recession spanned 22 months from December 2007 through September 2009. In the general population, many individuals and families in the United States experienced substantial negative impacts following the Great Recession including:

- Earnings and employment losses, totaling 8.1 million jobs lost.
- Unemployment rate rose to twice the pre-Recession rate to 10.0% (15 million U.S. residents).
- One in four U.S. households were in debt by the end of 2011.

The Recession also impacted family life. Several studies noted pervasive effects on mental and physical health and well-being during the Recession. In particular, adult children in the general population were more likely to live with their parents during the Great Recession and some parents with a newly co-residing adult child experienced an increase in depressive symptoms relative to their peers.

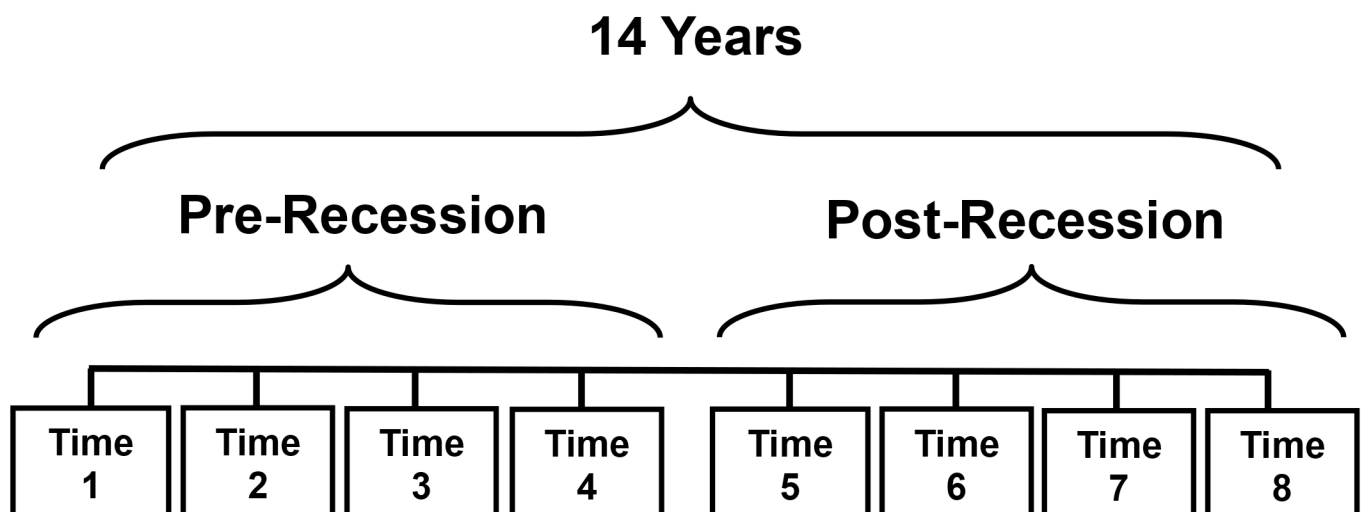
Yet little is known about how the Recession specifically impacted individuals with autism and their parents, some of whom already may be experiencing challenges with employment, health, and mental health. Thus, these families may be more likely to experience potential long-term effects of broader financial shifts. For individuals with autism and their families, impacts from the Recession may further amplify pre-existing health and financial issues over time.

Understanding the impact of the Great Recession on individuals with autism and their families may help to pinpoint what types of services and supports might be needed during other disruptive societal events. Notably, in this research we also sought to understand areas of strength and resilience among individuals with autism and their families.

Section III: Description of Study Participants and Data Used

Using eight waves of data from our longitudinal study collected over 14 years, we studied changes in the following variables: *physical health*, *problem behavior*, *vocational independence*, and *residential status* of individuals with autism. We also studied changes in the *physical health*, *depressive symptoms*, and *employment status* of their mothers.

To do this, we compared data from four time points that were obtained through interviews with family members that were conducted prior to the Recession, to data from four time points that were obtained during or after the Recession. The first four time points of data were collected between October 1998 and February 2005 during the “pre-Recession” period, and the final four time points of data were collected between October 2007 and May 2014, during the “post-Recession” period.



