Autism 201: The State of Autism in 2019

Jim Mancini MS, CCC-SLP
• What does inclusion mean to you?
Risk?

- Infant Behaviors
- Prenatal & Perinatal
- Genetic
- Environmental

Measurement of Risk
Infant behaviors | Social Attention Markers of Risk

• **6 & 12 months**
  - Decreased attention to the face,
  - Altered time to learn about a face,
  - Decreased brain activity to social information

• **12 – 24 months Early Red Flags for autism**
  - Poor eye contact
  - Lack of attention to others
  - Difficulties with joint attention
  - Failure to differentiate and respond to emotions
  - Poor imitation

Motor skills in infancy are related to object exploration, social communication and social skills.
• N=140 infants (51 LR and 89 HR)
  • 6 month Peabody Development Motor Scales
    • Less mature Visual – Motor integration was related to later ASD
    • Gross motor (stationary) and grasping were related to 3 year old language ability
Updating our understanding --> Infant Behaviors


DSM-5 added Sensory Symptoms to the RRB domain
‘hyper-responsivity or hypo-responsivity to sensory input or unusual interests in sensory aspects of the environment’ (DSM-5)

- IBIS N=331 HR & n=135 LR
- Sensory Experiences Questionnaire (SEQ) @ 12 months
- Children later diagnosed with ASD
  - higher in sensory hyper-responsivity & tactile stimulation
  - Increased in sensory issues over time
Globally ~13 million infants are born premature per year. 1 in 10 infants in the US are born premature.

Who is at risk for developing ASD?

- Meta Analysis of 18 studies
  - N=3366 pre-term infants
  - 25-32 weeks
  - 719 -1565 g
  - Follow up 1.5 to 21 years
- Prevalence of ASD
  - 7% in pre-terms
  - 1.5% general population

Risk for ASD has been associated with immune system response & higher rates of ASD are found in those with a family history of autoimmune diseases.
Study to Explore Early Development

- California, Colorado, Georgia, Maryland, North Carolina, Pennsylvania
- Children born 2003-2006; English and Spanish speaking

<table>
<thead>
<tr>
<th>Mothers @ Delivery</th>
<th>ASD (n=633)</th>
<th>DD (n=984)</th>
<th>TD (n=915)</th>
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<tbody>
<tr>
<td>Allergy</td>
<td>50.7%</td>
<td>47.6%</td>
<td>50.6%</td>
</tr>
<tr>
<td>Asthma</td>
<td>29.9%*</td>
<td>28.5%</td>
<td>25.5%*</td>
</tr>
<tr>
<td>Any Autoimmune</td>
<td>19.8%</td>
<td>20.7%*</td>
<td>16.9%*</td>
</tr>
<tr>
<td>Eczema / Psoriasis</td>
<td>13.4%*</td>
<td>12.4%</td>
<td>10.4%*</td>
</tr>
</tbody>
</table>

Table 4. Risk of ASD or DD Associated with Maternal Immune Conditions Diagnosed by Delivery of the Study Child, Study to Explore Early Development, 2003–2006 Births

<table>
<thead>
<tr>
<th>Maternal Conditions Diagnosed by Delivery of Study Child</th>
<th>ASD vs POP Crude OR (95% CI)</th>
<th>ASD vs POP Adj OR* (95% CI)</th>
<th>DD vs POP Crude OR (95% CI)</th>
<th>DD vs POP Adj OR* (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any Autoimmune</td>
<td>1.21 (0.93–1.56)</td>
<td>1.29 (0.97–1.70)</td>
<td>1.28 (1.02–1.62)</td>
<td>1.37 (1.08–1.74)</td>
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<td>Eczema/Psoriasis</td>
<td>1.34 (0.98–1.82)</td>
<td>1.39 (1.00–1.95)</td>
<td>1.22 (0.92–1.62)</td>
<td>1.32 (0.98–1.77)*</td>
</tr>
<tr>
<td>Asthma</td>
<td>1.25 (1.00–1.56)</td>
<td>1.26 (0.99–1.60)</td>
<td>1.16 (0.95–1.43)</td>
<td>1.21 (0.98–1.50)</td>
</tr>
<tr>
<td>Asthma Treated During Pregnancy</td>
<td>1.35 (1.05–1.73)</td>
<td>1.41 (1.07–1.85)</td>
<td>1.32 (1.05–1.66)</td>
<td>1.40 (1.11–1.78)</td>
</tr>
<tr>
<td>Allergy</td>
<td>1.00 (0.82–1.23)</td>
<td>1.13 (0.91–1.41)</td>
<td>0.89 (0.74–1.06)</td>
<td>0.98 (0.81–1.18)</td>
</tr>
</tbody>
</table>

