

Community Engagement Studio for Adults with Autism Spectrum Disorder



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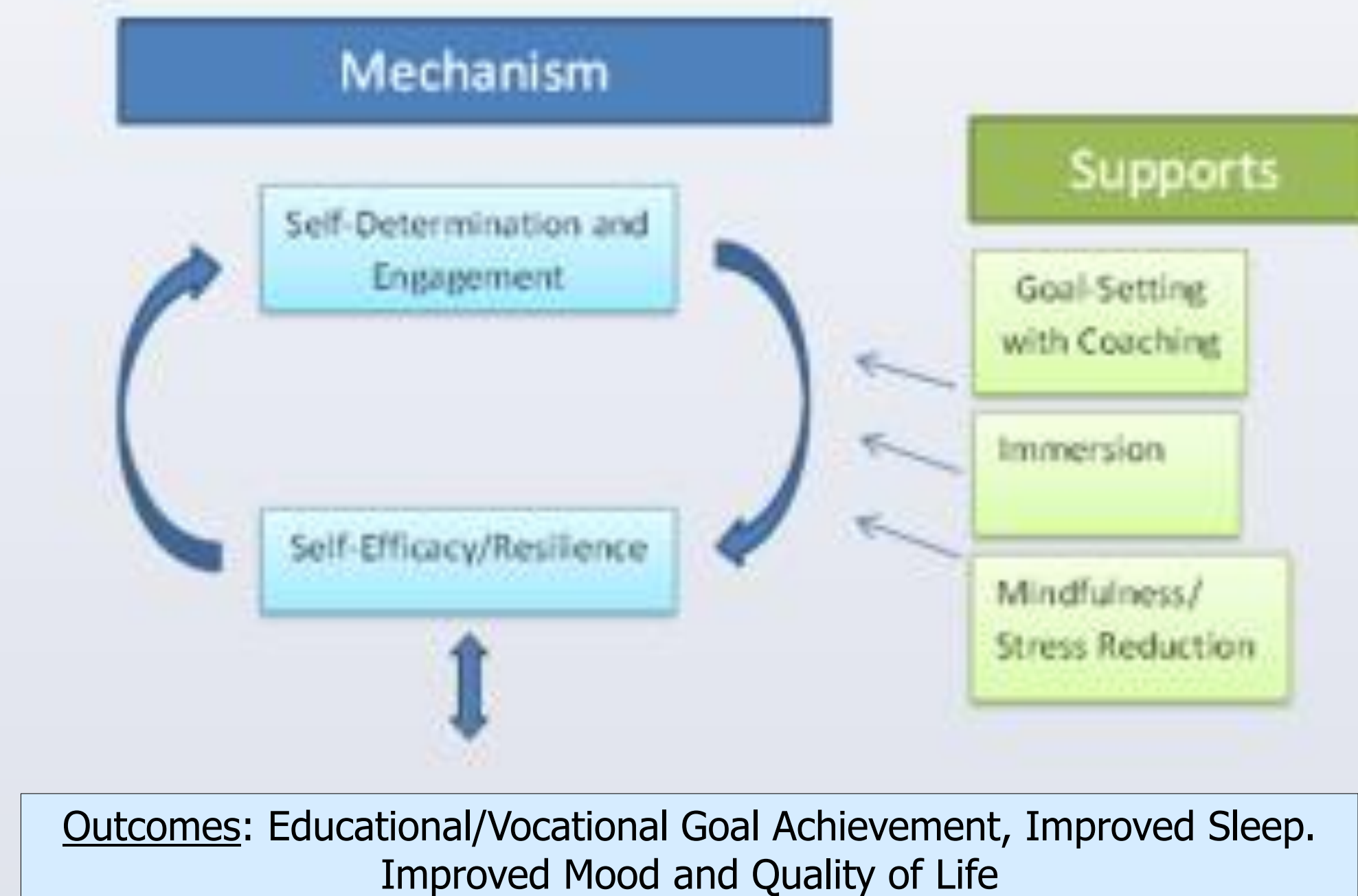
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Introduction

- Community Engagement Studios (CESs) are consultative sessions that provide project-specific input to researchers from patients, parents, caregivers, and other stakeholders.
- CESs were developed at Vanderbilt University Medical Center and supported by the Vanderbilt Institute for Clinical and Translational Research (VICTR).
- We describe our experiences with a CES focused on adults with autism spectrum disorder, conducted to obtain input regarding program content and ways to refine Spectrum Pathways, a novel multi-component self-determination program for adults with ASD.
- Spectrum Pathways consists of a five-day in-person immersive experience followed by three months of weekly coaching phone calls with Vanderbilt University students. Adults with ASD learn to set goals and are also exposed to supports such as mindfulness/stress reduction and conflict resolution.
- Goal of CES: Obtain input from stakeholders on ideas for increasing access to Spectrum Pathways Two-hour session was conducted.
- Stakeholders: Six adults with ASD (with and without prior experience with Spectrum Pathways) + one parent of an adult with ASD. Stakeholders were compensated with a gift card and dinner and parking was provided.

Spectrum Pathways Model



Conclusions

- Our CES was the first of its kind at Vanderbilt to focus on adults on the autism spectrum.
- It provided a vehicle to receive valuable stakeholder feedback as we plan future directions for our program.
- Obtaining this stakeholder feedback is consistent with the spirit of Spectrum Pathways, which emphasizes self-determination, inclusiveness, and respect for those with disabilities whom we serve.
- The CES model is applicable to a wide range of disabilities, and we welcome your questions.

Lessons Learned from CES

- Spectrum Pathways was valuable to participants in terms of promoting self-determination, health and well-being, and improved social interactions and sleep patterns.
Spectrum Pathways boosted my confidence and made me feel like a person
- The 5-day in-person immersive experience was identified as a major factor limiting access. Those in college or full-time jobs were not able to participate.
- Computer-based instruction was brought up as an effective way to reach more adults. Viewing modules was considered a way to “cement” the learning experience.
There could be modules at lunch hours and meetings on weekends.
- Need for ongoing social interactions (group outings or video-conferencing get-togethers) was emphasized.
- Parent involvement was viewed as important (by both adults with ASD and the participating parent) especially the need for parents to learn to “let go” and embrace “the dignity of risk.”

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