Neurodevelopmental disorders and clinical/research adaptations the during pandemic

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The CAN Lab
Converging Approaches to Neurodevelopment
Overall Objectives

• Discuss basic background on ASD, NDD, and developmental disorders. Where we were, are, and are going?

Look at what an integrated clinical-research approach has to offer families and professionals

What have we learned from the pandemic?

• Provide examples of local and regional resources for clinicians and families
Background

**Estimated Autism Prevalence 2020**

- 1943 – Leo Kanner – *Infantile autism*
- 1944 – Hans Asperger
- 1960s – Separation from schizophrenia
- 1970s – Biology / genetic underpinnings
- 1980 – DSM-III – Pervasive Developmental Disorders
- 1987 – DSM-III-R - Autistic Disorder / PDD-NOS
- 1994 – DSM-IV – Asperger’s Disorder
- 2013 – DSM-5 – Autism “Spectrum” Disorders

*If you see one child with autism, you’ve seen one child with autism*

*Centers for Disease Control and Prevention (CDC) prevalence estimates are for 4 years prior to the report date (e.g., 2020 figures are from 2016)*
Neurodevelopmental Disorders
ASD as an example: Multiple Risk Factors
(what we know now)

From Reductionism to
Systems Integration Approaches...
The Ideal Comprehensive Assessment
*a complete evaluation includes genetic testing*

Slide Credit: AACAP Genetics Lecture 2018

Incorporate genetic testing here!
Integrated Research Practice Approach

Approach to healthcare and research that focuses on generating knowledge that answers important questions that matter to patients, their health care providers, and stakeholder's system-wide.

In a digital area, data sets are becoming larger and offer great potential for improved care, better health for populations, and reduced health care costs.
Integrated Approach

What it takes to make research go hand in hand with clinical work

What can research tell us?

Research can be conducted in ways that provide more benefits to the families and participants

◦ What do we know about genetics to date?
◦ What do we know about early risk factors?
New Paradigm Shift in Treatment and Intervention
Transitioning from the ‘one-size-fits-all’ to ‘precision medicine’ model with multi-level patient stratification.
Developmental Perspectives Essential

Partner with clinical researchers and resources like SPARK

Adapted from: Loth, Murphy, & Spooren (2016)
What’s in it for families?

- Easy saliva **testing** of known (newly discovered) genes associated with autism
- Access to **interpretation** of findings (de novo vs. inherited) if something related to autism is identified
- Ongoing **community** that provides current access to resources
- Participation in SPARK can all be done from **home or with local staff**
- Being part of **SPARK** could provide **connections** to further national studies
Why do both clinical testing and SPARK?

- On an annual basis, SPARK will *iteratively re-analyze* the genomic data of participants. Results may be returned at the new point of discovery.

Currently, approximately 10-20% of ASD cases have an identifiable genetic etiology of large effect (Tammimies et al. 2015). As more genes are discovered, it is reasonable to *estimate that this percentage will increase* to 30 to 40% in the next five years.

Families will be *connected to local and national* resources and opportunities (e.g., services, support groups, future research, webinars, etc).
What did we learn during this Pandemic?

SPARK

Impact of COVID-19 on Families and Children with Autism

Impact of COVID-19 on Autistic Adults

SPARK Summary Report

How Has the COVID-19 Pandemic Affected Independent Adults with Autism?

https://sparkforautism.org/portal/page/spark-research-match/

SPARK Summary Report

How Did the COVID-19 Pandemic Affect People with Autism and their Caregivers?
Impact of COVID-19 on Families and Children with Autism

Who participated?

Parents and Guardians
- 93% Female
- 43 years old (on average)

Their Children with ASD are
- 80% Male
- 12 years old (on average)

Where do they live?

- South 33%
- West 26%
- Midwest 24%
- Northeast 17%

N > 8000 families
Impact of COVID-19 on Families and Children with Autism

**School**

- 98% of families report that their child's school is closed. This includes responses from parents and guardians of dependent adults with ASD.

**Child with autism's understanding of COVID-19**

- 42% of families report that their child with ASD understands information related to COVID-19 moderately well to completely.

**Disruptions in services and therapies**

- 63% of families report severe disruptions in services and therapies.
- 64% of families report that speech therapy is most disrupted.

Percent of families reporting settings for services or therapies that have been disrupted:

- School 84%
- Professional Clinic 52%
- Home (Administered by visiting staff) 26%
- Home (Administered by a parent or caregiver) 15%
- Daycare 7%
- Residential programs 6%
Impact of COVID-19 on Families and Children with Autism

Remote services and therapies

- 35% of families are receiving remote services or therapies.
- 43% of these families are benefitting moderately well to significantly from these services.

