The Rehabilitation Professional & Journal of Life Care Planning:

A Year in Review

IARP INTERNATIONAL ASSOCIATION OF REHABILITATION PROFESSIONALS

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The Rehabilitation Professional & Journal of Life Care Planning: A Year in Review is a peer-reviewed journal that is published yearly by the International Association of Rehabilitation Professionals (IARP) in order to promote the pro fession and to inform the public about the activities of the IARP organization and their affiliates.

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Editor's Message

Tanya Rutherford Owen

Dear IARP members,

I am thrilled to be writing to you in the augural Year in Review issue. In this issue, we hope to highlight for all of our members some of the outstanding articles that have appeared within the 2021 issues of *The Rehabilitation Professional* and the *Journal of Life Care Planning.* As I write this in November 2021, IARP has 1,611 members who hail from multiple professional disciplines and perform various types of rehabilitation-centered work. Yet, we each value what IARP provides to our professional endeavors. It is IARP's goal to provide offerings that each member finds useful. The needs of a member who provides transition services in the southern United States vary from the member who provides life care planning in Newfoundland and Labrador, yet as an organization IARP's goal is to meet the needs of both of these members. This is no small feat for IARP to accomplish.

But the reality is that IARP accomplishes this goal because we have a dedicated network of volunteer members. In this issue, many of IARP's leaders have written to you to tell you what their committee or section has done, is doing and will continue to do to meet your needs. Please take time to read their messages and consider how you can communicate with these leaders to express your ideas, your willingness to serve, and hopefully your gratitude for the efforts they have taken on your behalf. Trust me, a 'thank you' goes a long way to encourage the volunteers to continue their hard work!

By highlighting three articles each from 2021 issues of *The Rehabilitation Professional* and the *Journal of Life Care Planning*, it is my hope we will disseminate information more broadly through our readership. The cross-pollination of ideas is exactly what makes this multidisciplinary group so robust.

Nowhere is the strength of our community more palpable than at the annual IARP conference/ IALCP Symposium. This year, for the second year in a row, the conference was held virtually due to Covid-19. Last year, some of us were a bit nervous as the conference launched virtually, but this year, a whopping 448 of you had enough confidence in the benefits of this conference information that you signed up to attend. We had a stellar line-up of physicians, lawyers, researchers, practitioners, and academicians from organizations including the Bureau of Labor Statistics and the Centers for Disease Control, who covered topics from infertility treatment, to human trafficking, to Covid 19. Consider that for a second, typically a conference is centered around one practice—adult education, chemistry, etc. – but at IARP's conference we do our best to ensure that all 1,611 members find something (hopefully multiple things!) on the schedule that is relevant to them as a physician, vocational counselor, speech language pathologist, etc. Year after year, IARP offers conference sessions that exceed expectations, and based upon preliminary feedback from this year, we did it again.

At the annual conference, the organization recognizes professionals in our membership who have gone over and above to contribute to this group and this year's very-deserving recipients included:

International Association of Rehabilitation Professionals (IARP) awards

IARP Lifetime Achievement Award: Beverly Olson

IARP Outstanding Professional Membership Award: Emily Veith

IARP Outstanding Leadership Award: Erin Bailey

IARP Young Professional Award: Amy Peterson

IARP Outstanding Chapter Award: New England Chapter

International Academy of Life Care Planners (IALCP) Awards

IALCP Outstanding Life Care Planning Educator Award: Shelene Giles

IALCP Life Care Planning Lifetime Achievement Award: Ann Neulicht

IALCP Student Scholarship: Mary Beth Benoit

Foundation for Life Care Planning and Rehabilitation Research Awards

FLCPRR Paul Deutsch Professional Development Award: Debbie Berens

Congratulations to each of these outstanding professionals and thank you for what you have contributed to make IARP a stronger community.

As we close 2021, I want to thank all of you for being members of IARP, for attending the conferences, for reading the journals, and contributing to robust conversation on the professional listservs. For those of you serving in IARP leadership, thank you for volunteering your time to make our group better. This group continues to grow only because of the tireless efforts of you and people like you, who have since 1977, taken time out of their busy days to contribute to this professional organization. And for that, we are all grateful.

Be well, my friends. Have a safe and joyful holiday season. Happy reading.

Tanya

INTERNATIONAL ASSOCIATION OF REHABILITATION PROFESSIONALS

IARP President's Message

Dear Members of the International Association of Rehabilitation Professionals:

It is with great honor and gratitude that you chose me to be IARP's President for the 2021-2022 post-Covid year! While we have been through some difficulties with evaluations, research, interactions, workloads and not being "with" others, I believe that we have come through these challenges much stronger and more focused on continuing the work that we all do. Your IARP board has been working diligently through their fiscal responsibilities, chapter and section policy and procedures updates, and embracing the strategic plan for our goals and mission.

Please know that we are working diligently and continue trying to hold fast to our mission and vision statements:

Vision Statement: To become the leading international rehabilitation professional association.

Mission Statement: Strengthening the community of rehabilitation professionals over the course of a lifetime.

As members of IARP, we have benefits including our two peer-reviewed journals, *The Rehabilitation Professional* and the *Journal of Life Care Planning*. We have professional development opportunities through the IARP conference, IALCP symposium, and the IALCP summit. IARP provides multiple professional interest sections to serve the various interests of our multidisciplinary membership. IARP offers professional discounts to members to acquire the tools necessary to perform their work. IARP offers industry advocacy to educate interested parties in the work that we perform. Finally, IARP has multiple local chapters which members can join as well as IARP Connect where all members can engage in lively and knowledgeable conversations about our practices.

IARP's priorities for 2022 include:

- Continued promotion and growth of our two peer-reviewed journals
- Continued promotion of the Foundation for Life Care Planning and Rehabilitation Research
- Continued international membership growth with focus on the needs of international members needs
- Fiscal responsibility
- Legacy Planning
- Academic outreach and partnerships
- Strategic succession planning for all chapters and sections
- Continued work on inclusion and cultural awareness in our work

So many things-so many fantastic people and so many great memories will continue to be made, forged, and sought after. Please know your IARP leadership, chairs, members and volunteers continue working for you!!!

Remember I'm about the relationship and the stories-so reach out and call a new member, contact a young student or professional, find a mentor, find a colleague whom you can collaborate with, do some research, author an article, look for volunteer opportunities in YOUR organization: IARP!

I wish you a healthy, happy, joyous holiday season!

Sincerely yours,

Anne Savage Veh
IARP President

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IARP Announces: Proposals Open for Rehabilitation-Related Research Projects

ST. PAUL, MINN., November 2021 - The International Association of Rehabilitation Professionals (IARP) is pleased to announce that the Foundation for Life Care Planning and Rehabilitation Research (FLCPRR) is currently receiving proposals for rehabilitation-related research projects.

In 2002, Dr. Paul Deutsch launched the Foundation for Life Care Planning Research, which funded numerous research projects from 2002 through 2019. In 2019, under the direction of Foundation President, Dr. Debbie Berens, the original Foundation for Life Care Planning Research became an Affiliate of IARP and, in 2020, was re-incorporated as the Foundation for Life Care Planning and Rehabilitation Research, with the mission of inspiring, promoting, funding, and supporting research that advances practice in life care planning and rehabilitation.

With a vision of being recognized as a leader of innovative, valid, and reliable research, the Foundation remains committed to supporting rehabilitation practitioners, clinicians, and students who perform disability-related research. Additionally, the Foundation presents annual awards to recognize individuals who make significant contributions to the body of research or otherwise have a positive influence on research in the field.

President Debbe Marcinko states "*We are building on a long history of sponsoring important research projects that have contributed to the empirical knowledge base of our work and we look forward to reviewing future projects under the new, expanded scope of the Foundation*".

Current members of the Foundation board of directors include Debbe Marcinko (President); Karen Preston (Vice-President); Rick Robinson (Secretary); John Meltzer (Treasurer); Debbie Berens, Ann Neulicht, Tanya Rutherford-Owen, Laura Woodard, and Steve Yuhas.

For more information, visit the Foundation's website at https://connect.rehabpro.org/flcprr/home.

The Foundation's funding comes through donations by individuals interested in furthering the goal of engagement in research. Donations of any amount are accepted to fund these research projects at https://rehabpro.org/donations/donate.asp?id=20924

About IARP
IARP is the premier association for professionals involved in private rehabilitation. Originally founded in 1981, IARP members are some of the most accomplished and respected professionals in their respective fields of practice. IARP offers members a lifetime of learning and professional development opportunities in the form of national conferences, advance training classes, local chapter events, mentoring and coaching programs, and a growing repository of online educational courses.

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IARP Young Professionals Committee Annual Report: A Year-In-Review

Hello IARP Members,

The Young Professionals Committee has been working hard this past year to accomplish the goals we set for ourselves, and I could not be more honored to be a part of this organization.

Before reviewing 2021's accomplishments and future goals, I need to thank our present and past committee members for their contributions and efforts. Ms. Megan Baumunk, our past secretary, has been integral in our committee's vision to increase membership. Our committee members include Mr. Daniel Turner, Ms. Amy Peterson, Ms. Ariel Villareal, and Ms. Violet Magana. Their contributions to this committee have been invaluable. Thank you.

When we outlined our goals for this committee, the areas we wanted to focus on included increasing membership, contributing to the mentoring program, and assisting in planning the annual conference. Our efforts in the last year directly led to an increase in student membership by creating a database of all of the master's programs in the nation that are CACREP accredited. Our committee contacted each university through this database to provide information regarding IARP, the benefits of our student membership, and our 2021 National Conference. We will maintain contact with these universities for future events and foster a relationship to connect students to IARP.

Our second goal was undertaking the mentoring program available through IARP. We have identified that some mentoring/mentee enrollment had lapsed, had not been updated in some time, or had not enrolled at all in some individual profiles. As a result, a step-by-step instruction guide has been created for this year's virtual conference. In addition, a committee member has been designated to each section to assist with identifying a potential mentor/mentee match.

Lastly, Ms. Amy Peterson, a committee member and the committee's secretary serves as a liaison for the conference planning committee to assist with any matters where the Young Professional's committee can contribute meaningfully for the benefit of the annual national conference.

Our future goals for the Young Professional's committee include the following:

1. Maintaining regular contact with the universities for IARP-related activities throughout the academic year
2. Working with the Marketing and Membership committee to create strategies in increasing overall membership
3. Assisting in both the development and maintenance of the mentoring program
4. Continuing to recruit new committee members with an influx of new talent for the growth of IARP

Following the 2021 national conference, our committee will be adding three new committee members, increasing the committee from 5 to 8 members. We will also be nominating a new chair-elect to undertake the current and future work of this committee. We are excited about this endeavor and the new direction of the Young Professionals Committee.

It is an exciting time to be a Young Professional Member of IARP. We are thrilled to contribute meaningfully in 2022 for the development of IARP, fostering new relationships, and assuming new roles within the larger, overall community.

Hantac Chang, MS, CRC
Chairperson, Young Professionals Committee

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Considerations for Vocational Assessments in the Era of COVID-19

John R. Cary, Nick Choppa, Cloie B. Johnson1, Kourtney Layton, Donna B. Taylor, and Michelle McBroom Weiss

The year 2020 was unprecedented for many reasons. Few events during the past century have been more novel and far-reaching than the emergence and rapid spread of Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2), the virus that causes Coronavirus Disease 2019 (COVID-19). This pandemic has resulted in significant changes in the ways we socialize, work, and communicate. It has also created economic strain in many sectors and, by extension, reshaped and reconfigured the workplace. Many employers have drastically altered their operations; some have been forced out of business. With mass COVID-19 vaccinations underway, there remain many questions about the long-term implications of the global pandemic. The authors examined data from the pandemic of 1918, the impacts of economic recessions, and contemporary data on the impact of the COVID-19 pandemic in an attempt to extrapolate implications for future vocational analyses.

Keywords: COVID-19, labor market, economic damage, vocational expert, vocational opinion, pandemic

Historians will memorialize 2020 by its many benchmark events, the most prominent and far-reaching being the outbreak of Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2), the virus that causes Coronavirus Disease 2019 (COVID-19). *The American Journal of Managed Care* (2020) provided the following timeline for the emergence of the COVID-19 pandemic:

- December 31, 2019, outbreak of the SARS novel coronavirus was first reported in Wuhan, China.
- January 9, 2020, the World Health Organization (WHO) formally announced a coronavirus-related pneumonia in Wuhan, China.
- January 20, 2020, three major U.S. airports began screening passengers for coronavirus after cases emerged in Thailand and Japan. Less than two weeks later, a Washington state resident became the first confirmed case in the U.S.
- January 31, 2020, the WHO issued a global health emergency as human-to-human transmission quickly spread to major metropolitan cities in the U.S., Europe, and Asia.
- February 3, 2020, the U.S. declared a public health emergency.
- March 11, 2020, the WHO declared COVID-19 a global pandemic.
- March 13, 2020, COVID-19 was declared a national emergency in the U.S.

