The Americans with Disabilities Act Participation Action Research Consortium (ADA-PARC): Documenting & Targeting Participation Disparities experienced by People with Disabilities

Principal Investigators: Lex Frieden, LLD & Joy Hammel, PhD, OTR/L

Collaborating ADA Centers: Southwest ADA Center, Great Lakes ADA Center, Southeast ADA Center, Pacific ADA Center, Rocky Mountain ADA Center, & Mid-Atlantic ADA Center
Funding

• This research is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Grant Number H133A120008.
The ADA Participation Action Research Consortium
Purpose of ADA-PARC

• To collaboratively examine participation disparities experienced by people with disabilities post ADA & Olmstead

• To benchmark participation disparities and highlight promising practices at state & city levels

• To action-plan strategies for translating knowledge to ADA Centers, policy makers, service delivers in community capacity building & systems change initiatives
Participation Disparities Experienced by People with Disabilities

http://centerondisability.org/ada_parc/

- **Community Living (CL)**
  Community v. institution living choices and long term care spending, Olmstead systems

- **Community participation (CP)**
  Health insurance, housing access, community resources, transportation, education

- **Work/economic participation (WE)**
  Employment status, economic status, cost of living
## Piloting in Representative Cities

<table>
<thead>
<tr>
<th>ADA Center</th>
<th>States</th>
<th>Selected Cities</th>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Southwest (Region 6)</strong></td>
<td>Arkansas, Louisiana, New Mexico, Oklahoma, Texas</td>
<td>Houston, TX, Tulsa, OK, Austin, TX</td>
<td>Albuquerque, NM, Little Rock, AR, Baton Rouge, LA, New Orleans, LA</td>
</tr>
<tr>
<td><strong>Great Lakes (Region 5)</strong></td>
<td>Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin</td>
<td>Chicago, IL, Detroit, MI, Indianapolis, IN</td>
<td>Lansing, MI, Columbus, OH, Milwaukee, WI, Minneapolis, MN</td>
</tr>
<tr>
<td><strong>Southeast (Region 4)</strong></td>
<td>Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee</td>
<td>Raleigh, NC, Greensboro, NC, Asheville, NC, Gastonia, NC</td>
<td>Nashville, TN, Memphis, TN, Birmingham, AL, Montgomery, AL, Tampa, FL, St. Pete, FL, Columbia, SC</td>
</tr>
<tr>
<td><strong>Pacific (Region 9)</strong></td>
<td>Arizona, California, Hawaii, Nevada, the Pacific Basin</td>
<td>Oakland, CA, San Francisco, CA, Riverside, CA, Sacramento, CA</td>
<td>Fresno, CA, Santa Barbara, CA, Las Vegas, NV, Phoenix, AZ, Tucson, AZ, Honolulu, HI</td>
</tr>
<tr>
<td><strong>Rocky Mountain (Region 8)</strong></td>
<td>Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming</td>
<td>Denver, CO, Salt Lake City, UT</td>
<td>Missoula, MT</td>
</tr>
<tr>
<td><strong>Mid-Atlantic (Region 3)</strong></td>
<td>DC, Delaware, Maryland, Pennsylvania, Virginia, West Virginia</td>
<td>Baltimore, MD, Washington, DC</td>
<td>Richmond, VA, Pittsburgh, PA</td>
</tr>
<tr>
<td><strong>Northwest (Region 10)</strong></td>
<td>Alaska, Idaho, Oregon Washington</td>
<td>Seattle, WA, Spokane, WA</td>
<td>Tacoma, WA, Portland, OR, Boise, ID</td>
</tr>
</tbody>
</table>
Methodologies Used

1. GIS mapping (and accessible tables at: http://centerondisability.org/ada_parc/)
   - Visualize and analyze data to understand relationships, patterns, and trends
   - Show how geography, proximity, access to resources, services & built environment affect participation
   - Compare participation for people with and without disabilities
     - Potentially available at national, state, city and census tract/neighborhood levels (depending on dataset, samples and margin of error)
Methodologies Used

