



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?

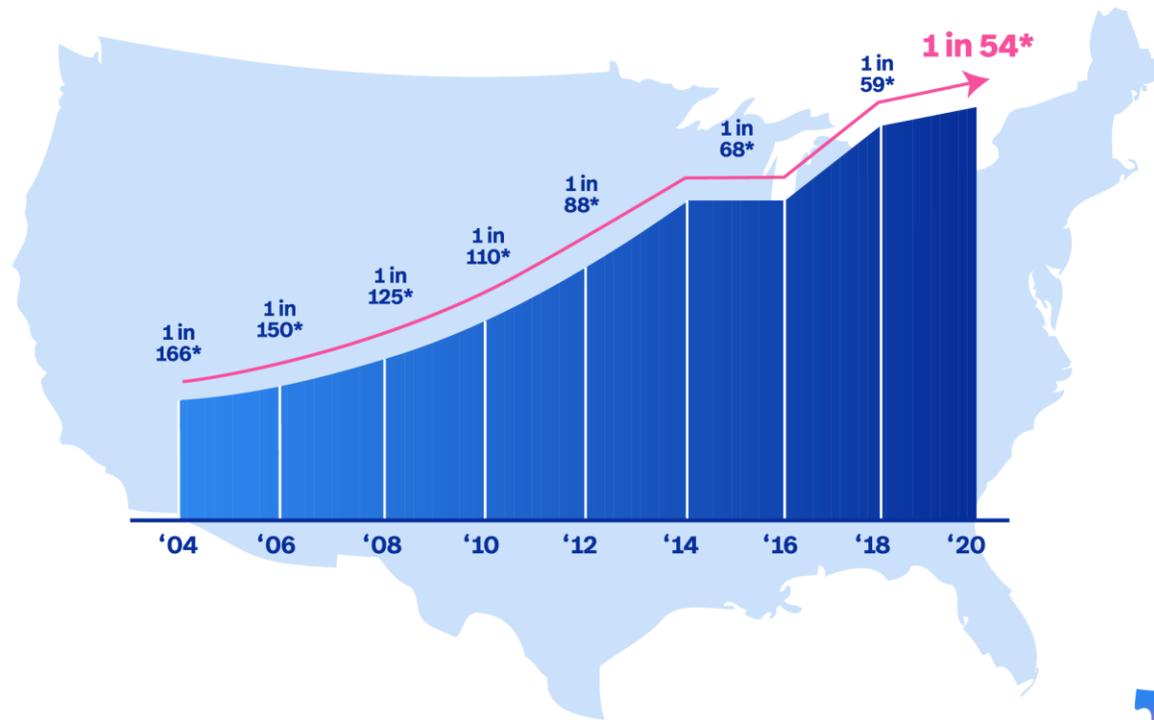
Look at what an **integrated clinical-research approach** has to offer families and professionals

