

# Quality of Life Indicators: Practical Guidelines for Meaningful Change

Michael J. Cameron, Ph.D., BCBA-D, LBA  
19 October 2019



Arizona Autism **COALITION**

Building an integrated community together



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# 2019 AUTISM & I/DD RESOURCE CONFERENCE

*ADVANCING COMPASSIONATE CARE THROUGH COLLABORATION*

SATURDAY, OCTOBER 19, 2019

DESERT WILLOW CONFERENCE CENTER | PHOENIX

## HOPE

GROUP

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“A successful talk is  
a little miracle –  
people see the  
world differently  
afterward”

Anonymous





# Minimum Standard Set of Outcome Measures



Conceptual Overview: Delphi Process



Depression



Macular Degeneration



ASD

Richard  
Feynman

“The first principle  
is that you must not  
fool yourself and  
you are the easiest  
person to fool”



# DEPRESSION & ANXIETY

## THE STANDARD SET

The ICHOM Standard Set for Depression & Anxiety is the result of hard work by a group of leading physicians, measurement experts, and patients. It represents the outcomes that matter most to patients with depression and/or anxiety. We urge all providers around the world to start measuring these outcomes to better understand how to improve the lives of their patients.

**1** Recommended to track via the Patient Health Questionnaire (PHQ-9).

**2** Includes symptoms of general anxiety, social phobia, agoraphobia, post-traumatic stress disorder, panic disorder, and obsessive-compulsive disorder.

**3** Recommended to track via the Generalized Anxiety Disorder (GAD-7), and for those with specific anxiety disorders: the Social Phobia Inventory (SPIN), the Mobility Inventory for Agoraphobia (MIA), the Impact of Event Scale - Revised for Post-Traumatic Stress Disorder (IES-R), the Panic Disorder Severity Scale (PDSS-SR), and the Obsessive-Compulsive Inventory (OCI-R).

**4** Recommended to track via the World Health Organization Disability Assessment 2.0 (WHODAS 2.0).

**5** Includes work status and disease-related absenteeism.





# A Proposed Minimum Standard Set of Outcome Measures for Cataract Surgery

Imran Mahmud, MD, MPH; Thomas Kelley, MD, MBA; Caleb Stowell, MD; Aravind Haripriya, MD, MS; Anders Boman, MD; Ingrid Kossler, MBA; Nigel Morlet, FRANZCO, FRACS; Suzann Pershing, MD, MS; Konrad Pesudovs, PhD; Pik Pin Goh, MD, MS; John M. Sparrow, DPhil, FRCOphth; Mats Lundström, MD, PhD

**IMPORTANCE** Aligning outcome measures for cataract surgery, one of the most frequently performed procedures globally, may facilitate international comparisons that can drive improvements in the outcomes most meaningful to patients.

**OBJECTIVE** To propose a minimum standard set of outcome measures for cataract surgery that enables global comparisons.

**DESIGN, SETTING, AND PARTICIPANTS** A working group of international experts in cataract outcomes and registries was convened, along with a patient advocate, to agree on a consensus of outcome measures for cataract surgery. In a modified Delphi process, the group met regularly between November 10, 2012, and November 21, 2013, to discuss which outcomes to include in a standard set. Included factors were based on extant literature, existing registries, and the experience of group members. Similarly, a series of consensus discussions were held to determine a set of risk factors to be gathered for each patient. The final shortlist was compiled into a standard set. Analysis was performed from November 22, 2013, to April 5, 2014.

**MAIN OUTCOMES AND MEASURES** Development of a recommended standard set encompassing preoperative metrics including patient risk factors, intraoperative factors including surgical complications, and postoperative cataract surgery outcomes.

**RESULTS** The recommended standard set encompasses all patients treated for cataracts by 1 of 4 surgical approaches (phacoemulsification, sutured manual extracapsular cataract extraction, sutureless manual extracapsular cataract extraction, or intracapsular cataract extraction). The recommended metrics to be recorded preoperatively include demographics, ocular history and comorbidities, preoperative visual acuity, and patient-reported visual function. The recommended outcomes were split into intraoperative and postoperative metrics. Intraoperative outcomes include capsule-related problems, dislocation of lens nucleus fragments into the vitreous, and other complications. Postoperative outcomes include visual acuity, refractive error, patient-reported visual function, and early and late complications of surgery. The suggested follow-up for collection of postoperative outcomes is up to 3 months.

**CONCLUSIONS AND RELEVANCE** A minimum standard set of outcome measures for cataract surgery is important for meaningful comparison across contexts. The proposed data set is a compromise between all useful data and the practicalities of data collection.

[← Invited Commentary](#)  
page 1253

[+ Author Audio Interview at jamaophthalmology.com](#)



# Minimum Set of Standardized Client-Centered Outcome Measures





A minimum standard set  
of client specific  
outcomes is  
required for  
Autism Spectrum  
Disorder and  
related disabilities.

