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11TH Annual Autism Programme

Theme

Life Beyond the Diagnosis

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AUTISM ACROSS A LIFESPAN: Principles and Guides for Intervention.

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AUTISM-Lets Cover the basics.

Autism is a developmental disorder that is characterised by impairments in three domains :

- Social skills
- Communication skills
- Behaviour

Autism is a "spectrum disorder" that affects individuals differently and to varying degrees. Autism Spectrum Disorders (ASD) ranges from mild to severe.

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Autism as a Spectrum Disorder.

- A spectrum refers to a wide a range of skills, symptoms and levels of disability that individuals with ASD has. Some require support to carry out everyday activities of daily living while others are able to carry out all activities of daily living.
- Note: That some individual display symptoms from infancy where they are noticed to be different from other children of the same age. Others develop typically until they are 2 or 3 years.
- Severity is determined by social communication, existence of repetitive behaviors, social engagement and ability to carry out daily living skills.
- Autism Spectrum Disorder is a formal terminology for all ASDs. Autism is a common informal term.

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ACROSS A LIFESPAN?

- Autism is mostly referred to as a childhood disorder.
- Children grow up to become adolescents and become adults.
- Children on the autism spectrum will become adults on the autism spectrum.
- Areas of deficits or excesses continue through the lifespan to varied degree, from individual to individual.
- Early intervention will help address areas of impairment as well as teach coping skills well into adulthood.
- The idea that autism is a childhood disorder is mostly because earlier studies were carried out among children.

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Historical Definitions of Autism

- Descriptions of features and conditions that look like Autism dates back to the 18th century
- Eufen Bleuler a Swiss psychologist is believed to have introduced the term autism as a way of describing children who withdraw themselves from the social life in 1908.
- Dr Leo Kanner first described autism as a specific condition in 1943 after a study he carried out on 11 children who had challenges with interacting socially, responding to stimuli especially sound, resistance and allergies to food, resistance to change and a repetition of words (echolalia).
- Dr Hans Asperger described a similar condition in 1944 called Asperger Syndrome after he carried out a similar study. This group of children did not however have language deficits like echolalia but spoke like grown ups , had very good memory high intelligence but had clumsy motor skills that were not age appropriate.

Dr Leo Kanner, Prof Bruno Bettelheim & Dr Rimland

- Leo Kanner in the 1940s described autism in terms of the Refrigerator Mother Theory. This Theory suggested that autism was caused by lack of warmth and care for the child from infancy resulting in poor bonding between mother and child.
- Professor Bruno Bettelheim was one of the first paediatricians to focus on autism.
- In 1964 Dr Bernard Rimland, a psychologist and a parent of a child with autism provided proof that autism is a biological condition. He published his findings in a journal : Infantile Autism: The Syndrome and its Implication for a Neural Theory of Behaviour.
- Up until the 1970s Autism was still thought to be due to psychosis and mental retardation. This view began to change in the 1980s when Dr Aspergers work was translated to English.
- The focus of most research was on children.

Identification and Diagnosis

Autism diagnosis can be diagnosed at anytime from childhood to adulthood.

Differential Diagnosis in Autism

- Several other disorders mimic or overlap with autism.
- Differential diagnosis refers to the ability to differentiate one condition from another though they may have similar symptoms or overlapping symptoms.
- It is important to differentiate and identify the different conditions in order to ensure early proper management.
- Conditions often used interchangeably with autism or have overlapping features include developmental delays, Fetal Alcohol Syndrome, Intellectual Disability, Fragile-x syndrome, Rett Syndrome, Tourette Syndrome, Norrie Disease, Prader-willi Syndrome etc
- As the individual grows, there may be Other conditions that co-occur with autism eg ADHD, anxiety disorders, seizures ,allergies etc.