There are many types of human coronaviruses, including some that cause mild upper-respiratory tract illnesses (Centers for Disease Control and Prevention [CDC], 2020). SARS-CoV-2 virus is not the same as the coronaviruses that cause the common cold. SARS-CoV-2 can lead to COVID-19, 'CO'

denoting 'corona,' 'VI' represents 'virus,' and 'D' disease. This is a new disease not previously found in humans (WHO, 2020).

Looking to the Past to Prepare for the Future

The COVID-19 pandemic, although contemporary and significant in its reach, is not the first of its kind. As documented by the CDC (2018), COVID-19 has joined the ranks of recent past pandemics such as the 1957-1958 H2N2 virus pandemic, the 1968 H3N2 virus pandemic, and the 2009 H1N1 pandemic. However, the COVID-19 pandemic has been most often compared to the 1918 influenza pandemic, commonly referred to as the "Spanish Flu," in terms of both scope and scale. The 1918 virus underwent several mutations, the first wave beginning in March of 1918, followed by three deadly waves through the spring of 1920 (CDC, 2018).

Although it has been over 100 years since the 1918 pandemic occurred, it is the most recent from which to derive comparisons as to the effect COVID-19 may have on our modern U.S. economy and labor market. Similar to the COVID-19 pandemic, the 1918 pandemic spread with remarkable speed in less than six-months, and in two subsequent waves through 1919 (Patterson & Pyle, 1991), and a third wave in 1920 (CDC, 2018). The first wave arrived in the U.S. in the spring of 1918, and the second arrived in the fall and winter of that same year. The third wave of trailing outbreaks was observed in 1919. Patterson and Pyle (1991) noted an enormous death toll, with estimates of up to 30 million deaths worldwide during this period, "more than three times the number of military casualties suffered by all of the belligerents during more than four years of fighting in what was then called the Great War [World War I]" (p.21). At the time of the writing of this paper, there were 31,672,240 confirmed cases and 567,233 deaths related to COVID-19 in the U.S., with 3,022,288 deaths worldwide (Johns Hopkins Coronavirus Resource Center, 2021).

The actual impact of the 1918 pandemic on the U.S. economy is difficult to assess. This is due to the intensity and scale of World War I overlapping with the pandemic's timeline (1914-1918), and the limited economic data available from that time period, mostly preserved through print media and Federal Reserve District data (Garrett, 2007). Notably, Velde (2020) described the impact of the 1918 pandemic on the economy as "just one of many headwinds in an eventful year" (p.15).

However, Garrett (2007) described how available data pointed to the significant economic effects of COVID-19 pandemic which indicated that many businesses, especially those in the service and entertainment industries, suffered significant losses in revenue. In contrast, other businesses that specialized in health care products experienced increases in revenue. Comparatively, COVID-19 pandemic shelter-in-place policies have most adversely impacted the service and entertainment industries throughout the U.S. (Garrett, 2007).

Velde (2020) showed that, "Manufacturing employment in New York state and Massachusetts rebound(ed) quickly from the 1918 epidemic" (p.15). Rockoff (2004), described a 44-month economic expansion from 1914 to 1918, and attributed this to the rise of government spending upon entry of the U.S. into World War I, which resulted in an unemployment decline from 7.9 percent in 1914 to 1.4 percent in 1918. An additional variable Rockoff (2004) considered was significant control of the economy by the government during wartime, which included increased federal centralized pricing, production controls, and rationing of supplies and materials.

It has become increasingly evident that the effects of COVID-19 are even more far-reaching than what we have seen in past pandemics. As such, there is a vastly different landscape between the 1918 and 2020 U.S. economies. Velde (2020) described the 1914 labor market as a "population [that] was roughly evenly split between rural and urban, whereas the ratio is 5 to 1 now," (p. 32) in favor of urban living. Perhaps more significant was that in 1914, "Agriculture accounted for 33% of employment, and manufacturing another 28%." While in 2020, employment in these two sectors were at 2% and 8% respectively (Velde, 2020, p. 32).

If the many headwinds described by Velde (2020) during World War I were not enough to complicate the empirical data surrounding the impact of the 1918 pandemic, efforts to compare 2020 pandemic

data are further convoluted by the economic landscape of the subsequent "Forgotten Depression" of 1920-1921 (Grant, 2014). It has been difficult to attribute to or divest from, the impact of the 1918 pandemic from the economic depression of 1920-1921 with such little data. The lack of reliable sources from the early 1900's has also made it difficult to objectively predict what may happen in a post-2020 pandemic economy.

Grant (2014) noted that by 1919, a predicted post-war recession had not yet occurred. In fact, business was booming, largely driven by the cancellation of huge amounts of war-time debts after the Armistice and further aided by a sudden spike in American consumerism, which was previously depressed by a combination of the 1918 pandemic and war-time economics. However, by early the 1920's, the combined effects of a mass influx of returning troops attempting to reintegrate into the labor market and extreme deflation caused the economic boom to wane, as employment rates rose to between two and six million and lasted well into 1921 (Grant, 2014).

It has been made clear that the effect of the 1918 pandemic contributed, at least in part, to the subsequent economic turbulence of the early 1920's. Again, the true extent of the current pandemic's impact on the economy remains difficult to assess with such limited comparable data. Barro et al. (2020) have postulated that data on mortality and economic contraction during the period of 1918 to 1920 are plausible in terms of their predictive value to the anticipated economic rebound from COVID-19. What remains to be seen is how or if other confounding variables such as political divide, social discord, and technological advances, along with a myriad of other significant global events, will impact the U.S. economy and labor market in the aftermath of the 2020 pandemic.

In parsing these issues out of time, Grant (2014) cited an apt adage that "the past is a foreign country" (p. 5). We have tasked ourselves with looking back into the past for future insights about the impacts of COVID-19. We have found that predicting future economic changes related to the COVID-19 pandemic has been difficult given the unique circumstances of the modern era and lack of comparative data from the 1918 pandemic. The challenges of 100 years ago are not the same today. There is no "Great War" and the federal government has not actively imposed control over industries and production for wartime efforts. Our recent economic landscape has been drastically different due to the evolution of the labor market subsequent to the proliferation of personal computers and information technology. This has allowed many sectors of the economy to continue to work largely uninterrupted through the COVID-19 pandemic, while others have succumbed to the effects of pandemic precautions.

The Effect of the Pandemic on our Day-to-Day Lives

Kramer and Kramer (2020) noted that occupational and socioeconomic statuses were interrelated. Occupations may often be perceived as "more important work" and "less important work," and the COVID-19 pandemic has further stratified how occupations are socially valued. For example, the "essential" or "non-essential" nomenclature has designated the social value of occupations, a new taxonomy that may persist. Kalleberg (2011) published widely on the topic of what was then described as "good" and "bad" jobs. Bad jobs as defined by Kalleberg (2011) were those with low pay, lack of benefits or access to healthcare. Kalleberg (2011) further defined non-traditional jobs, such as temporary work, as falling into the category of bad jobs.

Kramer and Kramer (2020) suggested that the divide between good and bad jobs will become even wider due to the aftereffects of COVID-19. The relationship between the impact of COVID-19 on the health of individuals and the economy has remained central to the discussion of long-term effects related to the pandemic. Most of the debate has focused on how to mitigate the immediate labor market effects, school and business closures, individual unemployment, and fluctuating COVID-19 case rates. Rojas et al. (2020), suggested a continuum between healthy populations and economic well-being, specifically related to how policies mitigating and controlling the spread of COVID-19 have impacted the economy. This was not a new discussion, as Preston (1975), Cutler et al. (2006) and Ruhm (2000) have each explored the continuum between a healthy population and economic well-being, although not in the context of a pandemic.

Pinsker (2020) highlighted two different observed employment-related experiences during the COVID-19 pandemic. There were some individuals who were able to work remotely, but who experienced high levels of stress related to childcare, fear of leaving home and other associated concerns. The second phenomenon included individuals who were unable to work remotely, which placed them at increased risk for exposure to contracting the virus and at higher risk for layoffs and negative financial impacts due to the pandemic. Although both groups were affected, Pinsker (2020) suggested the COVID-19 pandemic has increased the socioeconomic divide in the labor market. Specifically, Pinsker (2020) and Kramer and Kramer (2020) agreed that people considered at risk for unemployment, underemployment, adverse physical and mental health conditions and other family difficulties were at risk for exacerbation of these problems both during and after the pandemic.

Guan et al. (2020) addressed stressors related to the pandemic, such as working remotely, lack of available work, job insecurity, and their impact on one's mental health. Guan et al. (2020) further explored that "essential workers" had worked long hours in potentially dangerous situations that may have impacted their mental well-being.

Further, women have been negatively impacted by the COVID-19 pandemic, particularly women of color, who were more likely to have been laid off or furloughed during the pandemic (Coury et al., 2020). Pre-pandemic stalling of career growth jeopardizing financial security has been predicted to intensify the challenges faced by underemployed women and those already considered at-risk for financial insecurity (Coury et al., 2020; Blustein et al., 2020).

The reconfiguration of the labor market due to the effects of COVID-19 has gone beyond impacting employment. Some employers have curtailed benefits such as health care coverage, which in turn, has increased the numbers of uninsured individuals and families. According to Gangopadhyaya et al. (2020), more than 3 million individuals lost employer-sponsored health insurance coverage, and an additional 2 million became uninsured by the summer of 2020.

Nearly half of those who lost health insurance benefits identified as being of Hispanic/Latino descent (1.6 million). The data from spring to summer 2020 suggested that those who identified as being of Hispanic/Latino descent were disproportionately impacted by the pandemic-related recession, more than any other ethnicity (Gangopadhyaya et al., 2020). The loss of job-based insurance has resulted in an increase in reliance on public insurance coverage (Gangopadhyaya et al., 2020). An analysis from Avalere Health predicted that up to 12 million people were to lose job-based health insurance by the end of 2020, disproportionately affecting workers who identified as Black and of Hispanic/Latino descent (Sloan et al., 2020).

Although caution should be taken in reviewing job numbers as the COVID-19 situation is fluid and long-term impacts remain unknown, there were interesting features to note from the data presented by Wolf (2020). As of December 2020, occupational fields traditionally regarded as strong, such as those in health care, had seen a reduction of 527,000 workers compared to February 2020; while increases in employment for professional and business services, and transportation and manufacturing were appreciated over this same time period. However, many occupational groups have experienced losses, with industries such as government, retail, leisure, and hospitality realizing the greatest shortfalls in 2020. Wolf (2020) noted that industries in decline as of December 2020 included food service, transportation, arts and entertainment, and real estate.

As technology promotes an ability to work remotely, Vogels et al. (2020) found that 53 percent of Americans believed internet access had been essential during the COVID-19 pandemic, while 34 percent viewed it as important but not essential. Challenges related to internet accessibility have been noted, along with concerns over increased cost to acquire these services, incurred by families to work and attend school from home (Vogels et al., 2020).

Research has confirmed that workers with disabilities are often the last to get hired and first to get fired (Lengnick-Hall et al., 2001). The labor market in the era of COVID-19 has posed no exception. Data from the start of the pandemic has suggested that unemployment rates rose from 4.4% in March 2020 to 14.7% in April of 2020 for the general population, but much more so for persons with disabili-

ties (Bureau of Labor Statistics [BLS], 2020b). Maroto and Pettinicchio (2020) noted an increase of unemployment for persons with disabilities at a rate of 17%.

Data has suggested that vulnerable workers holding unskilled to semi-skilled jobs prior to the pandemic were more unlikely to see their jobs return (U.S. Private Sector Job Quality Index, 2020). One estimate projected 42 percent of all jobs lost will not return, while the same study suggested work reallocation will ameliorate some, but not all, restructuring of the labor market (Hite & McDonald, 2020). Brooks (2020) indicated the COVID-19 pandemic would increase economic and labor market inequality among those with disabilities.

