

# ***3rd Meeting "Lived experience"***

Co-funded by the  
Erasmus+ Programme  
of the European Union



## ***LECTURE 1***

### **From Shock and Denial to Acceptance and Hope'**

***Dr Antonios Vadolas***

***Dr Vassiliki Ntre,  
Psychiatric Nurse - Health Visitor of Children and  
Adolescents  
"Aghia Sophia" Children's Hospital, Athens,  
Greece***



- Psychological states parents and families get through (7 stage model)

Life stages families and children

Q&A

## ***Presentation outline***



# The reception of diagnosis

- Sequence which begins with the anticipation of the diagnosis, before receiving it officially.
- Once the diagnosis has been communicated, family members react in a variety of ways.
- Among these reactions identified are the phases **of shock, denial, guilt, anger, fear or a positive attitude**. The experience of grief is varied and ambiguous, including the disruption of expectations in virtually all cases as well as the existence of various **feelings such as uncertainty about the future, guilt and in some cases, optimism**



## Impact of the diagnosis on the family

- After diagnosis, the lives of parents are reshaped. They become *overburdened* and *exhausted* with little time for themselves, having to **give up many of the activities** they used to do, and experiencing significant changes in *family dynamics* which from now on are focused on the needs of the child with ASD.
- This *stress* is intensified by being in charge of *more family members*, i.e., other *children* who are *typically developing* but who also need their attention as well as other family members who need their attention. Therefore, the lives of these family members are also *affected*, such as leisure and time for themselves, their relationships or family dynamics.





# psychological states of parents and families

## After the diagnosis

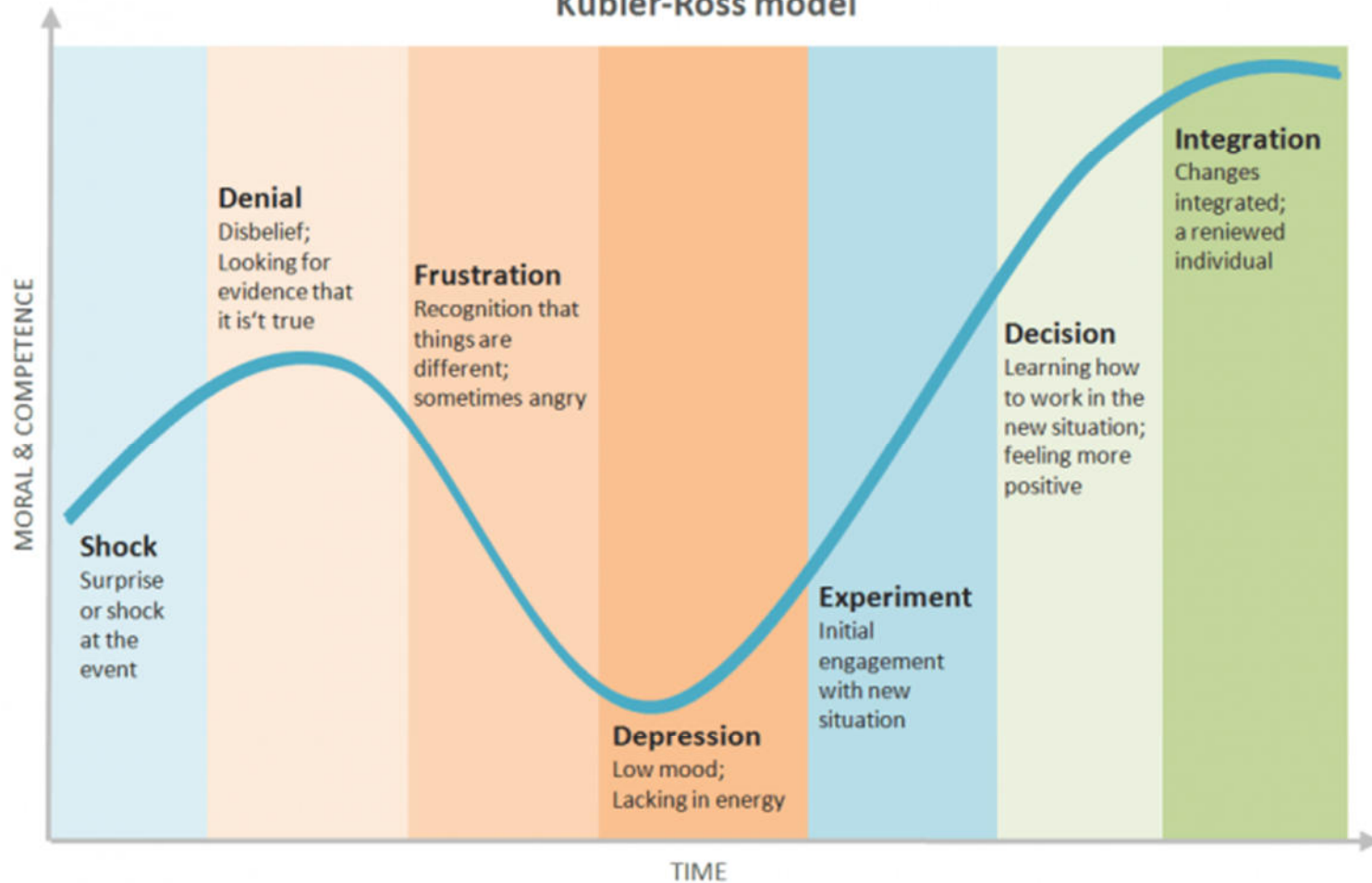
- I. Parents may be *shocked*, *cry* or become *irritated*.
- I. After the initial shock subsides they may experience ***denial***, ***refusing to believe the diagnosis*** and remain *focused* on the *past*. Sometimes, parents may express their feelings through *physical outbursts* or occasionally, *inappropriate laughter*
- I. The denial and isolation, tends to be brief. *Denial*, a common defence mechanism, serves to buffer the pain of loss. Some parents may deny their child's disability or some others, may try to seek a “cure” or try to bargain for a different diagnosis.
- I. The next stage, ***anger***, occurs when the individual realises and understands the *gravity* of the situation. They may become angry and many seek someone to blame. They may demonstrate their anger *outwardly*, in the form of rage, or become *withdrawn* and *passive* from intense feelings of guilt. This stage is a very positive point to reach in the process of adjustment.



