A highly significant change in the survival of people with Down syndrome (DS) has occurred during the last two generations, with life expectancy estimates increasing from 12 years in 1949 to nearly 60 years of age today (Bittles & Glasson, 2004). Research suggests that individuals with DS generally have stability in cognitive and functional ability before age 50, but after age 50, individuals with DS show greater declines when compared to their peers (Carr, 2000; Devenny et al., 1992, 1996). This includes a greater prevalence of dementia and early onset dementia (Ciganer, Schupf, Haveman, & Silverman, 1997). However, in typical populations, the behavioral presentation of dementia can be similar to that of psychopathology in aging adults, resulting in diagnostic confusion. We hypothesize that a similar concern may exist in an aging DS population. This study explores the differences in psychosocial and quality of life variables between three groups: DS with dementia (DEM), DS with psychopathology (PSY), and control.

**Aim**
To explore differences in psychosocial and quality of life variables among the three groups.

**Methods**
The sample included interview data from 75 family members of adults with DS identified as the primary caregiver (36 mothers, 4 fathers, 35 siblings). The adults with DS (100% Caucasian) were then categorized into three groups. Based on initial analyses, those with comorbid dementia and psychopathology were placed into the PSY group. The three groups were not significantly different in sex or level of intellectual disability, but there were differences in age. Hence, age was controlled for in all subsequent analyses.

### Demographics of Adults with DS

<table>
<thead>
<tr>
<th>Groups</th>
<th>n =</th>
<th>M</th>
<th>n =</th>
<th>Female</th>
<th>n =</th>
<th>Age Range (years)</th>
<th>Mean Age (years)</th>
<th>SD</th>
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</thead>
<tbody>
<tr>
<td>DEM</td>
<td>19</td>
<td>10</td>
<td>9</td>
<td>46-63</td>
<td>55.74</td>
<td>4.72</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSY</td>
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<td>15</td>
<td>37-65</td>
<td>50.02</td>
<td>5.50</td>
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<td></td>
</tr>
<tr>
<td>Control</td>
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**Conclusion**
While these are largely exploratory findings, this sample is representative of an aging DS population in that only 57% of the sample is classified as sub-clinical for dementia, reflecting the literature suggesting that a substantial portion of aging DS populations have early onset dementia. Related to diagnostic confusion, our data support that functional declines are present in the DEM group, but that behavior problems are more common in the PSY group. This suggests that the presence of behavior problems may indicate diagnostic concerns other than dementia. Based on these preliminary results, there continues to be a need for further examination of this aging population, the supports they might need, and differential diagnostic considerations.

**References**

**Acknowledgements**
Research was supported by NICHD DE016586, ES002013, NIA (P30 AG011427), and NIMH (R01 AG037689). Family members and caregivers tats research.

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**Aging in Down Syndrome: Behavioral Profiles of Psychopathology and Dementia**

By Joseph Amaral, MS, MA, Anna Ebensen, PhD, Emily Johnson, MA, Ryan Macks, PhD, Christine Tan, MS

Aging in Down Syndrome: Behavioral Profiles of Psychopathology and Dementia

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The Division of Developmental and Behavioral Pediatrics

Cincinnati Children’s Hospital Medical Center

The University of Cincinnati University Center for Excellence in Developmental Disabilities

**Introduction/Background**
A highly significant change in the survival of people with Down syndrome (DS) has occurred during the last two generations, with life expectancy estimates increasing from 12 years in 1949 to nearly 60 years of age today (Bittles & Glasson, 2004). Research suggests that individuals with DS generally have stability in cognitive and functional ability before age 50, but after age 50, individuals with DS show greater declines when compared to their peers (Carr, 2000; Devenny et al., 1992, 1996). This includes a greater prevalence of dementia and early onset dementia (Ciganer, Schupf, Haveman, & Silverman, 1997). However, in typical populations, the behavioral presentation of dementia can be similar to that of psychopathology in aging adults, resulting in diagnostic confusion. We hypothesize that a similar concern may exist in an aging DS population. This study explores the differences in psychosocial and quality of life variables between three groups: DS with dementia (DEM), DS with psychopathology (PSY), and control.

**Aim**
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**Results**
Preliminary differences were identified in this sample with regard to overall health, activity level, functional abilities, service use and behavior problems. Specifically, the DEM group was more likely to be described as having poor overall health compared to the other groups, X²(4) = 17.64, p < .01, and more likely to have this affect their activity levels, X²(4) = 17.51, p < .01. They also averaged fewer functional abilities than the other two groups, F(2,68) = 10.95, p < .001, and were most likely to be utilizing services surrounding daily self-care, X²(4) = 11.68, p < .05. However, individuals from the PSY group demonstrated significantly more behavior problems than the other two groups, F(2,65) = 3.18, p < .05.

Groups did not differ with regards to: respiratory, sleep, thyroid, pain, lifetime dental, sensory, lifetime gastrointestinal, internal medicine, or immune problems. They also did not differ with regards to general ratings of behavior problems, antisocial, internalizing, or externalizing problems. Service need/utilization did not differ with regards to nursing, nutritional, physical therapy, occupational therapy, speech therapy, psychological, social work, recreational, transportation, respite, or income assistance services. Furthermore, groups did not differ with regards to their residence type or social activities.

Preliminary analyses that continue to be explored suggest significant differences in lifetime cardiac problems, and dental and gastrointestinal problems within the last year. Several functional abilities (housekeeping, personal care, mobility, and communication), need/utilization of day and other support services, employment type, and maternal perceptions of the relationship with her son or daughter were also found to differ across groups. Post-hoc analyses of between group differences are ongoing.

**Conclusion**
While these are largely exploratory findings, this sample is representative of an aging DS population in that only 57% of the sample is classified as sub-clinical for dementia, reflecting the literature suggesting that a substantial portion of aging DS populations have early onset dementia. Related to diagnostic confusion, our data support that functional declines are present in the DEM group, but that behavior problems are more common in the PSY group. This suggests that the presence of behavior problems may indicate diagnostic concerns other than dementia. Based on these preliminary results, there continues to be a need for further examination of this aging population, the supports they might need, and differential diagnostic considerations.

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