Occupations That Have Benefitted

Long-term job demand for occupations in certain sectors has been likely to occur (Kramer & Kramer, 2020). Data from the BLS has projected that from 2019 to 2029 the number of jobs in the fields of information technology and medical research sectors will increase. Projections prior to COVID-19 noted that six of the ten fastest growing professions were in health care, including nurse practitioners, home health aides, physical therapists, health care managers and physician assistants (Wolf, 2020). Data utilized at the time of this publication is from the Employment Situation Summary from November 2020 (BLS, December 4, 2020). In keeping with what we might expect, health care added 46,000 jobs in November, 2020 alone with gains occurring in offices of physicians (+21,000), home health care services (+13,000), and offices of other health practitioners (+8,000) have shown trends for higher levels of employment in this sector, despite an overall decrease between February 2020 to December 2020 (Wolf, 2020).

The Duration of the COVID-19 Related Downturn is Impossible to Predict

Baker et al. (2020) projected a return to pre-pandemic market trends beginning by 2022 at the earliest. Christakis (2020) prognosticated that the economic impact of the pandemic will reach beyond 2024, potentially transforming economic compensation, benefits, and supply chains. The Economist (May 2, 2020) outlined its most positive scenario as indicating labor markets taking half a decade to return to pre-pandemic rates, with a full recovery taking up to two decades.

Dunford and Qi (2020) and [a]en (2020) postulated that the COVID-19 pandemic has been an opportunity that has naturally accelerated entrenched trends towards a geopolitical reset which will see the restructuring of the global economic focus away from traditional markets toward a multi-polar global economic structure based on technology and other modern innovations.

According to the BLS (2020a), concerns of subsequent waves of COVID-19 may see intensified economic recession that may result in hikes in consumer prices and job loss. Public health mandates, such as social distancing and limiting gathering capacities, have had a deflationary effect on the demand for goods related to socialization and close contact, which has contributed to increased unemployment and the restructuring of employer spending in industries such as restaurants and entertainment to mitigate new policies (BLS, 2020a).

The impact of lost and/or decayed skills for individuals who have experienced separation from the labor market has also been of considerable concern. Economists have further questioned the effects that social distancing, working remotely, and shopping online have had on city centers and commercial properties, which may reshape labor market sectors that support these services (BLS, 2020a), particularly for the real estate industry. Much like the BLS (2020a), Bloom (2020) suggested employers may opt to leave city centers for more industrial areas and suburbs, which may adversely affect the need for mass transit.

Bloom (2020) pointed out that, along with what many expect to be temporary repercussions from the COVID-19 pandemic, there are likely to be longstanding effects on the workplace as employers improvise and reconsider how they do business. With other pandemics events such as SARS, MERS, and Ebola considered to be “near misses” in terms of their global impact, and in preparation for future

COVID-19 outbreaks and other pandemics, working remotely may continue to be a common feature for years to come. It is fair to postulate that the economy would suffer even greater losses without the ability for many to work remotely.

These issues, along with many others, have had significant implications for post-COVID-19 assessments of earning capacity and economic damage calculations.

Consideration of the Effects of the COVID-19 Pandemic on Vocational Assessments

There has been a predictive value in knowing how labor markets have tended to respond to economic recessions and how COVID-19 may impact the U.S. labor market. Available data related to the study of past recessions has had direct application to vocational assessment, rehabilitation plans, and the COVID-19-induced recession.

It has been anticipated that those who continue to be employed during a recession, or pandemic-induced recession, will likely see minimal to no change in their earning capacity over time. Oreopoulos et al. (2012) explored the effects of recessions on the labor market, finding that unemployed workers, those who have not yet entered the labor force (i.e., recent graduates), workers displaced due to injury, individuals with disabilities, or those who have lost their jobs because of a recession, are more susceptible to having their average earnings depressed as a consequence and, thus, will have diminished earning capacity over time. For example, long-term earnings decline has been predicted for students who graduate from college during a recession economy. Oreopoulos et al. (2012) noted that some graduates experienced a persistent earnings decline that lasted for a decade or more. These individuals often entered the workforce in lower-paying jobs and gradually assumed positions which allowed them to earn wages more in line with their earning capacity had they begun working in a non-recession economy. Graduates with degrees from highly coveted institutions suffered less and moved toward more advantageous employment opportunities more quickly. Conversely, wages of graduates from less prestigious institutions were permanently affected due to the nature of labor market conditions during a recession (Oreopoulos et al., 2012). Graduates from less prestigious institutions realized lower earnings capacity, and faced four to five times the cost of economic recession than did the graduates from more elite institutions (Oreopoulos et al., 2008). This analysis of the impact of an economic recession on future wages was consistent with hypotheses that COVID-19 may have increased disparagements between those with higher educations and commensurate occupations that allowed them to work remotely, and those who were at risk for unemployment and underemployment prior to the pandemic (Pinsker, 2020). The latter of the two was expected to be at increased risk for negative employment outcomes secondary to the COVID-19 era economy (Pinsker, 2020). An example of this would be the difference between how service and entertainment-related industries have experienced job loss versus how technology, finance, and other similar professions have thrived during the initial phases of the pandemic (BLS, 2020a; Wolf, 2020).

Securing jobs offering opportunities for advancement has been more difficult during an economic recession, especially for workers with fewer skills and fewer opportunities for career mobility and growth (Topel & Ward, 1992). Again, these difficulties were expected without the added complexities of finding work during a pandemic. The long-term effects of graduating during an economic recession may have depended on how recessions affected the quality and availability of initial job opportunities, wage adjustments, productivity by employers, and human capital accumulation. Historically, the quality and availability of jobs has usually declined during economic recessions (Reder, 1955).

Further, when assessing access to employment and earning capacity, consideration of the length of time an individual would have the capacity to earn and the state of the current and future labor market has been central to an earning capacity analysis. As outlined above, the predictive nature of these analyses has been complicated by, among other factors, the lack of retrospective data available to predict the long-term implications of the impact of COVID-19. In addition to assessing an individual's ability to perform work activities when considering the effects of the COVID-19 pandemic, their abil-

ity to perform work activities, reduced access to the labor market, and potentially decreased earning capacity related to short-term erosion of available opportunities, must also be considered. This has been especially true for low-earning marginal workers who have lost access to segments of the labor market due to an acquired disability. This has also been true based upon human factor analyses and/or automation of jobs pre-pandemic, and will likely be accelerated because of the pandemic and resulting economic recession.

Additional Labor Market Considerations Related to Employment and Earning Capacity

- Shopping remotely.
- Impact upon retail jobs.
- Government decisions to limit travel and the implications for travel/tourism and restaurant jobs (e.g., amusement parks temporarily closed, cruise ship vacations have been cancelled, restaurants have closed and, therefore, staff have lost their jobs).
- Training program re-design: In-person occupational training has moved to online-based programs (e.g. nursing programs that have moved to online even for patient practicals).
- Increased use of video conferencing (e.g., Zoom Video Communications, Microsoft Teams, and other applications designed for remote corporate meetings that have become incredibly popular across industries).
- Work-Life Balance: The COVID-19 pandemic has changed the boundaries of routine work behaviors. It has caused many workers to work remotely, often from home.
- Flexible Work Arrangements: Standard workers with flexible locations have usually worked full-time with a set schedule, but typically have worked from home. This may have led to an increase in work hours because of distractions and interruptions from family obligations.

Additionally, the COVID-19 pandemic has the potential to affect the following work-related factors:

- Working conditions
- Work motivations and behavior
- Job and career attitudes
- Career development
- Personal health
- Well-being

There are few certainties in our post-COVID future; however, change is inevitable. The COVID-19 pandemic has appeared to be a catalyst for economic change and the evolution of the labor market, world of work, employment, and global business practices. Early adaptations for returning to worksites have already revealed changes in brick-and-mortar businesses as well as jobs in the service and manufacturing sectors. Workplaces have revamped interiors to accommodate social distancing and sanitation, even when working with the public has not been an essential function of the job (Hite & McDonald, 2020).

Length of Job Search and Placeability

Oreopoulos et al. (2008) reported that job search theory has predicted that a temporary decline of the wage offering distribution during an economic recession has resulted in a lengthy search for locating higher paying jobs. The cost of job searches has increased with age, and higher skilled workers have been more likely to relocate or change industries. Lower skilled workers may not have had the knowledge or resources to search as diligently and may have received fewer new job opportunities after ac-

cepting lower quality jobs during an economic recession. If they had learned employer-specific skills on the job, they may also have had more difficulty changing jobs the longer they stayed with their initial employer (Oreopoulos et al., 2008).

Gibbons and Waldman's (2006) model tied career progression to human capital accumulation at either the company or industry level. These same authors also suggested that students who graduated during an economic recession had a prolonged period of job and industry mobility, and usually had less time accumulating company- or industry-specific job skills. Gibbons and Waldman (2006) also suggested that human capital accumulation may explain the faster rates of recovery experienced within companies after economic recessions, as low earning workers generally caught up with their higher-paid peers. If recessions have been related to the lower supply of jobs that have led to a career track, or of jobs that offered opportunities for skill accumulation, this has explained the permanent effects that have resulted from temporary labor market conditions (Gibbons & Waldman, 2006). For example, if a new graduate was unable to find a job in their field of study, resulting in delayed entry to the occupation, this has resulted in diminished earning capacity that potentially spanned the life of the individual's career. As the state of regional labor markets has continued to influence earnings of more experienced workers, the estimate of the effect of the first unemployment rate exposure has resulted in the long-term effects of the first unemployment rate plus the weighted sum of the effect of unemployment rates a worker faced during the life of one's career (Blanchflower & Oswald, 1994).

The effects gig workers have had on unemployment and underemployment has also been an important consideration given the boom in these jobs due to COVID-19. Ashford et al. (2018) defined gig work as a type of temporary contract work connecting self-employed workers directly with clients by a digital platform. Gig workers have been classified into the category of crowd workers, who completed and delivered location independent tasks online, who were location independent, performed on-demand work, and who completed and delivered tasks offline. The level of skills needed to deliver the tasks has been either high (e.g., architects, software engineers), or low (e.g., drivers, deliverers). Because of contracting speed and flexibility to react to labor market demands, gig workers also have experienced change from the COVID-19 pandemic. The benefits of gig work have included greater autonomy and a high potential for work-nonwork integration, which has resulted in less restrictive, individualized, and whole careers based on the gig work model. Gig work has been associated with increased risks for workers, including demanding and precarious working conditions that have included low or sporadic pay, lack of welfare coverage, social isolation, overwork, fewer development opportunities, and job and career insecurity, which has resulted in more fragmented and bounded careers (Ashford et al., 2018). The downsides to the gig economy are likely to continue to be exacerbated by the effects of the COVID-19 pandemic as this sector grows.

Disruption in Career Trajectories

For younger or early-career adults, the COVID-19 pandemic may have been their first encounter with a significant global crisis, and this may have long-term psychological and financial effects. Mid-career workers generally have been more established, but if they lost their jobs, finding a new position may have taken longer. For late-career workers and retirees, the pandemic may have been even more stressful considering the rates of death among the elderly and the residual economic effects upon pensions and investments. It has been arguable that all workers, regardless of industry or time on the job, experienced some sort of "career shock" as a result of the COVID-19 pandemic.

A career shock has been defined as "a disruptive and extraordinary event that is, at least to some degree, caused by factors outside the focal individual's control, and that triggers a deliberate thought process concerning one's career" (Ackkermans et al., 2020, p. 428). It comprises an event and a process of sense-making. Career shocks may have different attributes to determine the impact on careers, such as frequency, controllability, intensity, valence, and duration. For example, in terms of valence, the pandemic has been generally viewed as negative because of issues such as job insecurity, loss of income, the emotional impact of social distancing, and increased general anxiety. However, there may also have been positive consequences, such as spending more time with immediate family and no

longer having to commute to work. Also, while most businesses have been negatively impacted, others, for example, software companies and home gym makers, have grown at an accelerated rate.

Chen et al. (2020) posited that career shocks related to COVID-19 have had mostly negative career and psychological consequences in the short-term, e.g., job loss, reduced salary, and lower career and job satisfaction, but over time workers may move into more satisfying careers or job roles based upon their own proactive behaviors. While social distancing measures may have mitigated the spread of COVID-19, the mental health consequences have likely been a substantial increase in rates of anxiety and depression as well as an exacerbation of pre-existing mental health vulnerability and/or treatment needs (Galea et al., 2020). This is an area where rehabilitation professionals can offer guidance to clients and evaluees to optimize their placement in the post-pandemic world of work.

Potential Impact Upon Persons with Disabilities/Employer Accommodations

Although the COVID-19 vaccines were rapidly developed and approved for emergency implementation (Graham, 2020; Paltiel et al., 2020), there has been concern about how access to it may impact the ability of persons with disabilities to remain in or re-enter the workforce. Due to age, health conditions or other factors, some populations have been recommended to wait before receiving vaccines or have been recommended against taking them altogether (CDC, 2020). Persons with disabilities, who may be immunocompromised to the point that they cannot safely tolerate a vaccine, may be unable to receive the vaccine altogether. If proof of vaccination becomes a pre-employment requirement, as has been discussed for travel, gatherings, and by some employers, this may further marginalize vulnerable individuals within this population.