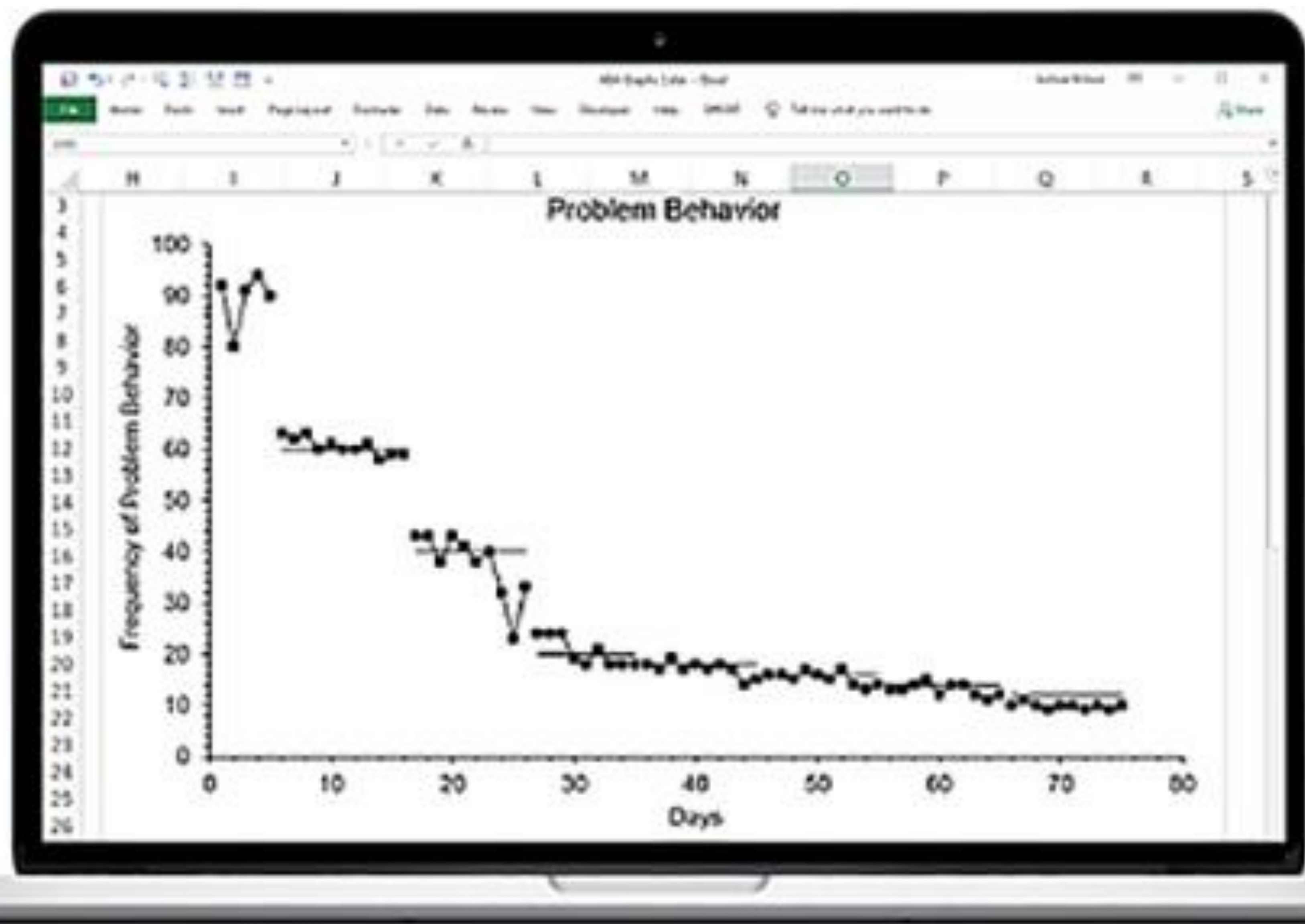
# Outcome Measures





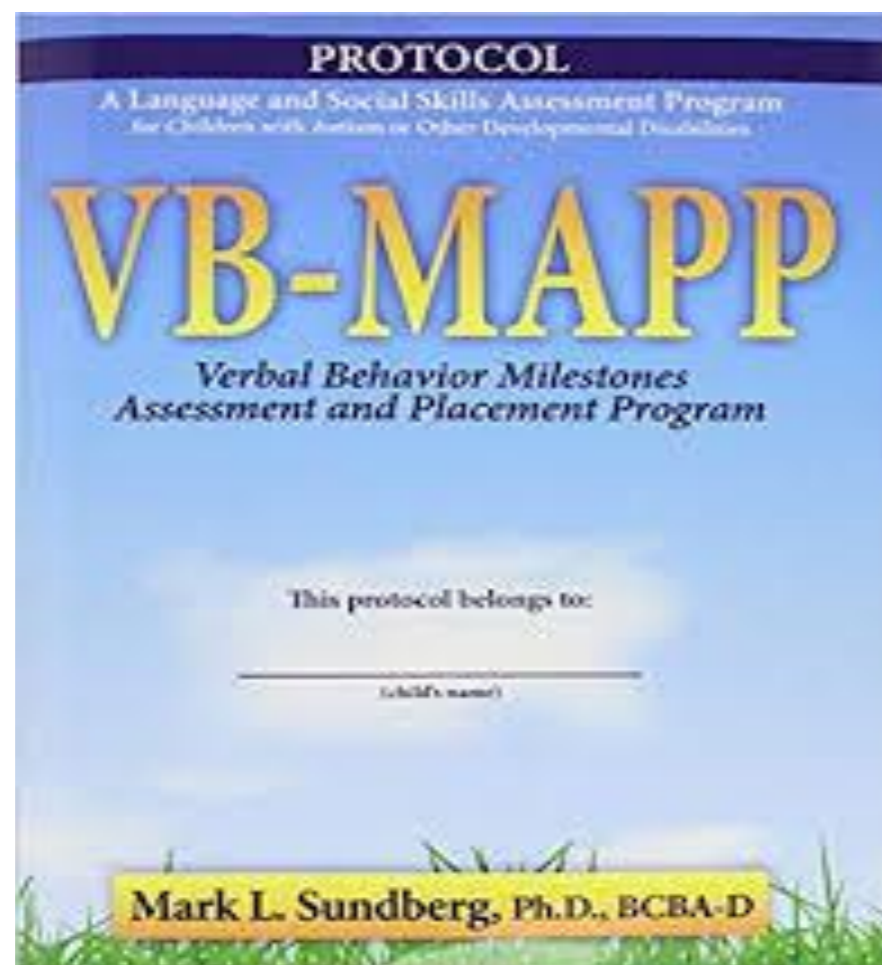






# Categories of Credible Outcome Measures

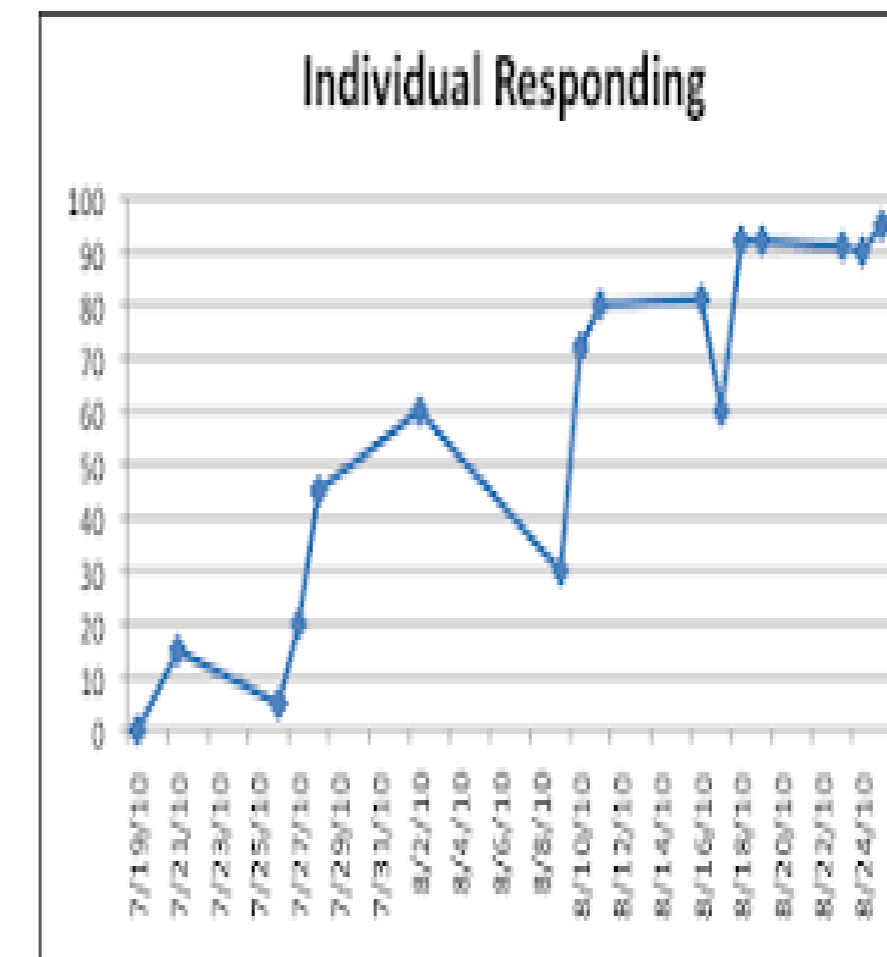
## Assessment



## Quality of Life



## Micro Data



# Quality of Life for People with Autism: Raising the Standard for Evaluating Successful Outcomes

**Audrey F. Burgess & Steven E. Gutstein**

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Quality of Life (QoL) is a critical measure of treatment outcome for people with mental and physical health concerns. However, little research has been conducted toward evaluating outcomes in autism by utilizing real-world measures, such as employability, self-sufficiency, and social support to gauge treatment success, despite longitudinal research that indicates poor outcomes for people with autism. Utilizing QoL indicators as the standard for developing treatments and evaluating outcomes in autism is advantageous. After a brief description of the domains and indicators comprising QoL, this paper reviews the literature describing the course of autism, followed by an examination of indicators which contribute to QoL for people with autism in particular. In conclusion, a model for utilizing QoL indicators to measure and evaluate outcome for people with autism will be proposed.

