

The ADARA Update

2018 Issue #4

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Artist's Notes

Cover Page Artwork: "Reach My Hands" By Oliver Jamin

Can you see the hands represented here moving? They serve to remind us that hands are used automatically when greeting each other with a simple handshake for example. The hands are also used simultaneously by the Deaf community as a means of communicating. A hand can be held out when someone is in need or falling, and a helping hand can come to the rescue and save. The colours used are most



familiar within the caveman era centuries ago, when drawings were created on walls of brown and red and yellow. You can also see the 'ghostly' effect of the moving hands which present us with the idea of humans having a soul. See more about the artist on page 15.



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2018, Issue 4

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Editorial Policy: ADARA Update strives to be a conduit for the voice of its members to express their ideas, opinions and share information beneficial to the membership. The views expressed by individual writers and columnists may not reflect that of ADARA as an organization or its Board of Directors.

For more information, or to submit an article/column to this newsletter, or information on how to place an advertisement, please contact Jessica Belwood at:

ADARA 6522 Calm River Way Louisville, KY 40299 office@adara.org

Editor's Notes

Tobias Wilde

I would like to thank Amy Hayes for all the hard work she has done for the ADARA newsletter over the past few years. She has done an amazing job of collecting news worthy articles that inform our members and foster opportunities to share the successes of work being done for the benefit the Deaf Community. We wish her the best in the next chapter of her life. This issue highlighted a presentation from the 2018 ADARA Breakout Conference (on page 11), along with exciting programs from around the country.



Up North: President's Corner John Gournaris

Strategic Planning and Policy Development for National Behavioral Health

Policy for Deaf, DeafBlind and Hard of Hearing: How Do We Get There?

In my previous President's Corner column (July 2018), I asked if we should have a national behavioral health policy for deaf, deafblind and hard of hearing and the answer is resounding **YES**. My next question is how do we get there? Jenkins et al. (2002) believed that strategic planning and policy development are best done on the national level by responsible federal government agencies. That being said, Jenkins et al. (2002) and Bryson (1993) proposed a ten-step model for national strategic planning and behavioral health policy development that we could model after. The steps are listed below:



Step 1 & 2: Deciding on the strategic planning process and identifying stakeholders

Steps one and two are closely aligned with each other, and a list of the interested parties, agencies, and individuals needs to be assembled. These key stakeholders can decide what the planning process will involve, the length of the process required, and how to best utilize the stakeholders. Jenkins et al. (2002) suggested that to recruit stakeholders, we must use different arguments for each key stakeholder. For example, when engaging with federal government officials, one could argue that individuals who are deaf, deafblind, and hard of hearing have a fundamental right to culturally and linguistically affirmative behavioral health services in their home states, and that setting up such a policy will enable them to become productive citizens. It is also imperative to include deaf, deafblind, and hard of hearing consumers in the planning process, as they can share their personal experiences of what is and what is not working well in the current behavioral health delivery system.

Step 3: Identifying mission and values

Stakeholders potentially have a wide range of different ideas on what the provision of behavioral health services should look like for individuals who are deaf, deafblind, and hard of hearing. That being said, no strategic planning and policy development will succeed unless most stakeholders come up with a mission and values that come to a group consensus. It may be necessary to identify stakeholders' key interests as well as their concerns and what they will want from the process. The leadership of this group must strive to take into account the views of both stakeholders and consumers. The overarching goals of public policy for behavioral health for the deaf, deafblind and hard of hearing consumers should include some or all of the elements listed below:

- 1. Reduce the incidence and prevalence of behavioral health disorders
- 2. Develop a continuum of culturally and linguistically affirmative behavioral health services
- 3. Increase the number of qualified ASL-fluent behavioral health clinicians nationwide in response to the current acute shortage
- 4. Promote recovery and reduce stigma
- 5. Protect human rights and dignity of the deaf, deafblind and hard of hearing consumers

Step 4: Utilizing the SWOT analysis

The SWOT analysis can provide an excellent framework for strategic planning and policy development. The list of adapted questions developed by Jenkins et al. (2002) below could be used to guide the SWOT analysis:

Strengths

- Who is committed to the mission and values?
- What are the strengths of current behavioral health services?
- What are the strengths of other relevant services?
- What is the attitude of the federal government?
- What resources are available (money/staff/networks)?

Weaknesses

- Who may be opposed?
- Are there any vulnerability factors?
- What are the weaknesses of the current behavioral health services?
- What are the weaknesses of other relevant services?
- Is the system able to commit and deliver?
- What is missing?