As we have reported before, at Time 1, the individuals with autism averaged 21.9 years of age. Approximately three-fourths (73.2%) were male. Just over two-thirds (70.6%) had a co-occurring intellectual disability.

Mothers ranged in age from 32.3 to 81.9 years at Time 1, with an average age of 51.2. The majority (92.6%) were White/Caucasian. Almost half (45.1%) of mothers in the sample had an Associate’s or Bachelor’s degree. Three-fourths were married (75.9%) and the median household income of the sample was between \$50,000 and \$60,000 at Time 1.

Section IV: Impact of the Great Recession on Individuals with Autism and Their Mothers

We compared the pre- and post-Recession variables to determine if there was a significant **change in the level** of each variable at the time of the Recession, or if there was a significant **difference in the trajectory** of each variable when comparing pre- to post-Recession. By “change in the level” of a variable, we are comparing the level of the variable from just before to just after the Recession. By “difference in the trajectory” of a variable, we are comparing the pattern of changes that occurred before the Recession to the changes that occurred after.

In other words, we wanted to determine if there were increases or decreases in a variable before the Recession, followed by a different pattern after the Recession. All variables were measured at each of the eight time points. Age of the individual with autism at Time 1 and whether or not they had a co-occurring intellectual disability was statistically controlled in all analyses. When there were statistically significant changes in a variable, we illustrate the change with a graph.

Recession Impacts on Individuals with Autism

Physical health was reported by mothers by responding to the following question: “In general, would you say your son/daughter’s physical health is excellent, good, fair, or poor?” (1 = *poor* to 4 = *excellent*). The data indicates that physical health was an area of resilience as there was no significant change in the level of *physical health* of individuals with autism at the time of the Recession, nor a significant difference in the pattern of change from pre- to post-Recession.

Problem behavior was measured using the Behavior Problems subscale of the Scales of Independent Behaviors-Revised. This subscale measures problem behavior, grouped into three domains: internalized behaviors (hurtful to self, unusual or repetitive habits, withdrawal or inattentive behavior), externalized behaviors (hurtful to others, destructive to property, disruptive behavior), and asocial behaviors (socially offensive behavior, uncooperative behavior).

Mothers who indicated that their son or daughter displayed a given problem behavior during the past 6 months then rated the frequency (1 = *less than once a month* to 5 = *1 or more times/hour*) and the severity (1 = *not serious* to 5 = *extremely serious*) of the behavior. The overall problem behavior score at each time point was used in the present analyses. Scores range from 0 to 170, with

higher scores indicating more severe problem behavior, and scores of 110 or above considered to be indicative of clinical levels of problem behavior.

As shown in the graph, there was a significant **change in the level** of *problem behavior* of individuals with autism at the time of the Recession (indicating that problem behavior worsened), as well as a significant **difference in the trajectory** from pre- to post-Recession.

