

## Improving Intervention Strategies for Autism Spectrum Disorders by Altering the Design of the Diagnostic Procedure

Rosalie E Seymour\*

ABC Learning Options SOUTH AFRICA

\*Corresponding author

Rosalie E Seymour, ABC Learning Options SOUTH AFRICA

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### Abstract

Since the identification of the childhood disorder Autism by Dr Leo Kanner in 1943 and Dr Hans Asperger in 1944, our understanding of this condition has evolved. At first it was described as an attachment disorder, then it was described as a psycho-social-educational disorder, which is largely where our thinking on the topic has remained. This thinking determines the interventions applied. There is little expectation by physicians, parents or educators of significant emergence from ASD. It is common for parents to report that they receive no real advice as to what to do after the diagnosis other than placement of the child in a special school and to start Speech Therapy. The increasing incidence of ASD (1 in 44 births: CDC) means the mounting pressure on service providers is unmanageable. However there have been changes in thinking that brought some promise of brighter outcomes. For example since the 1990's there has been increasing appreciation of the role of the biome, with reports of positive outcomes following metabolic interventions. Approaches have arisen that offer positive outcomes and have brought a greater understanding of the nature of ASD. This presentation proposes a change to the way the diagnostic protocol is executed in keeping with a more pervasive view of ASD. A new approach is needed in line with research and new developments, so that at the time of diagnosis parents get pointers for actions to follow that can greatly benefit the child, since all agree that early intervention brings better outcomes.

*“While diagnosis has traditionally been viewed as an essential concept in medicine, particularly when selecting treatments, we suggest that the use of diagnosis alone may be limited, particularly within mental health.” Macneil, Hasty et al. [1].*

When we assign a label such as Autism to a condition, we tend to be directed by that label when planning interventions. In this we do not adequately recognise the differences within each presenting individual profile, and thereby fail to meet the requirements of Best-Practice. It is of vital importance that suitably trained professionals be knowledgeable of all the factors that affect each child within the diagnostic category of Autism. This is a demanding task given the very pervasive nature of the disorder, and since profiles within the diagnosis of ‘Autism’ or ‘Autism Spectrum Disorder’ can vary considerably.

It is logical that the information to which we respond when dealing with a pervasive disorder as in the case of Autism, should naturally be as varied and pervasive. This assists us to best serve the needs of the individual.

### 1. The Influence of Early History

When the condition of Autism was first noted by Dr Leo Kanner in 1948, he described children displaying “inborn autistic disturbances of affective contact” Rosen, N.E., Lord, C. & Volkmar, F.R.

The emphasis in diagnostic interviews and research since Kanner has tended to focus on the factor of disordered ‘affective content’. The fundamental disorder of Autism has been viewed as that of attachment.

Dr Kanner described autism as a developmental condition, while Dr Hans Asperger described behaviours that more closely resembled a personality disorder. This view was developed more fully by Dr Bruno Bettelheim (The Empty Fortress, 197....) in which parents – particularly the mothers, were described as creating the child’s withdrawal from the ‘cold, hostile’ emotional environment. The intervention directed by this view was the removal of the children from these supposed toxic situations (*parent-ectomies*) and placement in supposedly ‘good-enough’ nurturing settings (special ‘orthogenic’ centres).

This concept has remained active despite having been discredited, as understanding of Autism as a pervasive developmental disorder has grown. In 1964 the book “*Infantile Autism*,” by Dr Bernard Rimland described Autism as a neuro-developmental disorder of brain function (1964) [2]. In 1974 Dr Carl Delacato published ‘*The Ultimate Stranger – the Autistic Child*’ in which he connected these childrens’ unusual behaviours with the behaviours of children with sensory differences related to neurological and physical conditions e.g. blindness [3].

Kanner’s suggestion that autism is not associated with other medical conditions was proven incorrect [4-6]. Autism has come to be seen as a brain-based disorder given its frequent association with epilepsy, often of adolescent onset [7]. Autism is also found to be strongly genetic. The shift in diagnostic emphasis to regard autism as a developmental disorder led to the DSM-III (1980 ) listing Autism separately from Childhood Schizophrenia for the first time, and indicated that mental handicap could be an associated feature.