**Keywords:** Autism; quality of life; outcome; treatment



QoL Measures

Social Support

Academic Success

Preparation for Employment

Health

Happiness of Family System

Self Determination



QoL Measures

Social Support

Academic Success


Preparation for Employment

Health

Happiness of Family System

Self Determination



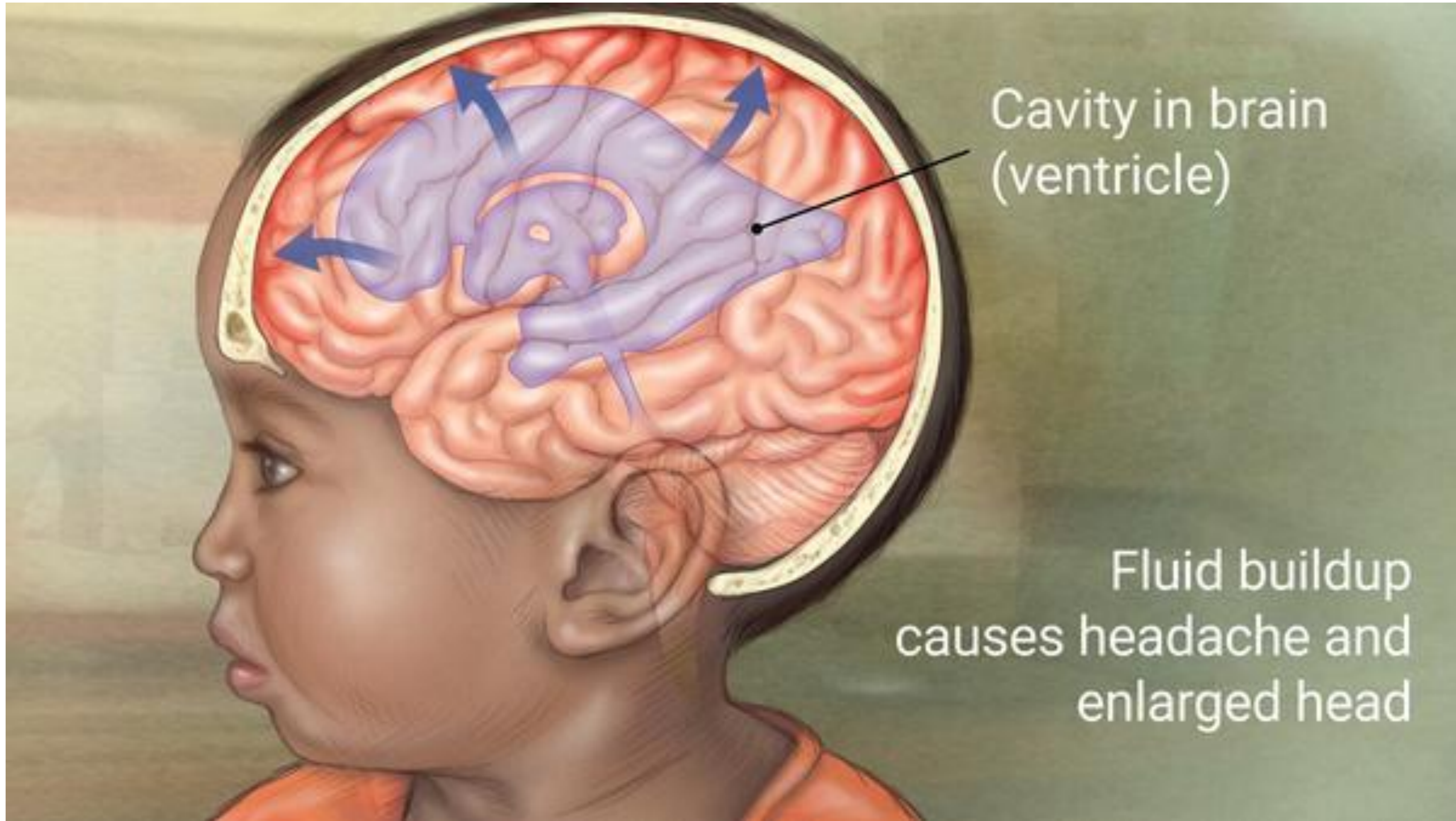


Prepare a family to  
optimize medical  
appointments to  
ensure proper medical  
care.





GRAND ROUNDS



Cavity in brain  
(ventricle)

Fluid buildup  
causes headache and  
enlarged head

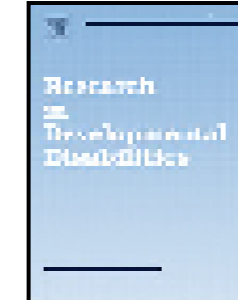




ELSEVIER

Contents lists available at ScienceDirect

## Research in Developmental Disabilities



### Parent training: A review of methods for children with developmental disabilities

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#### ARTICLE INFO

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Parent training  
Developmental disabilities  
Children  
Intellectual disability  
Applied behavior analysis


#### ABSTRACT

Great strides have been made in the development of skills and procedures to aid children with developmental disabilities to establish maximum independence and quality of life. Paramount among the treatment methods that have empirical support are treatments based on applied behavior analysis. These methods are often very labor intensive. Thus, parent involvement in treatment implementation is advisable. A substantial literature on parent training for children has therefore emerged. This article reviews recent advances and current trends with respect to this topic.

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Children with developmental disabilities are a heterogeneous group in many respects. However, the etiology of this group of conditions appears to be primarily neurodevelopmental in origin (Matson, 2007a,b; Matson & Boisjoli, 2007; Matson, Fodstad, & Boisjoli, 2008b; Matson, Nebel-Schwalm, & Matson, 2007). A number of common characteristics are evident. These deficits include problems with social skills (Hsieh, 2008; Paclawskyj, Rush, Matson, & Cherry, 1999), memory, emotional and cognitive problems (Ben Itzhak, Lahat, Burgin, & Zachor, 2008; Farran, 2008; Francoise, Marissiaux, & Nader-Grosbois, 2008), frequent comorbid psychopathology (Gonzalez & Matson, 2006; Holden & Gitlesen, 2008; Matson & Nebel-Schwalm, 2007b; Matson & Smiroldo, 1997; Matson, Smiroldo, Hamilton, & Baglio, 1997) and challenging behaviors (Coe et al., 1999; Matson, Dixon, & Matson, 2005; Matson & Logan, 1997; Matson et al., 2005; Matson & Nebel-Schwalm, 2007a). A great deal of attention has been given to these issues. Developmental disabilities also imply deficits in normal motoric skills and development sequences that can impede independence and normal development (Matson, Fodstad, & Boisjoli, 2008a). Among the most common and serious of the developmental disabilities is intellectual disability (ID; Hefziba, Merrick, & Morad, 2008; Myrbakk & von Tetzchner, 2008).

<sup>\*</sup> Corresponding author.  
E-mail address: johnmatson@aol.com (J.L. Matson).



Prepare parents and  
caregivers to secure  
responsible, proper, and  
effective treatment from  
the medical community.

Use Behavioral Skills  
Training.





Published in final edited form as:

*J Autism Dev Disord.* 2014 May ; 44(5): 1117–1127. doi:10.1007/s10803-013-1973-x.

## Gastrointestinal problems in children with autism, developmental delays or typical development

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### SCIENTIFIC ABSTRACT

**Objectives**—To compare GI problems among children with: 1) autism spectrum disorder (ASD), 2) developmental delay (DD) and 3) typical development (TD).

**Methods**—In 960 children from the Childhood Autism Risks from Genetics and the Environment (CHARGE) study, we assessed GI symptom frequency. We examined scores on five Aberrant Behavior Checklist subscales comparing ASD children with high vs. low frequency GI symptoms.

**Results**—Compared to TD children, those with ASD (aOR 7.92[4.89–12.85]) and DD (aOR 4.55 [2.51–8.24]) were more likely to have at least one frequent GI symptom. Restricting to ASD children, those with frequent abdominal pain, gaseousness, diarrhea, constipation or pain on stooling scored worse on Irritability, Social Withdrawal, Stereotypy, and Hyperactivity compared with children having no frequent GI symptoms.

**Conclusions**—Frequent GI problems affect young children with ASD and DD more commonly than those with TD. Maladaptive behaviors correlate with GI problems, suggesting these comorbidities require attention.

### Keywords

gastrointestinal problems; autism; developmental delays; maladaptive behaviors

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Frequent anecdotal reports of gastrointestinal (GI) problems in children with autism spectrum disorder (ASD) are beginning to be clarified by research efforts examining the