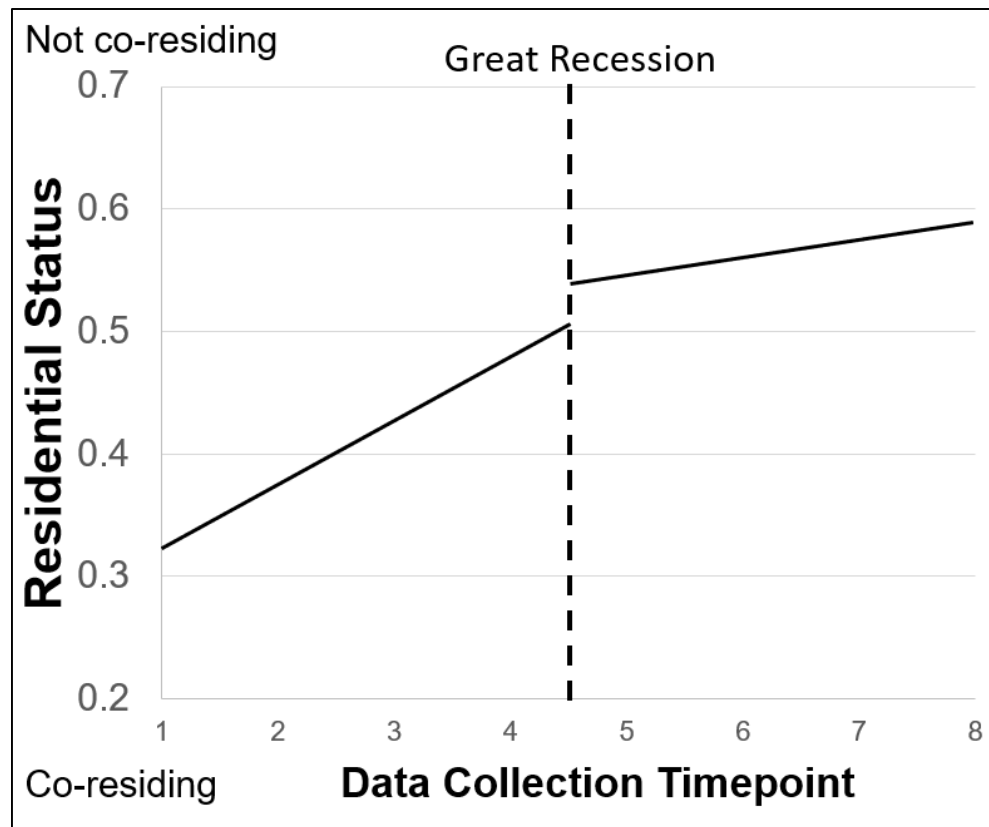


- *Problem behavior* **was improving** before the Recession
- *Problem behavior* **worsened** at the time of the Recession
- Following the Recession, *problem behavior* remained flat (in other words, was **no longer improving**)

Vocational independence was measured with the Vocational Index. This index, developed in 2012 by our research team, is used by many researchers to categorize the vocational and post-secondary educational activities of the individuals with autism. Based on information you provided during the AAA interviews, we coded this index into categories ranging from 1 (no vocational/educational activities) to 9

(degree-seeking post-secondary education program or employment in the community without supports greater than 10 hours a week). A higher score indicates a higher level of independence. Vocational independence was another area of resilience, as there was no significant change in the level of *vocational independence* of individuals with autism at the time of the Recession, nor a significant difference in the pattern of change from pre- to post-Recession.

Residential status was reported by mothers who described the living situation of their son or daughter. At each time point, mothers indicated whether their son or daughter with autism was living together with family (i.e., co-residing) or not. Before the Recession, individuals with autism were increasingly more likely to live separately from their mothers. This trend continued after the Recession, but at a slower rate.



- Before the Recession, there was an **increasing** percentage of adults with autism living separately from their mothers.
- Following the Recession, the trend toward living separately **continued, but the trajectory slowed**.

Recession Impacts on Mothers

Physical health was self-reported by mothers. Mothers were asked a single question, “In general, would you say your physical health is excellent, good, fair, or poor?” (1 = *poor* to 4 = *excellent*). There was no significant change in the level of *physical health* of mothers at the time of the Recession, nor a significant difference in the patterns of change from pre- to post-Recession. Again, this is an indicator of the resilience of mothers during the Recession.

Depressive symptoms of mothers was measured using the Center for Epidemiological Studies–Depression Scale. For each of 20 depressive symptoms, mothers were asked to indicate how many days in the past week each symptom was experienced from 0 = *never* to 3 = *5 to 7 days*. Scores range from 0 to 60, with higher scores indicating higher levels of depressive symptoms, and a score of 16 or higher indicating clinical levels of depressive symptoms. Although mothers’ level of depression was declining before the Recession, there was a significant **change in the level** of mothers’ *depressive symptoms* at the time of the Recession, as shown in the graph below.



- Mothers' depressive symptoms **became more severe** at the time of the Recession
- As can be seen in the graph, by the last point of data collection (Time 8), the level of depression symptoms of mothers was nearly as low as it was just before the Recession. This possibly suggests a pattern of recovery after the initial stresses of the Recession.

Mothers' employment status was measured on a 3-point scale (0 = *Not employed*, 1 = *Employed seasonally or part-time*, and 2 = *Employed full-time*) at each time point. There was no significant change in mothers' *employment status* at the time of the Recession, nor a significant difference in the pattern of change from pre- to post-Recession. Mothers' employment status was yet another indicator of resilience of families whose son or daughter had autism.

