

Poster

Title: Aspects of learning in deafblindness - opportunities and limitations for persons with Alström syndrome

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Main focus: Both research and practice/Both congenital and acquired deafblindness

Purpose: The aim was to explore aspects of learning, from a lifelong perspective, in individuals with Alström syndrome (AS). AS is an autosomal recessive disorder causing early blindness, progressive sensorineural hearing loss, cardiomyopathy, endocrine disorders, metabolic dysfunction, and abbreviated lifespan.

Method: Eleven individuals with AS participated. The study had a qualitative explorative design, giving voice to the participants' perspectives on their situation. Data were collected using semi-structured interviews, which were subjected to conventional (inductive) qualitative content analysis.

Results: The analysis revealed in the participants a quest for independence and an image of themselves as capable people willing to learn, but in constant need of support to continue learning throughout their lives to be as independent as possible.

Conclusion: Based on the levels of functioning, i.e. personal resources, revealed in the interviews, supervisors, caregivers, and teachers are encouraged to allow people with AS to be their own advocates, as they know best how, what, and with whom they learn, and what type of sensory material – tactile, auditory, visual, or a combination – is most helpful.