Rutter and Bartak demonstrated that an educational approach, that is applying structured and consistent teaching within educational settings, was far more effective than a psychotherapeutic approach [8].

Many schools were started for children with Autism, employing a specially-adapted educational curriculum, that featured a much-reduced and simplified content, repetitive experiences, and heightened individual support. Originally derived from existing programmes for children with mental handicap, these programmes include (where possible) access to a variety of therapies such as speech therapy, occupational therapy, behavioural therapy and others. However, the psychotherapeutic approach is still adhered to in a few countries, most notably in parts of southern Europe. Smith [9].

New theories about the nature and causes of Autism continued to arise. In 1993 Dr Simon Baron-Cohen proposed a psychological theory of Autism known as ‘*Theory of Mind*’ [10]. He suggested that cognitive impairments are responsible for the occurrence of autistic disorder . This theory is based on the idea that the child with Autism fails to understand that other people have different ideas and mental states. Because of this, the children seem to have difficulty in understanding that other people have different perceptions, experience and emotions. This is held to be the fundamental problem which leads to relational problems. Tager - Flusberg proposes a problem with *language learning* as the basis for Autism communication and relationship breakdown [11].

VIEW or THEORY OF ASD	ACTIVITIES / INTERVENTIONS
EMOTIONAL / SOCIO-EMOTIONAL	‘GOOD-ENOUGH’ ENVIRONMENT, PSYCHOLOGICAL
EDUCATIONALLY /MENTALLY RESTRICTED	ADAPTED CURRICULUM – SIMPLIFIED, RELATIONAL / PSYCHO-EDUCATIONAL
THEORY OF MIND / LANGUAGE	ADAPTED CURRICULUM, RELATIONAL/ PSYCHO-EDUCATIONAL

**These theories have influenced the development of intervention strategies, classified roughly in this table:**

### 1.1 Some Considerations on the Matter of Diagnosis

“*It is important to distinguish between validity and utility in considering psychiatric diagnoses.*” Kendall, Jablensky (....).

1. It is agreed that there is a need for a valid and accurate diagnosis of Autism, or Autism Spectrum Disorder(ASD). The main reason is that without a diagnosis, parents and their children are barred from access to such services as might exist, e.g. admission to a school or support or funding for children with ASD.
2. The Mayo Clinic initiative, ‘Operation autism’, has contributed much to the development of diagnostic services to families in the USA, and state that ‘*Studies show that the earlier the child is diagnosed, the sooner a treatment program can be started, and the better the results for the child*’
3. There is no definitive laboratory test to diagnose ASD. As a developmental disorder it relies on the skill of an experience doctor to evaluate a child’s developmental history and behaviour. At this time ASD can be diagnosed in a child by the age of 20 months [12].

4. The emotional impact of diagnosis on the parents is intense, but most parents report that there was relief due to finding an explanation for the child’s behaviours [13].
5. Despite many excellent checklists and assessments, no one assessment serves all presenting clients. But then, given the pervasive nature of the condition, no one assessment tool is likely to do so. ‘*Researchers are increasingly assuming that variation in symptoms is continuous*’ (Kendall and Jablensky).The very nature of Autism Spectrum Disorders is such that the presenting features in different individuals are infinitely varied and unique. *This term equally includes the young non-verbal child who w-sits in the sandpit rocking and flapping his hands, but also the adolescent who has obsessive and repetitive speech with poor social skills who enjoys doing pages of arithmetic, and also a child with echolalic speech who seems not to comprehend what is said, and has painful hearing but slams doors in the house obsessively and screams randomly through nights.*
6. Parents surveyed by Makino et al report that the journey to diagnosis is fraught with delays, between 12 months and 55 months [13]. They were equally accepting of online or face to face

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feedback, and accepted the ADOS and ADI used, but expressed concern at the lack of knowledgeable professionals. Parents are reported to be largely disappointed by how little useful action is recommended.

7. It is reported by parents that the diagnostic process as it exists does not readily point to effective interventions or actions that are indicated for each individual. This is the most problematic disconnect between the diagnostic process and the needs of the child and family.

