



CATALIGHT™  
RESEARCH INSTITUTE

# ASD & Outcomes

May 6, 2024



# Disclosures

## Disclosure Statement

Catalight is a TRICARE provider we I have no other relevant financial or non-financial relationships to disclose.



# About Catalight

Catalight is creating a more equitable world so people with disabilities can **choose their path.**



- Non-profit based in the U.S.
- Serving over **14,000** families a day
- About 12,000 families have an IDD/autism family member that participates in our behavioral health treatment programs

# Fastest-growing developmental disability



Autism is the **fastest-growing developmental disability** in the U.S., according to the Centers for Disease Control and Prevention (CDC)

Prevalence rate is

**1 in 36**



In California, it is

**1 in 22\***

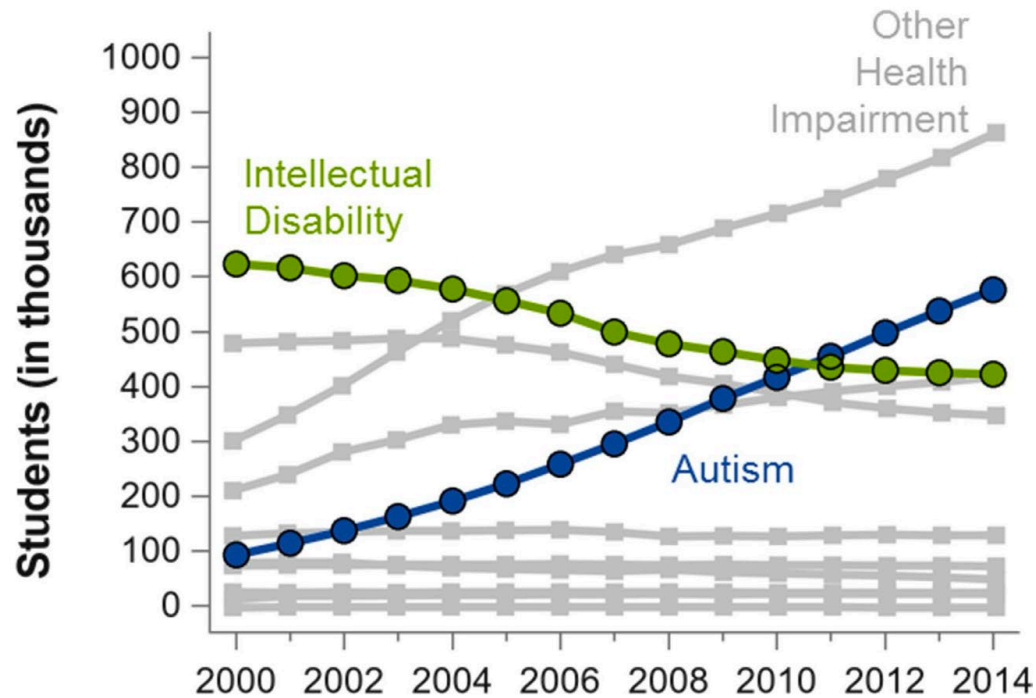


\*Maenner et al., 2023

Neurodivergent  
Syndromic  
Disability ID  
Profound ASD  
Autism-ID  
autism  
ASD-ADHD  
ASD ID  
ADHD Spectrum  
Autism ADHD

The Heterogeneity Problem

# Intellectual disability (ID) and Autism



**FIGURE 1** | Number of students (in thousands) in the US who receive special education services pursuant to the Individuals with Disabilities Education Act, adapted from a previous publication (6). Numbers are plotted by the beginning of academic year (X-axis) and by diagnostic group, which are mutually exclusive. Other diagnoses not explicitly labeled include deaf-blindness, developmental delay, emotional disturbance, hearing impairment, multiple disabilities, and orthopedic impairment. The most common diagnoses, specific learning disabilities (in 2014,  $n = 2,278$ ), and speech or language impairment (in 2014,  $n = 1,332$ ) are not shown. Figure produced from data obtained from the U.S. Department of Education (7).

## Complexity:

- Significant overlap of Sx
- Are we preferentially Dx autism over ID? (Thurm et al., 2019)
- Autism research excludes patients with ID (Russell et al., 2019)

Thurm et al., 2019





What should we measure?