Opportunities

- Who is ready to move forward?
- Is there funding available?
- Is a behavioral health system being reformed/developed that can be tapped into?
- Is awareness increasing?
- Are there enough culturally affirmative clinicians ready to be deployed for services?
- Are there enough trained behavioral health interpreters available?

Threats

- Are other priorities perceived as more important?
- Are budgets being cut?
- Are there any major political changes or changes in appointments within the Mental Health Authority?

Step 5: Pinpointing the key strategic issues

Pinpointing the key strategic issues should become clearer when the SWOT analysis is completed. Bryson (1993) shared that together the first four steps of the process lead to the fifth: the identification of key strategic issues. It can be done by establishing three separate areas or columns. Jenkins et al. (2002) recommended making a full table by using these three columns: *Strategic Area for Action*, *Expected Results*, and *Consequences of Not Acting*. The first column should include important areas that warrant the federal government's attention. The second column should include the desired outcomes, and the third and final column should include consequences of failure to address the issues. The authors believed that this process would pinpoint key strategic issues and priorities, as well as help convince others of the value of the developing a national policy.

Step 6: Formulating the strategy

The Step 6 should include information about timelines, costs, milestones, and targets, as well as evaluations and actions that will lead to either the strategic plan or operational plan. The strategy should flow naturally from the SWOT analysis. It is also important to be realistic, given that deaf, deafblind, and hard of hearing consumers are scattered all over within both urban and rural areas of the United States. Up to seven years may be a realistic period to enact a national policy, and allow for significant changes to happen. A shorter time-scale is likely to be unrealistic, while too long of a time horizon may leave many stakeholders cold, inactive, and cause them to lose interest. It is extremely important to focus on what can be realistically done, not leading with a "can't-do" thinking or attitude which is detrimental to strategic planning and public policy development.

Steps 7 and 8: Adopting the strategy and establishing the vision

It is, without any doubt, much easier to write a strategic plan than it is to have it adopted or implemented, particularly on the federal level. Adoption of a national strategy involves getting necessary approvals from the federal government and key stakeholders, which is no easy task. This whole process will require robust advocacy and solid arguments from all involved parties. It may be necessary to develop separate communication plans to support the overall strategy. The communication plans should include some well-placed individuals to champion the overall strategy at the highest levels within the state and federal governments and other key agencies.

In the same vein, it is also critical to communicate the vision across partner agencies, providers, and consumers. Jenkins et al. (2002) warned that the strategic planning could fail simply because of poor communication and lack of strong vision. It is also possible for some people to become too focused with contentious details that are not essential to the overall vision, which also can be detrimental to strategic planning and public policy development.

Step 9: Implementing the plan

The strategic plan will need to be aligned with an operational plan, or have operational elements embedded within it. The plan needs to describe who does what, by when, and with what resources. Below can serve as examples of implementation strategies (Jenkins et al., 2002):

Communications

- Work with public relations
- · Share information within organizations and stakeholders
- Organize feedback
- Target key partners and alliance building
- Relay the strategies with decision-makers
- · Keep the champions on board
- Publish successes
- Manage setbacks

Resources

- Access key budgets
- · Identify areas of need
- Build capacities
- Secure funding

Embedding the strategy

- Engage organizations, decision-makers, legislators
- Disseminate best practices
- Implement an R&D strategy, including evaluation
- Learn from mistakes and successes and fine-tuning the strategies
- Evaluate programmatic outcomes
- Maintain quality assurance

Step 10: Reassessing the strategy

According to Jenkins et al. (2002), it would be necessary to do a formal review of the strategies, possibly after three to five years. At this stage, there should be some data available to review. Federal government and stakeholders should be working together closely to reassess the strategy. In addition, the key questions to ask at this stage are (Jenkins et al., 2002):

- What are the successes?
- What are the setbacks?
- How can we do more?
- How can we adjust?
- Should we use our resources elsewhere?
- What uncertain areas do we know?
- Should we improve how we evaluate our strategies?

In closing, the federal government needs to make certain that all relevant agencies include deaf, deafblind and hard of hearing consumers in their policies, commit to designate a percentage of available federal grant funds to states in developing and expanding culturally affirmative behavioral health services, and that appropriate coordination between relevant agencies takes place. Obviously, there are no quick fixes to achieve good inter-agency collaboration, but it requires continuous attention for all involved parties and stakeholders, particularly those who are advocating the needs of the deaf, deafblind, and hard of hearing consumers.