*It is not unusual to see a family still in search of useful interventions three years after diagnosis, presenting a folder 10 cm thick with numerous assessment reports representing time and financial resources, but no practical intervention strategy evident. The IEP (Individual Evaluation Profile) fails to effectively become the IIP (Individual Intervention Profile).*

8. There is little inherent in the diagnostic process that charts a course of individualised action for the child with ASD. Whichever tools were used at diagnosis, once the diagnosis is received, the way forward presented to parents is, for the most part, a simplified and repetitive educational program followed by sheltered employment in adulthood (for the fortunate.)

If one considers the subcategories of two commonly used assessment tools, the ADOS with the ADI, one can understand that the intervention pathways are not readily evident post-diagnosis.

*The areas assessed are: The ADOS categories are pointing / gestures/ eye contact/ facial expression/ shared enjoyments/ showing/ spontaneous initiation of joint attention/ response to joint attention / quality of social overtures / stereotyped, idiosyncratic words or phrases/ unusual sensory behaviours / mannerisms / repetitive interests and behaviours. The ADI-R has three categories: language and communication / reciprocal social interaction / restricted, repetitive and stereotyped behaviours and interests.*

Much is now known about the factors associated with Autism. Thus, mapping the pathway to effective intervention is potentially more attainable than it was in the early days. Even though the exact cause of autism is still a medical mystery, it is generally accepted that it is caused by abnormalities in brain structure or function and has a genetic origin. Dr Mary Megson referred to 'a cascade of biochemical (immunogenetic) responses [14]. That can be identified. It is known that a wide variety of factors can be involved leading to a wide range of symptomatology.

### 1.3. Notes on the Biome And Environmental Triggers

Research has demonstrated that biological factors play a role in alleviating or intensifying some of the features of Autism.

Just as there is a genetic basis to Autism, there is a genetic basis to inborn errors of metabolism, allergies and food intolerances. It

is conceivable that these genetic factors could be linked. In the 1970's Dr Benjamin Feingold (...) published papers linking behavioural disturbances to the ingestion of food additives. He claimed that children could react to any of the thousands of food additives, as well as certain foods, but also that not all children reacted to the same substances. Dr Doris Rapp included the effect of dust, molds and chemicals on behaviour [15]. Dr W. Crook published work on the role of intestinal candida in disturbing cognitive, socio-emotional, and physical functioning [16]. There are almost 2000 metabolic processes known that if weakened (singly or in combination) can lead to developmental difficulties. Great amounts of support for this view have issued from the works of Drs Kalle Reichelt, Dr [17]. The current understanding is that Autism can be regarded as 'A neurological disorder of biological origin'. It is believed that autism is a disorder caused by a combination of a lowered immune response, toxic loading from various external sources, and problems triggered by ingesting certain substances to which the person is sensitive.

The mere existence of *neuro-biodiversity* does not invalidate this concept. It does however complicate the search for each individual's 'trigger' substances. Each person has a unique metabolic functioning, making it a challenge to map the route to optimal wellness in sensitive children. The ideal investigation must act on the widest platform, drawing on the broadest, most informed knowledge base. It is furthermore necessary to differentiate between those historical precipitating 'triggers' that are no longer active, and those which are very much active and continue to exacerbate the problem, and those that are (according to our current knowledge) insignificant.

What is indisputable is that reports are increasing of children having made significant improvements and the lessening of the severity of Autistic symptoms to the point of becoming 'indistinguishable from their peers', once the correct combination of neuro-biological cause-and-intervention is found. (*autism turnaround stories*).

### 1.4. The Biopsychosocial Model And Case Formulation [18]

*While diagnosis has traditionally been viewed as an essential concept in medicine, particularly when selecting treatments, we suggest that the usefulness of diagnosis alone may be limited, particularly within mental health. The concept of clinical case formulation advocates for collaboratively working with patients to identify idiosyncratic aspects of their presentation and select interventions on this basis [19].*

The current 2-tier diagnostic process comprises:

1. A screening assessment by a physician, to eliminate co-morbidities.
2. The Diagnostic Assessment by knowledgeable specialists, often using the ADOS and ADI.

This 2-tier process may afford the label of Autism to be given to the child.

