THE COWDEN PREAUTISM OBSERVATION INVENTORY

ABOUT THE AUTHOR

Doctor Jo E. Cowden was Professor of Motor Development and Pediatric Adapted Physical Activity at The University of New Orleans for more than 25 years. She also served as Director of the UNO Pediatric Motor Development Clinic, specializing in assessment and program development for infants and toddlers with delays and disabilities. Many of the infants and young children had a diagnosis of autism. No disability was too severe, and no infant or child was ever turned away from the clinic due to the nature of their disability.

Doctor Cowden served as Project Director of three federally funded training grants for infants and young children with delays and disabilities. Her last state grant on Project GUMBO (Games Uniting Mind and Body) for children with physical disabilities is presently continued by the Louisiana State Department of Education.

Doctor Cowden served as Director of the Third International Symposium on Adapted Physical Activity hosted by the University of New Orleans, which was the beginning of her tenure at The University of New Orleans. She also served as the Symposium Director of the Fifth North American Federation of Adapted Physical Activity in New Orleans. Experts on mental and physical disabilities, social-communicative, and developmental psychology were brought to New Orleans, providing numerous opportunities for teachers and professionals to attend and develop current knowledge.

Doctor Cowden served on the editorial board of the *Adapted Physical Activity Quarterly* from 1997 to 2005. She is highly published and has presented nationally and internationally on infants with delays in pediatric adapted motor development including autism.

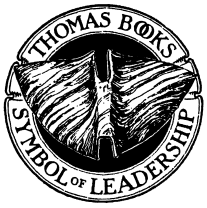
Pictured with Doctor Cowden is Addie Kara, an American Eskimo rescue dog and author pup!

THE COWDEN PREAUTISM OBSERVATION INVENTORY

With Effective Intervention Activities for Sensory Motor Stimulation and Joint Attention

By

JO E. COWDEN, PH.D.



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"Hope" is the thing with feathers . . .
That perches in the soul . . .
And sings the tune without the words . . .
And never stops . . . at all . . .

Emily Dickinson

FOREWORD

> Today, as I read Kanner's vivid descriptions of the eleven children, written in 1943 [primary source for academic and professional recognition of autism], I see my own daughter on almost every page. Though I thought Isabel was developing normally until the age of two, a look back at our home videos shows how little eye contact she made in infancy and how seldom she tried to communicate with us. Even today, she plays the same way, finding and maintaining sameness wherever she can, whether it be by repeatedly drawing the same picture over and over again, or rewinding a video or DVD to watch the same fragments of a scene multiple times. (Grinker, 2007, pp. 49–50)

This reflection from the anthropologist-author of *Unstrange Minds: Remapping the World of AUTISM* is illustrative of the many parents who report lack of awareness of risk behaviors or "preautistic symptoms" of their own infants from birth onward. Had they been better observers, these parents surely would have sought early intervention and basked in the hope that the life of their infant, as well as their family, would be changed for the better.

Dr. Jo E. Cowden is the author of this hope-inspired book you are choosing to read. To the best of my knowledge, it is the first book to specifically address **preautism**, a condition of unresponsiveness to and extreme lack of concern for caregivers and environment that is manifested by numerous risk behaviors from birth through age one year. Cowden gave considerable thought to the order of ideas in her title, *The Cowden Preautism Observation Inventory: With Effective Intervention Activities for Sensory Motor Stimulation and Joint Attention,* deciding that her original observation inventory should come first, with initial focus on enabling parents to interact with and screen young infants, then concentrating on professionals who will most likely help parents with further learning about preautism, the benefits of which they will pass on to their infants.

A look at the Table of Contents reveals comprehensive coverage of all aspects of preautism and autism, possible causes, the latest findings on related brain organization and brain plasticity, effective intervention and behav-

ioral strategies, theoretical principles of intervention, preautism sensory motor curriculum, therapeutic riding, and much more! Almost 300 illustrations clarify text and direct relationships between observation and intervention. Many photographs model ways that parents and professionals work together in maximizing integration of social interactions with sensory-motor stimulations.

A major strength of this book is encouragement of positive attitudes, self-confidence, and realization that power does come with increasing knowledge. Most persons love to look at babies; we are fascinated by the very young of every species; much of what some of us do is mindless gazing, loving, and marveling at the miracle before us. However, few persons who do this (or wish they had time to do this) know what to look for or that the process of observation is important. Parents must be carefully taught what to look for (especially interacting behaviors like making eye contact, responding to human sounds, and reaching arms toward caretaker); to make happy sounds of praise and love throughout observation; and to maintain an atmosphere of hope in discovery of new solutions. A key principle is to not look only for preautism or failure to behave as other babies do. Look because you want to get to know this tiny individual as much as possible and as soon as possible. Look because you know that observation (whatever it shows) will lead to creativity, altered perceptions of interventions as joyful play, courage to try new interventions in varied environments, and confidence in seeking help from specialists who use such therapeutic media as swimming, rhythms, and therapeutic riding.