ADARAly Yours,

John Gournaris, ADARA President Minnesota Department of Human Services Deaf and Hard of Hearing Services Division Mental Health Program john.gournaris@adara.org

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The Milwaukee Mental Health Task Force is committed to being a leader in identifying issues faced by all people affected by mental illness, facilitating improvements in mental health services, giving consumers and families a strong voice, reducing stigma, and implementing recovery principles.

The Milwaukee Mental Health Task Force *Karen Avery Award September 11, 2018*

The Milwaukee Mental Health Task Force is very pleased to present the fifth *Karen Avery Award* to **Denise Johnson**, in recognition of her outstanding advocacy. The award was established to honor Karen's legacy as an advocate, mentor, peer, and leader in advancing the rights of people with disabilities.

About Denise Johnson

Denise Johnson, BSW, is a Deaf professional working in collaboration with the 8 Independent Living Centers (ILCs) in Wisconsin as the Wisconsin Statewide Project Coordinator of SUD/MH Services for Persons who are Deaf, Hard of Hearing and Deaf-Blind. Denise has dedicated her career to advocating for and with persons with disabilities, and especially those who are deaf, hard of hearing, or deaf-blind and live with a mental illness or substance abuse concerns. Among her many contributions, Denise serves on the Wisconsin State Council on Alcohol and Other Drug Abuse



(SCAODA) Diversity Sub-Committee, is the Vice President of American Deafness and Rehabilitation Association (ADARA) and is the Chair of IndependenceFirst's Deaf Access Consumer Advocacy Team. Denise is one of the co-founding members of Deaf Unity in Wisconsin. She is an active member of the Milwaukee Mental Health Task Force.

The nomination commended Denise's willingness to improve program access and provide education on issues related to substance use and mental health as related to people who are deaf, hard of hearing and/or deafblind, and her tireless work to advocate and assist consumers and professionals in any way that she can.

Karen Avery was Denise's supervisor for 11 years, from the time she began her advocacy work, and a great mentor. In Denise's words, Karen "taught me a lot of things but one important skill that she taught me was to be a strong and stubborn advocate. I became a strong advocate not only in my professional life but the advocacy skills were useful during my personal journey with my two wonderful and beautiful children."

About Karen Avery

Karen Avery was an advocate, a mentor, a peer, friend, and leader in the fight for disability rights, dedicated to giving power and independence to people with disabilities. She began her career as an advocate for fair housing, then joined Independence *First* in 1998 as Associate Director. A respected leader in the mental health consumer/ survivor movement, she worked to advance the rights of people with mental illness and ensure a strong consumer voice. Karen was a founding board member of the Grassroots Empowerment Project and a leader in the Milwaukee Mental Health Task Force. She spoke about the system and



about recovery with such impact, because she lived it. She was generous in sharing the challenges of her experience with mental illness and her recovery journey.

In her work as a leader in the disability movement, as well as to friends and family, Karen set the standard for being "selfless to a fault." She gave everything – her intellect, corny sense of humor, time, attention, empathy, kindness, authenticity, love of family, wonderful laugh, zest for life with a bit of indignation. Karen never wanted to be the center of attention in the public eye, but she was willing to speak truth to power to advance the rights of her peers – and, even more impactful, to mentor and encourage others in finding their voice. She was known for her T-shirts featuring irreverent messages – "Feisty and Non-compliant" was a classic. Karen was also an incredibly loving and caring

Mother and Grandmother, and a treasured friend and mentor to so many.

When Karen passed away in 2013, the disability community lost a champion. The Milwaukee Mental Health Task Force established this award to honor Karen's legacy and her deep commitment to advancing the rights of people with disabilities, and to the mental health consumer movement.

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Call for Nominations for ADARA Board Positions 2019 – 2021

ADARA is calling for nominations for Officers and Board Members for the 2019 – 2021 term. The available positions are:

President-Elect:

The President-Elect shall assume the duties of the President in the latter's absence. In the event the Presidency is vacated, he/she shall assume the office. The President-Elect shall also act as a member of the Bylaws Committee. After serving one term of office as President-Elect, he/she shall serve as President for one term of office.

Vice President:

The Vice President shall submit copies of the proposed agenda to the Executive Board for its review at least 120 days prior to the date of the Conference, and subsequently notify the membership of the approved agenda at least 90 days prior to the Conference.

