

ACTIVITY HANDOUT: CASE STUDIES – A

[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?

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.

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.