



PATIENT INFORMATION BOOKLET FOR AUTISM



*Scaffolding the journey of
transformation*



A therapeutic guideline for Parents and Caregivers

APRIL 2023

**Centre of Excellence & Advanced Research for Childhood
Neurodevelopmental Disorders**

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Transforming the narrative: Contributions at home, at work, in the arts and in policymaking

AUTISM AWARENESS MONTH - APRIL 2023



go
blue
for
autism



Dedicated to our patients and caregivers



What is Autism Spectrum Disorder (ASD)?

The Diagnostic and Statistical Manual, 5th Edition of American Psychiatric Association (DSM 5) defines autism spectrum disorder (ASD) as a neurodevelopmental disorder characterized by symptoms such as “persistent deficits in social communication and social interaction across multiple context and restricted, repetitive pattern of behavior, interest or activities”.

The term "spectrum" describes the wide diversity of traits, skills, and capacities that exist among individuals with autism. Every person with autism has a unique experience and requires a different level of support. Although the fundamental traits of autism can lead to a variety of difficulties, it's crucial to understand that they can also provide distinctive skills and abilities.

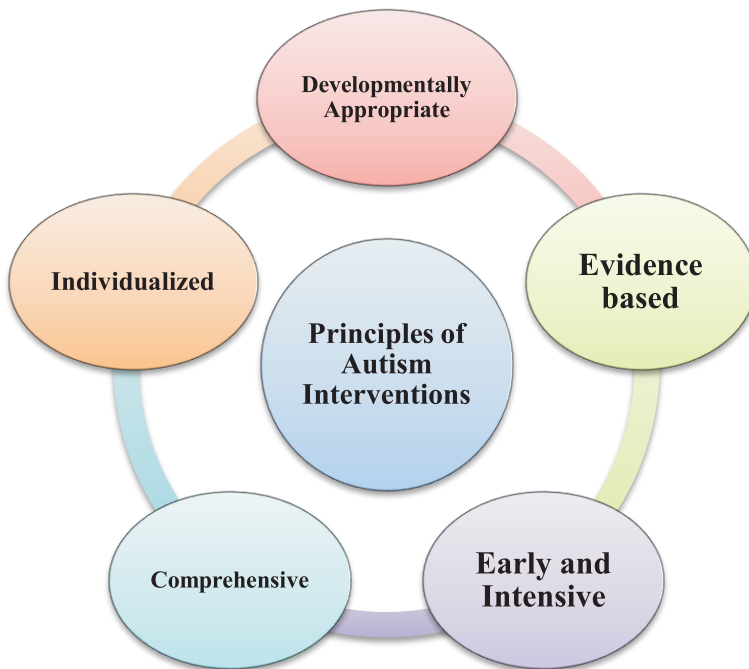
Despite the fact that autism is a lifelong condition, children with autism can make considerable progress with the right care and tailored support. The purpose of this booklet is to provide information about autism and evidence-based intervention and management for parents and caregivers to help them better care for their child.

Diagnosis and evaluation

Diagnosis of autism is purely clinical. Interviews and in-person observations serve as the sole basis for the diagnosis of autism. Autism Spectrum Disorder is initially diagnosed using DSM-5 criteria and AIIMS modified INDT-ASD (based on DSM-5 criteria). To determine the severity of autism spectrum disorder, the CARS (Childhood Autism Severity Scale) is used. Autism Diagnostic observation Schedule (ADOS) is a gold standard diagnostic tool, used to diagnose and evaluate autism. A supplementary tool called the Autism Diagnostic Interview- Revised (ADI-R) involves conducting a structured interview with the subject's parents in which the subject's entire developmental history is covered.

Treatment and Management

There is no standard treatment for autism but there are various strategies or interventions to improve the skills while reducing symptoms. If they receive the right therapies and interventions, people with ASD have the best chance of making use of all of their skills and abilities. Early detection and treatment, such as in preschool or earlier, are more likely to significantly improve symptoms and subsequent skills. For each patient, there is a different set of interventions. But for the most, specialized and highly organized programs work well. To be effective, intervention should be based on the aforementioned principles.