Secretary:

The Secretary shall be responsible for the transcription of minutes of the business meetings of the Executive Board, at Conferences, and carry on general correspondence of the Association. The Secretary shall also serve as a non-voting member of the Nominations and Elections Committee.

Treasurer:

The Treasurer shall be responsible for the preparation of financial statements of all liabilities and assets for the Association prior to each Executive Board meeting. The Treasurer shall also serve as a permanent member of the ADARA Finance Committee.

Board Member-At-Large (2 positions):

Voting Board members shall be elected to four-year terms, such terms to begin July 1 of the biennial year.

Nominations are accepted from any member of ADARA. All nominees must be members of ADARA in order to be elected.

If you are nominating yourself for any of the board positions mentioned above, please include a statement of interest. If you are nominating someone else, please be sure that the nominee is interested/committed before submitting the nomination.

The deadline for all nominations is February 1, 2019

All nominations must be submitted to Damara Paris, President-Elect via email at damara.paris@adara.org.

Adapting GROW for Deaf and Hard of Hearing families: Utilizing a trauma-informed curriculum developed specifically for families

Andrea Wohl, Frank Adams and Elisa Valles MA Walden Community Services, Framingham, Massachusetts

When present, trauma impacts all members of a family. Those families that include a person that is

Deaf are faced with unique challenges and fewer resources to process this impact; their experience exacerbated by a lack of language access and services equipped to meet their needs. In 2009, Walden Community Services, at The Learning Center for the Deaf in Framingham, Massachusetts, opened its doors to serve families that include both a Deaf member and at least one child with an emotional or behavioral diagnosis. The Deaf member can be either a caregiver or the youth. The hallmark of our program is that we deliver all services in the families' homes and communities.

We have noticed a prevalent pattern of trauma in the families we serve. This pattern has two components. First, these families have often experienced traumatic experiences regarding language oppression. Deaf individuals experience this trauma directly while trying to access services rarely offered in American Sign Language (ASL), their first, and often only, language. At the same time, the hearing parents and caretakers often confront similar trauma when trying to obtain linguistically and culturally appropriate services for their Deaf children. As Steinberg, Sullivan, and Loew write, "Mistrust of providers, communication difficulty as a primary cause of mental health problems, profound concern with communication in therapy, and widespread ignorance about how to obtain services are common themes in Deaf clients' experiences in accessing mental healthcare." (1998).

The second component of the pattern of trauma we have observed in the families we serve is more personal, rather than systemic or institutional. The oppression and marginalization due to language deprivation often coexists with, and is compounded by, sexual, physical, emotional, economic, or other more private traumas experienced by the youth and families.

In consequence of this two-fold pattern, trauma-informed care is paramount at Walden Community Services. While the DSM (Diagnostic and Statistical Manual of Mental Disorders) clearly outlines the symptoms of PTSD (posttraumatic stress disorder), the DSM fails to specify appropriate treatment for bilingual or culturally/linguistically oppressed people. Formulating an appropriate treatment strategy was our necessary task.

Drawing on the research of Nadine Burke Harris, MD, as discussed in her 2018 book, The Deepest Well: Healing the Long-Term effects of Childhood Adversity, we agree that a foundation for treating trauma in the families we serve must start with supporting parents. The challenge is first in answering the question, "How could we teach the parents necessary skills so they could appropriately support their children when one person is Deaf?" The concepts of supportive parents and breaking the cycles of trauma/abuse are complex and multilayered. They also tend to be theorized with respect to hearing families. What would characterize a linguistically and culturally-relevant program for Deaf families? What are the nuances in an approach that includes meeting the needs of both Deaf and hearing family members with varying levels of internal family language competency? How do we provide information without further traumatizing the family? After all, trauma does not only impact the child but the entire family system.

Fortunately, Walden Community Services received an opportunity to join a cohort of in-home providers trained by The Trauma Center at Justice Resource Institute (JRI), founded by Bessel van der Kolk of Brookline, Massachusetts to begin addressing those same questions. After undergoing a lengthy selection process, we were selected to work with the JRI trauma team in piloting a new curriculum titled "Grow: Attachment, Self-Regulation and Competency (ARC)" (Kinniburgh & Blaustein, 2016).

Our team consisted of one hearing clinician with an LMHC, one hearing clinician who is a PhD candidate, ABD in the area of clinical psychology, two Deaf clinicians with MA degrees, and one Deaf clinical support professional with a Bachelor's degree. We attended an intensive three-day training on the foundations of ARC, and then participated in monthly phone conferences with the leaders of the program and the wider cohort of service programs also undergoing training. The state-level department of Medicaid, or MassHealth, provided ASL interpreters for all trainings and phone conferences/consultations.