Child with autism’s mental and emotional health

- 62% of families report that their child with ASD is feeling good overall.
- 95% of families that report disruptions in services or therapies have negatively impacted their child with ASD’s behavior.
- 82% of families that report that COVID-19 has negatively impacted their child with ASD’s mental and emotional health.
Impact of COVID-19 on Families and Children with Autism

Parent and guardian’s mental and emotional health

- 51% of parents and guardians are feeling good overall.
- 97% of parents or guardians that report feeling stressed or overwhelmed due to disruptions in their child with ASD’s services or therapies.
- 95% of parents or guardians that report that COVID-19 has negatively impacted their mental health.

What’s working?

These suggestions are from comments that parents and guardians entered through an open-ended question in the survey.

- Social stories
- Breaks for rest and relaxation
- Telehealth appointments
- Pursuing hobbies
- Cooking for family
- Enjoying time with family in person and virtually
Who participated?

- Sex at birth:
  - 41% Male
  - 59% Female

Average age: 36 years

Impact of COVID-19 on Autistic Adults

Where do they live?

- West 29%
- South 28%
- Midwest 24%
- Northeast 19%
Which parts of life are most disrupted?

Parts of life that have changed due to COVID-19:

- Social life: 70%
- Employment (paid or volunteer): 53%
- Homelife: 48%
- Services or therapies: 41%
- Financial security: 36%
- School: 20%
- None: 6%

Impact of COVID-19 on Autistic Adults

Social life

The data below are from those who reported changes in their social life due to COVID-19.

- 97% of autistic adults report that COVID-19 has negatively impacted their social life.
- 68% of autistic adults report that they are coping minimally to moderately well with changes in their social life.
93% of autistic adults report that schooling has been negatively impacted by COVID-19.

65% of autistic adults report that they are coping with changes to schooling moderately to completely well.

50% of autistic adults are feeling good to excellent.

93% of autistic adults that report COVID-19 has negatively impacted their mental health.
Services and therapies

The data below are from those who reported changes in their services or therapies due to COVID-19.

Remote services and therapies

The data below are from those who reported changes in their services or therapies due to COVID-19.

97% of autistic adults report that services and therapies have been negatively impacted by COVID-19.

72% of autistic adults are coping moderately to completely well with changes in services or therapies.

63% of autistic adults are receiving remote services or therapies.

74% of these autistic adults are benefitting moderately to significantly well from these services.
95% of autistic adults are concerned about the impact of COVID-19 on their family and household.

The data below are from those who reported changes in their homelife due to COVID-19.

Percent of autistic adults that report COVID-19 has negatively impacted their homelife: 90%

Percent of autistic adults who are coping moderately to completely well with changes to their homelife: 67%

Impact of COVID-19 on Autistic Adults

What’s working?

- Telehealth
- Check-ins with therapists via email and phone
- Journaling
- Maintaining a schedule and sticking to it
- Walks and exercise
- Keeping in touch with family and friends via phone and video chat
Psychological Impact of COVID-19

“melt” of social skills

Inconsistency

Declined social gatherings

Isolation

Anxiety

https://www.ncbi.nlm.nih.gov/books/NBK361938/

Learning from the Pandemic

• Screening and diagnostic assessments for autism are not always available to families remotely.
• Due to the limitations of the pandemic, there is strong need for remote assessments.
• Novel telehealth approaches can be used to address this barrier.
• The current literature shows strong support for video, phone, and online screening and diagnostic assessment tools.
• Telehealth may be a feasible approach to increase accessibility of services during a pandemic.
Make it easier for parents and patients

Before the Day of Your Appointment
- Identify a private location for your appointment
- Check your technology
- Organize Billing Details
- Prepare your thoughts

On the Day of Your Appointment
- Get ready for your video session
- Do not forget...

Start Your Appointment
- Sign in and get started

Support and Protect Children’s Emotional Well-being

1. Understand that reactions to the pandemic may vary
2. Ensure the presence of a sensitive and responsive caregiver
3. Social distancing should not mean social isolation
4. Provide age-appropriate information
5. Create a safe physical emotional environment by practicing the 3 R’s: Reassurance, Routines, and Regulation
6. Keep children busy
7. Increase self-efficacy
8. Create opportunities for caregivers (and yourself) to take care of themselves
9. Seek professional help if there are signs of trauma
10. Emphasize strengths, hope, and positivity

3 R’s

- **Reassurance**
  - Reassure children about their safety and safety of loved ones

- **Routines**
  - Maintain routines to provide a sense of safety and predictability

- **Regulation**
  - Support development of self-regulation. “I know this might feel scary or overwhelming” and encourage them to engage in activities

Manage Your Own Mental Health

#SmallThingsMatter
Doing small things that make a big impact

#EverythingInteracts
What you do can positively influence others

#PatternsMatter
Mindful awareness of triggers to unhelpful patterns

#MeaningMatters
Take a moment. Meaningful moments make a positive impact.