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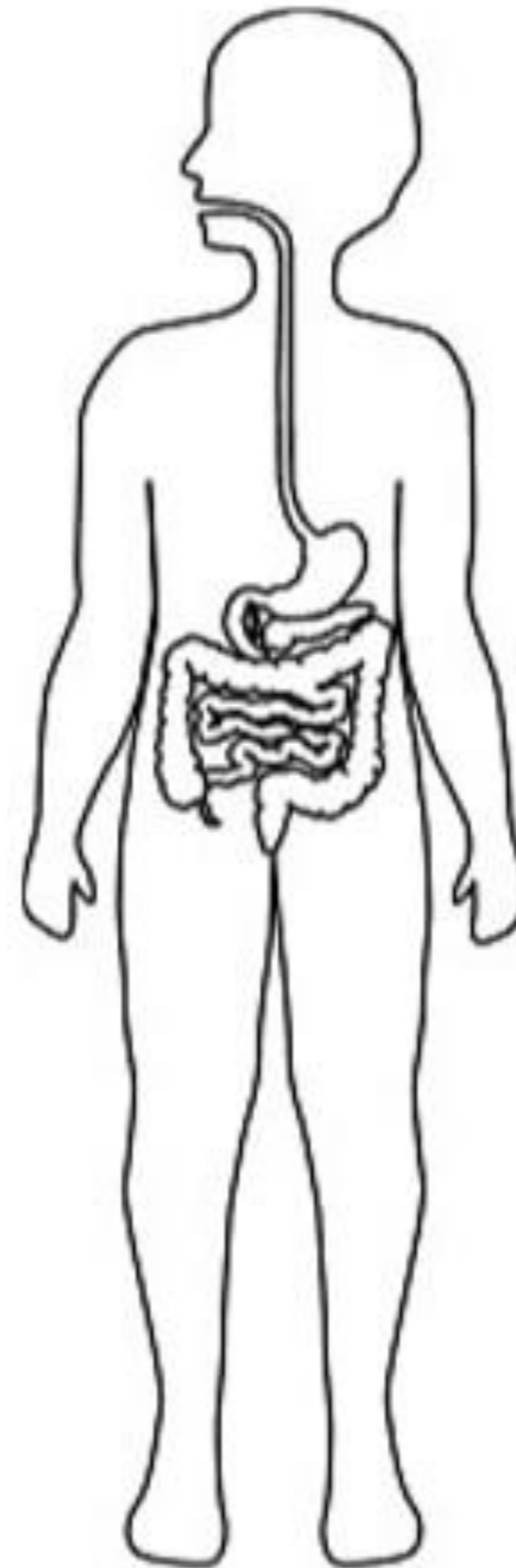
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Current contact information: vachaidez@ucdavis.edu, UC CalFresh Nutrition Education Program, State Office, University of California, Davis, 1103 Meyer Hall, Davis, CA 95616, Phone (530)754-7796, Fax (530) 752-1107

## Questionnaire on Gastrointestinal Symptoms in Children

(Walker, Caplan-Dover, & Rasquin-Weber, 2000)

### Research Form A: Parents of Children and Adolescents (4-17 years old)



#### Instructions

This questionnaire concerns the usual functioning of your child's digestive system and the gastrointestinal symptoms or problems that your child can have. Some of these symptoms apply to your child and others do not. In certain cases, you may not know about your child's more private problems and you will be able to indicate that you do not know.



1. Today's date: month:\_\_\_\_\_ day:\_\_\_\_\_ year:\_\_\_\_\_
2. Child's name: \_\_\_\_\_
3. Your relationship to child: \_\_\_mother \_\_\_father \_\_\_other (Please specify: \_\_\_\_\_)
4. Is your child a boy or a girl?
  1. \_\_\_ boy
  2. \_\_\_ girl
5. Child's date of birth: month:\_\_\_\_\_ day:\_\_\_ year:\_\_\_
6. To which ethnic group does your child belong?
  1. \_\_\_ African-American
  2. \_\_\_ Asian/Pacific Islander
  3. \_\_\_ Hispanic/Latino
  4. \_\_\_ Native American
  5. \_\_\_ White (Caucasian)
  6. \_\_\_ Other (Please specify: \_\_\_\_\_)
7. Does your child have any chronic (recurring) health problems (such as seizures, asthma, diabetes)?
  0. \_\_\_ No
  1. \_\_\_ Yes. Please describe your child's health problems: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
8. Does your child take any prescription or nonprescription medications or treatments?
  0. \_\_\_ No
  1. \_\_\_ Yes. Please list current medications or treatments: \_\_\_\_\_  
\_\_\_\_\_
9. Has your child ever had surgery?
  0. \_\_\_ No
  1. \_\_\_ Yes. Please specify type of surgery and child's age at the time of surgery: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
10. Does your child have any allergies? For example, does your child have hay fever or allergic reactions to milk, other foods, or medications?
  0. \_\_\_ No
  1. \_\_\_ Yes. Please specify type of allergy: \_\_\_\_\_  
\_\_\_\_\_

The Behavior Analyst

1996, 19, 147–161

No. 2 (Fall)

## Translating the Covenant: The Behavior Analyst as Ambassador and Translator

R. M. Foxx


Penn State University, Harrisburg

Behavior analysts should be sensitive to how others react to and interpret our language because it is inextricably related to our image. Our use of conceptual revision, with such terms as *punishment*, has created communicative confusion and hostility on the part of general and professional audiences we have attempted to influence. We must, therefore, adopt the role of ambassador and translator in the nonbehavioral world. A number of recommendations are offered for promoting, translating, and disseminating behavior analysis.

*Key words:* language, image, translations, conceptual revisions

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*Evaluate your clinical  
success against  
established quality of  
life outcomes.*

A photograph of a person with long, light-colored hair sleeping in a bed. The person is lying on their side, facing left, with their head resting on a pillow. The bed is covered with a dark, textured blanket. In the background, a window with white blinds is visible, partially open. The lighting is dim, suggesting a nighttime setting.

# 100 Sleep Disorders



# Sleep Disorder Classifications

Might you have a sleep disorder? There are over 100 to choose from. Most of us take sleep for granted until we get too much, too little or when things go bump in the night. The effects of sleep disorders can wreak havoc on our lives.

The list below is offered as an educational tool. If you have been diagnosed with a sleep or sleep related disorder, you may find it interesting to see where your diagnosis is categorized. If you are looking for answers to your sleep disturbances, you may be surprised to find your clues here and then seek an evaluation and diagnostic procedure to verify or rule out.

Each has its own protocol for treatment, whether medical device, medication regime or cognitive behavioral therapy. You cannot properly treat any disease or disorder without an accurate diagnosis. Make an appointment with a sleep specialist if you suspect you have a sleep disorder.

The American Academy of Sleep Medicine categorized 4 sections that make up the INTERNATIONAL CLASSIFICATION OF SLEEP DISORDERS. Each has its own diagnostic criteria and a unique diagnostic code number used by physicians and insurance providers.

## 1. DYSSOMNIAS

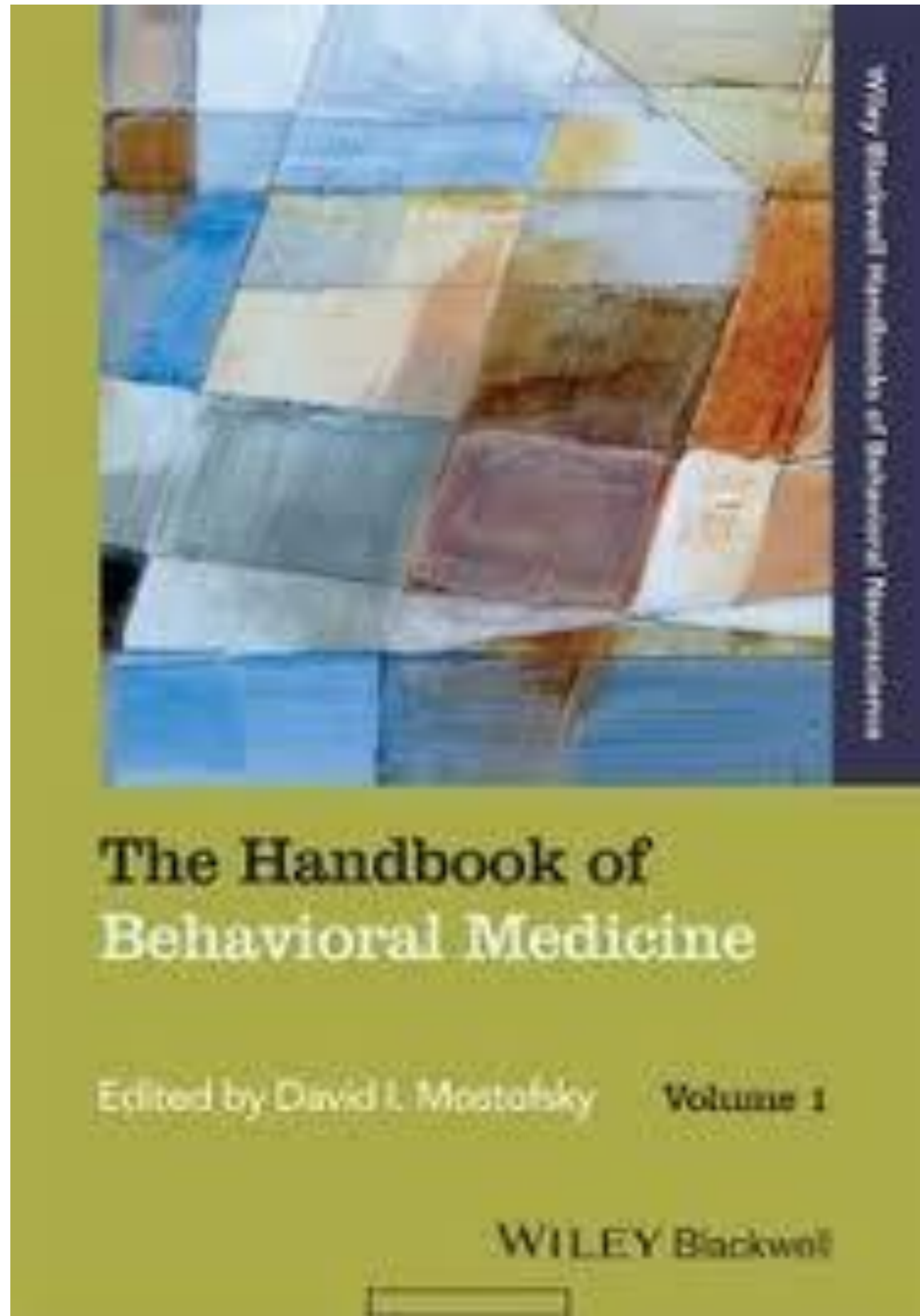
A broad category of sleep disorders characterized by either hypersomnolence or insomnia. The three major subcategories include intrinsic (i.e., arising from within the body) (SLEEP DISORDERS, INTRINSIC), extrinsic (secondary to environmental conditions or various pathologic conditions), and disturbances of circadian rhythm. (From Thorpy, Sleep Disorders Medicine, 1994, p187)