From our prior and extensive experience working with Deaf families and individuals, we knew that the existing ARC model would require some modification, as it was developed for hearing parents and children. What we did not anticipate was the tremendous support we would be given by the developers of the ARC program. Unlike so many other trainings and curriculums that needed retailoring for the Deaf, the authors of ARC were enthusiastic and encouraging about the adaptations we proposed to meet the needs of our community.

The curriculum did not claim to "cure" PTSD or trauma. Rather, ARC intended to give families tools for managing the stresses and behaviors associated with these conditions. Additionally, ARC validated both the importance of and the challenges faced by the caregiver in ameliorating the effects of trauma.

The 12-session ARC curriculum is designed for the clinical team to work in tandem with the caregiver in the home. The key concepts are outlined in each session and reviewed at subsequent meetings. The training starts with psychoeducation and covers topics such as: What is trauma? How does trauma impact youth and families? How does it shape a caregiver's affect and energy? What are the values of the family? How can we align parent and child so there is less conflict? What tools and techniques we can we harness to calm or increase energy, and to heighten or dampen affect?

Each session offers a different lesson. Instructional scaffolding and repetitive activities teach caregivers to become attuned to the needs of both their children and themselves. By learning to predict behaviors, the caregivers gain a sense of assurance that passes to the children. The caregiver also learns the value of providing consistency and structure.

With each new weekly topic, caregivers are given the opportunity to increase their understanding of what trauma is and how trauma impacts the individual, family and the child's development. Caregivers are also able to develop insights into their own struggles and traumas without having to discuss or disclose the specificities of the trauma itself. In fact, the GROW curriculum does not entail any conversation about the particular trauma the person may have experienced. Alternatively, the program focuses on how trauma in general manifests behavior and stressors. The rationale behind this strategy is to develop the necessary skills for managing stressors and triggers instead of focusing on the particularities of the trauma itself. In the absence of learning techniques to regulate the effects of trauma, simply talking about the trauma will only serve to recreate the traumatic response.

The ARC curriculum is complex, teaching a range of different cognitive, emotional, and behavioral tools and skills. As such, the Walden Community Services team developed techniques to best modify the information to fit the cultural and linguistic conventions of Deaf culture and Deaf caregivers.

Of paramount importance was to carefully translate the terminology of the curriculum into conceptually accurate signs in American Sign Language. Everyday ASL, for example, does not contain equivalent signs for the concepts of "self-regulation", "pause buttons", "Push buttons", "attunement", and so forth, which are integral to the ARC program. Since ASL is not, of course, a verbal language, translation entails more than simply substituting one spoken word for another in a manual form. Essential to our success was to respond by translating the ARC curriculum into ASL; a major task to which we devoted many team meetings. We also devoted our resources to developing ASL videos that summarize key concepts in order to augment the written materials which caregivers can review between sessions or after completion of the curriculum.

The developers of the curriculum used visual tools to assist caregivers in mastering the lessons. However, the visuals they utilized were largely drawn from hearing culture and assumed, in a sense, a universality of certain hearing knowledge, as well as sounds. Thus, these tools inherently were not accessible to deaf consumers. We were given the opportunity to eliminate visual representations that would not convey the intended meaning, and to substitute more appropriate ones for the Deaf community.

For example, the ARC curriculum included a concept of "energy mapping." Energy mapping is designed to help family members understand their own energy correlating to their moods as well as

understanding other family members' energy. Oftentimes, people assume that others may have similar energy and reactions to stressors when in reality, people will vary in how they respond to certain stressors/situations In order to make this concept visually accessible for the Deaf, we devised a chart, attuned to our Deaf families, that used anchor-points specific to the person. As an example of a High Energy/Positive experience, we suggested Christmas morning. For High Energy/Negative, we proposed a fire in the house. Low Energy/Positive might be meditation, and Low Energy/Negative could be a death in the family.

The self-modulation activities in the curriculum were often based on auditory experience, for example, music or sounds head in nature. We modified these lessons to include more

Negative • Positive

tactile activities, such as fine and gross motor activities, or other senses, including aromatherapy. We also focused on activities that could readily be shared within the Deaf families. A hearing mother may find listening to music to be a suitable strategy for soothing. She could not however share this activity with her Deaf children. Instead, we encouraged gentle stretching as a method of relaxation for herself that she could also share with her Deaf child. Further, we needed to correct for certain sensory assumptions made by the curriculum about particular modulation activities. Loud, rhythmic music (e.g.,ap or heavy metal) may be identified as an up-modulation exercise for some hearing individuals. Conversely, for many of our clients in the Deaf community the bodily sensation of feeling (not hearing) the sound waves of this music proved as an effective down-modulation activity.