On the other hand, it is also possible that a shift to remote work has been advantageous, at least to some degree, for persons with disabilities. Symptoms of fatigue and pain may become less of a barrier with goal-oriented tasks and flexible work hours available in remote work settings. Furthermore, functional limitations, such as difficulty with ambulation or mental health diagnoses (e.g., agoraphobia with resulting social limitations), may be accommodated by remote working trends; individuals may experience less push back from employers when requesting assistive technology or accommodations in the workplace. Employers have become more open to remote work opportunities, and the labor market is becoming more hospitable to these types of offerings, making room for the possibility that they may continue in perpetuity and may indeed become more plentiful as the labor market evolves.

Takeaways and Future Considerations

After considering the data available, and comparing this with what we have learned from past pandemics and economic recessions, some recommended takeaways for the reader are summarized here.

The first wave of the 1918 Pandemic began in March of 1918 and was followed by three subsequent deadly waves extending through spring 1920. The 1918 flu remained deadly for nearly a decade with only rudimentary means for mitigating its spread and the absence of an *mRNA vaccine technology*. From this, we can be optimistic that there will be an end to the COVID-19 pandemic. Until the COVID-19 pandemic subsides, however, it remains unclear what the true aftermath on our economy and society will be and how long it will take to realize. There are many interconnections in our complex society, and a shock to one sector often reverberates in others. Sometimes the effects occur close to the shock, sometimes long after; some shocks will be temporary and some long-lasting or even permanent.

Overall, it is likely that the pandemic will expose the resilience and vulnerabilities of gig work and other types of flexible employment relationships, while other effects upon the world of work remain to be seen. Governmental organizations, including the BLS, are proffering disclaimers with consideration to such unknown future outcomes. Illustratively, since mid-2020, the BLS labor market releases have indicated experts should reference labor market data with caution as the BLS's 2019-2029 projections have not included the impacts of the COVID-19 pandemic and subsequent re-

sponse efforts. The BLS has developed alternate scenarios for the 2019-2029 projections which have encompassed possible impacts from the pandemic (Wolf, 2020). Ultimately, the results from the alternate scenarios have demonstrated how changes in consumer behavior caused by the pandemic may alter the baseline projections for detailed occupations and industries. As is standard methodology, triangulating the available data related to the effects of COVID-19 to formulate and support expert opinions reaffirms the need to remain active as vocational practitioners instead of relying solely upon single-set data sources. A suggestion for best practice may be to include contemporary verbiage that indicates the opinions proffered are assuming "normal" labor market variability. Other disclaimer language may include an indication that the work product considered data sets most descriptive of the employment situation at the time the opinions were rendered.

Considerations for Future Research and Inquiry

It is important to examine the rules, knowledge, and attitudes developed during the current pandemic, and to determine if they will persist even after the COVID-19 pandemic ends. For example, monitoring trends such as whether remote work settings remain available, tracking whether jobs that have become classified as non-essential are eliminated in the future, as well as evaluating the effects of work-life balance over time.

It will be essential to monitor how or if the current market economy behaves differently from a traditional recession, and why it would or would not do so. This may be instrumental in determining if a pandemic-induced recession is merely an economic recession, or something entirely different, requiring novel solutions for repair. The same is true of monitoring which industries, if any, will be permanently impacted by the pandemic and determining if the landscape of the labor market permanently changes in the future or returns to its pre-pandemic trajectory. Similarly, paying attention to the accessibility of the COVID-19 vaccines and the longitudinal impacts of the vaccine on the labor market will be of value. Determining how access to broadband internet has been consequential to those with lower incomes and in rural areas for their employability, access to jobs, and use of virtual health care during the pandemic will provide further insight into the evolving socio-economic landscape. Monitoring how effective federal stimulus packages are in addressing delivery of broadband internet, as proposed, may also be helpful in keeping track of this issue.

The utility of data from past pandemics has appeared to be incompatible with current data sets and trends. However, it may be critical to track how data developed during the current pandemic will have utility in predicting the effects of future pandemics. This may also be instrumental in determining how the current pandemic influences the way vocational analyses are performed. As has been the case in most, if not all, sectors, vocational practitioners should consider how this pandemic impacts our work, particularly present and future analyses, changes in systems and delivery of goods services, as well as resources and how the pandemic may influence methodologies in the future.

Ultimately, whether there will be permanent methodological changes to vocational analyses because of the COVID-19 pandemic will rely upon many factors and variables, some of which may include: what we learn from how the pandemic influence future vocational plans, career counseling, and forensic opinions; whether there continue to be significant effects upon the labor market; how individuals with disabilities are impacted, both vocationally and economically; the fluctuation of wages and availability for "essential" and "non-essential" jobs and access to those jobs with evolving trends in novel occupational statuses; the net impact COVID-19 has on gender, racial and cultural inequality in employment; access to job opportunities and medical care; presumption of attempts to mitigate and ability to mitigate for injury, family law or employment discrimination cases; discovery of additional health concerns, longstanding physical or mental health problems that may arise in association with a COVID-19 diagnosis, or impacts of coping with the COVID-19 pandemic; what role technology continues to play to culturally and socially impact work, perceptions of work, future consumerism, and other industries after the pandemic dissipates; and finally, the overall economic legacy that the COVID-19 pandemic leaves behind.

Conclusion

As the United States transitions out of the first phases of COVID-19 adaptation, it has been clear that the vocational and economic landscape has changed, and adaptations will be reflected in the way that we approach the world of work moving forward. It is evident that analyses of vocational and economic conditions have followed suit. The immediate, short-term effects of the COVID-19 pandemic have been visible in changes to work, including arrangements, location, hours, and workloads. Changes have also been seen in worker attitudes, satisfaction with coworkers and supervisors, engagement, and work-life balance. Long-term effects must be investigated further and observed for potential fundamental changes in career development and/or job characteristics. Over time, researchers may choose to assess additional variables, such as lay-offs and employer restructuring, for more precise data pertaining to the impact of COVID-19 on workers and the labor market.

Reviewing workers' experiences during the period of the COVID-19 pandemic has the potential to inform employers on how to adapt employment relationships in the long-term. These could include minimizing turnover through support, promoting work performance, and improving the overall quality of their workforce. Further, flexible employment arrangements allow employees to become more aware of the impact of working conditions upon their health, work, and career development.

Although COVID-19 has provoked a global sense of social, economic, and personal uncertainty and has been the impetus for change on many levels, its legacy remains to be seen. Thus, the questions posed in this paper remain preliminary, as we have yet to see the full impact of the COVID-19 pandemic upon careers for all types of workers, as well as the economy as a whole. As the future unfolds, we will continue to have questions about what it holds and how we will function as practitioners moving forward.

As Soper (1919) mentioned in his discourse on the 1918 Pandemic, "We are still too close to the event to fully measure it" (p. 502). In accordance with Soper's (1919) thoughts, what is written here has only been an introductory view of the authors at present. It is speculative to speak authoritatively on the subject, and considering the parallels we have seen with COVID-19 and the 1918 pandemic, the best we can do at this time is to inform our opinions using the resources currently available. It remains critical to use peer-reviewed methodology, which is generally accepted within our fields of expertise to do so. We can use methodology and history to guide us and provide context for our approaches to vocational assessments in the age of COVID-19.

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INTERNATIONAL ASSOCIATION OF REHABILITATION PROFESSIONALS

IARP Life Care Planning - IALCP Section Status Report: A Year-In-Review

Dear IARP Members,

The Life Care Planning – IALCP Section has been hard at work on behalf of our section members this past year. Board members include Susan Riddick-Grisham, chair; Dr. Kristi Bagnell, chair-elect; Laura Woodard, representative to the IARP Board; Kirsten Thomas, secretary; Sarah Malloy, member-at-large; Dana Penilton, member-at-large; Elizabeth Davis, member-at-large; Nick Choppa, member-at-large; Elizabeth Zaras, member-at-large; Tricia Morrison, international liaison from Canada; and Mary Beth Benoit, our new student representative. Board members have been participating in various committees to coordinate events and services, including the IARP webinar committee, the IARP conference committee, the IALCP symposium committee, the IARP membership committee, the IALCP awards committee, and the IARP mentoring committee.

The IALCP section board has been dedicated to accomplishing our section goals. First, we have provided educational opportunities to advance the learning and professional development of life care planners. This involves developing topics for webinars and producing the first ever pre-symposium webinar series, geared toward educating beginning life care planners. We have also recruited speakers for the 27th Annual International Symposium of Life Care Planning and for breakout sessions at the IARP 2021 Virtual Conference, ensuring hours of valuable programming for life care planners.

A much-anticipated life care planning Summit is being planned for May 13-14, 2022, to be held in Dallas, Texas. Co-chairs include Elizabeth Davis and Evelyn Robert. The Summit will address a topic of concern in the specialty practice of life care planning-techniques of costing. Life care planners agreed at the 2017 Summit that a position statement should be prepared regarding the presentation of charges and/or costs in life care plans, the goal of which is to provide to life care planners based upon the variety of uses of life care plans and various jurisdictional requirements. The Summit committee has adopted this as its mission. As a first step toward the 2022 Summit, life care planners will be invited to participate in a survey to determine trends regarding costing. The survey will open at the 2021 IALCP Symposium.

Karen Preston and her committee members have also been hard at work on the *Standards of Practice for Life Care Planners - Fourth Edition*, which will be a seminal work encompassing core knowledge, skills, and behaviors that life care planners should use in the course of their work.

The IALCP section board has been working to enhance member benefits by pursuing partnerships with companies to offer products and services to members at a discount. We have discounts in place with FAIR Health and the American Hospital Directory and will be rolling out additional benefits in the next few months.

The IALCP section board manages the Fellow program through the College of Life Care Planning Excellence. The Fellow designation (FIALCP) recognizes life care planners who have achieved a high level of skill and who use their skills and knowledge to promote the advancement of life care planning. Another way the section recognizes life care planners with high levels of achievement in the specialty practice of life care planning is through the presentation of annual awards including the Outstanding Life Care Planning Educator Award and the Life Care Planner Lifetime Achievement Award. We look forward to opportunities in the future to serve our members and advance our practice.

Laura Woodard, MA, CRC, CLCP, CCM
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Life Care Planning for Vestibular Disorders

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Abstract

Vestibular disorders can follow injury or illness and they impact crucial aspects of a person's daily functioning. The aim of this article is to review case studies and treatment guidelines to both improve life care planners' knowledge of this set of disorders and better understand typically related treatment guidelines. This article will review the diagnoses of vestibular disorders, etiology, symptoms, and typical treatment guidelines along with three case studies demonstrating the implications for life care planning.

Life Care Planning for Vestibular Disorders

Vestibular disorders describe symptoms of varying diseases of differing etiologies (Strupp et. al., 2020). Individuals with vestibular disorders report symptoms of vertigo, dizziness, visual disturbance and/or imbalance (Farrell, 2015). These symptoms can significantly impact an individual's cognition, emotional state and daily functioning.

Merriam-Webster defines "vestibular" as relating to or affecting the perception of body position and movement. Life care planners often work with evaluees who have been diagnosed with a vestibular disorder following injuries such as whiplash and mild traumatic brain injury (Kolev, 2016). The diagnoses that a life care planner is most likely to come across in a medical review that may indicate vestibular symptoms include: Benign Paroxysmal Positional Vertigo (BPPV); Vestibular Hypofunction; otolithic deficits, vertigo and photophobia; mild traumatic brain injury or concussion; post-traumatic brain injury syndrome; post-traumatic headaches; balance system deficit from the inner ear; inner ear vestibular pathology; vestibular migraines; vestibular hypofunction; persistent postural-perceptual dizziness (PPPD); and multiple sclerosis (MS). Some of the causes of vestibular disorders may include medications, infections, inner ear problems, calcium debris in the ear canals, whiplash injury, and traumatic brain injuries (Vestibular Disorders Association [VEDA], 2021; Kolev & Sergeeva, 2016).

Individuals with vestibular disorders typically complain of dizziness. Dizziness is a subjective and often vague symptom and understanding the type of sensation being experienced can be helpful in understanding it's impact on daily activities. Dizziness can be described in terms of

- vertigo, a strong sense of motion or spinning;
- disequilibrium, feeling off-balance, unsteady, or wobbly;
- light-headedness, feeling woozy or disconnected from the environment;
- oscillopsia (vestibulovisual), the illusion that the world is jiggling whenever the individual moves; or
- presyncope, a feeling of losing consciousness or feeling about to faint (Post & Dickerson, 2010; Military Health System, 2020).