Behavioral Approach	Developmental Approach	Psychological Approach	Educational approach	Social Relational	Pharmacological Approach
<p>-The most popular and effective</p> <p>-Gained widespread acceptance among educators and medical experts</p> <p>-Focus on altering behaviors by comprehending what happens before and after the behavior for instance ABA therapy</p>	<p>-Focuses on enhancing a narrow range of inter connected developmental abilities such as:</p> <p>-Speech-language therapy</p> <p>-Occupational therapy</p> <p>-Sensory Integration Therapy</p> <p>-Physiotherapy or Physical Therapy</p>	<p>Developmental and psychological assessment helps identifying current level of functioning of the child.</p> <p>-Cognitive and behavior can be used to treat anxiety and depression.</p>	<p>-Improves adaptation by means of education and modifying environment.</p> <p>-Focused on structural teaching and visual learning such as TEACCH.</p> <p>TEACCH is Based on Generalist training means treat the child as a whole.</p> <p>Use visual support such as visual cards and schedules</p>	<p>The goal is to increase social competence and foster close relationships. Parents or peer mentors may be used in several social-relational strategies.</p>	<p>-The primary signs and symptoms cannot be treated by medicine.</p> <p>Co-occurring symptoms are treated by several drugs, For instance, medication may be used to regulate excessive energy, difficulty concentrating, or self-destructive tendencies etc.</p> <p>Medication can be used to treat co-occurring medical disease.</p> <p>Families and medical professionals must collaborate to track responses and side effect of the medications.</p>

Applied Behavioral Analysis (ABA) is a well-known behavioural therapy for ASD patients. To enhance a number of skills, ABA promotes desired behaviours while discouraging undesirable ones. Progress is monitored and quantified.

Commonly used techniques of ABA are as follows:

Antecedent-based interventions: ABA Theory (Antecedent Behaviour Consequence) views learning as a three-stage process. This ABC process states that an event called an antecedent (A) causes a behaviour called a behaviour (B). Following the action (B), there is a result (C).

Discrete Trial Training (DTT): DTT teaches a desired behaviour or response via detailed instructions. Lessons are simplified, and responses and actions that are desired are rewarded. Unwanted responses and actions are ignored.

Pivotal Response Training: This approach is predicated on the notion that some behaviours influence other behaviours. Instead, than focusing on particular behaviours, PRT therapists pay close attention to pivotal areas. PRT commonly takes place in natural setting such as game.

Functional Behaviour Assessment: Therapist will conduct a functional behavioural assessment (FBA) to determine which of child's behaviors need to be changed in order to support learning. The ABA therapist for your child can identify particular behaviours using this technique, as well as evaluate their function and the elements sustaining them. The ABA Therapist will utilize FBA as the foundation for the interventions they employ to help child learn and develop.

Functional Communication Training: Functional Communication Training (FCT) teaches a child to switch one behavior for another by using differential reinforcement (DR).

Modelling: Modelling is when someone consciously exemplifies a desirable behaviour for someone else. Therapist may utilise modelling during ABA therapy to help child comprehend the desired behaviour.

Extinction: The term "extinction" refers to a technique used to assist curb undesirable behaviours. Depending on how a certain behaviour is maintained, different tactics are devised to reduce it.

Some problematic behaviours persist because they receive favourable reinforcement. When your child speaks too loudly, for instance, he or she might get attention as a type of positive reinforcement. Ignoring him or not providing reinforcement can decrease that behavior.

Picture Exchange Communication System: A modified ABB programme called a Picture Exchange Communication System (PECS) enables persons who cannot talk to communicate via pictures. PECS can help in developing child's linguistic abilities, in expressing needs and in reducing the negative behaviours brought on by frustration at not being understood or being able to communicate. For instance, if your child is unable to request specific foods, you might give him or her a PECS with a selection of food items to choose.

Redirection is a method diverting a child's attention away from a problematic behaviour that is occurring. More suitable behaviour is brought to the child's attention.

In order to achieve the intended outcomes in children who potentially benefit from behaviour modification, applied behaviour analysis employs a variety of strategies. These are five of those useful methods:

Reinforcement:

- **Positive:** Using positive reinforcement right away to promote the behaviour in the future is one strategy to encourage desirable social behaviours.
- **Negative** Removing a child's favourite toy or pastime from them is an effective technique to discipline them for misbehaviour. This is an example of negative discipline. Negative reinforcement should be constant.