*Adjusted child sex, current household income, maternal age, race, and education.

Children with autism spectrum disorder from low-income, minority families or those with limited English proficiency are diagnosed at a later age, or not at all, compared with their more advantaged peers.
• N=376 24-60 mos
  • Federally qualified health centers
  • Daycares
  • Full evaluations regardless of scores

• The Developmental Check-in
  • Pictures (line draw & photo)
  • English & Spanish
  • Based on known red flags
  • from ADOS and STAT

• Cut-off of 7.5
  • sensitivity of .66 (True Positive Rate) and specificity of .76 (True Negative Rate).
School and Medical Collaboration to evaluate children for Autism in Rural Communities

Amy Carlsen, RN
January 17, 2019
Support for this work

- Support for this work comes from the University of Washington LEND program, the Washington State Department of Health (DOH), and the WA State Medical Home Partnerships Project (MHPP)
- This includes the federal **AS3D Grant** which has the goals of:
  - improving access to interventions for children, youth and families with ASD/DD
  - empowering families to partner with health professionals in decision making
  - strengthening state level leadership and systems integration needed to assure timely identification and access to services
How and Why:

- Lewis County Autism Coalition
- Workgroup to address challenges families faced to get a timely ASD diagnosis:
  - Long wait lists at Mary Bridge and Seattle Children’s, UW
  - Travel issues for families to go out of county – cost, time
- Support and encouragement from MB, Seattle Children’s, UW, and the WA State Dept. of Health
- Workgroup with help from Amy Carlsen, RN and UW graduate fellows created forms, processes
Family shares concerns about their child to their Primary Care Doctor

Primary Care Doctor & family agree for the family to contact SMART Coordinator

SMART Coordinator & the family begin the data collection process

SMART Data Review

No Evaluation Indicated ~ Refer family back to community, educational resources, Primary Care Doctor

Evaluation Indicated ~ Determination of possible evidence of ASD

SMART administer recommended assessments - ADOS STAT, as needed

Center of Excellence (COE) Evaluation scheduled

Results provided to family preferred providers and other providers of family choice

Medical Evaluations

School Evaluations; IEP, IFSP

Clinic Evaluations

Parent to Parent recommended as a family resource

SMART – School Medical Autism Review Team

ASD – Autism Spectrum Disorder

ADOS – Autism Diagnostic Observation Schedule

COE – Center of Excellence

Parent to Parent recommended as a family resource

Results provided to family preferred providers and other providers of family choice

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What is a Center of Excellence?

• A Center of Excellence (COE) is any medical practice, psychology practice, or multidisciplinary assessment team that has received the COE training from the Health Care Authority or has been judged by the HCA to be qualified to write a prescription for ABA services. There are many different ways for children and youth to get a diagnosis of autism. In order for a child or youth to be eligible for ABA therapy through Apple Health/Medicaid, a recognized Center of Excellence (COE) must conduct a comprehensive evaluation, and write an order for Applied Behavior Analysis therapy, within the last two years.
More Information:

Contact:
Rebecca (Becky) Peters
ABA Clinical Program Manager
CQCT
HCA ABA@hca.wa.gov
Tel: 360-725-1194
Who’s SMART?