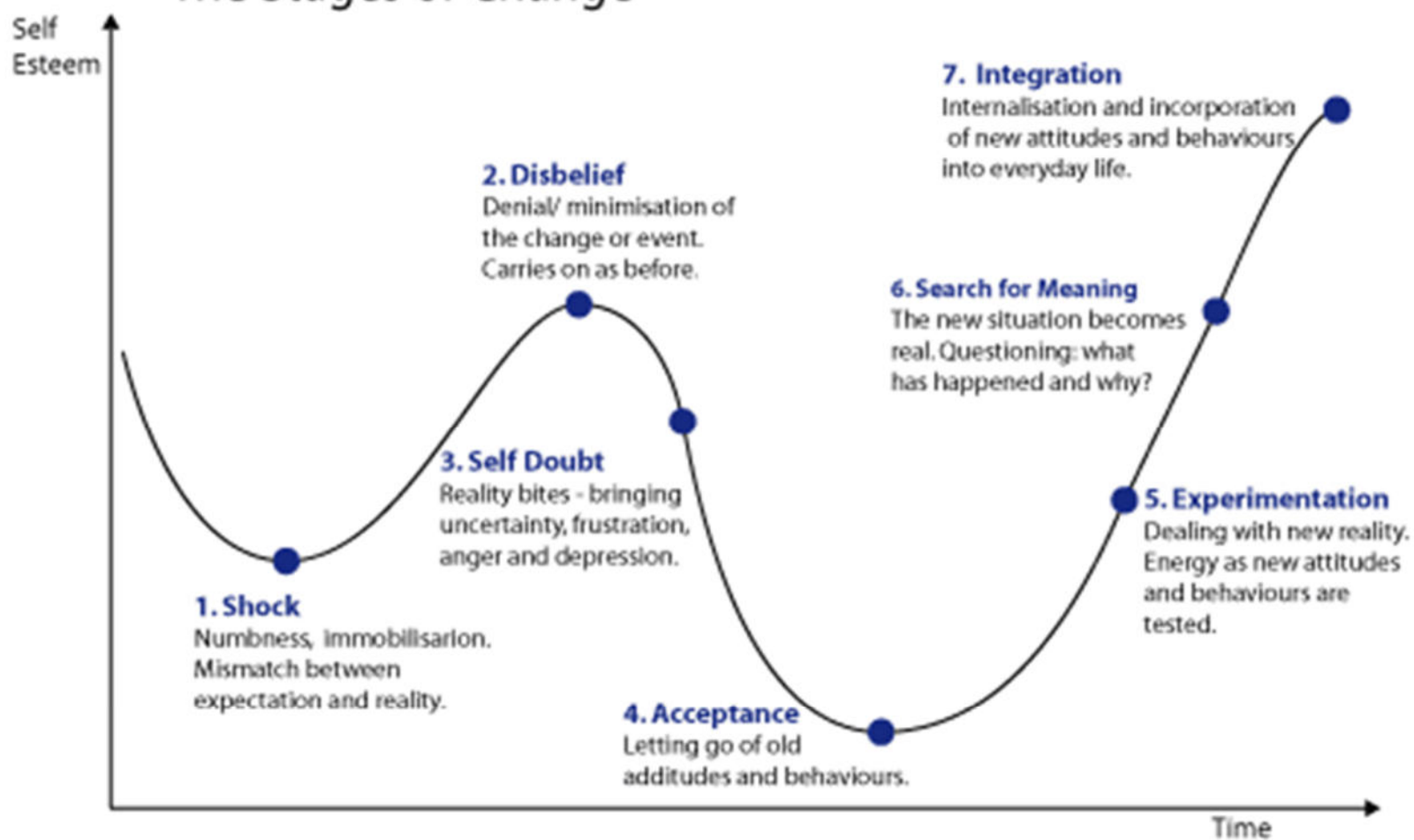
## psychological states of parents and families