Prompts are verbal or visual cues such as gestures or an eye contact that are used to support a specific behaviour. Visual signals are even less direct than verbal cues. Verbal cues are gentle reminders. This cue will serve as a reminder to the child to act simply.

Task analysis task is given to the child by simplifying subsequent tasks for that specific child by dividing them into manageable steps.

Parental Training: Parents are given information on proper ways to speak with children and how to teach them skills for communicating more effectively and appropriately, such as waiting, taking turns, paying attention to others, and complying with group rules etc. Parental training equips the parent to deal with difficult circumstances and communicate with the child more successfully.



Skill Building: assessment identifies emerging skills, and strength work, and then focuses upon these. (This approach is also applied to staff and parent training).

Based on above mentioned approaches and techniques few activities are designed.

Activity based Interventions

Eye Contact Exercise :

(Use reinforcement)

- Show reinforcement to the child and move the reinforcement from his eyes to yours, and once the child looks at you, give the reinforcement for establishing eye contact.



- Focusing the light/torch in darkroom.
- Always maintain eye contact while talking
- Face to face and at physical level.
- Use Visual Support.

Attention enhancement exercises :

- Joining dots
- Putting beads in a string
- Sorting grains, objects: Chana/rajma, two different colors of daal etc.
- Colouring and Drawing
- Alphabet cancellation
- Reading books



Reduce hyperactivity :

- Bear walk
- Use trampoline
- Involve in physical activity
- Weight compression (weighted jackets, running, cycling, ball throw and catch)
- Making a structured routines
- Wall/ Heavy weight pushing



Imitation Exercise :

- (Verbal and motor, use the method of direct role modelling and positive reinforcements)
- Imitating single activities, doing one activity at one time and receiving positive reinforcement after every successful completion,

physical prompting required initially.

- Copy actions
- Rhymes with action (like Johnny Johnny yes papa)
- Say bye-bye and hello or hi-fi in front of the child
- Teaching Body parts: To ask the child 'touch nose' touch your own nose with index finger.



Self-help skills / ADL training :

(taught using social stories, picture cards, and shaping, use reinforcement for each successful level of a multi-step procedure)



Receptive to instructions:

- Simple instructions such as "clap your hands", "Pat the table", etc.
- Identifying body parts such as touching the child's nose with his hand and saying "nose", and similarly for other body parts.
- Asking the child "what is this", while pointing to nose



- Asking the child " where is nose," where is nose",etc.
- Giving instructions for object identification: (sorting, matching, putting beads in a string, sorting grains.

Interactive play :

- A useful technique is Picture Exchange Communication System For e.g. For verbal children one to one conversation while playing
- Nonverbal children: Ball games, rolling, throwing; Hide and seek
- Sharing things and taking turns while Playing such as ball catch throw or passing the pass

Managing stereotypes and self-stimulation :

- Distraction, substitution
- Managing stereotypes and self-stimulation through ABC paradigm and modification technique

Speech Stimulation :

- Verbal imitations
 - Naming games (Don't give the desired object till the child make a verbal request for it, at least the child should try then give reinforcement)
- Picture books and dolls Context based communication (use picture card and story books)
- Asking small questions.
- Singing rhymes in continuation
- Storytelling and ask questions regarding the story
- Reading loudly
- Running commentary (making the child report his entire days activities with proper grammatical use of pronouns)



Cognitive performance:

- Picture cards and books (2to3yrs)
- Eye hand integration (use peg boards)
- To solve simple to complex puzzles
- Clay activity/Building blocks
- Solving Rubik's cube/ Lego building

Environmental Supports: Minimized auditory and visual distraction

- Proper seating arrangement
- Minimized clutters in the environment
- Using furniture to provide the boundary in the working area like shelves, almirahs, bookshelves, table, chair etc.
- Provision of proper light in the room home or at the Library.

Visual structure and schedule-

A methodological and scientific approach to provide structure to develop predictability in their life, in short and simple facilitated manner.

This includes:

- What? How?
- Where? When am I finished?
- When? What's next?

Structured Teaching: "Structure is a support for to help them realize their full potential"

- To make a routine for the child Sequencing and organizing the activities
- Provide a fixed schedule for daily activities

Visual Schedules :

- Have three levels: Object, picture, Word label
- Should be either in left to right or top to bottom sequence
- Initially introduce two visual cards in the schedule and
- Gradually one can increase the number of cards
- Use physical prompts to guide the child with minimal verbal prompts as physical prompts are more difficult to fade out.

