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University of Alabama at Birmingham
Diplomate, Low Vision Section, American Academy of Optometry
What is Low Vision?

• Vision that is not adequate for a person’s needs
• Term implies some reduction in visual acuity and/or visual field
• Legal Blindness is a subset of Low Vision

- 1 sees nothing
- 1 sees light
- 5 are legally blind
- 1 has vision impairment
- 4 have normal sight
- 2 are deaf-blind
Public Health Significance of Pediatric VI

- Estimated 1 to 3 per 10,000 children
- Significant PH problem due to number of life-years affected
- Global financial burden of childhood blindness (20/400 or worse by WHO definition) exceeds that of adult blindness
- Only cataract ranks higher on the global burden of eye disease when measured in DALY’s

Global estimate of the number of people with VI, by age, 2010

<table>
<thead>
<tr>
<th>Ages (in years)</th>
<th>Population (millions)</th>
<th>Blind (millions)</th>
<th>Low Vision (millions)</th>
<th>Visually Impaired (millions)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-14</td>
<td>1.848.50</td>
<td>1.421</td>
<td>17.518</td>
<td>18.939</td>
</tr>
<tr>
<td>15-49</td>
<td>3548.2</td>
<td>5.784</td>
<td>74.463</td>
<td>80.248</td>
</tr>
<tr>
<td>50 and older</td>
<td>1,340.80</td>
<td>32.16</td>
<td>154.043</td>
<td>186.203</td>
</tr>
<tr>
<td>all ages</td>
<td>6,737.50</td>
<td>39.365 (0.58)</td>
<td>246.024 (3.65)</td>
<td>285.389 (4.24)</td>
</tr>
</tbody>
</table>

http://www.who.int/blindness/GLOBA LDATAFINALforweb.pdf?ua=1

Prevent Blindness®

Focus on Eye Health National Summit

A Lifetime of Vision
July 17, 2019 | National Press Club | Washington D.C.
Rehabilitation for Children with Low Vision

- **GOAL**: to level the playing field – provide the tools and techniques to minimize the effects of vision impairment on daily activities, including school.

- **FOUNDATION**: a comprehensive eye health examination. Followed by low vision evaluation including prescription of devices and recommendations that are individualized for each child.

- **BEST PRACTICE**: team approach including optometrists, ophthalmologists, therapists, orientation & mobility specialists, parents and educators.

- **CHALLENGES**: shortages of teachers with certification in vision impairment, low reimbursement for vision rehabilitation, lack of funding for devices and equipment.
Common Causes of Low Vision in Children

• Hereditary
  • Albinism
  • Retinal Degeneration
  • Achromatopsia
  • Cataract
  • Aniridia

• Not-inherited
  • Retinopathy of prematurity
  • Optic Nerve Hypoplasia
## Quality of Life

### Child Focus Groups
- Psychosocial
- Glasses & adaptive equipment
- School-related
- Medical care & symptoms
- Mobility
- Participation
- ADL & IADLS
- Near vision
- Expectations & frustrations
- Dependency
- General vision

### Parent Focus Groups
- School-related
- Expectations & frustrations
- Psychosocial
- General vision
- Medical care & symptoms
- Mobility
- Glasses & adaptive equipment
- Participation
- ADL & IADLS
- Near vision
- Dependency

### Comparing Children with and without vision impairment using the PedsQL 4.0

<table>
<thead>
<tr>
<th></th>
<th>Total PedsQL 4.0 Score</th>
<th>Visual Imp Mean (SD)</th>
<th>Control Mean (SD)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Children (8-12)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child Report</td>
<td>n=32</td>
<td>n=19</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Report</td>
<td>77.0 (11.7)</td>
<td>85.1 (11.6)</td>
<td>0.02*</td>
<td></td>
</tr>
<tr>
<td><strong>Teens (13-18)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child Report</td>
<td>n=38</td>
<td>n=25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent Report</td>
<td>83.2 (11.2)</td>
<td>90.9 (8.4)</td>
<td>0.005*</td>
<td></td>
</tr>
</tbody>
</table>

*Submitted to JAAPSO, June 2019*
Prevalence of attention-deficit/hyperactivity disorder among children with vision impairment

Dawn K. DeCarlo, OD, MSPH, Ellen Bowman, MA, COMS, Cara Monroe, MSPH, Robert Kline, PhD, Gerald McGwin Jr, MS, PhD, and Cynthia Owsley, PhD, MSPH

Table 1. Demographic and ocular characteristics for the entire sample and for the subgroups of those who have ever had an ADHD diagnosis as well as those who have never had an ADHD diagnosis