5. The stage of anger subsides and bargaining begins with focus on ways to postpone the inevitable and the search for the best adaptation regarding the situation. Parents admit that their child has a disability. In some situations, one or more family members, may exhibit depression. For a few parents, retreating is accompanied by an attempt to hide the child from their social circle. During the depression stage the grieving individual tends to feel sadness, fear, regret, guilt, and other negative emotions.
6. It may feel as they have "hit rock bottom" as says Elisabeth Kübler-Ross. This is the stage of acceptance, meaning the parents have achieved an unconditional positive regard for the child. Reaching this stage is highly dependent to the school inviting parents to become team members in a program with caring **professionals that is designed to meet all of the child's needs.**
7. Parents are able to put their lives back together and enjoy living, visualise future, and talk of their child free of emotions. They can discuss and participate in planning the future projects or provide instructions regarding their child's routine objectively

## Kübler-Ross model



## The Stages of Change







# “Grief” and ASD

“Grief” is a common and healthy emotional reaction. This reaction to loss may take many forms, such as:

- ***Anxiety.***
- ***Panic attacks and chest pains.***
- ***Fear.***
- ***Crying/feeling emotional.***
- ***Finding it hard to sleep or fear of sleeping.***
- ***Insomnia/hypersomnia.***
- ***Fatigue or exhaustion.***
- ***Restlessness; feeling unable to sit still.***
- ***Difficulty concentrating.***
- ***Headaches, backache, neck pain.***
- ***Loss of appetite/comfort eating.***
- ***Weight loss/weight gain.***



## “Grief” and ASD

- The *comparison* of a child with ASD with *other children* of same age, who are *achieving milestones*, may *trigger* continuously the *grieving process*. Parents may feel deep *sadness* and *emotional pain* much like the emotions they experienced when their child was *initially diagnosed*.
- Due to the seemingly infinite number of developmental milestones (e.g., *physical/motor, cognitive, educational, social/emotional, communication/speech, language-related*, etc), parents of children diagnosed with ASD may repeatedly experience similar emotions → ***continuous grieving***



## **Events that trigger grieving:**

A variety of events appear to trigger continuous grieving:

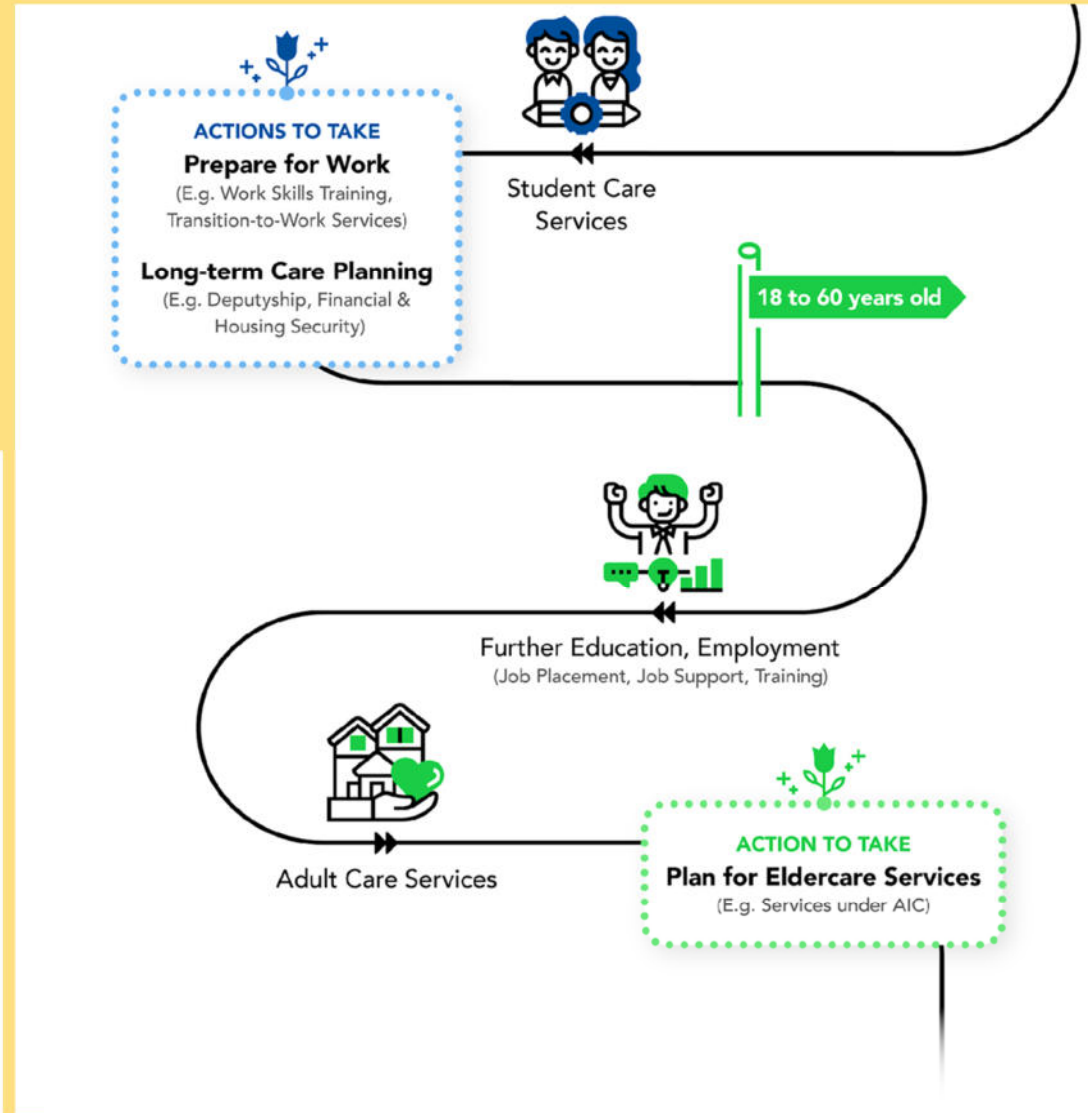
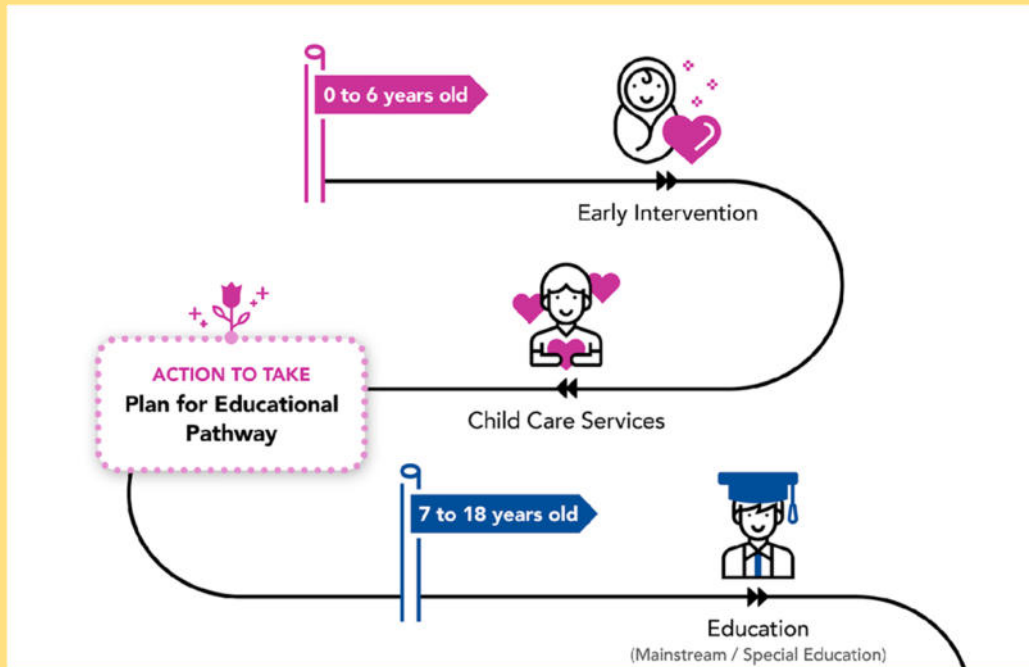
- ***The child's health or behaviour issues.***
- ***The child's developmental milestones or age-appropriate expectations for the child.***
- ***Family issues and relationships.***
- ***Old aged parents and retirement concerns.***
- ***Unusual/challenging caretaking demands.***
- ***Professional and programmatic issues (i.e., school and medical).***
- ***Society's lack of understanding and sensitivity;***
- ***Even seemingly insignificant events.***