The adaptions we made to the curriculum were well received by the developers, as well as our client families. The developers were also welcoming of our team continuing to make modifications and further refining the curriculum for use in the Deaf community.

In utilizing the curriculum, we found that our families were receptive to the information because they had something tangible and relevant to their own cultural and linguistic norms to practice following each session. The caregivers were able to understand the value of self-modulation tools because they saw positive changes in themselves when managing stressful situations that might otherwise have been re-traumatizing.

We are continuously learning how to make culturally-competent adaptions to the ARC curriculum so that we can apply the use broadly, inclusive of more diverse, Deaf populations, for example, multi-lingual Deaf families (Spanish speaking etc.). We have seen the positive outcomes of evidence-based progress in the families we serve, and we look forward to further opportunities to share our modified ARC curriculum with different agencies. We believe in what we do, and in the power the program offers as a catalyst for change when working with caregivers who are managing trauma within families.

Our passion for collaboration and sharing what we have seen transform the lives of those we serve is the cornerstone of our work. We invite and welcome any request for support. If you wish to learn more about our work, or desire a consultation with Walden Community Services, please contact Andrea Wohl at andrea_wohl@tlcdeaf.org. We are honored to have been selected as hosts for the ADARA breakout session in 2020.

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Blaustein, M.E. & Kinniburgh, K.M. (2010). Treating Traumatic Stress in Children and Adolescents: How to Foster Resilience through Attachment, Self-Regulation, and Competency. New York, NY: The Guilford Press.

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Write for the ADARA Update

Do you enjoy reading about what is happening in the community? Do you have something interesting to share? The Update is looking for *YOU*! Tell us what you have been doing in your community or organization.

The *Update* publishing schedule is listed below. In order to meet these deadlines, copy, including advertisement, must be in hand by the deadline date.

Submission Deadline

December 15, 2018 March 15, 2019 June 15, 2019 September 15, 2019

Projected Publication Date

January 2019 April 2019 July 2019 October 2019

Requirements: Have something interesting to share with our members about service provisions for Deaf individuals. If you are interested in writing, contact:

newsletter@adara.org



ADARA Update newsletter
July 2018

Olivier is an award winning artist who has been involved in a number of successful projects. His aim is to produce work that combines the effect of colours & patterns, raising imagination & awareness. Olivier delivers solo/joint workshops, tours and

displays art via exhibitions as well as displaying public arts, locally, Nationally/Internationally.

Art influenced products are sold online and in person at fairs. Artwork and products, such as calendars, trays, etc. can be purchased and delivered straight to the customer's home/business by post or in person. Artwork can be leased and displayed across various venues, or bought to own original artwork.

Olivier creates uniquely commissioned artwork / Canvas / fashion / public arts to meet the client's specification which can be bought as gifts, for the home, businesses, weddings, birthdays and many more.

Visit Olivier's website here: (www.ojart.net)

<u>Visit Olivier's facebook site here</u>: (www.facebook.com/olivierjaminartist)

<u>Visit Olivier's Instagram site here</u>: (www.instagram.com/olivierjaminartist)



Equitable Access to Healthcare for People who are Deaf and Hard of Hearing: Focus on the Whole Person

By Richard (Ric) Durity, Mary Sterritt & Denise McHugh

Introduction: The Colorado Daylight Partnership

The Colorado Daylight Partnership (CDP) launched its Integrated Care Initiative (CDP-ICI) in 2017 with support from Colorado's Office of Behavioral Health (OBH). CDP-ICI is composed of two phases. The first was the research and planning phase which has recently ended. The second is the implementation phase which is just getting underway this fall. By way of background, integrated healthcare is defined as the care that results from a practice team of primary care and behavioral healthcare professionals who work together to improve the health of the "whole person". Integrated healthcare exists upon a continuum with different levels ranging from coordinated care to full integration.

CDP-ICI aims to integrate behavioral health (mental health and substance use) services within a primary care practice in the Denver metro area to improve the overall health and well-being of people who are deaf and hard of hearing (D/HH). The results and lessons learned from the demonstration will inform future efforts to expand services statewide.