Barker writes of *Case Formulation* in psychiatry which is a way of understanding a patient as more than a diagnostic label. It structures the way one can consider the origins and causes of a patient's symptoms. This is done through the biopsychosocial approach, first described in 1980 by George Engel [20].

Biopsychosocial formulation combines biological, psychological, and social factors to understand a patient, and uses this to guide treatment. Case formulation is a core clinical skill that links assessment information and treatment planning. It is a hypothesis about the mechanisms that cause and maintain the problem. Importantly, formulations should incorporate new information as it emerges [21].

McNeill et al 2012 listed 5 P's of case formulation [1]. These are referred to as the standard:-

1. Presenting Problem
2. Predisposing factors
3. Precipitants – what triggered/ is exacerbating the problem
4. Perpetuating – what maintains / is worsening the problem
5. Positive – what strengths can be drawn on?

Where used, this approach would offer the parents of the newly-diagnosed child with Autism some structured and well-reasoned guidelines for the selection of indicated interventions. This in turn may provide a more positive outcome than is currently available. One such useful framework is presented below.

### 1.5. Stages In Development Of Neurological Self-Mastery

In the introductory chapters of their book, *M.O.R.E: Integrating the Mouth With Sensory and Postural Functions – March 1, 1999*, Oetter, Richter and Frick describe three stages of brain development required for effective self-regulation [22]. These three stages are seen as a hierarchy, in which each level must be well-established in order for the subsequent level to develop efficiently. As the infant progresses through these stages successfully, the pinnacle of development is reached in which the individual achieves effective neurological integration which supports self-mastery. This self-mastery is required to become a well-integrated sensory-motor-cognitive and socio-emotionally competent person.

In this paradigm, the acquisition of new skills requires cycling through earlier-achieved levels. A hiatus or interference in any of the stages will negatively impact on subsequent levels of development which could have lasting consequences on the individual's competence. If neurological integration is not achieved effective-

ly, there are likely to be cognitive, socio-emotional and physical consequences.

\*In the first order the lower brain centres are organized, such as thalamus, hypothalamus, lower brainstem, medulla and cerebellum. These areas regulate activities for survival, such as ingestion, digestion and elimination, heart rate and cortical tone, temperature, respiration, blood pressure and the sleep-wake cycle. Here too are integrated the functions of the endocrine, immune and nervous systems.

\*In the second order, the higher brain centres become organized, notably those of the brain stem, reticular activation centre, and cerebellum. These areas organize and integrate the sensory-motor loops such as the suck-swallow-breathe synchrony, selective attention, the righting response, reflexive babbling, and importantly the ability to achieve, maintain and change situation-appropriate states.

\*In the final, or third order in the development of self-regulation, the main areas of processing are of the cortex including the frontal lobes, regulating the higher cortical functions of intention, voluntary goal-directed behaviour, sustained attention, communication and organization of spaces, tasks, time and environments, such as speech and language, scholastic skills, and socialisation.

### 1.6. Application of This Construct During Case Formulation During the Diagnostic Process – The Neuro-Cognitive Mobilization Project (Seymour 1993)

This conceptualisation devised by Oetter, Richter and Frick can readily be applied for use in the case of Autism and related conditions. It provides a useful framework to create a diagnostic case formulation that can readily inform intervention and establish priorities in planning.

One such project that applies this is named Neuro-Cognitive Mobilisation. Firstly, the child's early development, symptoms and presenting problems are noted and categorized in this framework. Next the appropriate intervention to specifically deal with the most critical of these features is selected from the available interventions, as demonstrated in the tables below. The information required to develop this formulation is usually available from the parent interview, appropriately-designed questionnaires, observation and reports from teachers or carers involved. Where indicated one may call for further investigations if appropriate.