AUTISM & LIFE EXPECTANCY

- Unlike several other neurological disorders, autism has no DIRECT effect on life expectancy.
- However mortality risk is twice as high as that of the general population.
- Most deaths are from accidents such as drowning, wandering and co-morbid conditions such as epilepsy especially in childhood.
- In adolescence and adulthood, many deaths are from health related conditions such as heart problems as well as from suicide especially among those classified as ‘’high-functioning’’ or mild autism.
- **GUIDE: Autism is often a complex disorder. Interventions should focus on all symptoms and presentations.**

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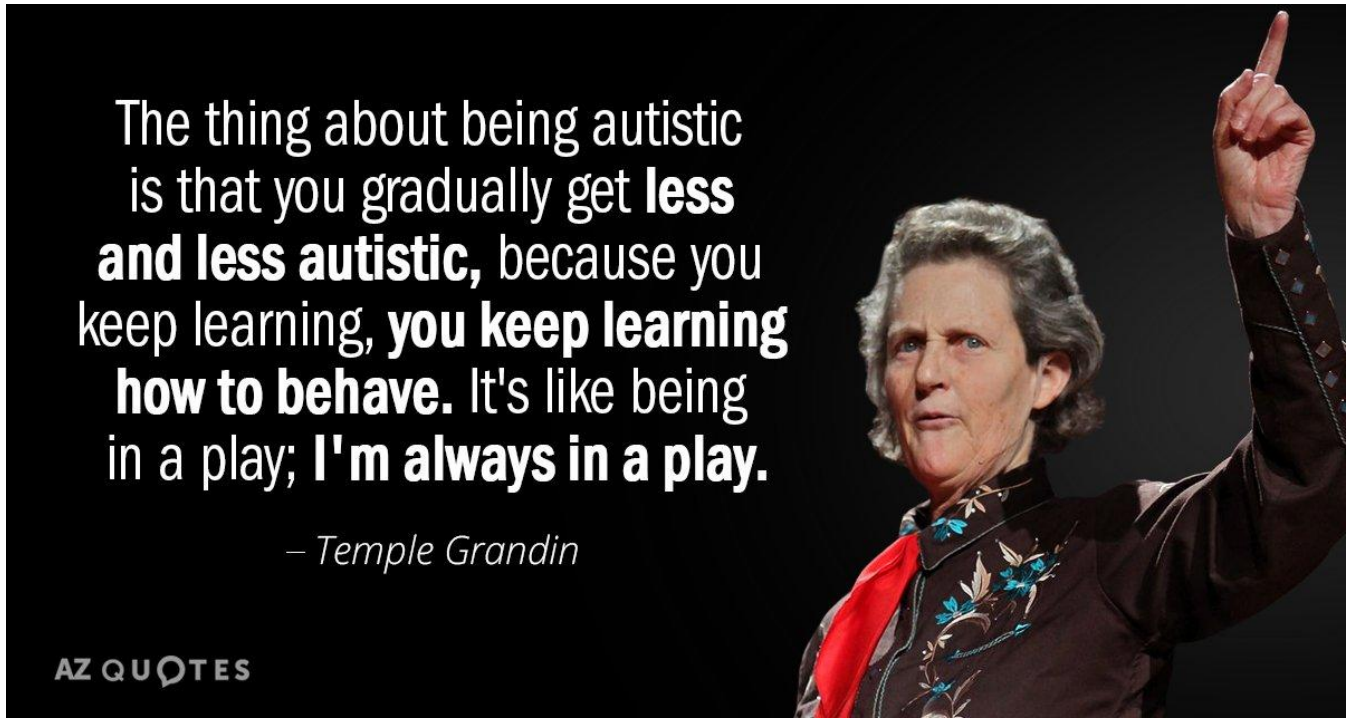
Autism continues throughout life.



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Principles that Guide Choice of Intervention and Education

- Ramey & Landesman Ramery (1998) specified six principles that should guide intervention.
  - Principle of developmental timing
  - Principle of program intensity
  - Principle of direct (versus intermediary) provision of learning experiences
  - Principle of program breadth and flexibility
  - Principle of individual differences in program benefits
  - Principle of ecological dominion and environmental maintenance of development

Principle of Developmental Timing

- **This principle states that interventions that begin earlier in development and continue longer, afford greater benefits to the individual than do those that begin later that do not last as long.**

How should this guide intervention?:

- Early Intervention is key!
- Start as soon a you notice the behavior. There is no time to “watch and see” or experiment.
- Remember there are no quick fixes. It's often a marathon not a sprint!
- Be prepared for the ‘long run’. Plan for the future. Some Individuals would continue to have challenges as long as they live.
- Research shows that interventions carried out during ‘sensitive periods’ and before onset of major symptoms which could be neurological or behavioral often work best.