Everyone seems to know about autism (commonly diagnosed around age 2 or 3), but few individuals understand the need for parents, parents-to-be, caretakers, and direct- and related services providers to become everyday (indeed, every minute) caring, fully engaged, expert observers of sensory motor behaviors from birth onward. This goal and subsequent attention to appropriate, individualized interventions can be achieved, however, only when professionals make the information in Cowden's book widely available through workshops, conferences, webinars, preservice and inservice university courses, practica, clinics, continuing education, and individual tutoring and mentoring. The demand for professionals who can do this is greater than ever before. So also is the need for print and online materials on preautism. This book aims to meet the urgent need of direct care providers and professionals to teach these providers.

Preautism is an area (or category) of new knowledge that Dr. Jo E. Cowden has developed for this book, the third in her series of outstanding, crossdisciplinary textbooks (1998, 2007, 2011) on typical and atypical infant and early childhood sensory motor development, assessment, and interven-

tion (both theory and practice). As author of *Adapted Physical Activity, Recreation, and Sport: Crossdisciplinary and Lifespan* (2004, now in its sixth edition), I strongly support Cowden's scholarly development of a well-documented crossdisciplinary body of knowledge that meets societal needs and is attractive to university undergraduate and graduate students specializing in such diverse areas as nursing, occupational and physical therapies, speech and creative arts therapies, kinesiology, special education, early childhood and family studies, and adapted physical activity sciences. Use of Cowden's book with rich opportunities for extensive home-school practica and mentoring by faculty representing different academic disciplines, will lead to meaningful research and publications that, in turn, will enhance the lives of families with infants with preautism and the continued development of our knowledge base on preautism.

My best wishes to those of you who share this book with us.

CLAUDINE SHERRILL
Professor Emeritus, Texas Woman's University

PREFACE

The incidence of autism is increasing at an alarming rate and now occurs in 1 percent of American children. The rate of autism is 1 in 91 births, and 1 in 58 are boys. Parents and professionals are becoming more aware of autism spectrum disorders (ASD) and want to positively affect the development of infants. This book provides guidance to families for detecting early signs of preautism in their infant or toddler. Mothers of infants born prematurely were given many prescriptions to control preterm labor. Procedures in the Neonatal Intensive Care Unit (NICU) were administered to help the baby survive. Medications administered during the prenatal, perinatal, and neonatal periods may be linked to autism.

Preautism is used in the title of this book and name of the observation inventory implying need for careful and thorough assessment of infants from birth through the first year of life. Avoiding the use of "autism" during this time period prevents labeling infants and newborn babies. It allows parents to record, videotape, and justify further testing by using *The Cowden Preautism Observation Inventory* (***CPAOI***) to establish a baseline of behaviors and skills. Instead of having a parent on the verge of panic, the concerned parent can eliminate his or her concerns or justify meeting with their pediatrician and other professionals. If further assessment is needed, the parent has documented all behaviors and movements of their baby. Videotapes have been used to record unusual or different actions. The parents are prepared because the ***CPAOI*** presents thorough information in a simple format. It allows them to learn what to look for in their baby, especially if other family members have a diagnosis of autism.

Preautism is defined as a condition in infants who demonstrate an extreme detachment, unresponsiveness, and lack of concern or interest in other young children or family. Infants are born with the predisposition for this condition. There are signs of immature neurological and brain development. One easily recognizable factor is extreme head growth in circumference during the first year of life.

The infant does not exhibit spontaneous and intentional shared enjoyment or affection toward anyone. There is impairment in the use of gestures and

nonverbal behaviors, joint attention with eye-to-eye contact, facial expressions indicating lack of facial recognition, and no spoken language.

Movements, such as attempts to roll or sit, are accomplished in unusual ways with a total lack of symmetry. Sitting posture indicates hypotonic or weak muscle tone, retention of primitive reflexes, and delayed righting and protective reactions. Infants with preautism demonstrate unusual visual scanning patterns, showing no recognition of other persons in their environment. Infants often demonstrate restless and purposeless movements in their cribs. There will be no imitative or pretend play.

This author believes that preautism can be assessed during the first year of life. The ***CPAOI*** is presented with criteria that are designed for parents who may suspect their baby is developing differently than other infants. The ***CPAOI*** is easily administered for families and professionals through critical observation. A cluster of clinical and developmental signs and symptoms can be detected from medical information, complications during pregnancy, cognition/prelanguage, social-communication-play, sensory motor skills, central nervous system maturity, and developmental movements.