Other symptoms of vestibular disorders include balance issues, blurred vision, falls, confusion or disorientation, headaches, nausea, vomiting, diarrhea, and anxiety or fear of movement. These symptoms typically impact one's ability to engage in daily life tasks in activities at home, at work, and in the

community. Individuals may avoid leaving the house and restrict participation in community activities (such as shopping, socializing, attending worship, playing sports, and/or working). Changes in head orientation, rapid changes in visual movement, bright lights, and/or loud noises can trigger symptoms.

Individuals with vestibular disorders are often at risk of falling, and this may increase their fear of movement (Agrawal et al., 2009). These individuals will generally benefit from environmental modifications such as proper lighting, grab bars, clear pathways, modifying living environments to minimize reaching overhead or bending, using equipment such as a reacher to retrieve objects, using laundry baskets on wheels, or adaptation of activities.

Benign Paroxysmal Positional Vertigo (BPPV)

Benign Paroxysmal Positional Vertigo (BPPV) is the most commonly occurring vestibular disorder and is diagnosed by a trained healthcare provider (typically a physician, physiotherapist, or audiologist) using the Dix-Hallpike maneuver (Dunlap, Holmberg & Whitney, 2019). Individuals with BPPV experience brief periods of mild to intense vertigo triggered by head movement, nausea, and vomiting. There is no known cause, but it can be associated with a blow to the head or damage to the inner ear (Strupp et al., 2020). For billing purposes, the Dix-Hallpike maneuver is typically billed using CPT code 92542. This code is bundled within 92540, but when performed in isolation, it is billed with the modifier 59.

Treatments include Canalith Repositioning Treatment (CRT), the Modified Epley Maneuver, or the Semont (Liberatory) maneuver and can be performed by a vestibular trained physiotherapist (Dunlap, Holmberg & Whitney, 2019). For billing purposes, these maneuvers are typically billed with CPT code 95992, with a modifier of 59 if billed with other codes.

Peripheral Vestibular Hypofunction

Peripheral vestibular hypofunction, a condition where the balance of the inner ear is not working properly either bilaterally or unilaterally, is usually caused by inner ear issues, most commonly due to toxicity to the ear, meningitis, labyrinthitis, progressive disorders, congenital loss, or neurofibromatosis. It can also be due to head trauma, or as a side effect of medication prescribed after head trauma (Kolev & Sergeeva, 2016).

In most cases however, etiology cannot be identified. Typically, vestibular hypofunction results in difficulty in maintaining balance, oscillopsia, disequilibrium, and becoming physically deconditioned due to inactivity (Vestibular Disorders Association [VEDA], 2021).

The American Physical Therapy Association published clinical practice guidelines for vestibular rehabilitation for patients with peripheral vestibular hypofunction in 2016. These are the first clinical practice guidelines for this population.

Vestibular rehabilitation can improve subjective symptom report, perceived handicap, gait performance, balance, and activities of daily living for persons with peripheral vestibular disorders (Dunlap, Holmberg & Whitney, 2019). As a general guide, The American Physiotherapy Association recommends supervised vestibular rehabilitation sessions ranging from once a week for two to three weeks for acute to subacute unilateral vestibular hypofunction; once a week for four to six weeks for individuals with chronic unilateral vestibular hypofunction; and weekly sessions for eight to twelve weeks for individuals with bilateral vestibular hypofunction (Hall et al.., 2016). For billing purposes, the CPT code associated with a basic vestibular evaluation is 92540, which is a bundled code consisting of four procedures: 92541, 92542, 92544 and 92545. If all four procedures are not performed, then a modifier 59 would be applied.

In addition to supervised sessions, patients are prescribed a daily home exercise program. Education is provided to the patient to help them understand the program goals and how to progress their program independently (Hall et al., 2016). Targeted exercise in treatment may include gaze stabilization exercises to improve vestibulo-ocular reflex (VOR) gain, habituation to improve sensitivity to body movements, or optokinetic exercises to improve visual motion sensitivity (Dunlap, Holmberg & Whitney, 2019). For billing purposes, the CPT codes associated with vestibular rehabilitation include: 97110 for therapeutic exercise and/or 97112 for neuromuscular re-education of movement. These codes are timed codes of 15-minute intervals.

Concussion/Mild Traumatic Brain Injury (MTBI)

Head trauma can cause the brain to communicate abnormal signaling about position and movement of the head in space, resulting in abnormal vestibular functioning. Inaccurate vestibular information results in visual-vestibular issues that coincide with concussion symptoms, as there can be damage to the areas of the brain that are involved in visual and vestibular function (Wallace & Lifshitz, 2016). Vestibular dysfunction after labyrinthine concussion (damage to the inner ear caused by head trauma causing microscopic hemorrhages in the labyrinth) is often manifested by vertigo, nausea and/or vomiting (Kolev & Sorgeeva, 2016). Individuals who have sustained head trauma or TBI may also experience balance-related symptoms; such as, dizziness, unsteadiness, or imbalance (Row et al., 2019).

Vestibular symptoms for concussions are often assessed using the Vestibular Ocular Motor Screening (VOMS) assessment, as the VOMS tool was developed to screen vestibular and/or ocular disorders in individuals, post-concussion (Dunlap, Holmberg & Whitney, 2019).

Treatments can include the use of coloured lenses to relieve photophobia, prism lenses to relieve double vision, vestibular rehabilitation, and gaze stabilization. In order to have one's eyes fixed on a particular target during head movement, we rely on the vestibular ocular reflex (VOR). The VOR ensures gaze stability with head movement. Gaze stabilization exercises are prescribed in an attempt to adapt the VOR and reduce visual blurring with head movement. Vestibular rehabilitation can include balance and ocular exercises. Ocular exercises can be done with checkered walls, Magic Eye 3-D pictures, walking in crowded areas or on patterned carpets, viewing optokinetic videos, or balance training. Often a 20-minute brisk-walking program, preferably outdoors and including uneven terrain, is generally recommended as part of the vestibular rehabilitation program for those with vestibular dysfunction in order to improve conditioning and provide realistic balance challenges to the central nervous system (Wallace & Lifshitz, 2016).

Persistent Postural-Perceptual Dizziness (PPPD)

Persistent Postural-Perceptual Dizziness (PPPD) is a chronic vestibular disorder characterized by symptoms of dizziness, unsteadiness, or non-spinning vertigo that last for over three months with unknown etiology, but are worsened by upright posture, active or passive motion, and exposure to moving visual stimuli or complex visual patterns (Staab et al., 2017).

Treatment for PPPD may involve education on nutrition, medication, vestibular rehabilitation, and psychotherapy (Bittar & Lins, 2015). Vestibular rehabilitation that may be beneficial includes education, threat reduction, integrated relaxation/mindfulness practice, graded habituation, balance retraining, and visual/optokinetic motion desensitization (Dunlap, Holmberg, & Whitney, 2019). Psychotherapy was not indicated for longstanding PPPD; however, cognitive behavioral therapy (CBT) was shown to be effective

within eight weeks after initial onset (Vestibular Disorders Association, 2021).

Vestibular Migraines

Vestibular migraines, considered the most common cause of vertigo, are characterized by spontaneous rotational or positional vertigo and balance problems that precede or occur during or after a migraine headache and may be accompanied by sensitivity to light, intolerance to noise or smell, and tinnitus (Dieterich, Obermann & Celebisoy, 2016).

There is no evidence yet to support any specific treatment for vestibular migraines (Strupp et al., 2020). However, studies show that patients who were treated with lifestyle adjustments and migraine prophylaxis medication outperformed those treated with vestibular rehabilitation; although, vestibular rehabilitation is also a consideration in conjunction with lifestyle adjustments and medication (Dunlap, Holmberg & Whitney, 2019).

Multiple Sclerosis (MS)

For about 20% of people with MS, the vestibular system is affected, causing symptoms like dizziness, the sensation of spinning, and feeling off-balance. There are limited studies on vestibular rehabilitation for use with MS; however, one study by Hebert et al. suggests that vestibular rehabilitation may improve balance, dizziness, fatigue, and health-related quality of life in ambulatory individuals with MS (Hebert et al., 2018).

The Role of the Life Care Planner in Vestibular Disorders

The standard methodology for life care planning involves conducting a medical review, interviewing the evaluee, performing an assessment within the life care planner's scope of practice and seeking relevant professional consultations to form the medical foundation for the recommendations within the life care plan. The medical review will provide information on the evaluee's functional difficulties, gratuitous or paid assistance provided, potential safety concerns, whether the typical course of rehabilitation has been received, and the response to treatments to date. Conducting a formal vestibular evaluation is not typically within the scope of practice of the majority of life care planners; therefore, it is important to rely on the appropriate medical diagnoses and prognosis provided to establish the medical foundation. If specific recommendations to address vestibular impairment(s) are not made within the medical information reviewed, it is recommended that consultation is attempted with the treating vestibular rehabilitation provider(s) or relevant physicians. If vestibular evaluation and rehabilitation is within the scope of practice of the life care planner, then the life care planner would be able to make recommendations for future vestibular treatments, aids and supports following their evaluation in accordance with their professional standards of practice.

Review of Case Studies

Case Study One

This evaluee was a 40-year-old female who was involved in a motor vehicle accident (MVA) five years prior and had sustained a mild traumatic brain injury and soft tissue injuries. She complained of daily headaches or migraines (weekly to monthly), dizziness (vertigo) and nausea from brisk head movement or bending down, and deficits in concentration, memory, and word recall. Otolaryngology reports ruled out BPPV and she was diagnosed with an otolithic deficit. Prognosis was guarded with a high likelihood that

she would need ongoing support for activities of daily living and a low likelihood that she would return to work.

Social/Environmental/Vocational Situation

Prior to the injury, the evaluee was living in a rented two-story 2200 square foot, three-bedroom home with her two children, and working part-time as a server. She was the primary caregiver at home, and primarily responsible for all housekeeping, childcare, and meal preparation. She socialized with friends regularly and had a "tight-knit" social group.

At the time of the assessment, she was living in the same rented two-story home with her boyfriend and her two children, ages 10 and 16. Her boyfriend and children were helping out with the housekeeping, meal preparation, and grocery shopping. She had attempted a gradual return to work but was unsuccessful.

Activities of Daily Living

The evaluee reported only being able to walk short distances when dizzy. Head position changes, particularly when transferring from lying to standing, triggered a sensation of vertigo. Head position changes in the shower triggered dizziness, and she relied on a shower bench, a handheld showerhead, and grab bars for modified independence.

Looking down to cook and prepare meals triggered symptoms of vertigo and nausea and she relied on her boyfriend for daily assistance with meal preparation. She also relied on her boyfriend for grocery shopping, as crowded, busy, or open spaces triggered her vertigo and nausea.

Housekeeping tasks that required looking down or bending over, such as vacuuming or washing floors, cleaning tubs and toilets, and unloading the bottom shelf of the dishwasher triggered vertigo. Migraines also impeded participation in housekeeping tasks.

Responsibility for childcare was shared with her live-in boyfriend, but she avoided driving her children to school and extracurricular activities due to migraines and vertigo symptoms.

The evaluee was instructed by her family physician to drive only on asymptomatic days and only for short distances, with no driving on days with vertigo symptoms. She was medically restricted from working due to her vestibular symptoms.

She reported socializing less due to her low mood and vestibular symptoms; not wanting to be a burden, she no longer saw her friends and would just talk to them on the phone from time to time.

Implications for Life Care Planning

- The Otolaryngologist recommended "vigorous" vestibular physiotherapy, a neuro-ophthalmology evaluation to determine the need for vision therapy, and that she avoid any activity that put her at risk for falls.
- Neurology evaluation was indicated by the physiatrist for management of migraine symptoms.
- The life care planner recommended psychological assessment and counseling; housekeeping assistance, weekly; a taxi account to attend medical appointments and taking children to and from school; aids for independent function (shower bench, reacher, and cane) replaced every three to four years; and grab bar replacement with every future move.

Case Study Two

This 29-year-old male evaluee was involved in an MVA about two years prior to the care assessment

and diagnosed with concussion, post-concussion syndrome, vestibular migraines, and soft tissue injuries. He complained of daily headaches and weekly migraines, vertigo, and nausea caused by moving his head quickly, screen time (working on computer, scrolling on phone, or fast paced movies), bright lights, and busy environments. If his migraines and vertigo were too intense, he would vomit. He had many visits to the emergency department due to the intense pain from his migraines. He also complained of lower back pain impacted by sitting and lifting and carrying; shoulder pain impacted by lifting and reaching up; neck pain impacted by looking down; and severe symptoms of depression and anxiety. Prognosis indicated that if he responded well to treatment with recommended medications, migraines and vestibular symptoms would resolve, but neck and back pain would likely be ongoing.