Section V: Summary of Findings

Resilience

The findings of the present study suggest two overall longitudinal patterns: resilience and vulnerability. First, there was a pattern of stability and *resilience* from before to after the Recession. Fortunately, the physical health of individuals with autism and their mothers were not negatively affected by the Recession.

Employment was another area of resilience, as there also were no significant changes in the level or trajectory of the vocational independence of the adults with autism or the employment status of their mothers from pre- to post-Recession.

Stable physical health and employment are two of the most important areas of quality of life for adults with autism and their families. Credit for these patterns of resilience may be due to the safety net provided by families and by the service system, an important focus for future research.

Vulnerability

On the other hand, there was a second pattern of *vulnerability*. In regards to mental health of the adults with autism, our results showed a significant increase in problem behavior at the time of the Recession as well as a significant increase (worsening) in the trajectory of problem behavior in the years following the Recession. Even under stable conditions, behavior problems of adolescents and adults with disabilities such as autism tend to improve over time. When there is instability, such as the Recession, those trends in improvement are difficult to sustain. This finding has important implications for service provision during major economic events. It is important for service agencies to provide and perhaps re-evaluate the needs of individuals with autism for behavioral supports during these challenging time periods and in the years that follow.

There was also an increase in mothers' depressive symptoms at the time of the Recession. This is consistent with previous research in the general population and suggests that services may need to be targeted not only to youth and adults with autism but also to their family system, as parents may also be at risk for depression during economic crises.

In regards to residential status, adults with autism in the current sample were moving away from their parents' home at a slower rate in the years after the Recession than in the years prior to the Recession. Previous research has documented that as individuals with autism age, they are more likely to live away from their parents' home. Our data was in line with these previous findings in the years before the Recession, with the number of adults *not* co-residing with families increasing over time. However, after the Recession, these individuals were moving out of the parental home at slower rates. This finding has important implications for supports for individuals with autism during national crises, as it is possible that adults with autism may be co-residing with their parents for a longer period than originally anticipated. Individuals with autism and their families may need additional financial and/or independent living supports during these times of transition.

Section VI: Conclusions and Future Directions

Behavior problems was the primary area of vulnerability associated with the Recession for adults with autism. The Recession disrupted the gradual improvement in behavior problems that was occurring before the Recession. Further, there were clear disruptions in residential arrangements during this time. In a sense, the Recession “put the brakes” on the gains that were being made previously.

These findings suggest that individuals with autism may need additional services to support behavior and independent living during times like the Great Recession or other societal disruptions. For mothers, the primary area of vulnerability associated with the Recession pertained to increasing depressive symptoms. Thus, mothers may also benefit from therapeutic and other support services during difficult societal shifts.

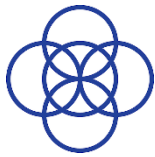
The other variables we studied indicated resilience. These patterns of resilience and stability suggest that there may be a safety net for adults with autism provided by the service system and by their families. These results suggest that it is critically important to provide a service safety net for families and adults with autism during difficult societal periods.

The findings are of special importance now, in the period since the beginning of the COVID-19 pandemic. Individuals with autism are particularly vulnerable to stress, disruptions to their daily living activities, and reduced community participation. Similar to the Great Recession, the pandemic has significantly worsened society-wide inequalities and could result in cumulative problems or disadvantages in employment, mental health, and household income over time. As we continue to gather data from you, our longitudinal study will be well-positioned to examine these potential impacts of COVID-19 in future analyses.

An important point to note is that the results of this study suggest that individuals with autism and their families may be at risk for long-term impacts, particularly for behavior challenges of the individuals with autism and the mental health of their family members. It highlights the need for continued comprehensive services and supports for the entire family system throughout adulthood. Our results also indicate potential areas of resilience for adults with autism and their mothers during societal disruptions, such as in physical health and vocational activities/employment.

We hope that this report informs policies and interventions that can support continued services for adults with ASD and their families. We thank you so very much for your participation and we look forward to sharing additional insights from the study with you.

To learn more about our study and to access other Family Reports, please visit our website: <https://family.waisman.wisc.edu/>



Lifespan Family Research

Advancement of knowledge about families who have a member with an intellectual and developmental disabilities

