Focusing on Now for Tomorrow: Using A Well-Rounded Curriculum to Strengthen Students with Usher Syndrome

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ISSUE

• Diagnosis without educational and psychosocial support

• Schools for the deaf have expertise in hearing loss but not eye diseases associated with vision loss
THEMATIC PROBLEM

• Great improvements in the area of US screening, but no curricula available for post-diagnosis

• Educators and related service providers are left to access scattered resources
APPROACH

• Design a multi-year Usher Syndrome Support Group curriculum that addresses all aspects of young adult life, specifically related to Usher Syndrome
• Identify outcome and performance indicators:
  • Understands the impact of his/her vision and hearing loss, specific to etiology
  • Identifies with his/her community and culture
  • Self-advocates for preferred accommodations (e.g., communication, alternate print media, orientation and mobility)
  • Understands age-appropriate service delivery systems, and how to access these systems
APPROACH

• Apply adult learning theory principles by way of various presentation media throughout to maintain student interest
  • Articles on age-appropriate content related to Usher Syndrome
  • Guest presenters with expertise in deaf-blindness
  • Session focused on group activities, less on lecture
  • Connection to community members via videophone
BEST PRACTICES

• Family engagement & education is critical

• Engaging in a transdisciplinary approach:
  — Follow-up & on-going support from counselor, Teacher of the Visually Impaired & Orientation & Mobility Specialist, where necessary
UNANTICIPATED OUTCOMES

• Content sections often took double, and sometimes, triple, the amount of allotted time to complete

• Self-reported change of knowledge across all content areas

• After two years group therapy phased out into individualized therapy, where needed

• Usher Syndrome Social for students and families was established

• Partnership across several schools for the deaf
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