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

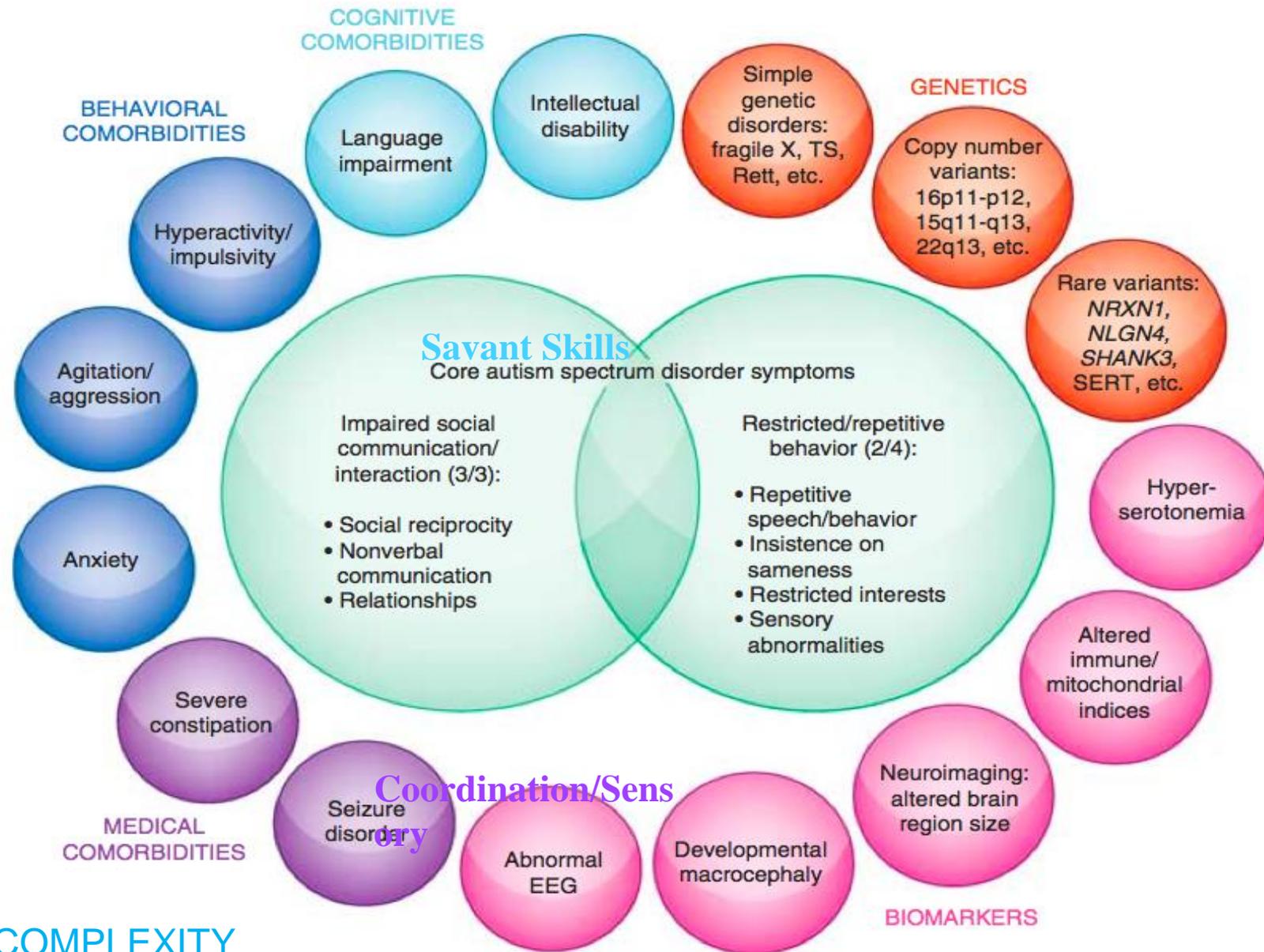
1994 – DSM-IV – Asperger's Disorder

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)





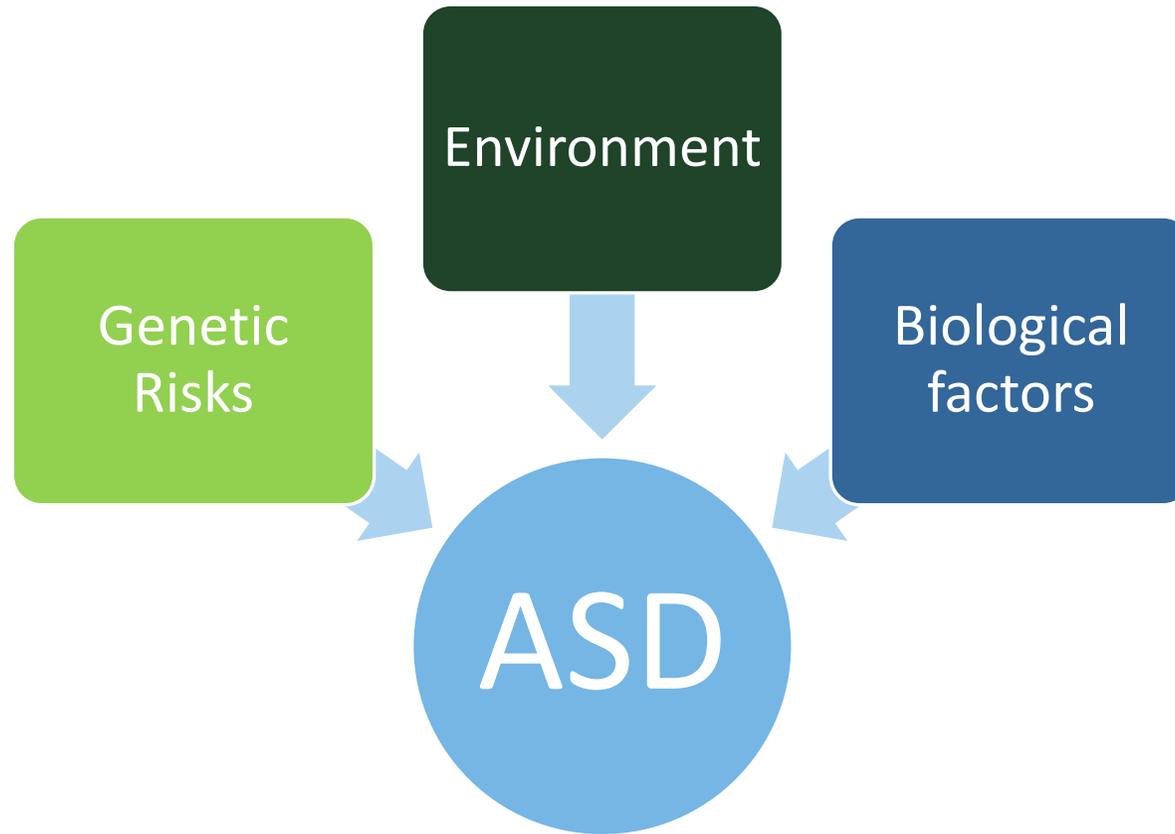
HETEROGENEITY AND COMPLEXITY

Veenstra-VanderWeele et al 2011

Neurodevelopmental Disorders

ASD as an example: Multiple Risk Factors

(what we know now)