- Pediatrician
- Special Education Director
- School Psychologists
- Speech Therapists
- Birth to Three
- ABA Therapist
- Coordinator, can be a RN, Community Health Worker, or Family Resource Coordinator
- Others at times: OT, other school/medical, parent representative
Why SMART Works

- Local people with passion
- Know many of the children and families
- Variety of agencies with broad knowledge – child development, medical, educator, IEP/evaluations etc.
- Coordinator keeps us organized and connects with families and agencies.
- Open discussion – all input welcome and valued
- BENEFITS wider than autism-
  - sharing info, knowledge, resources between schools, pediatricians and community services
Variation - Community Resources and Need

Criteria for children seen
- Age, specific to practice or insurance, ASD concerns or broader

Coordinator
- Role and funding

Diagnosis/eligibility for what systems/services – depends on who diagnoses
- For Developmental Disability Administration (DDA)? For Medicaid? For other insurance? For Special Education Services under the Autism category?

Outcome from evaluation
- Final Diagnosis or clear pathway to further evaluation
Future Opportunities

- Center of Excellence Training in Vancouver, WA on April 26-27
- Providers who are interested in being part of the SMART process, but want more training can visit Seattle Children’s Hospital for more training
- Talks are underway to bring an Autism ECHO project to Washington State to support COE trained providers to increase their knowledge and comfort with diagnosing and providing ongoing care of children with autism locally
- There is a partnership with the WA State Health Care Authority to support a change in the WAAC code to make an autism diagnosis by a COE provider valid for DDA services
- There is work being done with the HCA to increase Medicaid reimbursement for ABA therapy to attract more ABA providers
Why does this matter to me?
For more information:

WA State Medical Home Partnerships Project

• Amy Carlsen carlsa@uw.edu
• Kate Orville orville@uw.edu
Bits, Bytes, Bots: Autism Technology in Review 2018

Frederick Shic, Ph.D.  SCRI / UWSOM Pediatrics
UW CSE
A Brief Background
Seattle Children’s Innovative Technologies Lab
Technology in Autism Research: Translational Science

- Development
  - Technology Development

- Experimental
  - Between-group Differences
  - Individual Variation

- Clinical
  - Diagnostics
  - Phenotyping
  - Trajectories
  - Interventions
# Publications/Year: Autism Technology

![Graph showing the increase in publications per year for Autism Technology from 1990 to 2020.](image)

Figure 2: Screenshots from the Completed Phase I Prototype

- **A) VoiceMatch**
- **B) VoiceChart**
- **C) Library**
Exploratory study examining the at-home feasibility of a wearable tool for social-affective learning in children with autism

Jena Daniels1, Jessey N. Schwartz1, Catalin Voss2, Nick Haber1, Azar Fazel1, Aaron Kline1, Peter Washington2, Carl Feinstein3, Terry Winograd2 and Dennis P. Wall1,3,4

npj Digital Medicine (2018) 1:32; doi:10.1038/s41746-018-0035-3
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Superpower Glass

- 24 families of children with ASD consented
  - 5 withdrew (younger children, Age = 7.5 (2.5) years)
  - 5 did not meet study requirements (3 sessions/week, 20 min/session)
    - Age 8.5 (4.0) years, ABIQ = 75 (10)
- N=14, 9.6 (3.4), ABIQ=95 (22), 4-20 weeks (average 10 weeks)

Results:
- Increases in performance on emotion guessing game
- Decreases in SRS-2
- Not relation to intensity, IQ
- 12 of 14 families reported increases in eye contact

Limitations:
- No control group
In-home Social Robots

Improving social skills in children with ASD using a long-term, in-home social robot

Brian Scassellati¹*, Laura Boccanfuso²‡, Chien-Ming Huang¹‡, Marilena Mademtzi²‡, Meiying Qin¹‡, Nicole Salomons¹‡, Pamela Ventola², Frederick Shic²‖

