

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

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# ISSUE

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- 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

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- 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

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- Design a multi-year Usher Syndrome Support Group curriculum that addresses all aspects of young adult life, specifically related to Usher Syndrome

# APPROACH

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- 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

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- 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

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- 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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