Health Equity

CDP-ICI's overall goal is to promote equitable access to healthcare among Coloradans who are D/HH. Recent research continues to show that poorer health outcomes have been attributed to problems D/HH people experience in accessing healthcare and communication barriers with healthcare professionals (Emond, 2015).¹ Effective communication is the cornerstone of appropriate healthcare, and the foundation of the doctor-patient relationship. Ineffective communication can lead to misdiagnosis, misunderstandings of therapeutic regimens, medication dosages, patient engagement and other issues (lezzoni, 2004; Gulati, 2003).² Modes of communication have a direct effect on how individuals access timely and appropriate healthcare. The CDP-ICI full research report (with references) can be found at CDP's website: (mhcd.org/colorado-daylight-partnership)

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¹ Emond, A. (February 2015). Access to primary care affects the health of deaf people. British Journal of General Practice, 95-96.

² lezzoni, L. I., O'Day, B. L., Killeen, M., & Harker, H. (2004). Communicating about health care: observations from persons who are deaf or hard of hearing. Annals of Internal Medicine, 140(5), 356-362. Gulati, S. (2003). Psychiatric care of culturally deaf people. In N. S. Glickman & S. Gulati (Eds.), Mental health care of deaf people: A culturally affirmative approach (pp. 33-107). Mahwah, NJ: Lawrence Erlbaum Associates.

Research and Planning Phase Process

CDP-ICI's research and planning phase involved a variety of research methods including a literature review, surveys, and key informant interviews with national, state and community leaders. Two surveys were directed at Coloradans who are D/HH to identify strengths and challenges of the current healthcare system, and to inform CDP-ICI's model design. Forums were held at D/HH events and at natural gathering places for people who are D/HH. Efforts to engage the D/HH community will continue throughout the project. Finally, CDP continues to collaborate with key public healthcare agencies and funders to secure their engagement and commitment to serving the D/HH community.

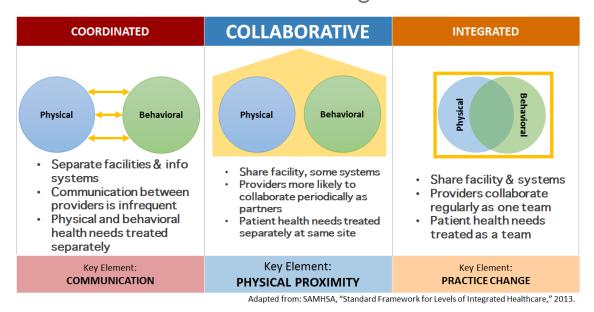
Keys Findings from the Research

Based on the research findings, and the preference expressed by people who are D/HH, CDP-ICI has designed a collaborative model of care to be implemented. Unlike a fully integrated model, the collaborative model of integration involves physical and behavioral healthcare providers sharing facilities and some systems; periodically collaborating as partners; and patients being treated separately at the same site. The D/HH community had reservations about a fully integrated model because of privacy and stigma concerns associated with behavioral health. Many reported being concerned about their primary care doctor knowing in great detail their behavioral health issues under a fully integrated model. Figure 1 below defines the differences between a full integrated model and a collaborative model.

Also, there were financing considerations about being able to sustain a fully integrated model under Colorado's current Medicaid structure and process. Instead, a collaborative model of care appears to be more sustainable at this time. From the research, we learned that Medicaid is a necessary funding source to sustain the model given its flexibility under Colorado's Capitated Behavioral Health Medicaid program versus relying primarily on third party insurance under a fee-for-service model.

Figure 1:

Levels of Collaboration/Integration



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The community-based model that has particularly informed CDP-ICI's model design is the Deaf Health Clinic at the Dexter Center located at the University of Michigan under the direction of Dr. Michael McKee. The clinic provides integrated healthcare (primary care and mental health) for adults who are D/HH. It was started in 2016, so it is relatively new.

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Figure 2 shows a prototype of the model that CDP-ICI intends to implement. The CDI-ICI model will have a sign fluent behavioral health consultant and navigator along with certified ASL/English interpreter for the primary care practice. Key findings from the community confirmed a universal dislike of Video Remote Interpreting (VRI).



Figure 2: Colorado Daylight Partnership - Collaborative Model of Care

Finally, the research demonstrates that there is a lack of culturally and linguistically appropriate health promotion and prevention materials for people who are D/HH. Therefore a key component of the CDI-ICI model is to develop and/or adapt materials so that they are accessible to the D/HH community to prevent conditions such as chronic conditions like hypertension, diabetes, and COPD and to promote access to specialty care.