Participant Information

- 14 families of children with ASD
- 2 withdrew
  - Unrelated health issue
  - Technical difficulties
- Children:
  - 5 females and 7 male
  - Age: 6 years to 12 years (M = 9.02, SD = 1.41)
  - Nonverbal IQ ≥ 70
    - Differential Ability Scales (M = 94.17, SD = 20.06)
- Autonomous: 30 days without contact
- Adaptive: alters curriculum and engagement patterns to match strengths and preferences of individual child
- In-home: complex and challenging environment
- Tests generalized skill use: high bar for showing learning; new context, standardized clinician validated protocol
Differences from Prior Art

- **Autonomous**: 30 days without contact
- **Adaptive**: alters curriculum and engagement patterns to match strengths and preferences of individual child
- **In-home**: complex and challenging environment
- **Tests generalized skill use**: high bar for showing learning; new context, standardized clinician validated protocol
Skill Performance Improvements

- Perspective Taking Game (“House”)
- Barrier Game (“Rocket”)
- Emotion Understanding Game (“Story”)
- Sequencing Game (“Train”)

Number of Sessions vs. Percentage of Participants Reaching Maximum Game Difficulty Level.
Clinical-Relevant Assessment

- Bean & Eigsti’s joint attention probes
- Clinician administered
- Naturalistic assessment
- For school-age children
- Similar to ADOS


Scassellati et al., SciRob 2018
Automatic emotion and attention analysis of young children at home: a ResearchKit autism feasibility study

Helen L. Egger, Geraldine Dawson, Jordan Hashemi, Kimberly L. H. Carpenter, Steven Espinosa, Kathleen Campbell, Samuel Brotkin, Jana Schaich-Borg, Qiang Qiu, Mariano Tepper, Jeffrey P. Baker, Richard A. Bloomfield Jr., and Guillermo Saprio.
ARTICLE  OPEN
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npj Digital Medicine (2018)1:20; doi:10.1038/s41746-018-0024-6
## Table 1. Demographic characteristics

<table>
<thead>
<tr>
<th>Child characteristics</th>
<th>N (%)</th>
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<tr>
<td>Total participants</td>
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<tr>
<td>Sex(^a)</td>
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<tr>
<td>Boys</td>
<td>1211 (69.0%)</td>
</tr>
<tr>
<td>Girls</td>
<td>543 (31.0%)</td>
</tr>
<tr>
<td>Mean age in months (SD)(^b)</td>
<td>40.4 (SD 16.3) (16.3%)</td>
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## Table 2. Autism risk status in cohort

<table>
<thead>
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<th>Composite</th>
<th>N (%)</th>
<th>Mean age (SD)</th>
<th>p-value</th>
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<tr>
<td>Autism high risk</td>
<td>555 (31.6%)</td>
<td>43.6 (SD 15.6)</td>
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<tr>
<td>Not autism high risk</td>
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<tr>
<td>Caregiver-reported ASD</td>
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<tr>
<td>Caregiver-reported ASD</td>
<td>435 (24.8%)</td>
<td>47.9 mos (SD 13.3)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Caregiver did not report ASD</td>
<td>1321 (75.2%)</td>
<td>37.9 mos (SD 16.5)</td>
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<tr>
<td>M-CHAT</td>
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<tr>
<td>M-CHAT eligible</td>
<td>479 (27.3%)</td>
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<tr>
<td>Completed MCHAT</td>
<td>407 (85.0%)</td>
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<tr>
<td>M-CHAT high score</td>
<td>159 (39.1%)</td>
<td>24.1 (SD 4.1)</td>
<td>0.3</td>
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<tr>
<td>M-CHAT low score</td>
<td>248 (60.9%)</td>
<td>23.2 (SD 4.4)</td>
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Mobile Computer Vision for Phenotyping