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Overall (n = 245)</th>
<th>Ever ADHD (n = 56)</th>
<th>Never ADHD (n = 189)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better eye VA, mean ± SD</td>
<td>0.73 ± 0.38</td>
<td>0.65 ± 0.33</td>
<td>0.76 ± 0.39</td>
<td>0.02</td>
</tr>
<tr>
<td>Worse eye VA, mean ± SD</td>
<td>0.93 ± 0.38</td>
<td>0.81 ± 0.32</td>
<td>0.97 ± 0.40</td>
<td>0.001</td>
</tr>
<tr>
<td>Age, mean ± SD</td>
<td>10.7 ± 3.8</td>
<td>11.2 ± 3.2</td>
<td>10.5 ± 4.0</td>
<td>0.9</td>
</tr>
<tr>
<td>Nystagmus, n (%)</td>
<td>165 (68.0)</td>
<td>135 (81.8)</td>
<td>30 (18.2)</td>
<td>0.03</td>
</tr>
<tr>
<td>Present, n (%)</td>
<td>72 (30.4)</td>
<td>23 (31.9)</td>
<td>49 (66.1)</td>
<td></td>
</tr>
<tr>
<td>Absent, n (%)</td>
<td>141 (57.8)</td>
<td>34 (24.1)</td>
<td>107 (75.9)</td>
<td>0.5</td>
</tr>
<tr>
<td>Male, n (%)</td>
<td>103 (42.2)</td>
<td>21 (20.4)</td>
<td>82 (79.6)</td>
<td></td>
</tr>
<tr>
<td>Female, n (%)</td>
<td>142 (57.8)</td>
<td>44 (26)</td>
<td>125 (74)</td>
<td>0.1</td>
</tr>
<tr>
<td>Race</td>
<td>169 (69)</td>
<td>44 (26)</td>
<td>125 (74)</td>
<td></td>
</tr>
<tr>
<td>White, n (%)</td>
<td>76 (31)</td>
<td>12 (15.8)</td>
<td>64 (84.2)</td>
<td></td>
</tr>
</tbody>
</table>

ADHD and Vision Problems in the National Survey of Children’s Health

Dawn K. DeCarlo, Mark Swanson, Gerald McGwin, Kristina Visscher, and Cynthia Owsley

Unadjusted associations between ADHD and vision problem severity

<table>
<thead>
<tr>
<th>ADHD Level</th>
<th>Mild VP</th>
<th>Moderate VP</th>
<th>Severe VP</th>
</tr>
</thead>
<tbody>
<tr>
<td>OR (95% CI)</td>
<td>OR (95% CI)</td>
<td>OR (95% CI)</td>
<td></td>
</tr>
<tr>
<td>Any level ADHD</td>
<td>1.8 (1.1–2.9)</td>
<td>2.6 (1.6–4.1)</td>
<td>1.6 (0.8–3.1)</td>
</tr>
<tr>
<td>Severity ADHD*</td>
<td>1.9 (1.2–3.0)</td>
<td>2.8 (1.7–4.4)</td>
<td>1.6 (0.8–3.3)</td>
</tr>
<tr>
<td>Medicated ADHD</td>
<td>1.4 (0.6–3.0)</td>
<td>0.5 (0.2–1.2)</td>
<td>1.3 (0.4–3.4)</td>
</tr>
</tbody>
</table>

Reference group: no vision problems.
*Ordinal regression, odds of being in higher ADHD severity category.
VP, vision problems not correctable with glasses or contact lenses.
## Reading by Children with Low Vision

<table>
<thead>
<tr>
<th>Grade</th>
<th>MNREAD Maximum Reading Rate (wpm)</th>
<th>Basic Reading Inventory Word Passages Reading Rate (wpm)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>VI</td>
<td>Control</td>
</tr>
<tr>
<td>1-3</td>
<td>122 ± 49</td>
<td>168 ± 63</td>
</tr>
<tr>
<td>4-6</td>
<td>144 ± 52</td>
<td>392 ± 180</td>
</tr>
<tr>
<td>7-9</td>
<td>201 ± 41</td>
<td>387 ± 224</td>
</tr>
<tr>
<td>10-12</td>
<td>174 ± 45</td>
<td>472 ± 243</td>
</tr>
<tr>
<td>All</td>
<td>163 ± 54</td>
<td>376 ± 209</td>
</tr>
</tbody>
</table>
Reading in Emerging Readers with Low Vision

Correlation of Visual Acuity and Basic Reading Skills Cluster Standard Score (all participants at first visit)

![Image of a child reading]

- Basic Reading Skills Cluster Standard Score
- Binocular Visual Acuity (logMAR)

$r = 0.03; p = 0.8 \text{ NS}$
Treatment for Hereditary Retinal Degeneration

- Treating hereditary retinal degenerations is not science fiction
  - Gene replacement
  - Gene editing
  - Trophic factors
  - Optogenetics
  - Cell therapy
  - Prosthetics
- We now have an FDA approved gene therapy for Leber Congenital Amaurosis (a severe early onset cause of blindness)
  - 3 patients seen in the UAB Center for Low Vision Rehabilitation have been treated with remarkable results
- Treatments for many other genetic eye diseases are under investigation
Summary and Future Work

- Children with vision impairment are a small proportion of the children in the US, however VI has lifelong impact.
- There are resources and equipment to help ameliorate the disability caused by vision impairment, however they are not universally available and children in rural areas are typically more affected by these shortages.
- Research on the impact of vision impairment in children is scarce, but our work shows that many of these children CAN and DO keep up with their normally sighted peers.
- Work is underway to better understand the relationship between impaired vision and learning so that we can maximize the success of children with low vision.
- Medical treatments for many genetic eye disorders are on the horizon.
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    • P30EY003039
  • EyeSight Foundation of Alabama
  • Research to Prevent Blindness
  • Songs for Sight

• Collaborators:
  • Cynthia Owsley, PhD, MSPH; Elizabeth Forte, BS; Gerald McGwin Jr, PhD; Liyan Gao, PhD; Tracy Matchinski, OD; Kara Crumbliss, OD; Mark Swanson, OD, MSPH: Ellen Bowman, COMS, PhD; Kristina Visscher, PhD
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