Principle of Program Intensity

- **This principle states that the intervention programs that are more intensive produce larger positive effects than less intensive interventions.**

How should this guide intervention?:

- Further, parents who participate the most actively and regularly in addressing the needs of their children are the ones who show the greatest developmental progress.
- You cannot ‘outsource’ parenting. Take a front bench and ensure you are a part of the process.
- ‘Microwave’ approach might work but will not be able to sustain change as well as move the child further up the ladder of functionality and independence
- Be wary of interventions or strategies that are created or planned to suit the intervener
- Interventions must be intensive especially at the onset and may only be tapered down and faded off when skills are learnt.

Principle of Direct (versus intermediary) Provision of Learning Experiences

This principle states that individuals receiving interventions that provide direct educational/practical experiences show larger and more enduring benefits than do individual in programs that rely on intermediary routes to change the individual's competencies.

How should this guide intervention?:

- Engage Therapists , teachers and other para- professionals who have received direct trainings to be able to work with the children directly.
- Every one must be equipped to address your child's needs. Do you provide orientation for your caregivers, domestic staff, other children, neighbors?

Principle of Program Breadth and Flexibility

- This principle states that interventions that provide more comprehensive services and use multiple routes to enhance children's development and address challenging behaviors generally have effects than interventions that are narrower in focus.

How should this guide intervention?:

- Choose programs that address a variety of needs-holistically.
- Use a comprehensive approach to address your child's needs.
- Strategies must be designed to address new behaviours and skill area.
- Parents must be trained on set goals as well as maintenance of those goals. Parents' involvement can never be over emphasized. You are your child's first resource material. Parents must be involved in all aspects of intervention.

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Principle of Individual Differences in Program Benefits

- **This principle states that some children show greater benefits from participation in early intervention than do other children. These individual differences appear to be related to aspects of the children's initial risk condition.**

How should this guide intervention?:

- No two individuals are the same.
- Beware of using a 'blanket' or 'one size fits all' approach. Approaches must be individualized to get the best benefits for each child.
- What works for one may not always work for the other. Do your own research.
- Stop the comparisons!! Its okay to ask what is working or not but remember your child's needs might be different
- Don't put your child under pressure to act or be like other children you see
- Don't put others such as your spouse or teacher under pressure to use the exact same program or procedure for your child. They are experts in their fields (well…….hopefully!)

Principle of Ecological Dominion and Environmental Maintenance of Development

This principle holds that over time, the initial positive effects of early interventions will diminish to the extent that there are not adequate environmental supports to maintain the beneficiary's positive attitudes and behavior; hence the need for continued learning and reinforcement of the learned skills and behaviors in various settings.

How should this guide intervention?:

- A person hit by a car may recover from the wounds but the scars may remain.
- Intervention is not a 'been there and done that' affair. Strategies must be put in place for maintenance
- Look out for the scars- little remnant of what used to be. The environment may need to be modified continuously to avoid regression
- Periodic reviews and re-assessments in line with the child's developmental progress is needed.

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Choosing the Right Intervention

The individual is key. Plan interventions to fit the individual's needs, strengths and interests.

Think safety and life skills.

Focus on pivotal skills that help the individual make widespread progress in several areas e.g attention, listener responding skills, motivation etc…

Build skills that will be needed in the long term.
Such as activities of daily living etc

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THE AUDACITY OF HOPE!

''You can take away everything from me but don't tell me my child wont get better. Don't take away my belief that someday soon there will be a cure for autism.

Don't ask me to stop dreaming……believing….hoping that someday my child will be typical". –Mum of a 19 year old on the autism spectrum.

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PLAN FOR THE ENTIRE LIFESPAN

- Intervention planning to include transition and preparation for adulthood.
- Resource mobilisation and allocation.
- Self advocacy, self care, self management.
- Continuity of Care: Who will take over?
  - Training and sensitisation of caregivers, siblings ..
  - Wills
  - Trusts
- Care for the caregiver.

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References

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Thanks for Listening.