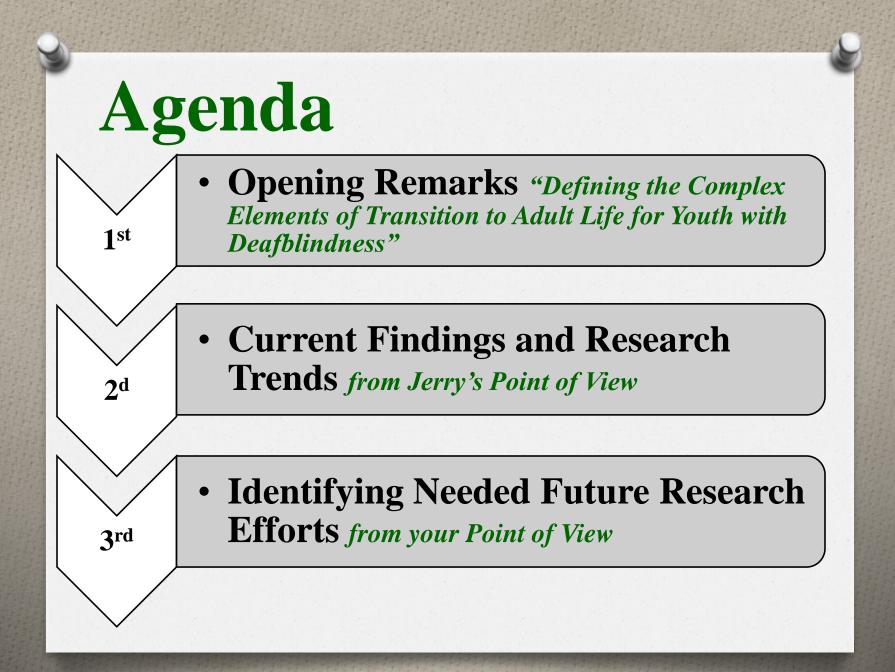
Transition from School to Quality Adult Life

"Research Efforts in Transition Planning, Programming & Outcomes"





Opening Remarks "Defining the Complex Elements of Transition to Adult Life for Youth with Deafblindness"

"When one door of happiness closes, another opens; but often we look so long at the closed door that we do not see the one which has been opened for us."

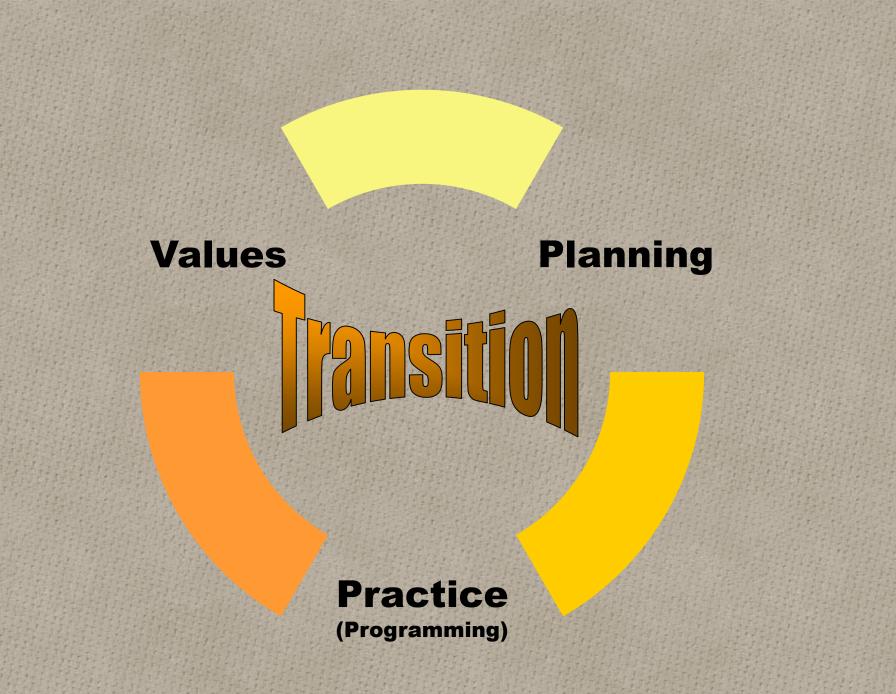
(Helen Keller)