CAUSES	PRIMARY		FIRST ORDER	SECOND ORDER		THIRD ORDER *	
	→		→	CO-ORDINATED INPUTS	SENSORY "GATE"	→	
GENETIC	DIGESTIVE DIFFICULTIES	EXCESS OPIOIDS IN THE SYSTEM	MONITORING FOR SURVIVAL AUTONOMIC FUNCTIONS	VISUAL Spatial / colour / depth		VOLUNTARY, GOAL-DIRECTED BEHAVIOUR	PERCEPTION CONCEPT KNOWLEDGE
GENETIC INBORN ERRORS OF METABOLISM TOXIC EXPOSURE HEAVY METALS CANDIDA ALBICANS VIRAL	AUTO-IMMUNE ANOMALIES	INFLAMMATION INFECTIONS	RESPIRATION	AUDITORY Hearing / processing speed Transmission time		ANTICIPATORY PLANNING, INTENTION	WIDENING RANGE OF INTERESTS AND ACTIVITIES
	ALLERGIES IGE, IGA		HEART RATE	TACTILE		RECOGNITION OF STATE CHANGE	INSIGHT
	SENSITIVITIES	GLUTEN, CASEIN, GLIADIN MSG / ASPARTAME	BLOOD PRESSURE	BALANCE TASTE		ORGANISATION OF SPACES, TASKS, ENVIRONMENTS, AND TIME	SPEECH & GESTURES ARTICULATION PROSODY SYNTAX SEMANTICS BODY LANGUAGE POSTURE DISCOURSE NARRATIVE
	DETOX PROBLEMS PST / SULPHATION	FEINGOLD ISSUES: FLAVOURANTS COLOURANTS PRESERVATIVES SUGAR	CORTICAL TONE	PROPRIOCEPTION SMELL WELL-BEING			
	NEUROLOGICAL	UNUSUAL DEVELOPMENT OF MIDBRAIN, CEREBELLUM, LEFT TEMPORAL	MUSCLE TONE SLEEP-WAKE CYCLES	CO-ORDINATED OUTPUTS MOTOR CO-ORDINATIONS inhibit reflexes defeat gravity, Isolating and combining		FORMULATION OF STRATEGIES	
			INGESTION	SUCK-SWALLOW BREATHE SYNCHRONY		FORMULATION OF STRATEGIES	
	EXPOSURE TO TOXINS, EVEN IN UTERO		DIGESTION	ADAPTIVE MOVEMENTS		SELF-MONITORING	USING LANGUAGE FOR ORGANISATION
		INTERFERANCE IN NEURO-TRANSMITTERS	ELIMINATION	VOCALISING IN PATTERNS-TICS		EXECUTION OF STRATEGIES	
			CO-ORDINATION OF ENDOCRINE-IMMUNO- AND NERVOUS SYSTEMS	REFLEX INHIBITION IMPULSE INHIBITION		EVALUATION OF STRATEGIES	ACADEMIC SKILLS
			LIMBIC SYSTEM / emotions WELL-BEING	SELECTIVE ATTENTION		SELF-CONTROL	LIFE-SKILLS
		TEMPERATURE REGULATION  STATE MAINTENANCE	ABILITY TO ACHIEVE, MAINTAIN, AND CHANGE SITUATION-APPROPRIATE STATES PERCEPTUAL CONSTANCY VACCINATION SWITCHING		SUSTAINED ATTENTION ABILITY TO SWITCH	SOCIAL SKILLS RESPONSIBILITY	

**An early sampling framework is presented below:**

One enters the information derived from observation and assessment, parent reports and professional reports onto this framework according to the neurological hierarchical 'order' as shown. For

example, in the table below, a sample formulation for Child A is summarized.

First Order	Second Order	Third Order
Sleep disturbance	Hyper-arousal, Cries easily, cannot be comforted	Problem making friends
Low muscle tone in upper body	Sensory defensive - touch	language disorder
Abnormal EEG (cortical tome)	Sound -sensitive	Poor self-help skills
Newborn Colic	Moro-reflex still present – check others	Poor following of instructions
Night sweats	Delayed motor milestones, clumsy	Handwriting poor, refuses to write or colour
Frequent diarrhoeia	Distractible, poor regulation of attention	Dyslexia
Repeated ear infections	Easily frightened, anxious	

First Order	Second Order	Third Order
Low muscle tone throughout the body	Hyper-active, restless, climbs furniture, the roof	Non-verbal, non-communicative vocalisations
Constantly hungry	Repetitive rocking	Does not imitate
Constipation, very smelly gas and stools	Destructive	Does not draw or write
Doesn't seem to feel the cold	Seeks pressure, rough play	Poor self- care skills
Some seizures reported	Poor attention except for TV	Does not seem to comprehend what is said.
	Does not make eye contact	
	Bites his wrist	

#### A sampling for Child B could look different:

Such a formulation framework can be useful to highlight areas requiring further investigation that may have been overlooked. e.g, an EEG, stool analysis, developmental occupational therapy assessment.