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AUTISM SCHEDULE	Brush Teeth	Toilet	Bath Time	Eat Breakfast	Therapy Session 1	Eat Lunch	Help in Cleaning	Park	Therapy Session 2	Spending Time With Family	Eat Dinner	Brush Teeth	Bed Time	Remarks
	MONDAY													
TUESDAY														😊😊
WEDNESDAY														😊😊😊
THURSDAY														😊😊
FRIDAY														😊😊 😞
SATURDAY														😊😊
SUNDAY														😊😊

Social Stories offer brief explanations of what to anticipate in social settings.

Autistic children are good visual learners. This strength is utilized by the visual structure support which reduces the burden of instructing each task repeatedly, verbally. The child becomes more independent and more calm. He/she develops different ways to communicate.

Challenging behaviours in ASD

Some autistic individuals may exhibit behaviours that are typically viewed as inappropriate or problematic such as hostility towards others, self-harming behaviours and extreme tantrums etc.

Why it is called Problematic?

- Negatively impact the child
- Cause distress to family or carers
- Affect process of learning
- Influence interaction and relationship

Why autistic child behave in such way?

- Trouble understanding what's happening around them
- Have difficulty communicating their own wants and needs
- Highly anxious and stressed

- Feel overwhelmed
- A form of communication
- Sensory overload

Common Triggers :

- Unable to communicate needs
- Rituals and routines
- Transitions between activities
- Unfulfilled Sensory needs
- Sensory overload
- Unrealistic expectations
- Tiredness or hunger
- Feeling discomfort, suffering, or ailment
- Comorbid conditions

Note: Some behavior might be the result of a medical issue or any physical ailment. Parents or carer needs to have a careful observation. Proper evaluation and Medical consultation is necessary in that situation.

How to handle?

Aim of the therapist is to reduce these behavior and increase appropriate one, to do that following strategies could be applied

- Prepare in advance
- Make adjustment
- Obtaining expert guidance
- To rule out a medical reason
- Relieve sensory and bodily discomforts
- Fulfill sensory needs
- Possibilities for relaxation

Strategy for parents and Caregivers :

- Identify the trigger
- Keep a diary

- Create predictable schedules
- Use pictorial timetables
- Give warning before changing routines
- Use social stories
- Use positive reinforcement such as praise, hugs, smiley etc.
- Establish a plan in advance and introduce new activities gradually
- Provide clear instructions
- Make one request at one time
- Prepare for circumstances assumed to be challenging
- Avoid introducing new activities in a stimulating situation
- Use distraction such as favorite toy or food etc.

If the challenging behavior poses serious risks to the child or family Try to get a specialized support. Make an appointment with the doctor to discuss the problem and, if necessary, obtain a referral to a behavior specialist.

Sensory Integration Therapy

Sensory integration is the ability to take in, sort and organize sensory information (body and the environment) for functional use. Most of the children with autism have prominent sensory issue and motor difficulty sometimes.

Sensory Integration: Benefits :

It improves postural functions, enhances body schemes, improved self-regulation, participation in play, self-care, social interaction. Sensory Integration helps in reducing aggression and anxiety and keeping the child calm.

Different types of sensory issue faced by autistic child are mentioned:

Sensory Modalities	Examples Of Behaviors Related To Sensory Abnormalities
Visual	Attraction of light sources Starting at spinning objects such as washing machine centrifuge, wheels, and propeller fans Impaired recognition of face expressions Gaze avoidance Refusal of foods because of their color
Auditory	Apparent deafness: the child does not turn to the verbal call Intolerance to some sounds, different from case to case Emission of repetitive sounds
Somatosensory	High pain tolerance Apparent insensitivity to heat or cold Self-aggressiveness Dislike of physical contact, including certain clothing items Attraction for rough surfaces
Olfactory	Smelling non-edible things Refusal of certain foods due to their odor
Taste, oral sensitivity	Oral exploration of objects Food selectivity due to refusal of certain textures
Proprioceptive / kinesthetic	Iterative rocking Inadequate balance

Home Based Intervention:

Olfactory	Visual	Tactile	Gustatory	Auditory
-Smelling kits -Scented creams -Essential oils -Fragrance clay -Room fresheners and Aggarbatti	-Mirrors -Hanging Objects -Colourful lights and balloons -Lightening ball -Torch in a dark room -Laser Light	-Texture board -Corn starch -Shaving foam -Finger paint -Fabric strips -Clay dough	-Spices to chew (Gram, Peanut and Puffed rice etc.)	-Soft or Loud Music -Musical Toys -Flute/ Mouth organ

Occupational therapy

Vestibular	Proprioceptive	Oro motor
-Bouncing on exercise ball -Crawling on floor -Jumping -Swinging -Bear Walk	-Pulling the band Ball catch through Bag packs Head message	-Chew tube -Vibrator brush -Straw -Cotton ball /Feathers -Whistle/Mouth organ/ hotter/Flute

Reduce aggression, tantrums, irritability and Hyperactivity

- Fidgets toys (Poppit game, Rubik's cube Spinner and clay etc.)
- Physical activity (Running, Cycling, Dancing etc.)
- Wall and weight pushing
- Colouring and drawing
- Smiley ball pressing

Special Education

General instructions for home management :

- Strict to daily routine
- Give clear small instructions
- Identify and appreciate child's small task
- Keep an eye over child performance
- Introduce new concept with concrete examples
- Provide kinaesthetic approach for learning
- Encourage child to accomplish task on his own
- Use every day opportunity as learning opportunity
- Stay calm and motivated

- Use educational toy
- Change teaching method if child is not able to comprehend

Prewriting skills :

- Provide crayons for scribbling
- Cutting and tearing of paper
- Encourage them to draw patterns and shapes
- Play with clay
- Use grippers to maintain grip
- Draw and paint
- Encourage the child to do buttoning and unbuttoning
- Use sand trays

Activity to encourage reading and writing :

- Use concrete examples
- Use visual aids and flash cards
- Give pattern to traces
- Encourage free writing
- Motivate the child to repeat rhymes and ask them to recited again

Autism: Pre-Vocational Skills:

Most of the children with Autism need to be able to do many of the following pre-vocational skills:

1. Understand and accept 'work times 'and' relax times' of day
2. Sustain attention to tasks (atleast15minutes)
3. Independently recognize feelings of anxiety, frustration, and anger in self
4. Do non-preferred tasks without complaining/arguing/ negotiating
5. Ask for help
6. Follow multi-step directions (out of sight of a prompter)
7. Be comfortable with getting temporarily interrupted

8. Accept suggestions/corrections
9. Read time on a variety of clocks/watches/phones
10. Understand various forms of authority
11. Regularly demonstrate semi-professional social nice ties
12. Attend to personal cleanliness/hygiene, including dress code
13. Explore self-awareness: understand/accept diagnosis, learn about accommodations, strengths and challenges.
14. Disclose diagnosis(if desired)
15. Make small decisions independently
16. Demonstrate self-advocacy skills (indicating preferences, not waiting for prompts, making goals, asking for accommodations)
17. Demonstrate safety skills in the community (strangers, unwanted advances, emergencies)

This is a large and possibly intimidating list of skills, which is why it is important to start early. Vocational training usually starts in the junior year of high school, and if these pre-requisites are not met, there is not enough time to learn these skills and access the next level of skills (how to get a job, learn a job, and keep a job).

Individualized Vocational Training:

Life skills and vocational skills: The vocational Training Education Program teaches students to obtain and retain salaried employment in the general community upon graduation. People with autism can function independently at jobs that are suited to their strengths and abilities, as long as the specific tasks involved in the job are taught to mastery criterion.

Social skills groups: People with ASD get the chance to practise social skills in a structured setting by joining social skills groups.

Self-Advocacy (Parents / Children with Autism):

Self-Advocacy is:

- Speaking up for yourself,
- Asking for what you need,
- Negotiating for yourself (working with other store a change arrangement that will meet your needs),
- Knowing your rights and responsibilities,
- Using there sources that are available to you,
- Being able to explain your disability either by the use of written words, pictures or gestures.

For most of the child's life, Parents have probably been advocating for their child– making decisions for him or her. However, as individuals with autism age, they will need to advocate for themselves to the best of their ability. Helping adolescents with autism to develop a sense of self will aid in the transition process and will develop a skill that will benefit them throughout their lives.