<table>
<thead>
<tr>
<th>Video clip</th>
<th>N</th>
<th>All children</th>
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<td></td>
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<td>High risk</td>
<td>Low risk</td>
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<td></td>
<td></td>
<td>Mean</td>
<td>SE</td>
<td>Mean</td>
<td>SE</td>
<td>p-value</td>
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<td>Neutral emotion</td>
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<tr>
<td>Bubbles</td>
<td>781</td>
<td>41.2</td>
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<td>Bunny</td>
<td>608</td>
<td>39.2</td>
<td>1.9</td>
<td>33.1</td>
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<td>0.01</td>
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<tr>
<td>Mirror</td>
<td>530</td>
<td>36.2</td>
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<td>31.4</td>
<td>1.2</td>
<td>0.02</td>
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<td>Toys and songs</td>
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<td>41.1</td>
<td>2.3</td>
<td>34.6</td>
<td>1.5</td>
<td>0.64</td>
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<td>Positive emotion</td>
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<td>0.02</td>
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<td>1.7</td>
<td>37.1</td>
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<td>1.9</td>
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<tr>
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<td>530</td>
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<td>1.7</td>
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<td>0.83</td>
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<td>35.7</td>
<td>2.1</td>
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<td>1.5</td>
<td>0.64</td>
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<td>Attention</td>
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<td>Bubbles</td>
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<td>92.3</td>
<td>1.9</td>
<td>91.3</td>
<td>1.3</td>
<td>0.65</td>
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</tbody>
</table>
Computer vision analysis captures atypical attention in toddlers with autism

Kathleen Campbell, Kimberly LH Carpenter, Jordan Hashemil, Steven Espinosa, Samuel Marsan, Jana Schaich Borg, Zhuoqing Chang, Qiang Qiu, Saritha Vermeer, Elizabeth Adler, Mariano Tepper, Helen L Egger, Jeffery P Baker, Guillermo Sapiro and Geraldine Dawson
Computer vision captures atypical attention in toddlers with ASD

<table>
<thead>
<tr>
<th>Table 1. Participant characteristics.</th>
<th>Comparison (N = 82)</th>
<th>Autism (N = 22)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>48 (59%)</td>
<td>17 (77%)</td>
<td>0.09</td>
</tr>
<tr>
<td>Developmental delay</td>
<td>8</td>
<td>–</td>
<td></td>
</tr>
<tr>
<td>Age (months)</td>
<td>21.91 (3.78)</td>
<td>26.19 (4.07)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>48 (59%)</td>
<td>10 (45%)</td>
<td>0.56</td>
</tr>
<tr>
<td>African American</td>
<td>11 (13%)</td>
<td>3 (14%)</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>5 (6%)</td>
<td>1 (5%)</td>
<td></td>
</tr>
<tr>
<td>Multiracial or other</td>
<td>18 (22%)</td>
<td>8 (36%)</td>
<td></td>
</tr>
<tr>
<td>Screen time (h)</td>
<td>1.15 (0.96)</td>
<td>2.18 (1.58)</td>
<td>0.02</td>
</tr>
<tr>
<td>ELC on MSEL</td>
<td>–</td>
<td>63.58 (25.95)</td>
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<tr>
<td>ADOS-T Total</td>
<td>–</td>
<td>18.81 (4.20)</td>
<td></td>
</tr>
</tbody>
</table>
Computer vision captures atypical attention in toddlers with ASD

Figure 3. Predicted means (lines) and 95% confidence intervals (shaded areas) for proportion of time engaged in the task from models covarying for the age by group interaction (p = 0.03). The autism group (blue dashed line) showed less time attending at older ages than the comparison group (pink solid line).
Technology use as a support tool by secondary students with autism

Susan H Hedges, Samuel L Odom, Kara Hume and Ann Sam

Table 1. Participant Characteristics.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (N = 472)</td>
<td>Male 87% (409)</td>
</tr>
<tr>
<td>Mean age (in years) (N = 469)</td>
<td>16.8 (SD 1.4)</td>
</tr>
<tr>
<td>Race (N = 439)</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>67% (296)</td>
</tr>
<tr>
<td>Ethnicity (N = 450)</td>
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</tr>
<tr>
<td>Non-Hispanic</td>
<td>79 (356)</td>
</tr>
<tr>
<td>Income (N = 370)</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>23 (84)</td>
</tr>
<tr>
<td>Medium</td>
<td>29 (107)</td>
</tr>
<tr>
<td>High</td>
<td>48 (179)</td>
</tr>
<tr>
<td>IQ (N = 443)</td>
<td></td>
</tr>
<tr>
<td>&gt;70</td>
<td>77 (342)</td>
</tr>
<tr>
<td>Diploma track (N = 471)</td>
<td></td>
</tr>
<tr>
<td>Standard</td>
<td>60 (282)</td>
</tr>
</tbody>
</table>

Table 2. Frequency of using technology to complete assignments.