### A. Intrinsic Sleep Disorders

1. Psychophysiologic Insomnia
2. Sleep State Misperception
3. Idiopathic Insomnia
4. Narcolepsy
5. Recurrent Hypersomnia
6. Idiopathic Hypersomnia
7. Post-traumatic Hypersomnia
8. Obstructive Sleep Apnea Syndrome
9. Central Sleep Apnea Syndrome
10. Central Alveolar Hypoventilation Syndrome
11. Periodic Limb Movement Disorder
12. Restless Legs Syndrome
13. Intrinsic Sleep Disorder NOS (Not Otherwise Specified)

### B. Extrinsic Sleep Disorders

1. Inadequate Sleep Hygiene
2. Environmental Sleep Disorder
3. Altitude Insomnia
4. Adjustment Sleep Disorder
5. Insufficient Sleep Syndrome
6. Limit-setting Sleep Disorder
7. Sleep-onset Association Disorder
8. Food Allergy Insomnia
9. Nocturnal Eating (Drinking) Syndrome
10. Hypnotic-Dependent Sleep Disorder
11. Stimulant-Dependent Sleep Disorder
12. Alcohol-Dependent Sleep Disorder
13. Toxin-Induced Sleep Disorder
14. Extrinsic Sleep Disorder NOS (Not Otherwise Specified)



13

## Cognitive Behavioral Treatment of Sleep Disorders in Children and Adolescents

Donna B. Pincus, R. Meredith Elkins,  
Courtney Weiner, and Christina Hardway



## The Pittsburgh Sleep Quality Index: A New Instrument for Psychiatric Practice and Research

Daniel J. Buysse, Charles F. Reynolds III, Timothy H. Monk,  
Susan R. Berman, and David J. Kupfer

*Received May 9, 1988; revised version received August 17, 1988; accepted November 12, 1988.*

**Abstract.** Despite the prevalence of sleep complaints among psychiatric patients, few questionnaires have been specifically designed to measure sleep quality in clinical populations. The Pittsburgh Sleep Quality Index (PSQI) is a self-rated questionnaire which assesses sleep quality and disturbances over a 1-month time interval. Nineteen individual items generate seven "component" scores: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction. The sum of scores for these seven components yields one global score. Clinical and clinimetric properties of the PSQI were assessed over an 18-month period with "good" sleepers (healthy subjects,  $n = 52$ ) and "poor" sleepers (depressed patients,  $n = 54$ ; sleep-disorder patients,  $n = 62$ ). Acceptable measures of internal homogeneity, consistency (test-retest reliability), and validity were obtained. A global PSQI score  $> 5$  yielded a diagnostic sensitivity of 89.6% and specificity of 86.5% (kappa = 0.75,  $p < 0.001$ ) in distinguishing good and poor sleepers. The clinimetric and clinical properties of the PSQI suggest its utility both in psychiatric clinical practice and research activities.

**Key Words.** Sleep, sleep quality, depression, sleep disorders.

## Appendix. Pittsburgh Sleep Quality Index (PSQI)

Name \_\_\_\_\_ ID # \_\_\_\_\_ Date \_\_\_\_\_ Age \_\_\_\_\_

### Instructions:

The following questions relate to your usual sleep habits during the past month *only*. Your answers should indicate the most accurate reply for the *majority* of days and nights in the past month. Please answer all questions.

1. During the past month, when have you usually gone to bed at night?  
USUAL BED TIME \_\_\_\_\_
2. During the past month, how long (in minutes) has it usually take you to fall asleep each night?  
NUMBER OF MINUTES \_\_\_\_\_
3. During the past month, when have you usually gotten up in the morning?  
USUAL GETTING UP TIME \_\_\_\_\_
4. During the past month, how many hours of *actual sleep* did you get at night? (This may be different than the number of hours you spend in bed.)  
HOURS OF SLEEP PER NIGHT \_\_\_\_\_

For each of the remaining questions, check the one best response. Please answer *all* questions.

5. During the past month, how often have you had trouble sleeping because you...
  - (a) Cannot get to sleep within 30 minutes  
Not during the past month \_\_\_\_\_ Less than once a week \_\_\_\_\_ Once or twice a week \_\_\_\_\_ Three or more times a week \_\_\_\_\_
  - (b) Wake up in the middle of the night or early morning  
Not during the past month \_\_\_\_\_ Less than once a week \_\_\_\_\_ Once or twice a week \_\_\_\_\_ Three or more times a week \_\_\_\_\_
  - (c) Have to get up to use the bathroom  
Not during the past month \_\_\_\_\_ Less than once a week \_\_\_\_\_ Once or twice a week \_\_\_\_\_ Three or more times a week \_\_\_\_\_
  - (d) Cannot breathe comfortably  
Not during the past month \_\_\_\_\_ Less than once a week \_\_\_\_\_ Once or twice a week \_\_\_\_\_ Three or more times a week \_\_\_\_\_
  - (e) Cough or snore loudly  
Not during the past month \_\_\_\_\_ Less than once a week \_\_\_\_\_ Once or twice a week \_\_\_\_\_ Three or more times a week \_\_\_\_\_
  - (f) Feel too cold  
Not during the past month \_\_\_\_\_ Less than once a week \_\_\_\_\_ Once or twice a week \_\_\_\_\_ Three or more times a week \_\_\_\_\_
  - (g) Feel too hot  
Not during the past month \_\_\_\_\_ Less than once a week \_\_\_\_\_ Once or twice a week \_\_\_\_\_ Three or more times a week \_\_\_\_\_



## *Review Article*

# **Pain Sensitivity and Observer Perception of Pain in Individuals with Autistic Spectrum Disorder**

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Correspondence should be addressed to C. S. Allely; [clare.allely@glasgow.ac.uk](mailto:clare.allely@glasgow.ac.uk)

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Academic Editors: C. Gillberg and H. Minnis

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The peer-reviewed literature investigating the relationship between pain expression and perception of pain in individuals with ASD is sparse. The aim of the present systematic PRIMSA review was twofold: first, to see what evidence there is for the widely held belief that individuals with ASD are insensitive to pain or have a high pain threshold in the peer-reviewed literature and, second, to examine whether individuals with ASD react or express pain differently. Fifteen studies investigating pain in individuals with ASD were identified. The case studies all reported pain insensitivity in individuals with ASD. However, the majority of the ten experimental studies reviewed indicate that the idea that individuals with ASD are pain insensitive needs to be challenged. The findings also highlight the strong possibility that not all children with ASD express their physical discomfort in the same way as a neurotypical child would (i.e., cry, moan, seek comfort, etc.) which may lead caregivers and the medical profession to interpret this as pain insensitivity or incorrectly lead them to believe that the child is in no pain. These results have important implications for the assessment and management of pain in children with ASD.



