

Learning Activity:

| LEARNING OBJECTIVES | EXPANDED CONTENT OUTLINE |
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| <p>The learner will be able to describe factors that led parents to seek answers from a health care provider.</p> | <p>I. Pre–diagnostic experiences</p> <p>a. Condition specific factors</p> <p>i. Challenging behaviors, including displays of defiance and anger</p> <p>ii. Lack of cooperation, including defiant refusals, resistance and insistence</p> <p>iii. Communication, including use of unusual words and methods of talking</p> <p>Unusual eating habits, including obsessive interests and dislikes</p> <p>iv. Developmental delays, including walking, talking and communication</p> <p>v. Unusual patterns of walking and/or crawling</p> <p>vi. Perseveration, including repetitive words, bits of communication, actions and interests</p> <p>vii. Transition issues: activities, clothing, food, bed, adulthood</p> <p>viii. Challenging sleep patterns, including short sleep, heavy sleep, early rising, vivid dreams, sleep talking and sleep walking</p> <p>ix. Unusual patterns of food preference and eating</p> <p>x. Unusual difficulty with potty training and bathroom use</p> <p>xi. Sensory issues: sound, light, clothing, food</p> <p>xii. Negative attitudes, including negative feeling about self, activities and others</p> <p>xiii. Poor hygiene/excessive hygiene</p> <p>xiv. Resistance to college or job</p> <p>xv. Resist closeness, including nursing, being held close, and being hugged</p> <p>xvi. Poor socialization, isolated play, poor playing skills with other children</p> <p>b. Physical and social environment</p> <p>i. Parental and child criticism from family, extended family and friends</p> <p>ii. Concerns from day care and school; removal from day care; removal from school</p> <p>c. Individual and family factors</p> <p>i. Fathers resist acknowledging unusual behaviors</p> <p>ii. Mothers push for diagnosis, then resist acceptance of the diagnosis</p> <p>iii. Divorce/separation is common when fathers continue to resist seeking help</p> <p>d. Capacity to self-manage</p> <p>i. Mothers overwhelmed and stressed</p> <p>ii. Mothers fatigued</p> |
| <p>The learner will be able to describe factors that affected parental access to a diagnosis for their children with ASD</p> | <p>II. Diagnosis</p> <p>a. Physical and social environment</p> <p>i. Health care providers</p> <p>ii. Communication challenges</p> <p>iii. Stigma, including claims of poor parenting and lack of discipline</p> <p>iv. Geographical availability and access</p> <p>b. Condition-specific factors</p> <p>i. Higher function children – later diagnosis</p> <p>ii. Lower functioning children – earlier diagnosis</p> <p>iii. Comorbid conditions diagnoses often delayed ASD diagnosis</p> <p>iv. Earlier diagnosis</p> <p>v. AA moms</p> <p>vi. Parents in HC</p> <p>vii. Later diagnosis - rural</p> <p>c. Individual and family factors</p> <p>i. Although participants were highly educated, they struggled accessing diagnosis for their child</p> <p>ii. AA mothers “pray on it”</p> <p>iii. Mothers not wanting to “claim it” or “speak it into real”</p> <p>iv. Fathers resist acknowledging diagnosis</p> |

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| <p>The learner will be able to describe factors that affect access to services for their children with ASD</p> | <p>III. Access to services</p> <p>a. Condition specific factors</p> <p>i. Medication side effects</p> <p>ii. Discontinue medications</p> <p>iii. Difficulty managing comorbid conditions</p> <p>iv. Adult children resist services</p> <p>v. Children resistive to services</p> <p>b. Physical and social environment</p> <p>i. Difficulty communicating and connecting with HCP</p> <p>ii. Services do not meet the needs of parents</p> <p>iii. Services not available to meet needs of parent/child</p> <p>c. Individual and family factors</p> <p>i. AA mothers do not want their children to be 'double different'</p> <p>ii. All mothers were proactive and protective in seeking services and care for their child – AA mothers were particularly protective, wanting to ensure their child was treated fairly</p> <p>iii. Fathers typically resistive to services, won't talk about it, won't acknowledge it, focus on other children and work, ignore child</p> <p>iv. Fathers typically mourn loss of activities with child, try to force sports, force high performance in sports</p> <p>v. Mothers leave job to care for child</p> <p>d. Capacity to self-manage</p> <p>i. Parents fatigued</p> <p>ii. Parents overwhelmed</p> |
| <p>The learner will be able to identify challenges and implications related to facilitating early diagnosis and entry into ASD-related services</p> | <p>IV. Implications for nursing – referrals and information</p> <p>a. Parent support and networking</p> <p>i. Children resist school and jobs – navigating DVR</p> <p>ii. Menstruation</p> <p>iii. Negative attitude</p> <p>iv. Socialization/screen use</p> <p>v. Health care management</p> <p>vi. Child – Managing procedures</p> <p>vii. Managing chronic HC conditions</p> <p>viii. Adult children –</p> <p>ix. Accepting diagnosis</p> <p>x. Managing chronic conditions</p> <p>b. Parent education</p> <p>i. Transition – school/graduation</p> <p>ii. Violence</p> <p>iii. Coping skills</p> <p>c. Professional, legal and government services</p> <p>i. Guardianship</p> <p>ii. Finances</p> <p>iii. Respite</p> <p>iv. Medical insurance companies (payment for ABA)</p> <p>v. Driving</p> <p>vi. Independent living arrangements</p> |