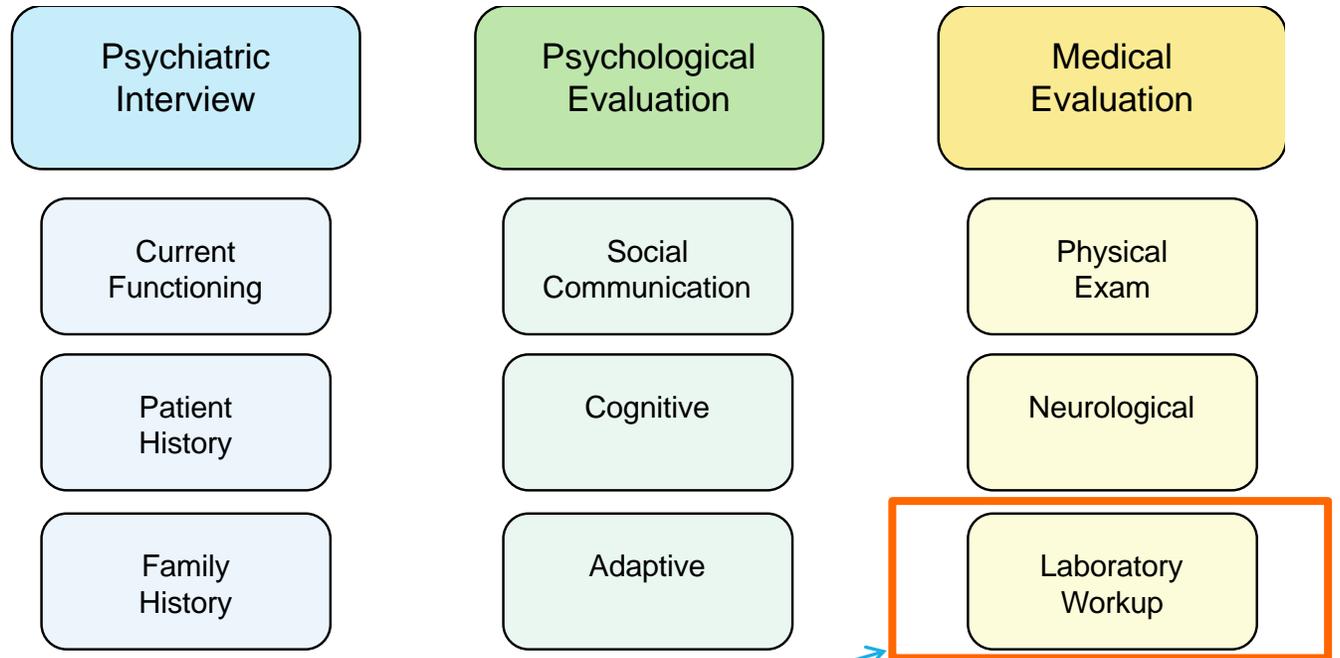


*From Reductionism to
Systems Integration Approaches...*

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

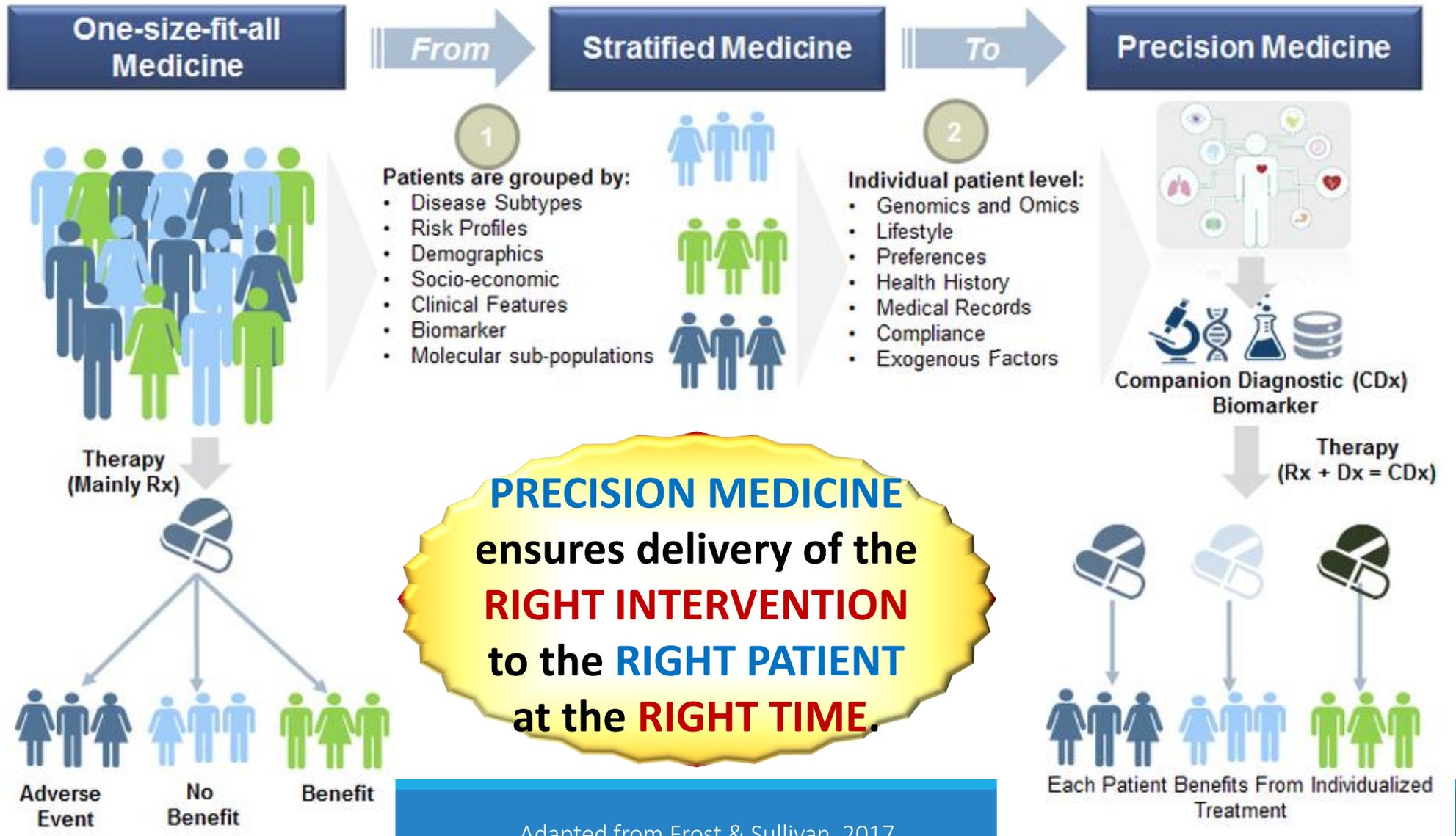
What can research tell us?