# Population vs Individual measures?





# Outcome Measures Considerations

Includes  
caregiver/family

Addresses  
disability &  
support needs

Scalable

Standardized

Rolls up to a  
global measure

# Measures - Options

## Child

1. Adaptive behavior scale (e.g. Vineland-3).
2. Measures of disruptive or dangerous behavior (e.g. Vineland externalizing/internalizing scales or stand-alone measure).
3. Goal measures that include measurement of goals that are partially met (e.g. goal attainment scale - GAS).
4. Wellbeing or QoL (youth/adults) measure.

## Caregiver/family

1. Measure of parental stress.
2. Measure of parental self-efficacy.
3. Family wellbeing or QoL.

Measures of autism core symptoms or IQ are not included as these measures lack good empirical support and their relationship to wellbeing is weak.

# Outcome Pyramid

Wellbeing as a global outcome measure

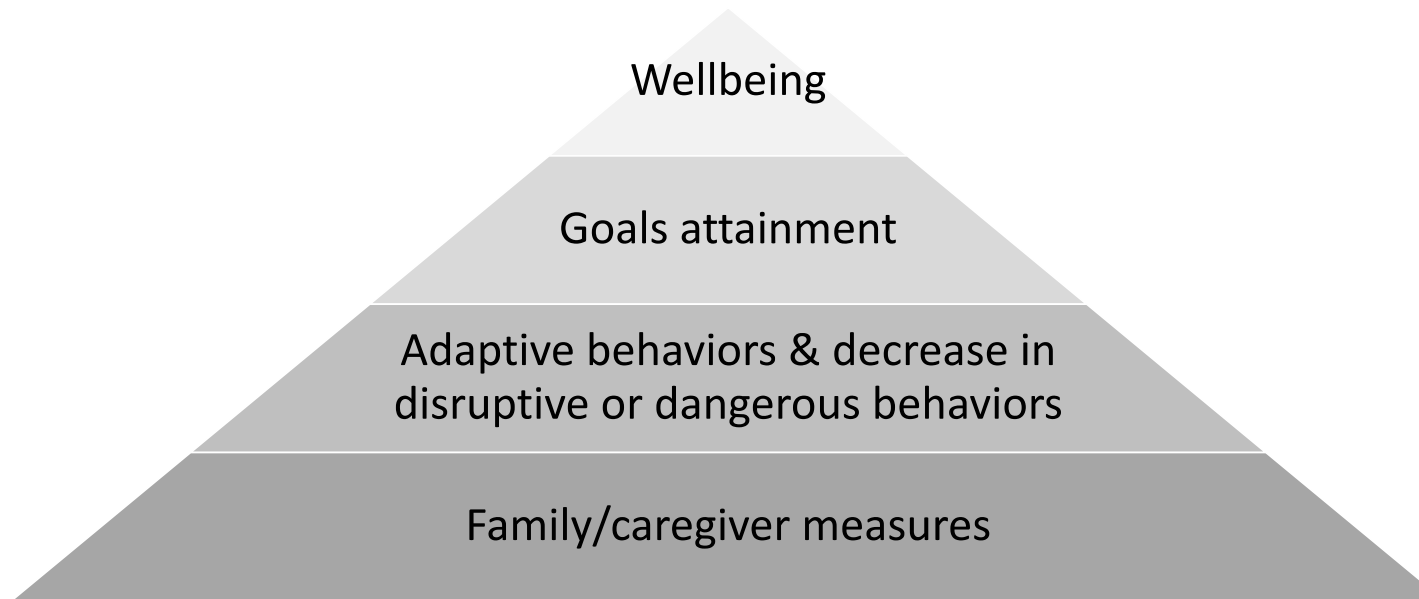


Figure 1::Example of how all outcome measures can roll up to wellbeing

# Catalight

## Outcome Measures

Wellbeing (Catalight Family, Youth or Adult Wellbeing Scale) (15 items-parent/patient scale)

Catalight Parental Self-Efficacy Scale (2-4 items-parent scale)

Parental Stress Survey-IDD version (15 items-parent scale)

Adaptive behavior with the Vineland-3 (parent or provider)

Disruptive behavior (Vineland -3 Internalizing and Externalizing scales)

Catalight Continuous Dangerous Behavior Surveillance Scale (provider scale)

Sleep questionnaire (provider scale)

Goal Attainment Scale (provider scale)



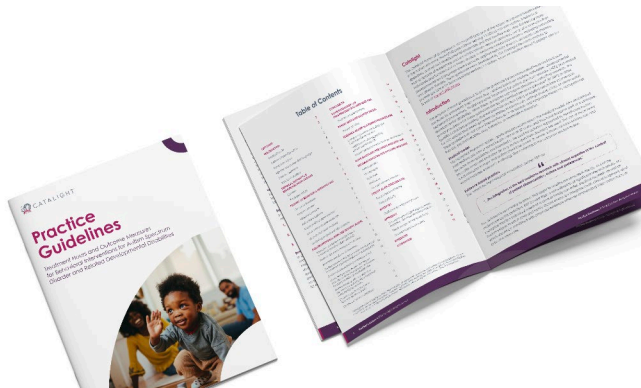
# Catalight.org

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Catalight Practice  
Guidelines with  
outcomes measures  
and more!