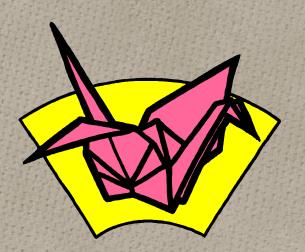


Transition Planning

and compatible

Educational Programs and Services





Origami Activity

Lessons in Making Transitions

It's not easy!

It's difficult to get it perfect, if not impossible.

It's easier with help.

It looks different each time.

You need the right kind of paper (resources).

Some are more difficult to make than others.

It takes time!

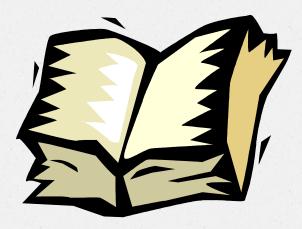
You need the directions.

| | NOW | 21-23 | 24-26 |
|-------------------------------------------------------------------|-----|-------|-------|
| Where & How will your the youth live? | | | |
| Where & How will your youth have fun and with whom? | | | |
| Where & How will your youth be employed or volunteer? | | | |
| What role will the youth play in the family and in the community? | | | |

Lessons Learned

Transition to Adult Life for Youth with Deafblindness

Jason's Story



.... The story that inspired and began my interest in Transition to Adult Life for Youth with Deafblindness Stories that inspired my interest in helping youth with deafblindness to live quality lives . . .

Jason
Miguel
Timmy
Sean











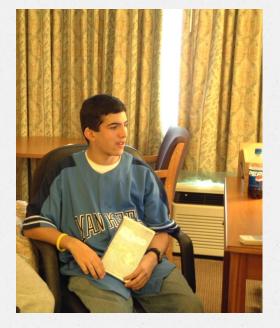
Miguel's Story

It is critical that are young people define themselves and are represented by who they are as individuals rather than being defined by their limitations or by others.



Fimmy's Story

You need to find the right environment, combination of supports and keys to assure a successful transition to adult life.



Span's Story



Make sure that the people you are talking to and working with . . are listening closely



Beliefs and Assumptions regarding the Transition and Post-School Lives of Youth with Disabilities

- All students should leave school equipped to be successful, interdependent adults.
- Adult Life is more than work and care.
- All students can and have the right to become adult citizens of their community.
- Each student's voice must guide the transition process.
- Families are a critical component to the planning and success of any youth's transition from school to adult life.
- Each family has its own unique culture that must be respected as factor in the planning and support of youth in transition.
- Quality of life is defined by the individual.

Current Findings and Research Trends *from Jerry's Point of View*

Approaches to the **Transition to Post-School Life** for Youth with Deafblindness

Transition Planning and Associated Practices for Youth with Disabilities continues to promote practices that are replete in the literature yet reflect a range of levels of evidence by CEEDAR Standards. These practices have been the basis of transition planning and programming for youth with deafblindness and include:

- Person-Centered / Futures Planning
- Development of Self-Determination & Skills of Self-Advocacy
- Community-Based Instruction (e.g. jobs, transportation, etc.)
- Support for Social Network Development
- Career Development and Work Experiences
- Youth and Family Involvement
- Direct Instruction in Career Development (Vocational Education), and Independent Living
- Community-Based Instruction including Work Experiences (while in Secondary Education)
- Opportunities for inclusion with peers without disabilities
- Interagency Involvement and Collaboration

However...

Most of these generic transition practices used for youth with deafblindness do not reflect specific evidence regarding youth with deafblindness or reflect the basic "emerging" evidence within a few studies in the literature. (CEEDAR Standard)

Transition to Adult Life – Sample Research

Person-Centered Planning

Halle, J.W. & Lowrey, K. A. (2002). Can person-centered planning b e empirically analyzed to the satisfaction of all stakeholders? Research & Practice for Persons with Severe Disabilities. Vol 27 (1) 268-271.