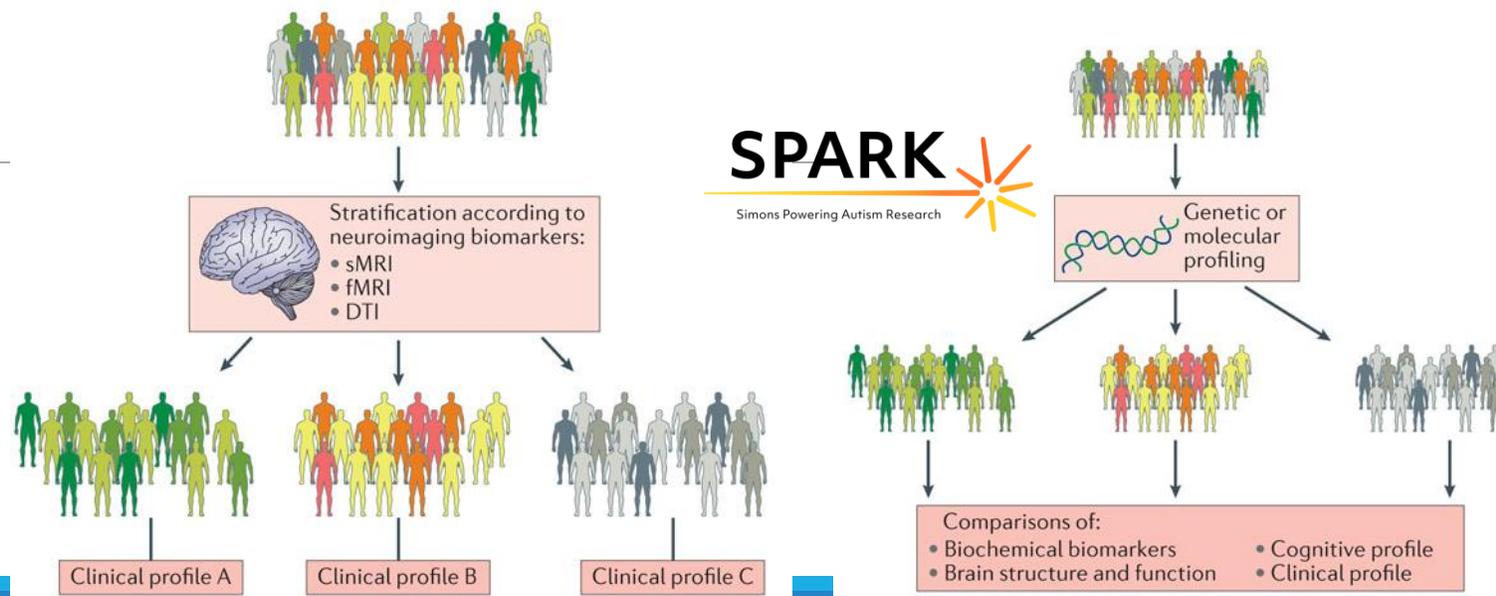
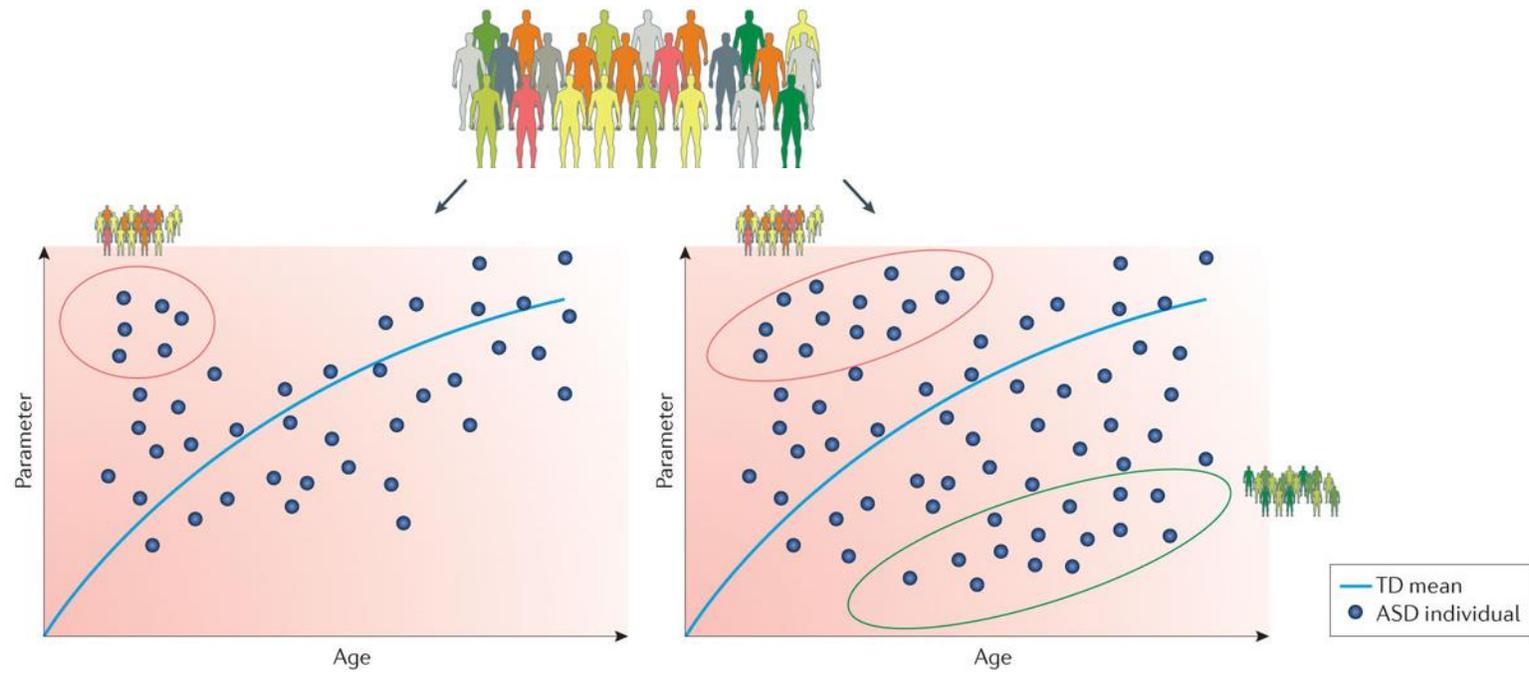
Research can be conducted in ways that provide more benefits to the families and participants

- What do we know about genetics to date?
- What do we know about early risk factors?