2. Indexing and benchmarking (Einhorn & Dawes, 1974; Analytis, Kothiyal & Katsikopoulos, 2014)
   - Compare, or benchmark, your state or city to others
   - Process
     - Standardize indicators (to make them all equivalent)
     - Take mean of individual indices into composites indices
     - Transform the standard scores into a 1-100 metric
   - Multiple studies have found indexing to be a valid method of making decisions and it is used extensively in health disparities research
Interpretation of the Scores

100: best opportunity

50: average

0: least opportunity (potential disparity)
Methodologies Used

3. Risk Ratios

- Compare PWOD to PWD on likelihood of participation or disparity/difference in participation
  - Example Indicator: Likelihood of living in poverty for PWOD compared to PWD in a specific state or city
    - Risk ratio of 2.62 in Washington DC indicates that PWD in DC are 2.6 times (262%) more likely to live in poverty than PWOD
Participation Area 1: Community Living Findings
Indicator 5. Ratio of **HCBS (Community-based) Expenditures** to Total Long Term Care State Spending (LTSS), 2013

**Data source.** HCBS Participants & Expenditures from UCSF Annual Data Collection; Nursing Homes and ICF/DD participants from MSIS; Nursing Homes and ICF/DD Expenditures from Burwell et al. 2010.

**Note.** HCBS includes 1915(c) waivers, Home Health & State Pan PCS; Long Term Support & Services (LTSS) includes HCBS, nursing homes and ICF/DD. AZ, HI, RI & VT served most of their HHBS population within managed care programs.
## Benchmarking Community Living at State Level

<table>
<thead>
<tr>
<th>1. Ratio of HCBS participants to total long term support services</th>
<th>Best States</th>
<th>Worst states</th>
</tr>
</thead>
<tbody>
<tr>
<td>79 Arizona</td>
<td>6 Rhode Island</td>
<td></td>
</tr>
<tr>
<td>76 New Mexico</td>
<td>31 Mississippi</td>
<td></td>
</tr>
<tr>
<td>73 Alaska</td>
<td>34 Alabama, Indiana</td>
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</tr>
<tr>
<td>66 California, Oregon</td>
<td>35 Georgia, Tennessee</td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Ratio of HCBS expenditures to total long term support services</th>
<th>Best States</th>
<th>Worst states</th>
</tr>
</thead>
<tbody>
<tr>
<td>93 New Mexico</td>
<td>26 Mississippi</td>
<td></td>
</tr>
<tr>
<td>79 Oregon</td>
<td>31 New Jersey</td>
<td></td>
</tr>
<tr>
<td>73 Minnesota</td>
<td>35 Indiana</td>
<td></td>
</tr>
<tr>
<td>70 Arizona</td>
<td>36 Florida</td>
<td></td>
</tr>
<tr>
<td>69 Alaska, Virginia</td>
<td>37 Michigan</td>
<td></td>
</tr>
</tbody>
</table>

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<tr>
<th>3. Number of MFP transitions since inception</th>
<th>Best States</th>
<th>Worst states</th>
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</thead>
<tbody>
<tr>
<td>135 Utah</td>
<td>47 Alabama, Alaska, Arizona, Colorado, Delaware, DC, Florida, Hawaii, Idaho, Iowa, Maine, Minnesota, Mississippi, Montana, Nebraska, Nevada, New Hampshire, New Mexico, North Carolina, North Dakota, Oregon, Rhode Island, South Carolina, South Dakota, Vermont, Virginia, Wisconsin</td>
<td></td>
</tr>
<tr>
<td>64 Texas</td>
<td></td>
<td></td>
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<tr>
<td>56 Ohio</td>
<td></td>
<td></td>
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<tr>
<td>54 West Virginia</td>
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<td></td>
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<tr>
<td>51 Connecticut, Maryland</td>
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<tr>
<th>Composite: Community living resources</th>
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<th>Worst states</th>
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<td>65 Arizona</td>
<td>39 Indiana</td>
<td></td>
</tr>
<tr>
<td>64 Oregon</td>
<td>40 Alabama</td>
<td></td>
</tr>
<tr>
<td>63 Alaska</td>
<td>41 Florida, New Jersey, North Dakota</td>
<td></td>
</tr>
</tbody>
</table>
ADA PARC Olmstead Interviews

• Interviewing people with disabilities who are moving out of nursing homes/institutions to the community (Olmstead sample)
  ▪ N=300 across collaborating ADA regions
  ▪ Learn about the community living, participation and work opportunities in nursing home as compared to in community long term with an underrepresented group