  
Wellbeing  
Scales



  
Parental  
Self-Efficacy Scale

# Appendix



## Initial Psychometric Properties of the Catalight Family Wellbeing Scale

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### Abstract

**Purpose** Wellbeing refers to a person's overall happiness and satisfaction with life. Wellbeing for people with Intellectual and Developmental Disabilities (I/DD) and their families is historically significantly lower compared to the general population. It is important in the context of behavioral health treatment to not only measure the individual who is receiving treatment's overall wellbeing, but also the wellbeing of the family. The purpose of this study was to understand the initial psychometric properties of the Catalight Family Wellbeing Scale.

**Methods** The Catalight Family Wellbeing Scale was developed for families who have a child with I/DD. Caregivers of 3106 families who have a child with a diagnosed I/DD, including autism spectrum disorder, completed the scale as part of their onboarding for behavioral health treatment along with three other questionnaires. The psychometric properties including internal reliability and factor structure were completed as well as initial convergent and divergent validity.

**Results** Results of the analyses revealed very strong internal reliability and a three-factor structure. Validity analyses revealed a moderate positive relationship with parental self-efficacy and a moderate negative relationship with parental stress. Additionally, the sample population represents an ethnically diverse group with multiple co-occurring diagnosis in addition to I/DD.

**Conclusions** The initial psychometric properties of the Catalight Family Wellbeing Scale are positive and support the use of the scale for families who have a child with I/DD across a diverse sample.

Catalight  
Family  
Wellbeing  
Scale  
Sneed et  
al., 2024

## Catalight Family Wellbeing Scale

**Table 2** Rotated structure matrix for PCA with varimax rotation of CFWS

Item	Rotated Component Coefficients			Communalities
	Relationship	Family Management	Family Determination	
R1 - We are able to resolve conflict and support each other when things go wrong	<b>0.82</b>			0.72
R2 - We have good communication in our family	<b>0.80</b>			0.71
R3 - In my family we share our feelings and support each others emotional needs	<b>0.76</b>			0.63
R4 - We prioritize individual family health needs.	<b>0.67</b>			0.54
R5 - We enjoy spending time together	<b>0.67</b>			0.60
R6 - Family members feel safe in our family	<b>0.61</b>			0.51
R7 - Working members of my family are able to balance work and caregiver/ childcare responsibilities	<b>0.54</b>			0.58
R8 - We are able to balance family needs so that we can pursue our own interests.	<b>0.51</b>			0.51
FM1 - We have support outside of our family to help with caregiver/childcare responsibilities.		<b>0.75</b>		0.57
FM2 - Financial cost of caregiving for our family member with a disability, autism or a developmental delay is manageable		<b>0.67</b>		0.51
FM3 - Our family is part of a larger community		<b>0.66</b>		0.45
FM4 - We have access to disability, autism or developmental delay related resources		<b>0.65</b>		0.47
FD1 - In my family, we have what we need for food and shelter			<b>0.80</b>	0.71
FD2 - We care about one another			<b>0.75</b>	0.71
FD3 - Our family is able to make decisions that benefit us.			<b>0.58</b>	0.52



# Catalight Continuous Dangerous-Behavior Surveillance (CDS) Measure



- Developed in 2021
- The CDS defines dangerous behavior (DB) as severe behaviors that could result in **physical injury requiring first aid, medical attention or behaviors that could result in law enforcement involvement**
- The CDS measures both frequency and severity of DB across **eight** DB types
- The CDS allows Catalight to monitor an individual's DB as well as provide a population measure of DB (CDS Population Score)
- Challenging or disruptive behavior is tracked separately and is not part of CDS

# CDS Dangerous Behaviors Types

Only behaviors that cause or have a high probability of causing physical injury or law enforcement involvement are included.

- Physical harm to others (severe aggression)
- Self-injurious behavior
- Dangerous elopement that is not age-appropriate

- Property destruction
- Pica
- Behaviors connected to elimination
- Other behaviors that might lead to physical harm or law enforcement involvement