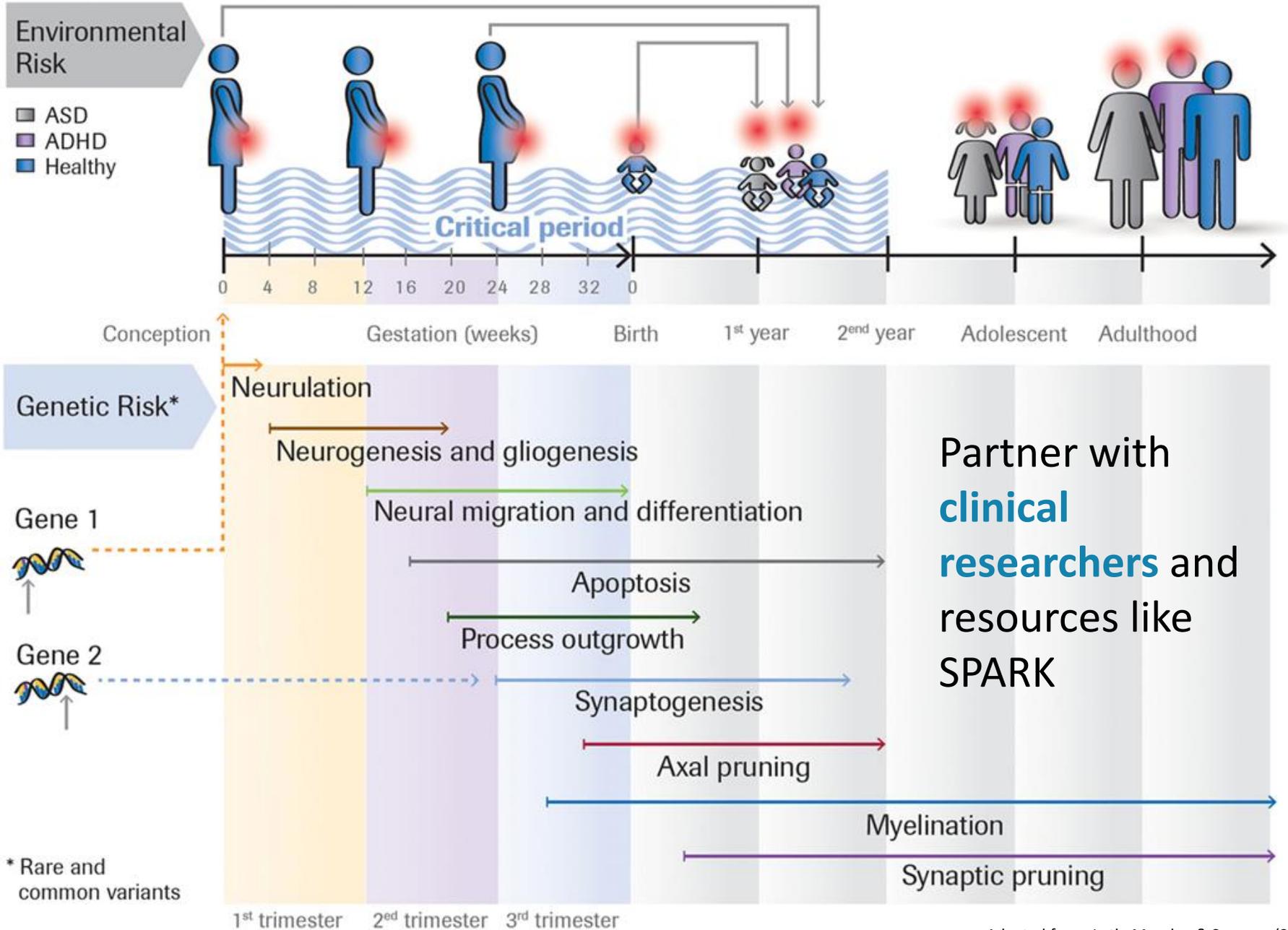
New Paradigm Shift in Treatment and Intervention

Transitioning from the 'one-size-fits-all' to 'precision medicine' model with multi-level patient stratification.