Self-Determination (EMERGING)

Haakma, I., Janssen, M., & Minnaert, A. (2017). Intervening to Improve Teachers' Need-supportive Behaviour Using Self-Determination Theory: Its Effects on Teachers and on the Motivation of Students with Deafblindness. International Journal Of Disability, Development & Education, 64(3), 310-327. doi:10.1080/1034912X.2016.1213376

Bruce, S.M., Zatta, M.C., Gavin, M. & Stelzer, S., (2016). Socialization and Self-Determination in Different-Age Dyads of Students Who Are Deafblind. Journal of Visual Impairment & Blindness, May-June. AFB.

Transition to Adult Life – Sample Research

Social Network Development (EMERGING)

Arndt, K., & Parker, A. (2016). Perceptions of social networks by adults who are deafblind. *American Annals of the Deaf*, *161*(3), 369–383.

Post-Secondary Education (EMERGING)

Wolsey, J. A. (2017). Perspectives and Experiences of DeafBlind College Students. The Qualitative Report, 22(8), 2066-2089. Retrieved from <u>http://nsuworks.nova.edu/tqr/vol22/iss8/1</u>

Transition Planning (EMERGING)

Lieberman, L. J., Kirk, T. N., & Haegele, J. A. (2018). Physical Education and Transition Planning Experiences Relating to Recreation among Adults Who Are Deafblind: A Recall Analysis. Journal Of Visual Impairment & Blindness, 112(1), 73-86.af

A Transition Follow-Up Study of Youth Identified as Deafblind in the United States

"An Ongoing Research Project Spanning Nearly Two Decades" 1999 - 2004 - 2007 - 2010 - <u>2017</u>

Jerry G. Petroff, PhD & Nadya Pancsofar, PhD

Why are post-school studies important?

It seems important to examine the lives of young adults with deafblindness for the purposes of . . .

- Assuring that these young adults are living <u>quality lives</u> with appropriate access to continued education, employment, housing, social networks, etc.;
- Identifying if educational practices & experiences are yielding the outcomes expected;
- Validate indicators that may support successful adult lives; and
- Identifying other variables or unexpected trends that may need to be addressed.

A Transition Follow-Up Study of Youth Identified as Deafblind in the United States <u>OVERALL GOAL</u>

What is the status of young adults with deafblindness who have left high school? and

What are the factors that promote youth with deafblindness to transition from school to successful adult lives within their communities?

Parameters & Design of the Study

103 Question Survey

Individuals Characteristics

Attributes of Secondary Education

Post-School Lives

Historical and Research Context

- No Prior Data*First National Survey Study was conducted
- Written for parents and guardians to complete

Prior to 1998-1999

2004-2010

- A pilot study and a few years later a full launch of the Survey
- Adding young adults to those completing the survey

• A full launch of the Survey with modifications to assure that young adults could complete it themselves.

2017

* with the Exception of a Small Michigan Study

Past Highlights (Descriptive ONLY)

1998-1999

- The majority of students did not received adequate transition planning; and when they did majority didn't begin until one year prior to school exit;
- Only a small percentage of youth and their families were involved in person-centered planning;
- A very few number of students received community based experiences (vocational or otherwise)
- No youth were reported as having friends outside of people being paid or family.

2004 - 2010

- Improvement in secondary educational experience
- Trending improvement in employment outcomes, however, remaining low
- Youth remain primarily living with their parents but trending toward having friends and a social network
- Transition planning is much more deliberate yet does not seem to be yielding the desired results.

LIMITATIONS Up-Front

- The combination of low incidence and high variability has contributed to the problem of gathering reliable and detailed descriptive information that can be further analyzed with correlations;
- With exception of the first study, the difficulty in the number of surveys completed has resulted in fairly low numbers which is further complicated by a less than accurate accounting of how many young adults are in the population; and

Current Findings and Data Trends

Post-School Outcomes of Youth with Deafblindness in the United States *"Building Further Understandings for Future Practice"* 2017 - 2018

Participants completed a survey adapted from the 1998 National Post-School Study of Youth with Deaf-Blindness (Petroff, 1999).