#WeAreStrongerTogether
Join groups, make groups, and foster, enrich, and appreciate the connections you already have.

#SelfCareAsLove
Reflect on an act of love toward them by others. Look at themselves through the eyes of a loved one

Coyne et al., 2020
Innovation

RESEARCH

INTEGRATION required for NDDs

Computational Innovation

Technological Innovation

Methodological Innovation

Precision Health and Medicine

Strategic Prevention (via Community & Education Partnerships)
Regional network stay connected to research, resources, current news, and events

Go to find.umn.edu

◦ How to get families connecting to research through this One-Stop?
◦ What kind of research do they hear about?
University of Minnesota Services

Voyager Autism & Neurodevelopment Clinic

• Social Skills & Other Therapy Services
• Best practice diagnostic evaluations
• Developmental Behavioral Pediatrics & Psychiatry in clinic

FIND Network

• The Focus in NeuroDevelopment (FIND) Network connects individuals in the autism spectrum disorder (ASD) and neurodevelopmental disorder (NDD) community to research, resources, and events.
Additional Resources

MN Children’s Mental Health Crisis Line by County

MN Adult’s Mental Health Crisis Line by County

NAMI COVID-19 Resources

Telehealth Services
- Current and hybrid models will continue to be developed
Practice Points

• Community practitioners are ideally positioned to begin a dialogue about resources to help families learn more about their child’s development and diagnosis.

• A diagnosis of idiopathic ASD necessitates a genetic evaluation and should be part of our overall evaluation process.

• Clinicians can better monitor for symptoms and co-morbid conditions that are known to be associated with specific risk variants.

• Families that receive a genetic diagnosis can be better informed regarding family recurrence risks and other studies and resources.

• If a family has a child with autism and is expecting or has another child, early monitoring can make a world of difference.

• Refer families with positive genetic findings for genetic counseling.

  • Ethical implications of genetic testing in adolescents (ex. right to know) and the parents (ex. reporting of secondary findings) deserves thoughtful consideration. (slide credit: Autism and developmental group of AACAP)
In Summary

Beneficiaries: community, patients, clinicians, researchers

Knowledge-enabled Discovery

Knowledge-enabled Innovation

Information Commons

Computational Health

Digital Health

Ethics and Engagement

'Omics

Imaging

Basic Molecular

Population Science

Clinical Discovery

GENOMICS
MICROBIOME
EXPOSURES
BEHAVIORS
CLINICAL TESTS
PATIENT CONTRIBUTED DATA
Knowledge Network

https://precisionmedicine.ucsf.edu/elements-precision-medicine
Gut-Brain Axis
➢ 30% of individuals with ASD who experience gastrointestinal symptoms

New Medication Targets
➢ Working to develop new pharmacotherapies for ASD through investigator-initiated and industry-sponsored trials to assess drug targets

Genetics
➢ Serving as Minnesota partner for SPARK, a landmark national autism research study investigating genetic associations with ASD in over 50,000 families

Community Outreach
➢ Leading the FiND (Focus in Neuro-Development) Network to improve communication between the NDD community and the researchers, professionals, and organizations who work to serve them

Computational Modeling
➢ Applying machine-learning and computational techniques to predict and identify individuals with Autism Spectrum Disorder (ASD) in the population

Neuroimaging
➢ Studying brain development and neural correlates of behavior using functional and structural magnetic resonance imaging (MRI)

Cognitive Training
➢ Assessing the efficacy of computerized, adaptive, and brain-based targeted cognitive training (TCT) in adolescents and adults with ASD

Devices and Brain Circuits
➢ Augmenting cognitive training with neuromodulation to reduce symptoms across neurodevelopmental disorders (NDDs)
➢ Eye-tracking studies to understand information processing
➢ Using tasks and sensors to see how individuals learn
➢ Creating tools children and adults can use at home or in the community to measure learning

Computational Innovation
Technological Innovation
Methodological Innovation
MULTI-DISCIPLINARY EXPERTISE
Right Intervention
Right Dose
Right Time
Right Person
Precision Medicine
Strategic Prevention

NDD Discoveries and Interventions Across the Lifespan (CANeurdeveloPLAB, Jacob & Conelea)
Questions?