<table>
<thead>
<tr>
<th>Using technology to complete assignments</th>
<th>Everyday M-F (%)</th>
<th>Some days (%)</th>
<th>Never (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>To look things up on the Internet</td>
<td>54</td>
<td>41</td>
<td>5</td>
</tr>
<tr>
<td>To type things up</td>
<td>45</td>
<td>46</td>
<td>9</td>
</tr>
<tr>
<td>To make presentations (e.g. PowerPoint)</td>
<td>21</td>
<td>59</td>
<td>20</td>
</tr>
<tr>
<td>To turn in assignments</td>
<td>33</td>
<td>43</td>
<td>23</td>
</tr>
<tr>
<td>To work with other students (e.g. Google docs)</td>
<td>18</td>
<td>48</td>
<td>33</td>
</tr>
</tbody>
</table>

N = 358.

Table 3. Frequency of using technology to stay organized.

<table>
<thead>
<tr>
<th>Using technology to stay organized</th>
<th>Everyday M-F (%)</th>
<th>Some days (%)</th>
<th>Never (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>As a calendar</td>
<td>20</td>
<td>44</td>
<td>36</td>
</tr>
<tr>
<td>As a planner</td>
<td>13</td>
<td>33</td>
<td>54</td>
</tr>
<tr>
<td>As an alarm</td>
<td>29</td>
<td>25</td>
<td>45</td>
</tr>
<tr>
<td>As a timer</td>
<td>17</td>
<td>40</td>
<td>42</td>
</tr>
<tr>
<td>As a camera</td>
<td>18</td>
<td>47</td>
<td>35</td>
</tr>
<tr>
<td>As a video/sound recorder</td>
<td>13</td>
<td>32</td>
<td>54</td>
</tr>
<tr>
<td>To take notes</td>
<td>22</td>
<td>38</td>
<td>39</td>
</tr>
</tbody>
</table>
Technology as supports for secondary schools

- **Positives:**
  - Makes learning easier (87%) and fun (85%)
  - Ability to reach parents (66%)
  - Used to relax (84%) and play with friends (49%)
  - Communication:
    - Friends (81%)
    - Family members (74%)
    - Keep up with what’s going on (55%)
    - Make new friends (47%)
    - Find people with same interests (47%)
    - Avoid talking to people (32%)
    - Communicate with Teachers (36%)

- **Barriers:**
  - “Cyberslacking”/distractio n (58%)
  - Not permitted in all classes (44%)
Technology as supports for secondary schools

• Benefits:
  • Increases in independence
  • Facilitates social opportunities
  • Reduce stress and anxiety

• Recommendations:
  • Technology-aided instruction – evidence based (Wong et al., 2014)
  • Teachers/institutions will need to facilitate
    • Coaching and supports for how technology can be incorporated
  • A shift towards focusing on how to use technology responsibly (Aakash et al., 2015)
Notable other works

  - 12 adults with ASD interviewed
  - Overarching theme of managing uncertainty: Crystalized Safe, Social Aspects

  - 8 studies
  - Coaching support/focus on face features = effective
Areas of advancement

- Wearables
- Virtual reality
- Augmented reality
- Video games
- Robots.. Lots of robots
- “Biomarker” technologies
  - Eye Tracking
  - EEG and other brain-based techniques
  - Computational Behavioral Vision
- SGDs/AAC
- Things we didn’t expect:
Chat with us: scitl@seattlechildrens.org
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