• HAPPENING NOW!!
Participation Area 2:
Work & Economic Participation
Indicator 1. People with and without Disabilities That Are Employed: Age 18-64, 2013

Data source. 2013, American Community Survey, 3 Year Estimates, Table B18120

Calculation. This percentage is calculated by dividing the number in each group (people with disabilities or people without disabilities) who are currently employed by the total population of each group.
Indicator 2. People with and without Disabilities That Are Unemployed: Age 18-64, 2013

Data source. 2013 American Community Survey, 3 Year Estimates, Table B18120
Calculation. Number in each group (people with disabilities or people without disabilities) who are currently unemployed but are actively looking for work divided by the total number of persons in the labor force for each group
Note. Number in each group (people with disabilities or people without disabilities) who are currently unemployed but are actively looking for work divided by the total number of persons in the labor force for each group

Data source. 2013 American Community Survey 3 Year Estimates, Table B18120
Calculation. Number in each group (people with disabilities or people without disabilities) who are not in the labor force divided by the total number of persons in each group.
Note. Individuals not in the labor force include students, homemakers, retired workers, seasonal workers interviewed in an off season who were not looking for work, institutionalized people, and people doing only incidental unpaid family work (less than 15 hours)
Indicator 12: Percentage of People with and without Disabilities Below the Poverty Level: Age 18 to 64, 2013

Data source. 2013 ACS, 3 year Estimates, Table B18130, Age by Disability Status by Poverty Status.
Calculation. Number in each group (people with disabilities or people without disabilities) who are below the poverty level divided by the total population of each group.
Note. The poverty level refers to income that is below a minimum threshold based on family size and composition.
# Work/Economic Benchmarking at State Level

<table>
<thead>
<tr>
<th>1. Percent of people below poverty level</th>
<th>Best States (least poverty, etc.)</th>
<th>Worst states (most poverty etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>81</td>
<td>Alaska</td>
<td>15</td>
</tr>
<tr>
<td>75</td>
<td>Wyoming</td>
<td>30</td>
</tr>
<tr>
<td>71</td>
<td>Delaware</td>
<td>31</td>
</tr>
<tr>
<td>70</td>
<td>New Hampshire</td>
<td>33</td>
</tr>
<tr>
<td>68</td>
<td>New Jersey</td>
<td>35</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Percent of people not in labor force</th>
<th>Best States (least poverty, etc.)</th>
<th>Worst states (most poverty etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>77</td>
<td>North Dakota,</td>
<td>20</td>
</tr>
<tr>
<td>77</td>
<td>South Dakota</td>
<td>28</td>
</tr>
<tr>
<td>72</td>
<td>Wyoming</td>
<td>29</td>
</tr>
<tr>
<td>68</td>
<td>Minnesota</td>
<td>31</td>
</tr>
<tr>
<td>66</td>
<td>Alaska, Nebraska</td>
<td>34</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Percent of people unemployed</th>
<th>Best States (least poverty, etc.)</th>
<th>Worst states (most poverty etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>81</td>
<td>North Dakota</td>
<td>22</td>
</tr>
<tr>
<td>79</td>
<td>West Virginia</td>
<td>26</td>
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<tr>
<td>70</td>
<td>South Dakota</td>
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<td>69</td>
<td>Oklahoma</td>
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<table>
<thead>
<tr>
<th>Composite: Not working and poor</th>
<th>Best States (least poverty, etc.)</th>
<th>Worst states (most poverty etc.)</th>
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<tr>
<td>73</td>
<td>North Dakota</td>
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</tr>
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<tr>
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<td>South Dakota</td>
<td>40</td>
</tr>
<tr>
<td>64</td>
<td>Nebraska</td>
<td>41</td>
</tr>
</tbody>
</table>
## Work/Economic Benchmarking at City Level