Social/Environmental/Vocational Situation

Prior to the injury, he was living with his wife in a rented two-bedroom 700 square foot apartment and was responsible for 20–30% of housework, and 100% of indoor home maintenance (such as minor repairs or changing lightbulbs). He was working full-time as an accountant. He participated in outdoor sports, such as jogging and soccer, and socialized with friends.

At the time of the assessment, this evaluee was living with his wife and child (age 2) in the same two-bedroom apartment. He and his wife were expecting a second child. He worked as an accountant part-time and was doing a gradual return to work with modified duties but had not managed to increase back to full-time.

Activities of Daily Living

The evaluee was medically restricted from working full-time with full duties. He was working five days a week for five hours a day. His family physician recommended that he could increase to six hours a day within the month. He has a limited sitting tolerance of between 30 to 40 minutes and needed to take microbreaks throughout his day to manage his pain. He was also provided an ergonomic workstation by his workplace and would alternate from sitting to standing throughout his day.

The evaluee did not participate in housework duties due to fatigue and migraines. Housekeeping tasks that required looking down, such as washing dishes, vacuuming and mopping, and cleaning the washrooms triggered neck pain and dizziness. His wife had taken over responsibility for all housework and meal planning.

He no longer participated in any indoor home maintenance due to fatigue and migraines. Indoor home maintenance responsibilities were taken over by his wife, or his brother would come by to help.

He experienced pain and fatigue when caring for his child but reported doing it despite the pain. He reported limiting the frequency and duration he would take his child on outings due to fear of symptom exacerbation when he was away from home. He has difficulty falling asleep and staying asleep due to pain symptoms. He reported a reduced frequency in socializing with friends and family due to mood and pain.

Medical and Rehabilitation Program

At the time of the assessment, the evaluee was engaging in a rehabilitation program consisting of weekly physiotherapy, chiropractor, kinesiology and massage therapy, and counselling every two weeks. He had also received occupational therapy for case management, education on pain management strategies, and ergonomic assessment. For workplace equipment, he has a sit-to-stand desk, ergonomic chair, and footrest.

He was also attending neurology appointments every three months. He was receiving BOTOX injections

for migraines every three months, and Emgality (120ml self-injectable) monthly.

Implications for Life Care Planning

- The neurologist recommended ongoing BOTOX every three months and Emgality (120ml monthly) to manage migraines.
- The physiatrist recommended ongoing chiropractic care, physiotherapy and massage therapy to manage neck and back pain.
- The psychiatrist recommended psychology for CBT and a trial of nortriptyline.
- The life care planner recommended home support services, housekeeping and handyman services, to prevent the evaluee from regularly triggering his vestibular symptoms while restoring household roles.

Case Study Three

Case study three is a 34-year-old woman who was involved in an MVA three years prior to the care assessment. She was diagnosed with a mild traumatic brain injury (mTBI), post-concussion symptom disorder, soft-tissue injuries, post-traumatic stress disorder (PTSD), and depression. She complained of symptoms of vertigo, disequilibrium, and lightheadedness; nausea, vomiting, and nosebleeds that accompanied the vomiting (one to five times weekly); difficulty with memory, concentration, and attention; and fatigue and pain related to soft tissue injuries. During balance testing, she was observed to lose her balance and fall over spontaneously; thus, safety was a concern. Prognosis for mTBI was guarded. Prognosis for PTSD indicated possibility for improvement; however, may worsen if a future MVA occurred. Prognosis for depression indicated that symptoms may improve with treatment.

Social/Vocational/Environmental Situation

Prior to the MVA, the evaluee lived alone in an owned, 400 square foot studio apartment. She worked full-time at an architectural firm as a project manager (40–60 hours a week). Prior to the injury, she was responsible for all housekeeping, meal preparation, grocery shopping, laundry, and indoor home maintenance. She had an active lifestyle and enjoyed hiking, travelling, and socializing with friends.

At the time of the assessment, the evaluee was living in an owned, 600 square foot one-bedroom apartment and working from home in her previous full-time job. She was relying on friends for support with some housekeeping. In order to manage her workload, she spread her eight-hour workday over a 14 hour day, seven days a week, with breaks for naps, walks, and rehabilitation appointments. She was receiving assistance with meal preparation and housekeeping for four hours weekly, and ordering her groceries online.

Activities of Daily Living

The evaluee was limited with walking and standing, especially after symptoms of vertigo were triggered. She was limited to a sitting tolerance of about 30 minutes at a time.

She was restricted with work due to cognitive issues (memory, concentration, attention), headaches, fatigue, and vestibular symptoms. She reported making errors and using adaptive strategies to manage her limitations (using technology and taking notes).

Her ability to drive was reduced to driving no more than 10 to 20 minutes at a time due to vestibular and pain symptoms which restricted her ability to travel (driving on road trips).

She was limited with housekeeping, meal preparation, grocery shopping, and home maintenance. She

reported forgetting to turn off household appliances used for cooking, ironing, etc. She demonstrated the ability to do simple household tasks such as heat up a prepared meal, wipe counters and put away groceries. She required weekly assistance for meal preparation, housekeeping and used an online grocery service.

She no longer hiked and reduced her participation in travel and socializing due to mood, vestibular and pain symptoms.

Implications for Life Care Planning

- The physiatrist recommended ongoing therapies including physiotherapy, chiropractor, massage therapy, and active rehabilitation programming with a kinesiologist to work on strength and endurance for pain symptoms, and balance exercises to manage poor balance issues.
- The neurologist recommended continuing vestibular rehabilitation for one more year.
- The life care planner recommended housekeeping and meal preparation weekly for one year then to be reduced by 25% after a course of OT; occupational therapy for education on pain management, cognitive adaptive strategies, cognitive remediation, and assistance with obtaining ergonomic equipment; and an ergonomic workstation, including a sit to stand desk, ergonomic chair, blue light filter for her screen, and footrest was recommended.

Conclusion

Vestibular disorders are commonly diagnosed after injuries affecting the neck and head. Treatment and management of vestibular disorders is typically a multidisciplinary effort that involves a combination of medical services, medications, therapies, aids for independent living, ergonomic equipment, and home support services for optimal functional outcomes. This article can assist life care planners, without direct clinical experience working with individuals with vestibular disorders, to understand the basics of the diagnoses, treatment, and functional impairments that often arise in the context of vestibular disorders as well as relevant implications for life care planning.

Author Note

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IARP Social Security Vocational Expert Section Status Report: A Year-In-Review

Dear IARP Members,

First, we would like to thank our current and former board members for volunteering their time and energy to serve on the SSVE section board. Our section is robust because of the people who have served on the board before us- they are the true trailblazers. Our board is a diverse group of professionals from different areas of the country who share the same passion and commitment to provide unbiased expert testimony in Social Security administrative hearings and influence and shape policy that impacts the interests of our members.

This year, the SSVE section has focused on three goals: government relations, growing the SSVE membership and membership retention.

The Government Relations team includes Dr. Michelle Aliff, Dr. Amy Vercillo and we added a new member this year, Todd Gendreau. The Government Relations team has been hard at work this year. We have continued to build relationships with SSA staff as well as continue to build upon our relationships with BLS. This year we have continued to address issues such as:

- The team has continued to remind SSA that utilizing a regional vendor or national vendor scheme for VEs would be inappropriate and lead to a deterioration of services.
    - We have reminded SSA that CSU and the new coming online billing removes two large administrative burdens for SSA.
    - Preserving independence of VEs is essential to a fair adjudication process.
- SSA this past year began to enforce their existing policy that rotation occur only in the Region the BPA was located, i.e., a BPA holder should only be on the primary rotation in the Region their BPA is held. Rotation lists were addressed, and individuals were removed from out of region rotation lists. The team continues to monitor this issue to ensure that rotation is fair.
- VEs are now being rotated across regions and this has caused issues. The team has continued to address these issues.
- The team has confirmed several times this past year that BPA holders with multiple VEs only receive one spot in the rotation process.
- The team has continued to address issues relating to office closures and the impact that these closures have had on the number of hearings.
- The team has continued to address the development of ORS and its use in SSA hearings.
    - SSA has indicated its continued intention for ORS to replace the DOT.
    - BLS has indicated that ORS data can be utilized, and simple probability can be utilized to determine relationships between variables.
    - We will continue to address concerns and holes in the ORS data to ensure adequate information is collected for VE uses, both in the SSA realm as well as in other forensic work.

The team's goals for the upcoming year include:

- Continuing to advocate against a regional or national vendor scheme.
- Continuing to advocate for a fair rotation process.
- Continue to advocate for all offices to reopen to ensure people can gain access to benefits they are entitled to apply for.
- We will advocate for a fee increase as SSA indicated that a fee increase was not off the table in the middle of the contract year.

John Yent has been spearheading recruitment efforts by reaching out to future graduates of rehab counseling programs. He has also researched ways to integrate technology with continuing education and future conference presentations.

Mike Rosko has been instrumental in member retention by personally reaching out to individuals when their membership is lapsing or has lapsed. His efforts have netted multiple people who may have otherwise not renewed their membership.

Our future goals include continuing to build relationships with SSA and BLS staff and advocate for vocational experts and the interests of our members; continue to grow and expand SSVE membership, particularly with younger professionals; and provide continuing educational opportunities relevant to SSVE members.

We are excited for the challenges and successes that lie ahead in the upcoming year.

Todd Harden
Representative to the IARP Board

LONGITUDINAL RESEARCH STUDY ANNOUNCEMENT - IN NEED OF INTERNATIONAL ASSOCIATION OF REHABILITATION PROFESSIONALS (IARP) PARTICIPANTS!!

The IARP Salary Survey (Beveridge & DiNardo, 2016) was the first study examining rehabilitation counselors' earnings. The study builds upon prior research on counseling salary surveys completed by the American Counseling Association (ACA) and the Commission on Rehabilitation Counselor Certification (CRCC). This specific effort is to determine the current state of salary distribution within the IARP. The purpose of the study is to enhance our understanding of salaries in the rehabilitation counseling profession. We are conducting the 5-year follow up to this 2016 study. This is a pro bono study conducted by the George Washington University and IARP and we request your assistance. In 2016, 412 IARP members participated in the study. At this time, we have 138 IARP members that have participated for the longitudinal follow-up of the 2016 study. Your assistance in this research study is greatly appreciated. Data will be collected through an anonymous online survey. Section one of the survey collects general demographic information. Section two contains a few open-ended questions to allow you to share your experience. The results of this study will be published in IARP's Journal, The Rehabilitation Professional.

Here is a link to the IARP Salary Survey that will only take a few minutes to complete:

https://survey.alchemer.com/s3/6432481/IARP-Salary-Survey-2021-copy

(You may have to cut and paste the web address if the link does not work)

THE GEORGE WASHINGTON UNIVERSITY

WASHINGTON, DC

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The Impact of Nonexertional Limitations on Loss of Earning Capacity Evaluation in the Litigated Case

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Vocational experts have appeared and testified in the courts in the United States for the better part of half a century. The systematic process used by vocational experts to arrive at their conclusions has been well-documented, and many are comfortable dealing with questions requiring them translate a disabled person's physical limitations into reduced labor market access or loss of earning capacity. The same is not true when it comes to nonexertional limitations. This article speaks to the need for addressing the manner in which a vocational expert may deal with nonexertional limitations in a logical and defensible way.

Keywords: Vocational rehabilitation; transferable skills; expert testimony; nonexertional limitations; earning capacity; labor market access; vocational methodology; clinical evidence; forensic evidence; individualized assessment.

This article speaks primarily to vocational rehabilitation experts who provide opinions for litigated cases. By litigated cases, we refer to matters in the Federal District Courts, Superior Court, and States' Circuit Court. The target audience also could involve those who practice state workers' compensation, but it does not involve those practicing in the area of Social Security Disability. A vocational rehabilitation expert whose practice includes case assignments in jurisdictions such as those listed above will undoubtedly be requested to do an analysis of a matter which pivots on a construct called nonexertional limitations. It is part of the vocational expert's territory, and it is a territory containing risks. The vocational expert whose testimony has been limited by a motion in limine, or whose testimony has been barred by a trial court, is liable to bear the burden of explaining that exclusion for the remainder of his or her career. This is a rather broad topic. Yet, we feel it has not been fully addressed up to this point. We do not presume to cover every aspect of nonexertional limitations which may be encountered by the vocational expert, but we feel it is an area which bears investigation.