How Do Parents teach Self-Advocacy Skills?

When helping individuals to learn self-advocacy skills, both parents and educators can still assist them in decision making, help to explain things, and guide them. It starts with making choices –choices for meals, choices for leisure activities, even choices for which chores to do around the house. You may want to consider the following ways to further promote an individual's preferences as well as his or her ability to be more independent:

FOLLOW UP- CHART

Follow Up - Monthly observation by Parents / Caregivers				
	Skills	<i>Remarks</i>		
		<i>1st Month</i>	<i>2nd Month</i>	<i>3rd Month</i>
1.	Communication (Verbal and nonverbal)			
2.	Sharing of interest			
3.	Interaction with Peer, Siblings and parents			
4.	Eye contact			
5.	Follow instructions			
6.	Hyperactivity			
7.	Concentration			
8.	Repetitive or self-stimulatory behaviour			
9.	Balance and coordination			
10.	Behavioural issue (Aggression, Anxiety and tantrums)			
11.	Sensory issue			
12.	Cognition			
13.	Reading skills			
14.	Writing skills			
15.	Academic Performance			

Progress is measured in each session of therapy. Regular meets with family members to track the progress in order to plan further and adjust teaching plans and goals accordingly.

AUTISM SPECTRUM DISORDERS – PROGRESS SHEET

Name:
Age :
Mob. No.:

Autism File No.:
Sex:
Date:

<p><u>Parental Concerns :</u></p> <p>1) 2) 3)</p>	<p><u>Clinician's /Therapist's Concerns :</u></p> <p>1) 2) 3)</p>
<p><u>Progress noted by Clinician/Therapist since last visit :</u></p> <p>- - -</p>	

Short - Term Goals :

Time to achieve

-
-
-

Long Term Goals :

Time to achieve

-
-
-

Session Details :

-
-
-
-

Home Plan :

-
-
-
-

	<p><u>TARGETS / GOALS</u></p>	
<p><u>Short Term: Current Progress</u></p>		<p><u>Long Term:Current Progress</u></p>
<p><u>Weekly Goals:</u></p>		
<p>➤ <u>Occupational Therapist –</u></p>		
<p>➤ <u>Physiotherapist –</u></p>		
<p>➤ <u>Speech Therapist–</u></p>		

Clinician's Overall Assessment :

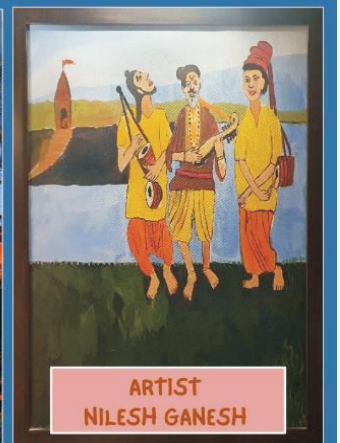
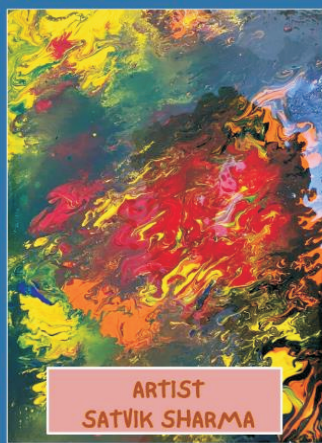
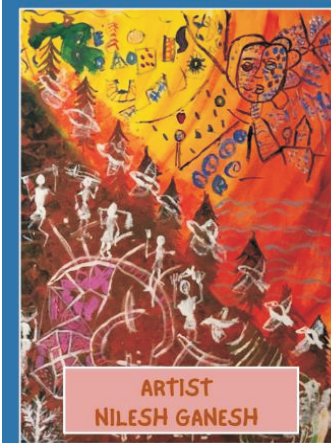
Transformation: Toward a Neuro-Inclusive World for All

AUTISM
didn't stop Einstein,
Newton, Mozart or
Temple Grandin.
Neither will it stop
my child. ✨

APRIL is World Autism Awareness month

World Autism Awareness Day, observed on **April 2**, aims to increase understanding about Autism spectrum disorder.

Theme for the year 2023:
*"Transforming the narrative:
Contributions at home, at work, in
the arts and in policymaking"*



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