## Family resilience

- In spite of all this, some family members show signs of *resilience* and recognize they have also gained from this experience. Resilience becomes a *fundamental element* for *coping* with the problems these families have .
- It is very helpful to *encourage* family members to listen, express their opinions and needs *freely*, seek *support* from their *community* and/or *loved ones*, and use constructive problem-solving strategies. These findings are consistent with *Walsh's theory of family resilience* . This theory states that *individual resilience is connected to the resilience of the whole family, which is the positive adaptation to a significant adversity.*

# Challenges that may trigger grief across the life span





## REFERENCES :

1. Baron-Cohen S., Chaparro S. *Autismo y Síndrome de Asperger*. Alianza Editorial; Madrid, Spain: 2010.
2. [Organización Mundial de la Salud \(OMS\)](#)
3. Mansell W., Morris K. A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. *Autism*. 2004;**8**:387–407. doi: 10.1177/1362361304045213.
4. Ozgul S. Parental grief and serious mental illness: A narrative. *Aust. N. Z. J. Fam.* 2004;25:183–187. doi: 10.1002/j.1467-8438.2004.tb00616.x.
5. Gardiner E., Mâsse L.C., Iarocci G. A psychometric study of the Family Resilience Assessment Scale among families of children with autism spectrum disorder. *Health Qual. Life Outcomes*. 2019;17:45. doi: 10.1186/s12955-019-1117-x.
6. Walsh F. Family resilience: A framework for clinical practice. *Fam. Process*. 2003;42:1–18. doi: 10.1111/j.1545-5300.2003.00001.x.
7. Bhana A., Bachoo S. The determinants of family resilience among families in low-and middle-income contexts: A systematic literature review. *S. Afr. J. Psychol.* 2011;41:131–139. doi: 10.1177/008124631104100202.
8. Hawley D.R. Clinical implications of family resilience. *Am. J. Fam. Ther.* 2000;28:101–116. doi: 10.1080/019261800261699.
9. Rutter M. Resilience concepts and findings: Implications for family therapy. *J. Fam. Ther.* 1999;21:119–144. doi: 10.1111/1467-6427.00108.

Co-funded by the  
Erasmus+ Programme  
of the European Union



# THANK YOU!

*Dr. Ntre Vassiliki , Psychiatric Nurse - Health Visitor of  
Children and Adolescents , "Aghia Sophia" Children's  
Hospital, Athens, Greece  
Mail: [vassilikintre@yahoo.gr](mailto:vassilikintre@yahoo.gr)*



# Interactive material

- <https://www.parents.com/health/autism/mom-receives-autism-diagnosis-along-with-her-3-children-it-was-life-changing-in-a-good-way/>
- <https://www.superherome.sg/>
- [Life Stages & Transitions - Disability Info | Enabling Guide](#)