

ACTIVITY HANDOUT: CASE STUDIES – A (ANSWERS)

[MODULE 1: Understanding Disability and Inclusion]

What is the context in which each infant lives? How could 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 Fatima benefits from a supportive family and community and better access to resources, Hamza 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 Fatima and Hamza underscores how a person's impairment may be more disabling or less disabling depending on the context in which they live.

Case Scenario 1

Fatima is a 5-month-old infant with Down syndrome living in a rural village. Her father has a stable job as a farmer and her mother stays at home with her. Fatima experiences low muscle tone that makes breastfeeding difficult and has mild developmental delays.

Fatima's diagnosis of Down syndrome came as a shock to her parents, who had limited knowledge and access to healthcare services. They were initially overwhelmed and uncertain about how to care for her but received guidance and support from a local community health worker. Her mother recently joined a parent support group in her village and brings Fatima with her once a week. Fatima's grandmother, who lives nearby, is now actively involved in her care and provides additional emotional support. She loves making Fatima handmade toys.

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

Environmental factors:

- Limited access to healthcare 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 Fatima's grandmother that may support development.
- + Supportive family dynamics with active involvement from Fatima's grandmother.

Personal factors:

- Limited knowledge about Down syndrome initially, leading to uncertainty and stress.
- + Fatima's father's stable job as a farmer, providing financial stability to the family.
- + Fatima's mother staying at home, enabling her to provide direct care to Fatima.



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- + Emotional support from Fatima's grandmother, contributing to the family's resilience.
- + Commitment from Fatima's family to ensure she receives opportunities for development despite limited access to specialized services.

Case Scenario 2

Hamza is a 5-month-old infant with Down syndrome living in an urban slum in a poor community. His parents moved there with their two other young children in search of better opportunities but struggle to find stable jobs.

Hamza has low muscle tone and has struggled with breastfeeding since his birth. His father is often away from home for long hours looking for work, leaving Hamza's mother without much support. Needing to attend to her two other young children, Hamza's mother leaves him much of the time confined to a playpen. She feels overwhelmed by his diagnosis and isolated saying that she often feels judged by her neighbors.

Hamza'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 no experience working with infants with Down syndrome.

Environmental factors:

- Limited access to resources and healthcare services.
- Absence of Hamza's father for long hours reducing support for Hamza'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 Hamza's needs.
- Feelings of isolation and judgment from neighbors, contributing to the mother's stress and sense of isolation.
- Uncertainty and lack of knowledge about Down syndrome and where to seek appropriate support and resources.
- Past experiences with community health workers who were unable to help.