- Surveys were distributed to parents, deafblind project staff, Helen Keller National Center Representatives, and young adults with deaf blindness, ages 18-35 who reside in the United States. Surveys were completed for youth residing in 24 different states.
- Due to the large data set that has been generated, data continues to be abstracted and analyzed within subsets and correlational statistics.

Demographic Results . . .

This survey collected <u>demographic data</u>, along with data describing the young adults' characteristics, high school curriculum and experiences with transition planning, as well as students' current experiences with housing, employment and higher education, and social experiences, including friendships and social media:

□ Surveys were completed by 93 participants.

 \Box The average age of youth in this study was 24.5 years.

Out of the 93 participants, 61 identified themselves as White (73.5%), 9 identified as African American (10.8%), 8 identified as Hispanic (9.6%), 2 identified as Asian American (2.4%), and 3 identified as Other (3.6%).

Out of the 93 participants, 92% were from families in which English was their first language.

Many participants reported their community as Suburban (n=43; 52.4%), while a smaller number reported living in Urban (n=22; 26.8%) and Rural (n=17; 20.7%) communities.

Descriptive Results . . .

The following is a <u>selection of descriptive data</u> yielded from this current 2017 Study in the following areas:

□ Characteristics

□ Secondary Education Experiences

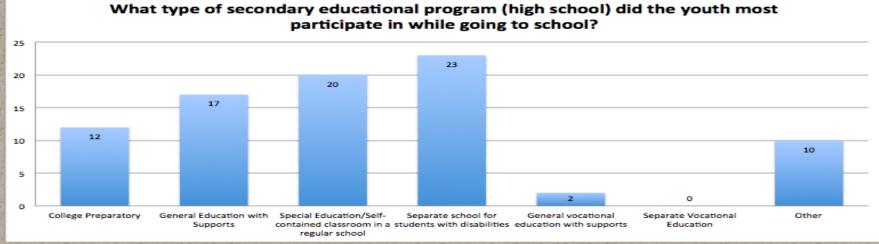
Post-School Lives

Characteristics

Consistent with past survey data, the characteristics of youth with deafblindness that participated in this study reflected a somewhat polarized grouping as measured by:

- □ Skills of Communication
- Reading Levels
- Mathematical Competency
- Degree of General Knowledge
- Problem-Solving Ability

Secondary Education (High School)

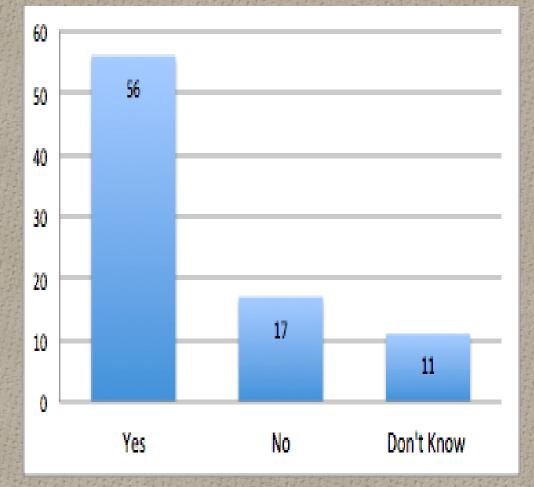


| Item College Preparatory* | |
|--------------------------------------------------------------------|-----|
| | |
| General Vocational Education w/ Supports* | |
| Special Education / Self-Contained Classroom in Typical HS School* | |
| Separate School for Students w/ Disabilities | |
| Other | 12% |

* Includes Schools for the Deaf and Schools for the Blind

Secondary Education (Transition Planning)