More about the Colorado Daylight Partnership

CDP helps Colorado community mental health centers and publicly funded substance use providers improve access to culturally and linguistically appropriate behavioral health services for Coloradans who are D/HH across the state through training and technical assistance. CDP is led by the Mental Health Center of Denver and the Colorado Commission for the Deaf, Hard of Hearing, and Deafblind. For more information about CDP and/or its Integrated Care Initiative, please contact Mary Sterritt at mary.sterritt@mhcd.org.

JADARA

JADARA is a widely read publication which deals with research findings (pragmatic applications), program descriptions and articles on deafness, and the disciplines of rehabilitation, social services, mental health, and other related areas.

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<u>Articles</u>

A Place to Belong: A Support Group Curriculum for Hearing Adolescents of Deaf Parents (Kodas)

Meghan L. Fox, University of Rochester Medical Center

Subject area

Counseling, Psychology

Abstract

Hearing children of deaf parents (C/Kodas) comprise a unique group that carries experiences as interpreters, protectors, and advocates. Kodas also have distinct experiences family dynamics and are bilingual and bicultural. Consequently, Kodas have complex identities and related identity development processes with few places to find support. There is a need for culturally sensitive and informed programs to create spaces for Kodas to process complexities and connect with others similar to them. This manuscript focuses on presenting an original research-informed support group program (*Kids of Deaf Adults: A Place to Belong*) for adolescent Kodas.

Book Review - Language Deprivation and Deaf Mental Health

Judy Mounty, Private Practice

Abstract

Book review of Language Deprivation and Deaf Mental Health



DeafLEAD Announces Two New Services for the Deaf Community

Dr. Stephanie Logan, Ph.D., M.B.A.

Executive Director, DeafLEAD (formerly The L.E.A.D Institute)

DeafLEAD, a Deaf-run non-profit agency located in Missouri, is now offering two new services for Deaf victims of crime. The first services is a 24/7/365 crisis videophone hotline for the Deaf community called the Deaf Crisis Line. Crisis line advocates fluent in sign language are trained to provide immediate emotional support, recognizing that trauma can have an ongoing impact on an individual's life, regardless of when the event occurred. By providing the crisis line services in sign language directly through the videophone, Deaf individuals receive unprecedented access to immediate assistance and resources that are both culturally and linguistically accessible utilizing a trauma-informed approach.

This crisis line focuses on meeting the needs of Deaf individuals who are victims of crime (past or present) including: domestic and sexual violence of adults or children, bullying (cyber, physical, or verbal), teen dating violence, burglary or robbery, child abuse or neglect, elder abuse, drunk driving or other vehicular victimization, human trafficking, any hate crime, identity theft or other financial crime, any form of mass violence, terrorism whether domestic or international, and a violation of a court order. Here is a link explaining the new Deaf Videophone Crisis Line: https://youtu.be/_i042-DJWt8.



The second service developed by DeafLEAD is free sign language interpreting for Deaf individuals who have been victims of crime, as well as for hearing service providers working with Deaf victims.

Through the use of a videophone, Facetime, or Skype, DeafLEAD interpreters can facilitate culturally and linguistically effective communication to ensure that Deaf victims are provided accessible services and support. Services may include interpreting crisis intervention, legal and mental health appointments, shelter intakes and support, case management, services provided by law enforcement, and any other victim-related services.

The DeafLEAD crisis interpreters are CI/CT nationally certified with extensive training and experience working with Deaf victims of crime. The goal of the program is not to absolve agencies from their responsibility of providing accessible accommodations. The goal is to improve communication accessibility for Deaf victims with victim service providers more closely to the time that it is needed. It is hoped that this access to communication will increase the likelihood of Deaf victims successfully living free from their abuser. DeafLEAD staff then work closely with service providers to find interpreters in their area as needed.

Executive director, Dr. Stephanie Logan, is Deaf and has been the administrator of DeafLEAD for over 23 years. She is encouraged by the overwhelming success of the two new services in the short period of time they have been providing them.

DeafLEAD's mission is to provide advocacy, crisis intervention services, case management, mental health services, free crisis interpreting and other direct victim services for Deaf, hard of hearing, DeafBlind, and late-deafened victims of crime, survivors and their families. More information about DeafLEAD and the services they offer is available at DeafLEAD's website: (www.deaflead.com)



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Professionals Networking for Excellence in Service Delivery with Individuals who are Deaf or Hard of Hearing ADARA

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