Parents who have any doubts about their baby's development should screen now with the ***CPAOI***. If recorded signs begin to develop in clusters of negative items within different areas of the ***CPAOI***, parents should take their copy of the ***CPAOI*** to their pediatrician. Concerned parents can record and videotape observations throughout each day. Questions will arise about behaviors observed or medications that were administered and recorded information will be available. There will be no guessing when asked questions by physicians, psychologists, and interventionist.

The ***CPAOI*** has simple directions for recording observations of behaviors as present, absent, or emerging. Parents need to realize that all typical behaviors do not always appear within the specific months provided on the ***CPAOI***. Infants do mature slightly differently in time and rate of development. If months are not written beside the behavior, they are not considered typical developmental skills or behaviors. Immediate attention should be paid to skills that are not developing as scheduled for infants and behaviors that do not appear to be normal.

Look over the ***CPAOI*** items immediately and begin to determine whether they are applicable to infants and toddlers with whom you are concerned. If there is any doubt about a baby's development, act now. Early screening and intervention have demonstrated improved outcomes for young children with autism.

An in-depth chapter is included on brain plasticity, the ability of the brain to change and reorganize neural pathways. The brain is not "hard-wired" like a machine. The brain can change structure and function, allowing for the

process of adaptation. An understanding that knowledge is not fixed can be extremely positive for professionals and families faced with challenges of infants demonstrating signs of preautism. It is important to realize that if the brain begins to lose functionality and skills, it has the ability to find other pathways for learning. Brain plasticity is the foundation for success of early sensory stimulation programs for infants with preautism.

Genetic and environmental causes are discussed in detail. Acetaminophen (administered for pain to infants), terbutaline (drug used for preterm labor), glutamatergic dysfunction (excitatory neurotransmitter of the brain), and calcitriol (vitamin D deficiency) are linked to causes of preautism. Vaccines are not linked to autism, and the much debated study (Wakefield et al., 1998) and its retraction from *The Lancet* are critically reviewed.

An entire chapter is devoted to neurological problems, immature brain development, and medical problems associated with preautism. Medical complications are also included in the ***CPAOI***.

Sensory motor curriculum and joint activity skills specific to preautism are detailed.

Activities presented include:

- Tactile stimulation of infants for awareness, recognition, and discrimination.
- Vestibular stimulation for developing equilibrium reactions and balance.
- Visual motor awareness and joint attention exercises.
- Visual motor and joint attention to engage eye contact.
- Visual motor recognition and joint attention for facial expression and memory.
- Visual motor tracking and control to coordinate eye movements.
- Auditory awareness, recognition, and sound discrimination.
- Kinesthetic awareness, imitation of movements in play, and social routines.

Other specific activities and exercises are included for developing muscle tone, strength, and reflex integration. This book has more than 250 new figures/pictures and activities for infants and toddlers.

I strongly believe that therapeutic riding is one of the most beneficial activities for infants indicating signs of preautism. Infants and toddlers who demonstrate signs of preautism on the ***CPAOI*** should be enrolled in a certified therapeutic riding program. Horseback riding gently and rhythmically moves their bodies in a manner similar to upright locomotion, developing balance, equilibrium, strength, and motor control. Infants and toddlers increase patience, confidence, and discipline. Socialization is a valuable asset

for infants, young children, and the entire family. Riding is more than a physical experience. A special calming effect creates time for interaction and the beginning of unwritten communication.

What are the signs for preautism that parents can identify and detail for their pediatrician? Can behaviors demonstrated by older children be eliminated if sensory stimulation activities are provided during early periods of brain growth during the first year of life? Causes and clinical indicators of autism are thoroughly discussed. Using the ***CPAOI*** as an observational assessment guide allows parents to begin to verify any concerns about the development of their infant.

Effective intervention can alter genetic expression, brain development, and behavioral outcomes. There is no doubt that early intervention improves skills and behaviors when initiated during the infant and toddler developmental period. The ***CPAOI*** provides the information to discover and identify weaknesses and strengths of infants and toddlers who may have preautism.

Specific principles for intervention will assist with planning and program development. More than 20 comprehensive strategies for effective intervention have been summarized from past experiences, and a section to assist parents with their concerns includes specific guidelines for selection of early intervention programs.

J.E.C.

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Margaret Huffman, my sister, who always provides love, faith, and incredible strength.

Dr. John Hevron, who has the knowledge and curiosity to seek ultimate answers for autism and medical problems of infants.

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Addie Kara, American Eskimo rescue dog, who never leaves my side.