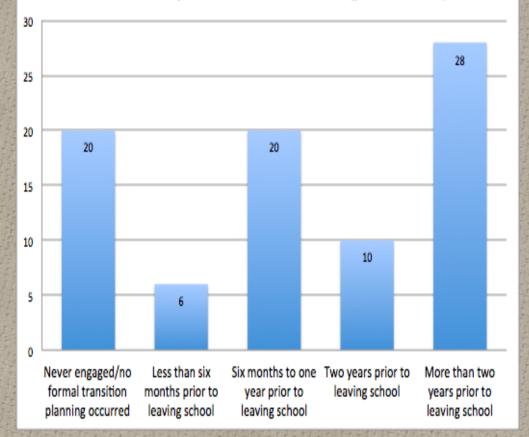
Did the youth have a written transition plan?



| Item | % |
|------------|-----|
| YES | 67% |
| NO | 20% |
| Don't Know | 13% |

Secondary Education (Transition Planning)

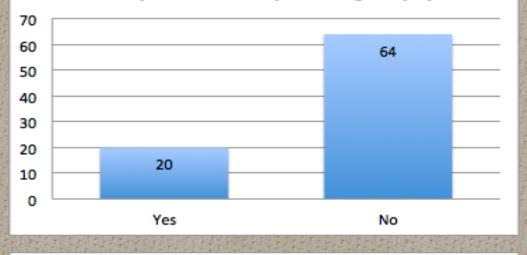
When did you engage in formal planning with the school regarding the transition of the youth from school to adult life (post- school life)?



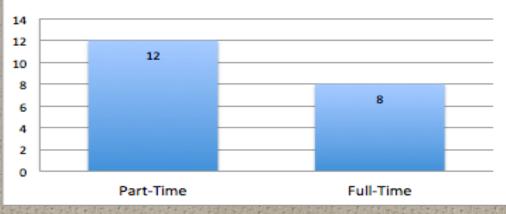
| Item | % |
|--------------------------|-----|
| Never Engaged | 33% |
| Less than 6 months prior | 7% |
| 6 months to 1 year Prior | 24% |
| 2 years | 12% |
| More than 2 years prior | 24% |

Post-School Lives (Employment)

Is the youth currently working for pay?

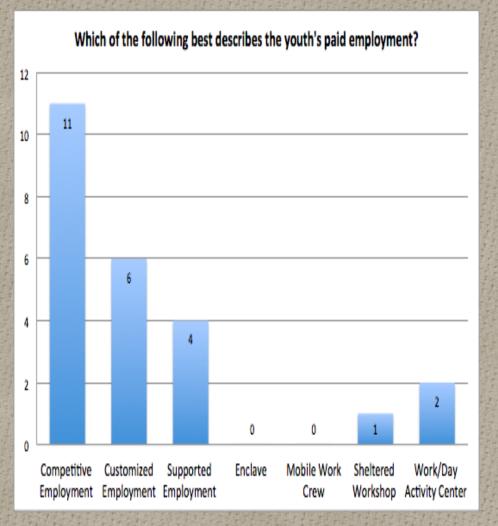


Does the youth usually work part-time or fulltime?



| Item | % |
|---------------------|-----|
| Working for Pay | 24% |
| Not Working for Pay | 76% |
| Working Full-Time | 40% |
| Working Part-Time | 60% |

Post-School Lives (Employment)



| Item | % |
|--------------------------|-----|
| Competitive Employment | 46% |
| Customized Employment | 25% |
| Supported Employment | 17% |
| Enclave | 0% |
| Mobile Crew | 0% |
| Sheltered Workshop | 4% |
| Work/Day Activity Center | 8%* |

N = 24

* Not Considered Work

Post-School Lives (Reasons for Not Being Employed)

| Item | % |
|---------------------------------------------------------------|-----|
| Lack of Initiative / doesn't appear to want to work | 11% |
| Lack of jobs in the area | 22% |
| Don't want wages to impact on social security benefits | 8% |
| Lack of on-going supports | 28% |
| Not able to work because of health | 16% |
| Placed on waiting list for sheltered employment | 3% |
| Placed on a waiting list for supported work services | 3% |
| No transportation available | 14% |
| No one to help find a job | 14% |
| Lack of job training programs | 19% |
| Lack of / Underdeveloped job skills | 34% |
| Parent / guardian or other does not want him/her/they to work | 2% |
| Employment is an unrealistic goal | 27% |
| Lack of Support Services | 27% |