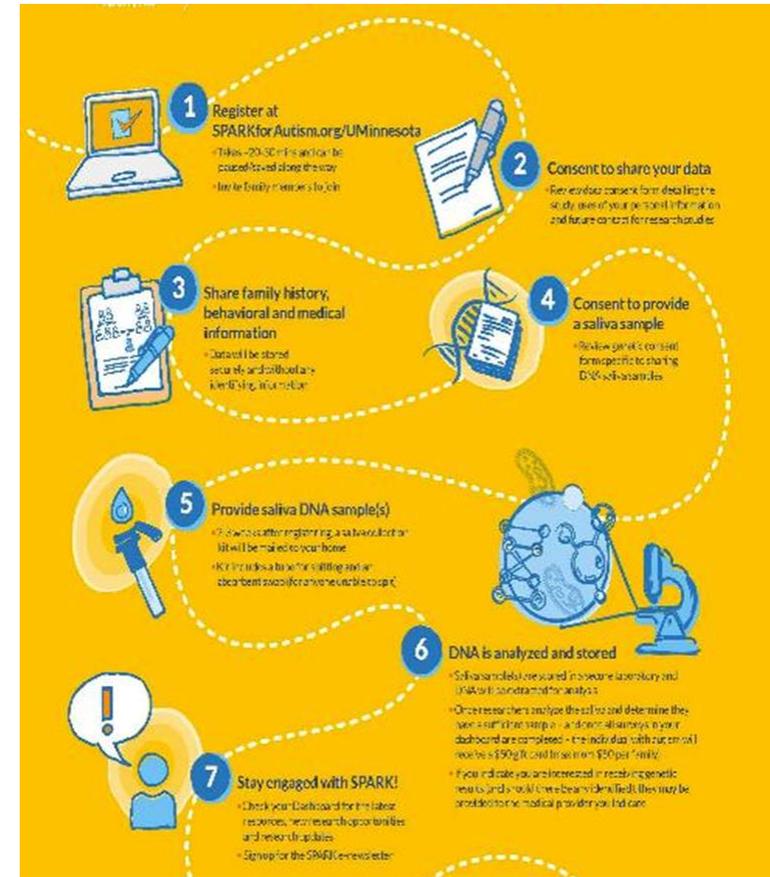
Developmental Perspectives Essential



Partner with **clinical researchers** and resources like **SPARK**

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**

SPARK 

Impact of COVID-19 on Autistic Adults



SPARK Summary Report  Research Match

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

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

SPARK Summary Report  Research Match

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



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

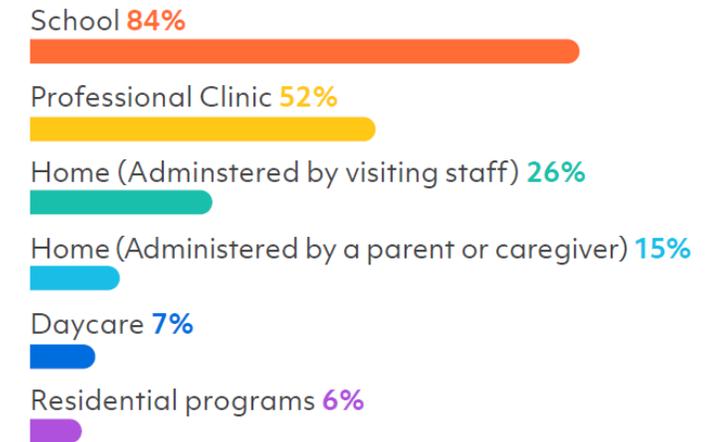
63%

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





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.

Percent of families that report disruptions in services or therapies have negatively impacted their child with ASD's behavior.

95%

Percent of families that report that COVID-19 has negatively impacted their child with ASD's mental and emotional health.

82%



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.

Percent of parents or guardians that report feeling stressed or overwhelmed due to disruptions in their child with ASD's services or therapies.

97%

Percent of parents or guardians that report that COVID-19 has negatively impacted their mental health.

95%

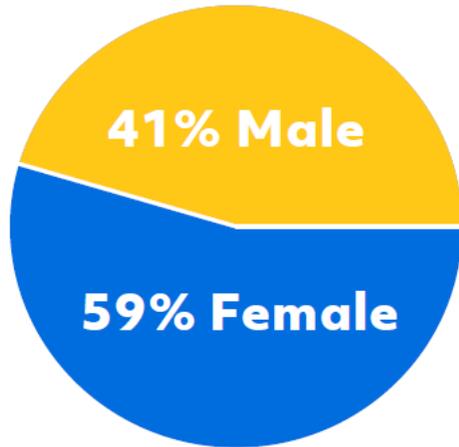
What's working?

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



Average age
36
years

SPARK 

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%**



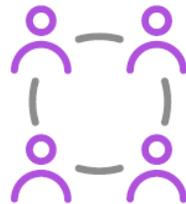
None **6%**



SPARK 

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.

School



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



- 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.

SPARK

Impact of COVID-19 on Autistic Adults

Mental and emotional health

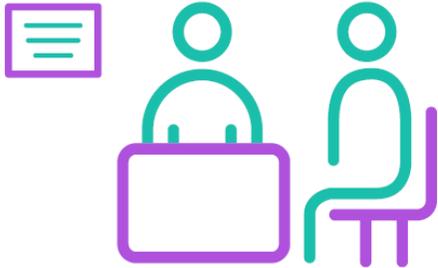
50%
of autistic adults are
feeling good to excellent.

Percent 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.



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.

SPARK 

Impact of COVID-19 on Autistic Adults

Remote services and therapies

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



63%

of autistic adults are receiving remote services or therapies.

74%

of these autistic adults are benefitting moderately to significantly well from these services.

Homelife

95%

of autistic adults are concerned about the impact of COVID-19 on their family and household.



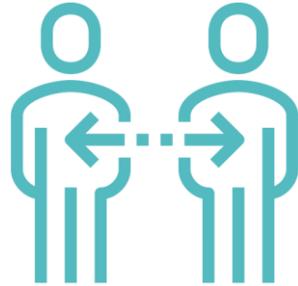
The data below are from those who reported changes in their homelife due to COVID-19.

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%



SPARK 

Impact of COVID-19 on Autistic Adults

What's working?

The following are suggestions from autistic adults who completed the survey.