CONTENTS

THE COWDEN PREAUTISM OBSERVATION INVENTORY

Chapter 1

UNDERSTANDING AUTISM

INTRODUCTION

The ***Cowden Preautism Observation Inventory*** (***CPAOI***) is a criterion-referenced screening instrument used for identifying preautism behaviors in infants and young children. It is not intended to provide a standardized evaluation or diagnosis. The inventory presented as preautism signs and symptoms was selected from a broad range of infant developmental literature and assessment instruments, as well as from experience and collaboration with families, teachers, therapists, and other medical personnel. As director of a university-based clinic for infants and toddlers with disabilities for more than 25 years, a comprehensive foundation of knowledge was utilized to develop the inventory. The purpose of the ***CPAOI*** is for immediate screening for medical and intervention services.

The first section of the inventory is devoted to family history. Parents complete this section, providing information for siblings who have a diagnosis of autism. Birth order of siblings should be identified.

Medical information related to the infant's birth is extremely important. Brain circumference at birth should be recorded and thereafter in 6-month intervals, until 2 years of age. Prematurity, low birth weight, muscle tone, hyperbilirubinemia, phototherapy, respiratory distress, terbutaline (Brethine), acetaminophen, glutamatergic dysfunction, vitamin D deficiency, and seizures are other pertinent birth history that should be carefully examined.

Selected items included are considered the most relevant for identification of social behavior abnormalities and developmental skills. It is

important to recognize skills that should be acquired, in addition to observation of different or unpredictable behaviors. They are classified as core areas of infant development:

- Cognition/Prelanguage (34 behaviors/skills)
- Social-Communicative-Play (34 behaviors/skills)
- Sensory Motor Skills
  Visual System (18 behaviors/skills)
  Auditory System (11 behaviors/skills)
  Tactile System (8 behavior/skills)
  Vestibular-Kinesthetic Systems (16 behaviors/skills)
- Central Nervous System Maturity (Reflexes, Righting Reactions, 10 skills)
- Developmental Movements (15 skills)
- Fine Motor Development (20 behavior/skills)

Specific attention was given to abnormalities of social orienting of infants throughout all sensory systems. Lack of attraction to people, facial expressions, or emotional responses to others were strongly emphasized in each core area of infant development. The inventory includes early signs of central nervous system immaturity and atypical developmental movements.

For the purposes of this book, *preautism* is defined as the period from birth to 1 year old. An infant is born with signs of preautism, and all research indicates that autism is genetic. There are signs of immature neurological development, and the infant was most likely born premature and with low birth weight. From the very beginning of life, the infant appears distant, unresponsive, and detached and has an inability to relate to others. There is no cooing or babbling. Language will not develop, and the child will remain completely nonverbal. The infant does not respond to gestures or to his own name. There is no eye contact with anyone, and the infant's eyes appear to focus to the side of his face rather than straight ahead. Interest is shown in inanimate things. There is no focus on new toys, shared enjoyment, fun, or affection to anyone. The infant lacks facial recognition or any facial expressions. Joint attention with family and play does not exist.

An infant exhibiting signs of preautism is obsessed with lining up toys or objects, at times from smallest to the largest, or other times

attention may be given to stacking blocks as high as possible. When the blocks fall, the infant will repeat the procedure over and over again. Any disturbance in selected routines will be upsetting to the infant or toddler.

The ***CPAOI*** is presented in the first chapter so that concerned parents can easily find the inventory. Parents should carefully read the ***CPAOI*** and observe their infant to confirm whether there may be problems related to preautism. A description of the ***CPAOI*** follows with simple instructions for recording observations.

COWDEN PREAUTISM OBSERVATION INVENTORY (*CPAOI*)
Birth to One-Year-of-Age

NAME _____ **DATE OF BIRTH** _____ **DATE OF EXAM** _____

OBSERVER _____ **FAMILY PRESENT** _____ **OTHER** _____

CHRONOLOGICAL AGE _____ **DEVELOPMENTAL AGE** _____ **SEX** _____

Medical Information

Brain Circumference (Size inches) **Birth** _____ **Six mos** _____ **One yr** _____ **Two yrs** _____

Premature **Age** _____ **Adjusted age** _____

Birth Weight **Lbs** _____ **Ozs** _____ **Apgar score** _____

Muscle Tone **Hypotonic** _____ **Hypertonic** _____ **Variable** _____

Birth Complications

Hyperbilirubinemia **Present** _____ **Describe** _____

Phototherapy (time under lights) **Present** _____ **Describe** _____

Respiratory Distress (time in seconds) **Present** _____ **Describe** _____

Seizures **Present** _____ **Describe** _____

Moebius Mouth (tented upper lip & flat lower lip) **Present** _____ **Describe** _____