N= 64

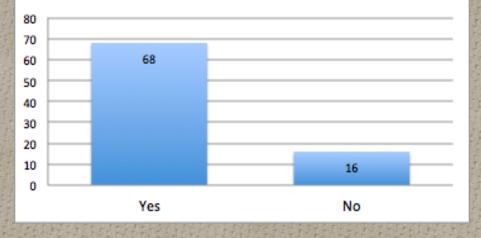
Post-School Lives (Living Situation)

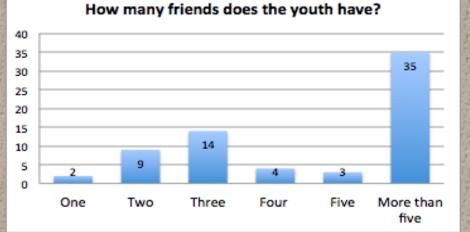
Which best describes the youth's current living arrangement?

| Item | % |
|---------------------------------------------|-----|
| At home with parent | 64% |
| At home with other family member | 2% |
| Living alone independently | 4% |
| Living alone w/spouse, partner, or roommate | 13% |
| Supportive living/ semi-independent | 7% |
| Foster home | 0% |
| Nursing home | 0% |
| Residential school / college | 5% |
| Public institution | 1% |
| Private institution | 0% |
| Other | 4% |

Post-School Lives (Friends)

Does the youth have friends other than family members or paid people (Service Providers)?





| Item | % |
|------------------------|-----|
| Has friends | 81% |
| Does not have friends | 19% |
| | |
| One friend | %3 |
| Two friends | 13% |
| Three friends | 21% |
| Four friends | 6% |
| Five friends | 5% |
| More than five friends | 52% |

N= 84

Correlational Analysis NO SURPRISE HERE

- Youth who demonstrated higher skills in the areas of reading were significantly more likely to be living independently (r = 0.27, p = 0.017), working for pay (r = 0.35, p = 0.002), and experiencing friendships (r = 0.35, p = 0.002).
- Youth who demonstrated higher problem-solving skills were significantly more likely to be living independently (r = 0.30, p = 0.006), working for pay (r = 0.30, p = 0.007), and experiencing friendships (r = 0.40, p < 0.0001).
- Youth who were in inclusive high school settings were significantly more likely to be living independently (r = 0.26, p = 0.021), working for pay (r = 0.33, p = 0.003), and experiencing friendships (r = 0.26, p = 0.018).
- The outcomes are much different for youth whose overall skills are not as advanced, as those youth are less likely to have access to general education settings and curriculum, and less likely to experience independently living, paid employment, or friendships.

Correlational Analysis A BIG SURPRISE

There were no findings of no significant correlation between **transition planning** and any **post-school outcomes**!

What does this mean?

Important to note . . .

General results from post-school studies of youth with deafblindness, indicate that these practices need additional research as it applies to youth with deafblindness, as evidenced by such findings as . . .

Transition planning for these youth with deafblindness was not significantly associated with their post-school outcomes.(Petroff, Pancsofar, & Shaaban, 2018) EMERGING – LIMITED

Youth with deafblindness who were educated within inclusive settings and had access to the general education curriculum were significantly more likely to be living independently, working for pay, and having friendships. (Petroff, Pancsofar, & Shaaban, 2018) EMERGING – LIMITED

Parent expectations, paid work experiences, and vocational education services are relevant and applicable to youth with deaf- blindness and should be infused into educational and transition services. (Cmar, 2017) EMERGING - LIMITED

Identifying Needed Future Research Efforts from your Point of View

Future Research Directions

- Conduct Qualitative Study / Studies possibly within a Mixed Research Design to further identify details of the post-school lives of youth with deafblindness
- Consider conducting separate research initiatives with youth who are demonstrating academic skill and age-appropriate language AND youth who are using emerging communication / literacy skills and significantly below developmental levels for problem-solving, academic skills and functional skills of independence.
- Design specialized person-centered planning protocols that will yield adult life outcomes with an emphasis on detailed action planning and on-going evaluation.
- □ Examine the effects of transition planning and associated programming that begins much earlier than 14-16 years of age; and develop more robust efforts
- Develop evidence that a focus on social network development, recreation/entertainment and community involvement will result in better employment and living outcomes for youth with deafblindness.