- ★ **Behavioral Pain Scale (BPS)**
- ★ **Checklist of Non-verbal Pain Indicators (CNPI)**
- ★ **Critical Care Pain Observation Tool (CPOT)**
- ★ **Face, Legs, Activity, Cry, and Consolability (FLACC) Pain Tool**
- ★ **Multidimensional Observational Pain Assessment Tool (MOPAT)**
- ★ **Non-Verbal Pain Scale**
- ★ **Children's Hospital of Eastern Ontario Pain Scale (CHEOPS)**

<http://www.modernmedicine.com/sites/default/files/legacy/mm/Resource-Centers/Children%27s%20Hospital%20of%20Eastern%20Ontario%20Pain%20Scale%20%28CHEOPS%29.pdf>



**BMJ Open Parenting acceptance and commitment therapy: a randomised controlled trial of an innovative online course for families of children with cerebral palsy**

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Koa Whittingham,<sup>1,2</sup> Jeanie Sheffield,<sup>2</sup> Roslyn N Boyd<sup>1</sup>

AZ Employment First, Susan Voirol, MSW, Sonoran UCEDD, Betty Schoen, AZ Vocational Rehabilitation Services, Steven Marcelo, AZ DES-DDD.

Increasing University Accessibility for Students with Autism, Cortney Volmering, Arizona State University.

Special Needs Dentistry, Michelle Krasch, Dr. Benjamin Wachter, DMD, Pacific Dental Services Foundation Dentists for Special Needs.

Approaching Medical Crises in Individuals with ASD, Alice Ridgway, RBT, Jill Haglund, BCBA, Brent Seymour, BCBA, SARRC.

Inclusion Revolution, Amanda Metcalf, MPH, Special Olympics Arizona.





# Microdata

Individual Response Data

**A hallmark of behavior analysis**

# Measures

Mastery of goals (number and percentage)

Mastery of programs (number and percentage)

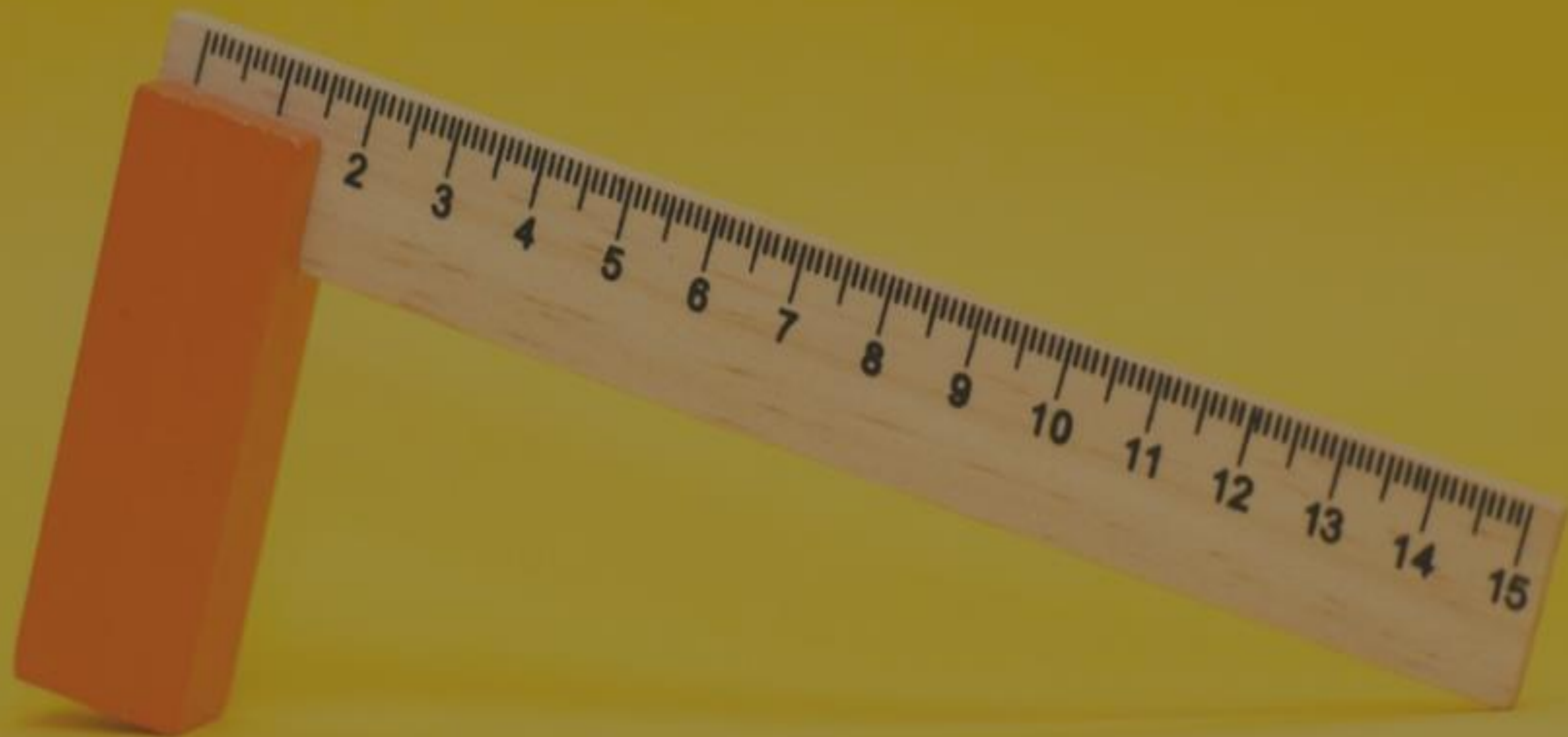
Deceleration in aberrant behavior

Acceleration in skills

Generalization of skills to the natural environment



Sometimes we have to  
measure progress in inches





# What is the PND?

## Percentage of Nonoverlapping Data (PND)

The percentage of nonoverlapping data (PND) is a widely used metric for the measurement of progress in applied behavior analysis.