Self-Preservation for the Vocational Expert

Nonexertional limitations were first defined by the Social Security Administration. Social Security is the largest disability determination agency in the world; as such, it is the source from which much of the vocational expert's process flows (Traver & Ferrari, 2020). Section (404.1569 a) of the Code of Federal Regulations (CFR) opens with a general statement addressed to disability applicants: "Your impairments and related symptoms such as pain, may cause limitations of function or restrictions which limit your ability to meet certain demands of jobs. These limitations may be exertional, nonexertional, or a combination of both" (CFR 404.1569). The document continues in subpart "b" by defining exertional limitations: "When the limitations and restrictions imposed by your impairment(s) . . . affect only the strength demands of jobs (sitting, standing, walking, lifting, carrying, pushing and pulling), we consider that you have only exertional limitations" (CFR 404.1569). Subsection C next speaks to nonexertional limitations (1) "When the limitations and restrictions imposed by

your impairment(s) and related symptoms, such as pain, affect your ability to meet the demands of jobs *other than the strength demands*, we consider that you have only nonexertional limitations or restrictions" (CFR 404.1569). The CFR goes on to delineate a nonexertional taxonomy:

> (i) difficulty functioning because you are nervous, anxious, or depressed; (ii) difficulty maintaining attention or concentrating; (iii) difficulty understanding or remembering detailed instructions; (iv) difficulty in seeing or hearing; (v) difficulty tolerating some physical features of certain work settings, for example dust/fumes . . ."(CFR 404.1569).

Interestingly, the CFR's taxonomy includes a sixth category: "(vi) difficulty performing manipulative or postural functions of some work such as reaching, handling, stooping, climbing, crawling, or crouching" (CFR 404.1569). This article is concerned with *the first five subcategories of the taxonomy* (Items i through v). However, since the activities delineated by Item (vi) are addressed by *The Revised Handbook for Analyzing Jobs (RHAJ)*, we feel it unnecessary to address them because they have objective numeric ratings/rankings (USDOL 1991). The main purpose of this article is to address the difficulties encountered by vocational rehabilitation experts tasked with analyzing a matter involving symptoms such as pain, which either have no objective measurement/ranking, or do not readily lend themselves to such.

There are three fundamental areas in which a vocational expert must be conversant: vocational theory; process or methodology; and, the requirements of the courts in which the vocational expert will be appearing. The area focused on in this paper is methodology and where it applies to matters with nonexertional limitations. According to Beveridge et al. (2020), a significant percentage of vocational experts indicated they are aware of the need to train themselves to use proper methodology to avoid having their testimony stricken. Shahnasarian (2011) asserts that the entire reason for having a vocational expert testify is to help the court understand technical information beyond the comprehension of lay people, and, this cannot be accomplished without the proper use of accepted methodology. For years, vocational experts have utilized a method for systematically analyzing exertional limitations – see below. However, the same is not true for nonexertional limitations. The following are three examples of situations which may confront a vocational expert in relation to nonexertional limitations. This not an exhaustive set; however, these are three examples of nonexertional case scenarios frequently encountered by vocational experts.

Areas of Risk for the Vocational Expert

Below we address three common categories of nonexertional difficulty for the vocational expert. The three selected categories are concentration, pain, and prescription medications.

Attention and Concentration

Even though the CFR acknowledges that inability to concentrate may hamper an evaluee's ability to work and hold a job, it presents a dilemma for vocational experts (CFR 404.1569). Numerous factors including pain may interfere with an evaluee's ability to attend to or concentrate on a task. While an evaluee's report of poor concentration may sound plausible, most forensic vocational experts do not possess the qualifications to use standardized tests powerful enough to scientifically measure the evaluee's attention or concentration span. No matter how tempting it may be in a particular litigated matter, a vocational expert who merely assumes that these impairments are barring the evaluee from employment without substantiation by a properly qualified clinician, such as neuropsychologist, assumes the risk to be excluded either on the basis of lack of foundation or for testifying outside of one's scope of practice.

Chronic Pain

Certainly, chronic pain can be a terrible experience for the evaluee. Its presence also constitutes a dilemma for many forensic vocational experts. First, pain has its own sort of compelling logic; that is, if

an individual was severely injured through a catastrophic event, it is not surprising to hear there is residual pain. However, the vocational expert must be informed by function rather than diagnosis. The effect of residual pain frequently is described as mentally fatiguing, dominating the thought life, and sapping the person's energy. A key distinction which the vocational expert in a litigated case must realize is no one is there to fulfill the function of a Social Security Administrative Law Judge. The Social Security administrative judge bears the responsibility to "carefully consider the individual's statements about (pain) symptoms . . . ," (SSR 16-3P superseding SSR 96-7P); but, the vocational expert in a litigated case must operate on the assumption that it is his/her responsibility alone to give clear justification when making the evaluee's pain a factor in the vocational analysis.

Pain is relatable to the triers of fact because everyone has experienced pain to one degree or another. However, pain is subjective and sometimes elusive and is especially difficult to measure. Further, the vocational expert has no means of discerning how long and to what degree an evaluee's pain is going to endure. For that reason, litigated matters in which the evaluee's pain was a salient feature have proved a trap for more than one vocational expert. Appropriate methods for the forensic vocational expert to address chronic residual pain are discussed later.

Prescription Medications

Prescription medication is technically not a nonexertional limitation. Yet, it is closely related, and it has proven challenging for more than one vocational expert. It is routine during the initial interview for the vocational expert to inquire about medications, and it is not unusual to learn that the evaluee is taking one or more prescription medications. Some prescription medications have side effects such as drowsiness which could conceivably interfere with the performance of work activities. [These can be found within the categories of sedatives, muscle relaxants, and opioid pain medications]. It may be very tempting for the vocational expert to assume that the prescription medicine causes the evaluee to experience side-effects that preclude working, but this poses significant risk. Making this assumption exposes the vocational expert to the criticism of practicing medicine or pharmacology without a license. Worse, it can lead to an effort by opposing counsel to exclude the vocational expert's testimony entirely.

Methodology

The vocational expert dealing with nonexertional impairments has a far better chance of surviving when using established methodology. While there are various approaches that have been published, Field and Dunn (2014) recognize there is one prevalent vocational rehabilitation component common to the majority, the Transferability of Skills Analysis (TSA). The TSA originated from the early work of Sidney Fine in 1955 and was extensively developed in the work done at the University of Minnesota in the 1960's giving rise to the Minnesota Theory of Work Adjustment (Dawis & Lofquis, 1984). It is the one essential cog which the well-prepared vocational expert should not ignore. Most loss-of-earning-capacity analyses in the past 40 years have the TSA as a component. The TSA is based upon the foundation of quantitative data from the U.S. Department of Labor's *Dictionary of Occupational Titles* (1991) (*DOT*) and the *RHAJ*. These resources contain the only operational definitions of the traits of workers performing occupations in the national economy. These definitions provide a lexicon for communication between clinicians and are the basis for the conduct of a transferable analysis. TSA is well recognized in both Social Security practice and non-Social Security practice, and it has direct application in the practice of vocational rehabilitation. TSA extends beyond the fundamental question of whether an evaluee has any transferable skills; it is a systematic means to compare the evaluee's characteristics as a worker to the characteristics of occupations as defined in the *DOT* and the *RHAJ*. And the TSA provides a crosswalk for considering occupations related to the evaluee's prior relevant work. By permitting the expert to isolate on an occupation, TSA also provides a logical path to post-event earning capacity.

If anything is the traditional generally accepted methodology for vocational experts, it is the TSA. And nowhere is this more essential than in the context of nonexertional limitations. While the vocational expert may utilize a combination of practice models for a litigated case (Barros-Bailey, 2018), he/she should have a clear basis if they are electing to omit the TSA from their analysis. Stated in another way, the nonexertional case is a poor place for the vocational expert to try using an obscure methodology. The temptation to forgo methodology considerations in a litigated matter can be considerable for the vocational expert. Referral sources often have a vested interest and may place some pressure on the expert to generate an all-or-nothing work product. Instead of yielding to direct or indirect pressure to eschew the accepted peer-reviewed methodology, we offer some thoughts for the vocational expert's consideration when tasked with analyzing a case which has nonexertional limitations.

Court Decisions

A now well-known federal court ruling cited in previous studies of admissible vocational expert testimony is Kinnaman v. Ford Motor Company, 2000 (Field & Choppa, 2006). This case involved a forensic vocational expert who used a computerized job matching software program in performing the TSA. The vocational expert, when questioned, was unable to explain the reliability of the computerized job matching software program, or to articulate that the method was generally used by other experts in her field. Today we understand there is nothing out of the ordinary about a vocational expert using a computerized job matching software program. But it was the vocational expert's inability to explain the methodology that proved disastrous. Her expert testimony was excluded by the court.

Recent rulings have shown a similar trend. In the 2017 case of Smith v. Union Pacific (Case No. 11-cv-986), United States District Court for the Northern District of Illinois, Eastern division, a vocational expert was retained by plaintiffs to testify to an injured railroad worker's fitness to return to work and regarding medical expenses. The court, in its opinion, cited the case of *Kumho Tire*, arguing that an expert's testimony may not be based upon "subjective belief or unsupported speculation" (p.3). The vocational expert's testimony was excluded because he offered opinions outside of his scope of expertise. The court ruled that he failed to "substantiate his opinion" electing rather to "simply provide the ultimate conclusion without analysis." The opinion eliminating this vocational expert's testimony further stated that he erred by speculating as to "his subjective and uninvestigated beliefs regarding plaintiff's stress levels and tolerance." In addition, the Vocational Expert's mathematical calculations were excluded because he "did not involve the application of specialized knowledge to the facts of the case."

In the case of Henry Luwisch vs. American Marine Corporation (2018), defendants challenged the vocational expert's ability to testify regarding Luwisch's need for medical treatment, his earning capacity, and his work life expectancy. The vocational expert had made inferences in his narrative report that went beyond a simple description of the plaintiff's medical treatment. The court agreed with the defendants. The vocational expert was prevented from testifying as to Luwisch's medical condition, medical causation, prognosis, or history of treatment. Further, he was not allowed to testify concerning diminished work life expectancy because he had done no more than assign the plaintiff to a catch-all category of a "disabled individual." In this case the VE failed to apply specialized knowledge to the facts.

Also pertinent is a recent Tennessee Supreme Court ruling in Thompson vs. UPS (2016). It originated as a Tennessee Worker's Compensation case in which the plaintiff underwent spinal surgery as the result of an on-job-injury. Following his spinal surgery, the plaintiff complained of chronic residual pain. Mr. Thompson began taking OxyContin, reporting it took the edge off his pain. (Tennessee is a vocational disability rating state for Workers' Compensation). A vocational expert retained by the plaintiff gave an opinion in which Mr. Thompson had a 41% reduction of access to the labor market and a 70 percent loss of earning capacity. However, the plaintiff's vocational expert testified further that he had also added consideration for the fact Mr. Thompson was taking narcotic medication, and he had assigned weight to Mr. Thompson's pain. Further, he considered Mr. Thompson's four-year absence from the labor market, and he considered Mr. Thompson's appearance. Based upon weight-

ing the pain and assigning weight to the other three variables, the plaintiff's expert decided it tipped the scales and yielded a 100 percent vocational disability rating. At trial the defendants elicited testimony from a second vocational expert, who explained why she did not feel it appropriate to assign weight to Mr. Thompson's pain, choosing instead a more conservative approach. The trial court found no evidentiary basis for the testimony of the plaintiff's vocational expert, and ruled Mr. Thompson had only a 44 percent disability. Plaintiffs appealed the decision to the Tennessee Supreme Court which affirmed the decision of the trial court.

Recommendations for Minimizing Risk

Attention and Concentration

The first dilemma posited above had an evaluee reporting diminished ability to concentrate. It is important to remember this is a hypothetical concern, unless the vocational expert already possesses clear evidence in the records to supporting it. The vocational expert's first step should be a careful study of the report of the clinical psychologist or the neuropsychologist. A second step would be getting the psychologist involved to help translate the evaluee's diminished concentration into a framework where vocational analytical tools can be employed. The vocational expert must be prepared to take the added step of seeking input from the medical professional or clinical psychologist because it is function, not diagnosis, that informs the vocational expert's analysis. In this particular matter, if the vocational expert learns from the psychologist that the evaluee cannot concentrate on a task more than 20 minutes, he or she has a finite unit of time from which to start. The vocational expert may then wish to conduct a labor market sample. He or she may wish to eliminate occupations where a worker is required to meet precise limits and tolerances. Another step might be eliminating occupations higher than specific vocational preparation four, but, the point is that by taking the additional step of seeking input from the appropriate clinician, the vocational expert has gained access to a quantified piece of data and is thus able to operate within the standard accepted methodology.