-  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



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

<https://www.theatlantic.com/education/archive/2020/04/special-education-goes-remote-covid-19-pandemic/610231/>



Learning from the Pandemic

A systematic review of technological approaches for autism spectrum disorder assessment in children: Implications for the COVID-19 pandemic

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Angela Scarpa^{a,b}

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- 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

<https://2a392k31wksy2wkejf1y03dp-wpengine.netdna-ssl.com/wp-content/uploads/sites/188/2020/07/How-to-Prepare-for-a-Video-Appointment.pdf>

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

<https://www.childtrends.org/publications/resources-for-supporting-childrens-emotional-well-being-during-the-covid-19-pandemic>

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

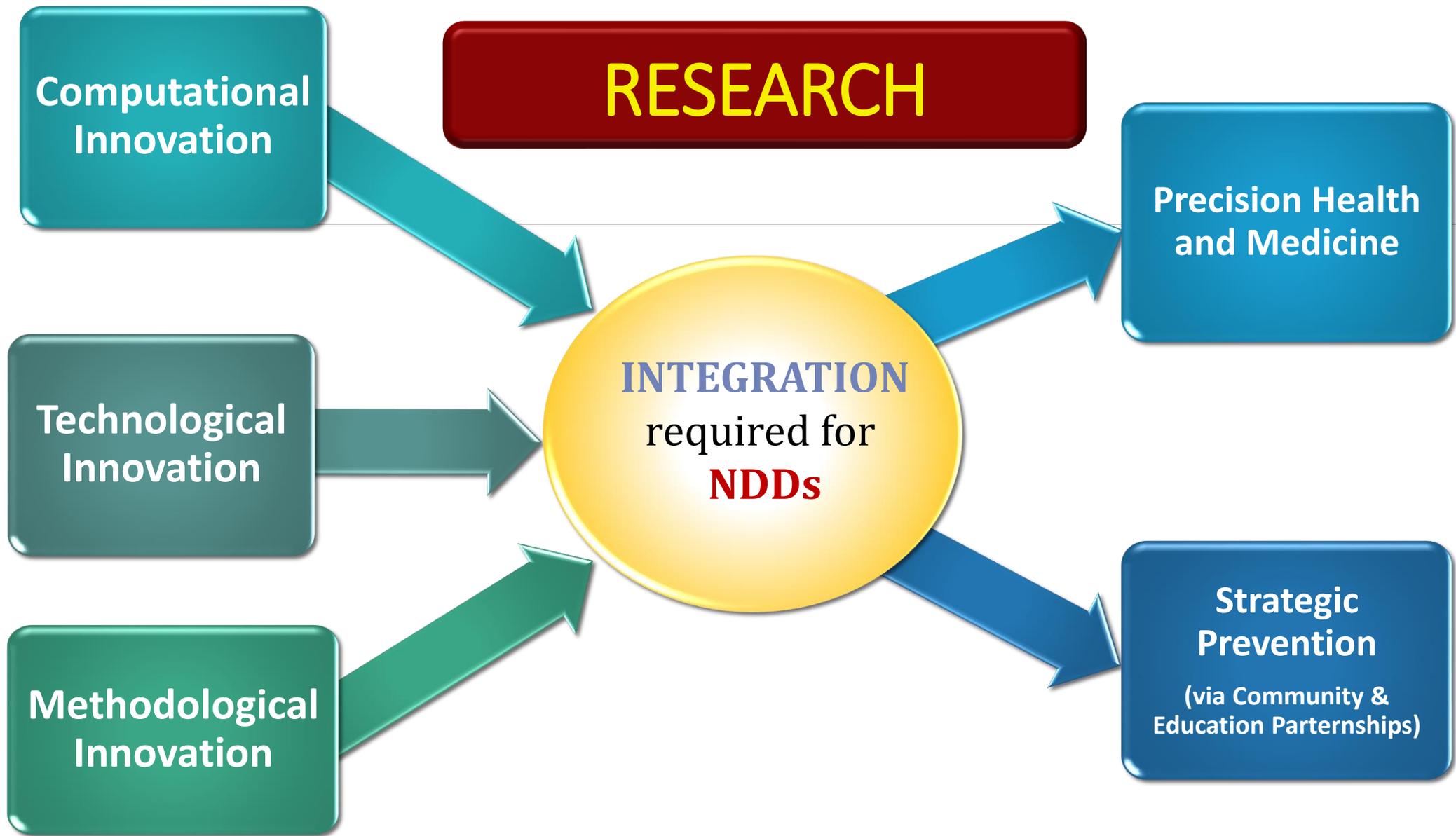
Take a moment. Meaningful moments make a positive impact.

#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



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?

Focus in
NeuroDevelopment
(FiND) Network



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

- <https://mn.gov/dhs/people-we-serve/people-with-disabilities/health-care/childrens-mental-health/resources/crisis-contacts.jsp>

MN Adult's Mental Health Crisis Line by County

- <https://mn.gov/dhs/people-we-serve/people-with-disabilities/health-care/adult-mental-health/resources/crisis-contacts.jsp>

NAMI COVID-19 Resources

- <https://2a392k31wksy2wkejf1y03dp-wpengine.netdna-ssl.com/wp-content/uploads/sites/188/2020/09/NAMI-COVID-19-Resources-8.31.pdf>