Following this analysis of causative factors, one turns to the prioritising of the most appropriate interventions for each individual.

There are a wide variety of available interventions that have been reported as useful in research and anecdotally (e.g. Seymour, R.E., *Autism – Options Galore*. 1995 ). One can equally categorise these in the same three orders according to their targeted action and outcomes, as shown in a small sample below,e.g.

First Order	Second Order	Third order
Gluten-free-caseien-free diet	The sensory diet-brushing protocol	Speech Therapy
Cod-liver oil	Motor reflex-inhibition therapy	Remedial reading/ therapy
Melatonin	Sensory-integration training, rocking / swinging / ball-pool play	Visual schedules (TEACCH)
The GAPS diet	Auditory Integration Training	Floor-Time DIR
The Feingold Diet	Horse Riding	Counseling
Detoxification programme	ABA	AAC/ signing /
	Swimming	

#### 1.7. Neuro-Cognitive Formulation Directs Effective Interventions

All interventions can be categorised in this way, according to whether they are chiefly designed to act on the first, second or third order of developmental difficulty. One then matches the intervention to the indicated area of difficulty, e.g. speech therapy for a language disorder; AAC ( Alternative and Augmentative Communication) for a non-verbal child; reflex-inhibition when primitive reflexes remain inappropriately active.

The next step is to assign an order to the introduction of activities, for example by using the 4 P's of McNeill, to determine which interventions to initiate as the most pressing.

This NCM Formulation can be applied by well-informed and suitably trained educators, carers, therapists and professionals. In this way the waiting period between diagnosis by a specialist and the commencement of intervention (the IIP mentioned earlier) can be significantly shortened.

Using such a construct, parents can immediately start to act, and thereby ensure the most positive outcomes for their child. In a situation where the parents have to navigate the various services offered on their own, such a formulation could act as a helpful guide through the maze of contradictory and confusing options available [23-32].

## 2. Conclusion

The process of diagnosing Autism in children remains an active topic of discussion. The assigning of a diagnostic label to a child does not of itself direct best-practice interventions to ensure the most positive outcome for each individual. It has become apparent that a further tier to the diagnostic process is required in order to be useful to parents, educators and therapists. It is proposed that the concept of Case Formulation become common practice, to link assessment results and treatment planning. Besides asking the 5 questions as advised by McNeill, it is presented here that the Neuro-Cognitive Framework (Seymour) based on the three orders of

development of neurological self-regulation (Oretter, Richter and Frick) can provide a ready and useful framework in this process.

### Parent Comments Regarding Diagnosis [13]

Parents want information specifically geared towards their child rather than generic.

Parents want information on intervention at diagnosis in writing

Parents want post-diagnostic support specifically with service navigation

• THE SCREENING ASSESSMENT	By a knowledgeable physician, to identify co-morbidities
• THE DIAGNOSTIC ASSESSMENT	e.g. Using ADOS, ADI-R as gold-standard
• THE NEURO-COGNITIVE FORMULATION OF CAUSES AND ACTIONS	Trained teachers, professionals, health workers, therapists, to plan intervention priorities and sequence.

### Towards A Three-Tier Diagnosis For A Brighter Outcome

Examples Of Programmes That Implement The Above

- *ABC Learning Options, South Africa, R Seymour; ncm4kids*
- *iMap and iDevelop, South Africa, Dr Beulah van der Westhuizen*
- *Connect Therapy, Australia, Monique Simpson*
- *Giant Steps, Canada, Darlene Berrenger*
- *Alia for Early Intervention, Bahrain, Princess Rania AlKhalifa*
- *Matahati Autism Clinic, Surabaya, Java, Mingseh Andranusa*

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