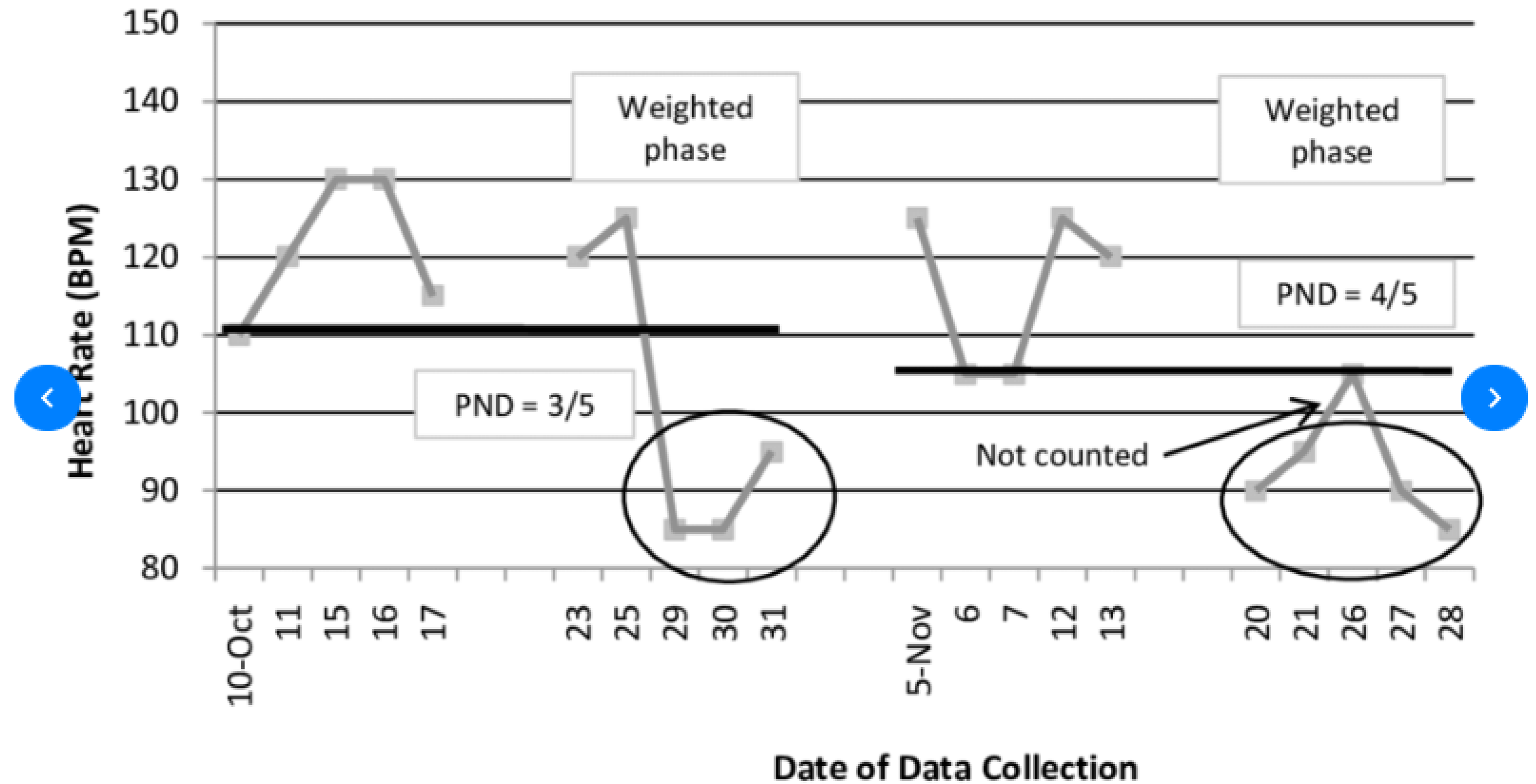
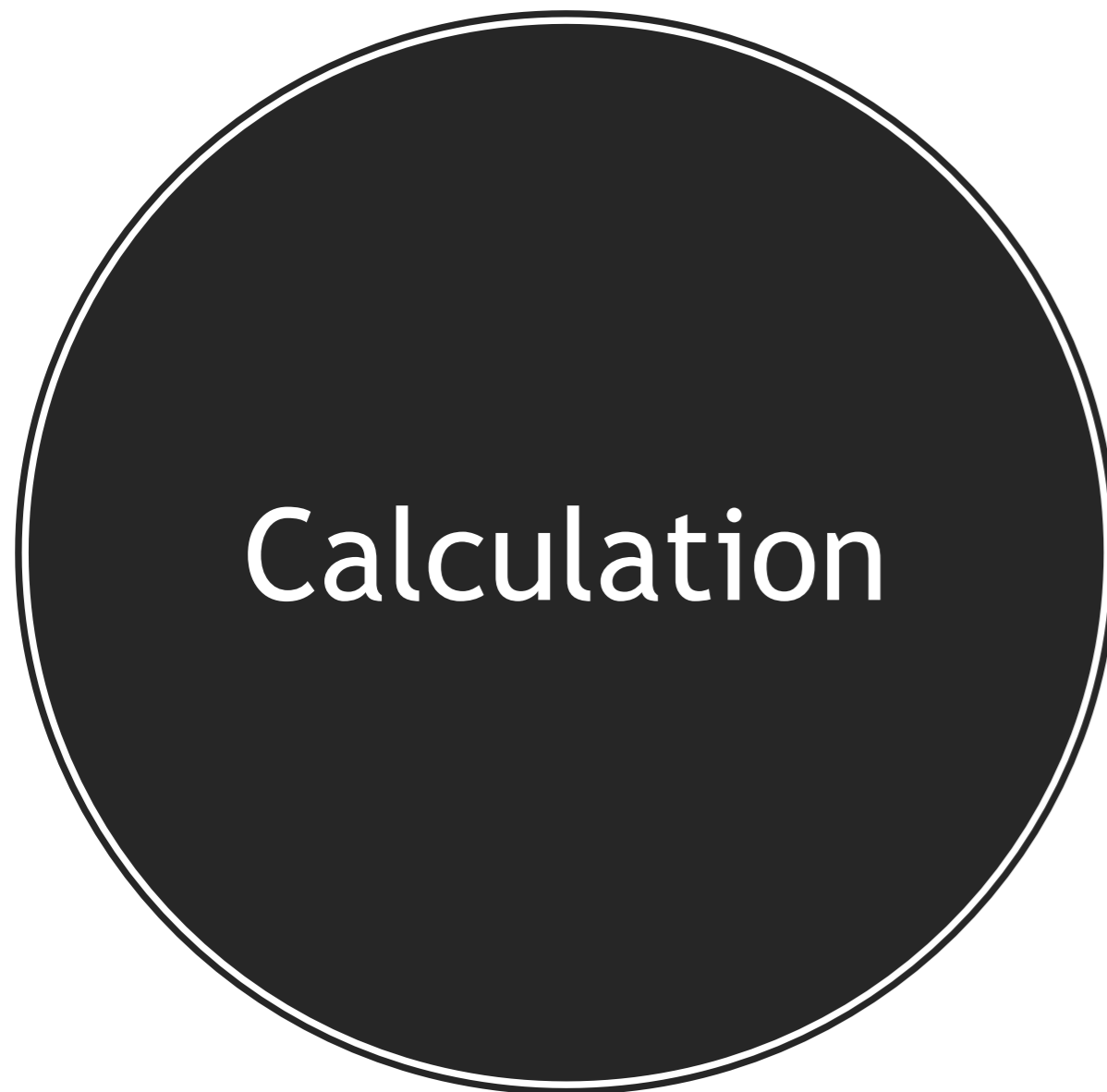


Figure 3 - uploaded by [Sandra Hodgetts](#)

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Example of percent non-overlapping data (PND) calculation for mean heart rate.

*Percentage of non-overlapping data (PND)*

One common method of calculating the effectiveness of a practice or program using the results of single-case design studies. Below are general guidelines for interpreting a PND.

<b>Effectiveness</b>	<b>Interpretation</b>
91% to 100%	Highly Effective
71% to 90%	Moderately Effective
50% to 70%	Minimally Effective
Below 50%	Not Effective

*Adapted from "A Teacher's Guide to Meta-Analysis" by D. R. Banda and W. J. Therrien, 2008, TEACHING Exceptional Children, 41(2), 66-71.*



# Macrodata

Developmental Assessment

**Learning Gain Scores and  
Effect Size**

# Measures

Iterative assessment scores (criterion referenced)

Parenting skill assessment scores

Parent stress index

Social validity

Progress toward less restrictive environments

Academic reports

## How Should We Determine Treatment Effectiveness with Single-Case Design Research for Participants with Autism Spectrum Disorder?

Monica E. Carr · Angelika Anderson ·  
Dennis W. Moore · William H. Evans

Received: 30 June 2014 / Accepted: 1 July 2014 / Published online: 19 July 2014  
© Springer Science+Business Media New York 2014

**Abstract** Guidelines to inform research evidence standards have acknowledged that there is currently no agreed-upon method for treatment effect size estimation in single-case research. This study has examined the application of treatment effect size calculations to supplement visual analysis in single-case research designs (SCD) for participants with autism spectrum disorder (ASD). Ethical considerations for researchers regarding the collection of baseline data in light of behaviors often associated with ASD are discussed. The adequacy of the volume of data points from baseline and treatment phases was explored, and the conclusion had drawn that the majority of studies were not suitable for regression calculations. The median length of total data series was also explored, and the suitability of three nonparametric hand calculations, percentage of nonoverlap (PND), percentage of all nonoverlapping data (PAND), and nonoverlap of all pairs (NAP), is discussed in this light.

**Keywords** Autism · Treatment effect · Regression · Nonparametric

This study was completed in partial fulfillment of the requirements for a PhD for the first author.

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### Introduction

Heterogeneity presents a unique challenge within the field of autism research, as individuals with Autism Spectrum Disorder (ASD) exhibit significant variability in the kind and extent of symptomatology. Research conducted in 2006 has shown that parents use a wide range of treatments with their children, with a greater number of treatments being used for younger children, and for children with greater severity of symptoms (Green et al., 2006). Green and colleagues also reported that the most commonly utilized treatments included those without empirical evidence.