<table>
<thead>
<tr>
<th>Percent of people below poverty level</th>
<th>Best Cities (least poverty etc)</th>
<th>Worst Cities (most poverty etc)</th>
</tr>
</thead>
<tbody>
<tr>
<td>91</td>
<td>Anchorage</td>
<td>20</td>
</tr>
<tr>
<td>71</td>
<td>Honolulu</td>
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<tr>
<td>69</td>
<td>Riverside</td>
<td>33</td>
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<tr>
<td>67</td>
<td>Las Vegas</td>
<td>33</td>
</tr>
<tr>
<td>66</td>
<td>Austin, Raleigh</td>
<td>32</td>
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<tr>
<td>83</td>
<td>Missoula</td>
<td>19</td>
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<td>76</td>
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<td>69</td>
<td>Santa Barbara</td>
<td>36</td>
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<tr>
<td>82</td>
<td>Gastonia</td>
<td>24</td>
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<td>74</td>
<td>San Francisco</td>
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<td>72</td>
<td>Montgomery</td>
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<td>Tulsa</td>
<td>36</td>
</tr>
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</tr>
</tbody>
</table>
Work Economic Risk Ratio: Poverty Likelihood at City Level

<table>
<thead>
<tr>
<th>Risk Ratio</th>
<th>Top Cities</th>
<th>Bottom Cities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Likelihood of having more PWD in poverty than PWOD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.38</td>
<td>Detroit</td>
<td>2.81</td>
</tr>
<tr>
<td>1.48</td>
<td>Riverside</td>
<td>2.71</td>
</tr>
<tr>
<td>1.49</td>
<td>Tucson</td>
<td>2.70</td>
</tr>
<tr>
<td>1.53</td>
<td>Baton Rouge</td>
<td>2.65</td>
</tr>
<tr>
<td>1.55</td>
<td>Phoenix</td>
<td>2.62</td>
</tr>
</tbody>
</table>

- Risk ratio of 1.38 in Detroit indicates that PWD in Detroit are 1.38 times (138%) more likely to live in poverty than PWOD.
- Risk ratio of 2.81 in Asheville indicates that PWD in Asheville are 2.8 times (281%) more likely to live in poverty than PWOD.
- What are we doing in rehabilitation to take this level of poverty into account? Are we seeing “surviving on very limited incomes”, “system management” & “accessing resources & information” as key functional skills we work on in rehabilitation?
Participation Area 3: Community Participation

What key resources do PWD need access to to fully participate in the community?
Proximity to Community Resources (Walk Score)

Data source: www.walkscore.com
Access to Public Transit (Transit Score)

Data source: www.walkscore.com
Transportation Access

Houston, TX Train Lines

Number of PWD
- 3 - 218
- 219 - 333
- 334 - 456
- 459 - 634
- 635 - 1431

City Boundary
- METRO Stations
- METRO Train Lines
Transportation Access
Houston, TX Train Lines

Within ½ Mile of Train Stop
-5% of PWD
-4% of all persons
Transportation Access

Chicago, IL EL Lines

Within ½ Mile of Train Stop
-31% of PWD
-34% of all persons

Data Source: 2009-2013 American Community Survey
Analysis: Voorhees Center, University of Illinois at Chicago
Transportation Access
Houston, TX Bus Lines

Within ¼ of a Bus Stop
- 52% of PWD
- 49% of all persons
Transportation Access

Chicago, IL Bus Lines

Within ¼ of a Bus Stop
- % 94 of PWD
- % 93 of all persons

Data Source: 2009-2013 American Community Survey
Analysis: Voorhees Center, University of Illinois at Chicago
Transportation Survey

• Consumer self report survey of transportation access, accessibility, availability, use, and quality
  ▪ NOW OPEN FOR SECOND ROUND OF MORE DATA COLLECTION!!!
Ongoing Research & Actions

- Update GIS maps, Indexes & Risk Ratios & add to website
- Add more transportation data (survey, access to less publicly available data)
- Interview people with disabilities moving out of nursing homes/institutions to community (Olmstead group) to document participation experiences, barriers & supports
- Share data with people with disabilities, ADA Centers, Community Advisory Boards & policy makers to assess value, accessibility & usability, and educate rehabilitation professionals about value/use of data
- Develop online resources to provide accompanying technical assistance, training & promising practice cases for use by communities to take action = Knowledge Translation
Thank you to the individuals & organizations collaborating on and contributing to the ADA PARC

For more information, visit: http://centerondisability.org/ada_parc/

or email Joy Hammel: hammel@uic.edu