



ACTIVITY HANDOUT: CASE STUDIES – A (ANSWERS)

[MODULE 1: Understanding Disability and Inclusion]

As you read each case study:

- Underline any contextual factors that could negatively impact the infant's life
- Circle any contextual factors that could positively impact the infant's life

Then, discuss the following questions:

- What is the context in which each infant lives?
- How might this context impact their experiences of disability and participation in everyday life, in a positive or negative way?

The two case studies highlight the profound impact of environmental and personal factors on the experiences of two infants with Down syndrome. While Maya benefits from a supportive family and community and better access to resources, Rami faces significant barriers to his growth and development due to his family's socioeconomic challenges, stigma, and poor access to services and support. The contrast between Maya and Rami underscores how a person's impairment may be more disabling or less disabling depending on the context in which they live.

Case Scenario 1

Maya is a 5-month-old infant with Down syndrome living in a rural village in northern Lebanon. Her father works as a farmer and her mother stays at home with her. Maya has low muscle tone, which makes breastfeeding difficult.

Maya's diagnosis came as a shock to her parents, who had limited awareness of Down syndrome and were initially uncertain about how to care for. Access to specialized services in their area is limited and traveling to the nearest specialist requires significant time and cost. A local NGO working with families of children with disabilities connected them with a local community health worker who provided basic guidance on feeding and early stimulation.

Recently, Maya's mother joined a parent support group organized by the NGO. Maya's grandmother, who lives nearby, is now actively involved in her care. She loves making Maya handmade toys.

While Maya does not have access to specialized services, her family is committed to making sure she has opportunities to progress in her development.

Environmental factors:

- Limited access to specialized services in the rural village.
- + Presence of a local community health worker offering guidance and support.
- + Involvement in a parent support group, providing additional resources and information.
- + Availability of handmade toys made by Maya's grandmother that may support development.
- + Supportive family dynamics with active involvement from Maya's grandmother.

Personal factors:

- Limited knowledge about Down syndrome initially, leading to uncertainty and stress.
- + Maya's father's job as a farmer, providing financial stability to the family.
- + Maya's mother staying at home, enabling her to provide direct care to Maya.
- + Emotional support from Maya's grandmother, contributing to the family's resilience.
- + Commitment from Maya's family to ensure she receives opportunities for development despite limited access to specialized services.

Case Scenario 2

Rami is a 5-month-old infant with Down syndrome living with his family in a densely-populated, low-income neighborhood on the outskirts of Beirut. His parents moved there with their two other young children in search of better opportunities but struggle to find stable jobs.

Rami has low muscle tone and has struggled with breastfeeding since birth. His father is often away from home for long hours looking for work, leaving Rami's mother without much support. She often places Rami in a playpen for long periods while attending to the needs of her two other young children.

His mother feels overwhelmed by his diagnosis and isolated saying that she often feels judged by her neighbors. Rami's parents are unsure of where to turn for help and rely on sporadic advice from overburdened community health workers who tell them that they have little experience working with infants with Down syndrome.

Despite these challenges, Rami's parents are trying to do their best for him. They are open to connecting with support networks if given the opportunity.

Environmental factors:

- Limited access to resources and healthcare services.
- Absence of Rami's father for long hours reducing support for Rami's mother.
- Recent relocation, which could lead to lack of social support network in the community.
- Limited availability of experienced community health workers familiar with Down syndrome.
- Disability-related stigma from the community.

Personal factors:

- Struggle to find stable jobs, leading to financial instability and stress within the family.
- Overwhelmed mother with two other young children to care for, leading to limited time and attention for Rami's needs.
- Feelings of judgment from neighbors, contributing to the mother's stress and sense of isolation.
- Lack of knowledge about Down syndrome and uncertainty about where to seek appropriate support and resources.
- Past experiences with community health workers who were unable to help.
- + Family's commitment to do their best for Rami and openness to receiving support.