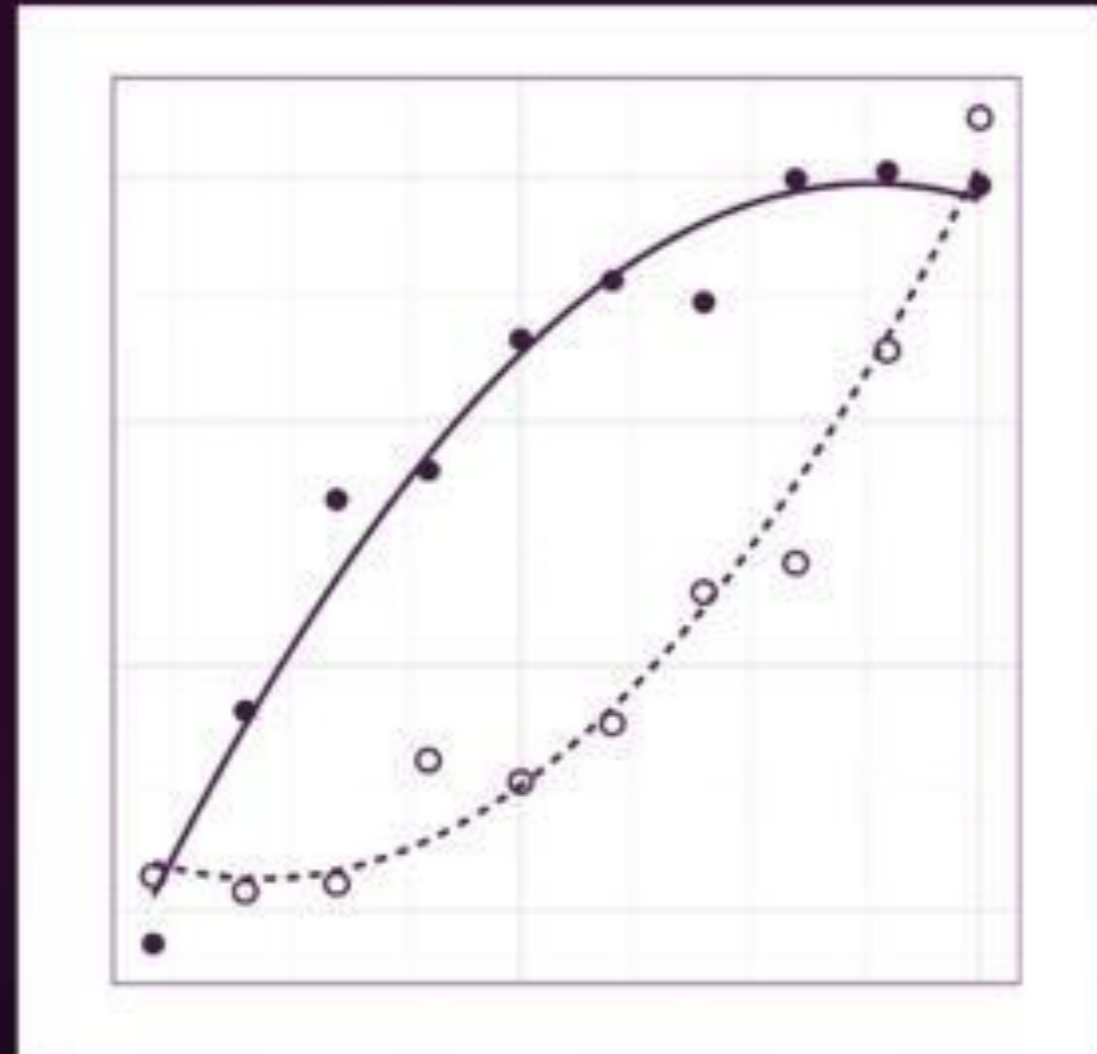
Applied Behavior Analysis (ABA) is an applied science that focuses on socially significant behavior change (Baer, Wolf, & Risley, 1968; Sigafoos & Schlosser, 2008). While most published psychological research is based on between group research designs, ABA typically examines behavior at the level of the individual and generally utilizes single-case research designs (SCD), thus permitting a scientifically valid conclusion to be drawn from the intensive investigation of an individual (Blampied, 1999). Interventions based on such research have been used extensively in working with participants with ASD since the early 1980s.

Systematic reviews and meta-analyses of SCD literature are becoming increasingly important to a variety of stakeholders and have been conducted within academic literature, by government agencies, and health service providers to address the need for evidence based practice guidelines as well as to inform decisions at a policy level. Across the broader field of healthcare, the PRISMA Statement (2009) sets forth a checklist of 27 items that should be addressed in systematic reviews or meta-analyses of literature (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009). The PRISMA Statement (2009) has been used to guide reviews that are ultimately read by clinicians to inform practice, granting agencies to fund future research, and other stakeholders. Such reviews may include between-group design



The R Series

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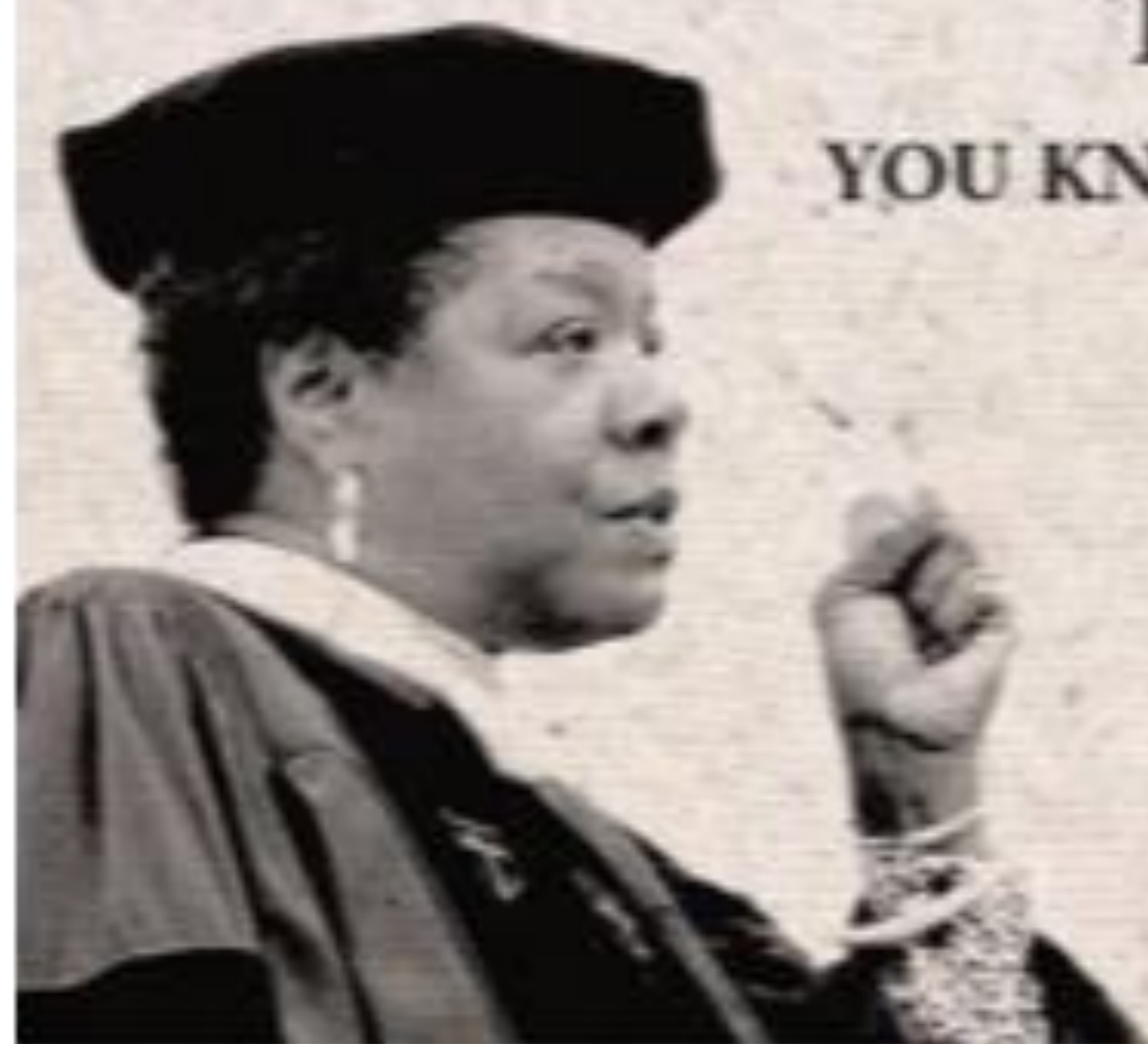


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