Future Research Directions

Lastly, are the experiences of American Youth with Deafblindness as presented in this study, similar to those in other parts of the world?

Time to Generate Future Research Ideas



1) With those around you, discuss research initiatives that would be relevant to your country / culture that address the MOVEMENT to ADULTHOOD;

 Pick 1 or 2 ideas – Outline the Idea(s) on Chart Paper to share with the Entire Group.



Future Areas of Highest Need in Transition Planning & Associated Interventions / Support

- □ Continued efforts in Strong-Moderate **Post-School Outcome Studies** that use Mixed Research Designs across the range of heterogeneity within the population of youth who are deafblind
- The study of Person-Centered Planning Protocols using moderate to strong research efforts with an emphasis on Action Planning and Continued Team Support for youth who are deafblind
- Measuring and Actualizing Self-Determination and Autonomy in Youth with Deafblindness
- □ College and Post-Secondary Programs for Students with Deafblindness – Avenues to Engage in Continued Learning and Development through 21 – 25.

"Research is formalized curiosity. It is poking and prying with a purpose."

- Zora Neale Hurston

If anyone is interested in this Research Topic, and would like to engage with me or could use guidance, please complete a Transition Research Form



Thank-You

Jerry G. Petroff, Ph.D. The College of New Jersey petroff@tcnj.edu

References

Arndt, K., & Parker, A. (2016). Perceptions of social networks by adults who are deafblind. *American Annals of the Deaf*, 161(3), 369–383.

Bruce, S.M., Zatta, M.C., Gavin, M. & Stelzer, S., (2016). Socialization and Self-Determination in Different-Age Dyads of Students Who Are Deafblind. Journal of Visual Impairment & Blindness, May-June. AFB.

Cmar,J.L., McDonnall, M.C., & Markoski, K.M. (2017) *In-School Predictors of Post-School Employment for Youth who are Deaf-Blind*. The National Research and Training Center on Blindness and Low Vision Mississippi State University

Haakma, I., Janssen, M., & Minnaert, A. (2017). Intervening to Improve Teachers' Needsupportive Behaviour Using Self-Determination Theory: Its Effects on Teachers and on the Motivation of Students with Deafblindness. *International Journal Of Disability, Development & Education*, 64(3), 310-327. doi:10.1080/1034912X.2016.1213376

Lieberman, L. J., Kirk, T. N., & Haegele, J. A. (2018). Physical Education and Transition Planning Experiences Relating to Recreation among Adults Who Are Deafblind: A Recall Analysis. Journal Of Visual Impairment & Blindness, 112(1), 73-86.af

Petroff, J. G. (1999). A national transition follow-up study of youth identified as deafblind: Parent perspectives. Doctoral Dissertation, Temple University, Philadelphia.

References (Continued)

Petroff, J. G. (2010). A national transition follow-up study of youth with deaf-blindness: Revis ited. *AER Journal: Research and Practice in Visual Impairment and Blindness, 3,* 132–138.

Petroff, J.G., Pancsofar, N. & Shaaban, E. (2019). Post-school outcomes of youth with deafblindness in the United States: Building further understandings for future practice. *Journal of Visual Impairment and Blindness.*

Wolsey, J. A. (2017). Perspectives and Experiences of DeafBlind College Students. The Qualitative Report, 22(8), 2066-2089. Retrieved from http://nsuworks.nova.edu/tqr/vol22/iss8/1

Zatta, M., & McGinnity, B. (2016). An overview of transition planning for students who are deafblind. *American Annals of the Deaf, 161*(4), 474–485.