Telehealth Services

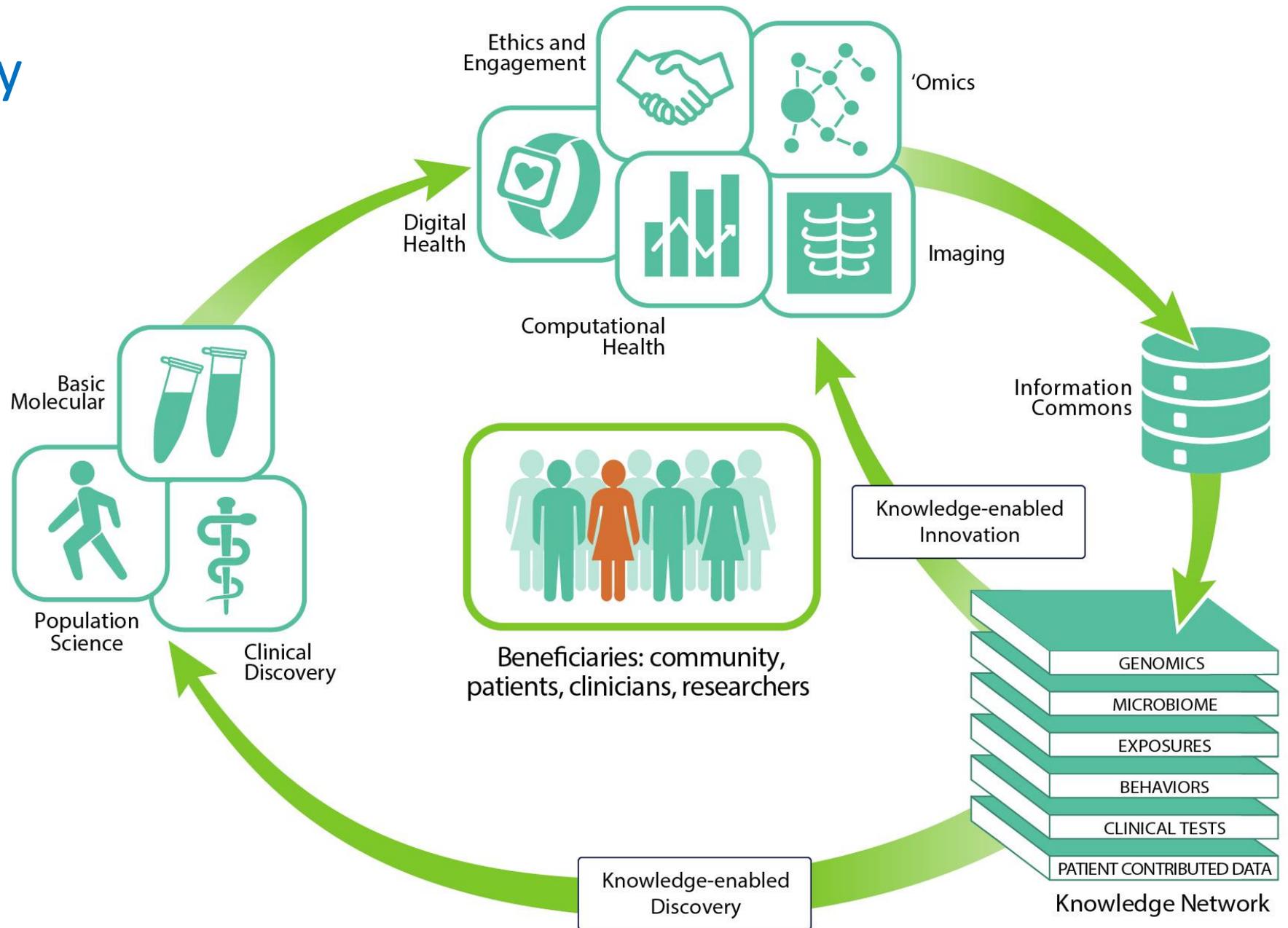
- Current and hybrid models will continue to be developed



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



NDD Discoveries and Interventions Across the Lifespan (CANeurdevelopLAB, Jacob & Conelea)



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

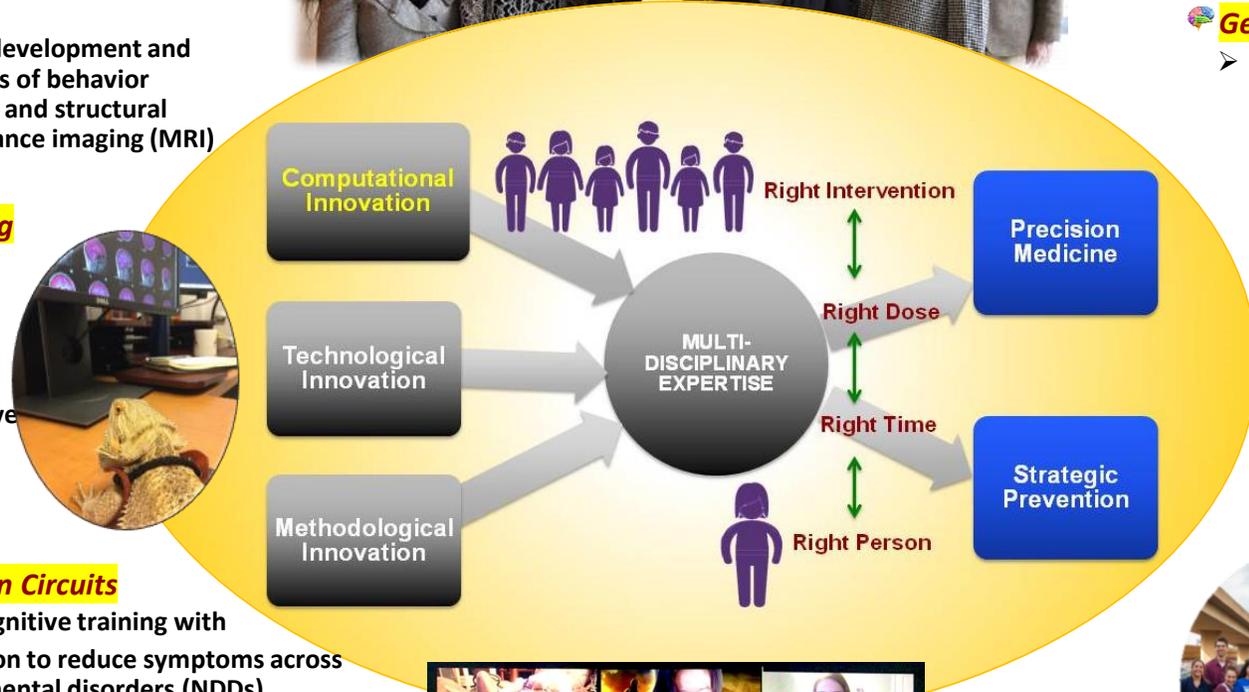
- Neuroimaging**
 - Studying brain development and neural correlates of behavior using functional and structural magnetic resonance imaging (MRI)

- 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

- 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



- Gut-Brain Axis**
 - ~30% of individuals with ASD who experience gastrointestinal symptoms

Questions?