Chronic Pain

What can the expert do if the evaluee reports to be significantly impaired by chronic pain? First, it is important to complete a systematic interview with the evaluee. Listen carefully and ask follow-up questions to get clarification about the effects of the evaluee's pain. The expert should inquire about the manner in which the chronic pain has changed the evaluee's ability to engage in necessary and discretionary activities such as personal care, participation in social activities, and how it has changed the evaluee's ability to participate in pastimes they enjoy such as hobbies. Of course, if the evaluee is still working, he should be asked about difficulties in work functions, difficulties in sustaining work activities over a full day and on successive days as well as the impact of needing to call in sick. Then the vocational expert can begin to form a hypothesis about how Physical Demands, Environments, and Temperaments might be affected by the evaluee's post-event condition. Again, everything must relate back to *DOT* and the *RHAJ* if the vocational expert wishes to strongly defend his or her conclusions. Armed with this information, the forensic vocational expert can talk with the treating physician, or with a therapist who performed the functional capacity evaluation, or with a neuropsychologist who has administered a test battery. But, again, the forensic vocational expert must orient that conversation around the authoritative sources: either inquire about physical functioning (e.g., standing) with the medical doctor; or inquire about *RHAJ* criteria related to mental functioning (e.g., precise tolerances, dealing with people, performing under stress, and making judgments) with the neuropsychologist.

If the treating physician advises that the evaluee cannot engage in prolonged standing, you have a starting point. This could indicate the evaluee is limited to sedentary work. If the neuropsychologist tells you the person is no longer capable of attaining precise set limits, tolerances, and standards, you again have a starting point. This may indicate the need to eliminate that temperament from the

evaluee's post-event worker profile. The well-prepared forensic vocational expert, when afforded the opportunity, should elicit as much detail from the medical expert as possible to solidify the basis for the vocational opinion. It is quite an accomplishment when well executed. To use a baseball analogy, the forensic vocational expert must frequently be prepared to play "small ball," rather than swing for a homerun every time. This will help achieve credibility and generate a report product which can be respected.

Prescription Medication

The third dilemma was prescription medications. Once again, the vocational expert must have a medical foundation. The vocational expert should query the physician because he or she recognizes that a vocational expert cannot make a medical decision/conclusion. The expert should inquire specifically about the medication side effects whether the physician feels it would be safe for the evaluee to operate power tools such as presses or saws, to be involved working in an environment with moving machinery, to safely drive a motor vehicle, or to engage in higher order cognitive activities involving making calculations or forming judgments. It is important to learn of the projected duration of the prescription and the physician's expectation of its effectiveness. If the evaluee is going to be taking the prescription pain medication less than 30 days, it is not wise for the vocational expert to attempt to draw any conclusion about its long-term effect. Armed with documented feedback from the physician, the vocational expert may choose to eliminate categories of jobs post-event that would require identified functional impairments connected to the side effects of medication.

Conclusion

We have given examples of the manner in which a vocational expert should identify gaps and missing information. We have also offered an illustration of ways the vocational expert may resolve these gaps by seeking appropriate guidance from clinical professionals. By doing so, the vocational expert is operating squarely within his scope of practice and using proper methodology. This helps to arrive at a defensible conclusion, and ultimately can contribute to a resolution of the litigated matter. Addressing a matter in which the evaluee's limitations are nonexertional has historically been a risky area as seen by the court cases cited. It is a challenging area of practice for the vocational expert. The scenarios presented are representative but not exhaustive. Our suggestions of actions the vocational expert could take are just a starting point. Much will vary according to the individual case. There are a variety of steps that can be taken to factor nonexertional impairments into a vocational assessment. Our objective is to counsel vocational experts against assuming too broadly, and to seek as much clinical corroboration for their professional judgments as possible. Some recommendations are made; however, this is an area that needs additional research and publication. We strongly feel this area must be further addressed with our colleagues. Additional research should be directed into means to represent various nonexertional impairments within the framework of the *RHAJ* operational definitions of Worker Traits. As this article is being written, we recognize the U.S. Department of Labor is in the process of gathering and reporting information for the Occupational Requirements Survey (ORS) which is in line to replace the ratings of the *DOT* and *RHAJ* (https://www.bls.gov/ors/). Nevertheless, it is virtually certain the vocational expert's challenge of dealing with nonexertional limitations is going to endure.

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Author Notes

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George Cyphers is an independent case consultant. He holds a MEd in Rehabilitation Counseling from Kent State University. He is now retired from 46-years' practice. He formerly was a Licensed Professional Counselor (Ohio), a CRC, CDMS and a member of IARP, NRA/NRCA, and ARCA. As a forensic expert, he prepared opinion reports in 14 states, multiple Federal and state jurisdictions in matters involving lost earning capacity, and cost of future care. Mr. Cyphers' experience includes working in the public, private non-profit, and proprietary rehabilitation sectors as well as teaching in the Kent State Rehabilitation Counselor Education program. He frequently presented at local, state, and national chapters of rehabilitation and allied professional organizations with subjects ranging from clinical practice and professional ethics to medical/legal applications of rehabilitation philosophy and principals.

Daniel V. Turner has been employed as a forensic vocational rehabilitation counselor at Ascendant Consulting, Inc, since 2011. Mr. Turner provides vocational expert testimony in Social Security Office of Hearing Operations (OHO) hearings and performs contract work for the U. S. Department of Labor's Office of Worker's Compensation. Mr. Turner also provides vocational rehabilitation assessments for workers compensation cases in Mississippi, Tennessee, and Alabama.

IARP Vocational Rehabilitation Transition Section: A Year-In-Review

Dear IARP members,

The VRTS Section Board includes Bruce Bloom (Representative to the IARP Board), James Williams (Chair-Elect), Tabitha Monahan (Secretary), Julian Shields (Representative to Legislative and Government Affairs Committee), Erin Bailey (Representative to IARP Membership and Marketing Committee), Julie Pickens (Representative to Education Committee), and me Whitney Paine (Section Chair). It is an honor to serve alongside the members of the Section Board. We will continue to work hard to strengthen our section and remain committed to the area of Transition Services.

In 2021, The VRTS Section continued to work hard to promote and distribute our Position Paper which stresses the importance of having a Certified Rehabilitation Counselor present when planning and implementing transition services. We continued our efforts as an exhibitor at the annual Council of Parent, Attorneys, and Advocates (COPAA). We continue to reach out to and work with various organizations and professionals to continue our sections mission.

The VRTS Section's goals for 2022 include, developing ways to reach out to the educational community on behalf of our section, increase our section participation and membership, along with assisting IARP as a whole to expand their membership and connection with the Rehabilitation Community as a whole. Our Secretary, Tabitha Monahan, has recently developed the idea of a monthly journal review book club related to our section goals. We continue to work diligently to find ways to support and encourage members of our section. We are currently working on a web training series in the area of Transitional Services and are open to topic suggestions that are of interest to our community.

As a section we would like to ask for your assistance with ideas on how to better serve our community and IARP as a whole. We continue to have a vacant Student Representative Position and would appreciate any referrals for students who show an interest in the area of Transition Services. We hope 2022, is our most productive year and personally I hope to improve our efforts in the area of transitional services.

Whitney Paine, MS, CRC, PVE, ABVE-IPEC
IARP Vocational Rehabilitation Transition Services: A Year-In-Review

The Rehabilitation Professional & Journal of Life Care Planning: A Year in Review Vol.1, No. 1, (49-59)

Reinventing Therapy Frequency: Recommendations for the Medically Complex Patient

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Abstract

This article outlines the differences between a traditional restorative model of therapy and a maintenance model of therapy. It defines medical complexity and skilled care as it pertains primarily to physical, but occupational and speech therapy as well, and explores why the medically complex therapy patient requires consistent skilled care. Individualizing therapy frequency by properly quantifying the utilization (frequency and duration) for the medically complex patient enables the life care planner to better meet the rehabilitation needs of this population.

Definitions

Rehabilitation in physical therapy has traditionally been focused on a model of restoring or improving functioning, which means functioning is either improved from one's normal state or improved when function is lost. Consider these two definitions: "Restoration especially by therapeutic means to an improved condition of physical function" (Webster, 2020) and "the action of restoring someone to health or normal life through training and therapy after imprisonment, addiction, or illness" (Lexico, 2021). In both these definitions restoration to normal health or improved function is the goal. Rehabilitation professionals are experts in the art of maximizing function and restoring the individuals in their care to their prior level of function or as close as possible given the nature of their injury or illness. Restoring function is ingrained in therapist's education, training and ultimately their clinical experience. Historically, the traditional restorative therapy model is the prescribed course of therapy with very few exceptions and is typically of short duration and relatively high frequency (e.g. three times per week for four weeks). The need for a restorative course of therapy is almost always preceded by an incident of onset, such as a sports injury, car accident or stroke. There are instances where the incident of onset is more vague such as in cases of exacerbation of underlying conditions like knee osteoarthritis. However, in both circumstances of exacerbation

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and acute injury, the unifying goal of therapy is always improvement. The traditional therapy model involves making focused goals towards improvement, with subsequent discharge when the goal is met, or the patient's progress plateaus. Examples include pain reduction, improvement of a range of motion deficit, independence with transfers etc. The expectation is that patients will improve in a reasonable amount of time.

Maintenance therapy differs from traditional, restorative, therapy in that improvement is not expected. Maintenance is defined as "the process of maintaining or preserving someone or something, or the state of being maintained." (Lexico, 2021) Return to the prior level of function is not anticipated. Often a recent and/or clear incident of onset is not obvious and chronic disease and/or disability is front and center. This course of therapy is intended to stabilize or slow the natural course of deterioration with a progressive condition or to prevent potential sequelae that may occur. Maintenance therapy is frequently the appropriate course for medically complex patients. These services are typically delivered at a decreased frequency but with a much longer duration (e.g. one time a week for 50 weeks/year). Need for maintenance therapy depends not on the patient's restoration potential, but on whether skilled care is required, along with underlying reasonableness and necessity of the services themselves (CMS Centers for Medicare & Medicaid Services, 2021b). The clinical diagnosis on its own does not determine the appropriateness of a maintenance course of therapy though many individuals suffering from chronic diseases such as ALS or multiple sclerosis would benefit as would some patients with complex orthopedic injuries, chronic pain or status post stroke for instance (CMS Centers for Medicare & Medicaid Services, 2021b). This type of therapy is indicated when the therapeutic interventions cannot be safely and effectively carried out by the patient themself or with the assistance of unskilled caregivers.

Maintenance Model vs. Restorative Model of therapy

When comparing the maintenance therapy model to the restorative model there are several key criteria that must be met in either scenario. In this respect maintenance and restorative courses are the same. The services must be reasonable, necessary and skilled. In order to compare these two models of therapy, we must first understand the following definitions.

Reasonable and Necessary

CMS defines reasonable and necessary as: "a.) safe and effective (versus experimental or investigational), b.) appropriate, including the duration and frequency that is considered appropriate for the service, in terms of whether it: is provided within accepted standards of medical practice for the diagnosis or treatment of the patient's condition, or to improve the function of a malformed body member; is furnished in a setting appropriate to the patient's medical needs and condition; is ordered and provided by qualified personnel; meets, but does not exceed, the patient's medical need" (Palmetto GBA, 2021). CMS defines skilled care as: Is medically necessary care that can only be provided by or under the supervision of skilled or licensed medical personnel (CMS Centers for Medicare & Medicaid Services, 2021a).

Skilled Therapy

Skilled rehabilitative therapy occurs when "The skills of a therapist are necessary to safely and effectively furnish a recognized therapy service whose goal is improvement of an impairment or functional limitation." It is predicated on proficiency, facility, or dexterity that is acquired or developed through training or experience, an art, trade, or technique (CMS Centers for Medicare & Medicaid Services, 2020).

Skilled maintenance therapy occurs when the skills of a therapist are necessary to safely and effectively furnish a recognized therapy service whose goal is to maintain the patient's practicable level of function and/or slow deterioration.

Skilled care may be necessary to improve a patient's current condition, maintain the patient's current condition or prevent or slow further deterioration of the patient's condition. Skilled therapy must be of a complexity that requires the services of a skilled therapist. A layman could not safely and effectively carry out the treatment. Given the definitions above, a care process must be reasonable and necessary, but the goal of may differ depending on whether it is an improvement process or one of maintenance. The determination on which is emphasized is not only a matter of the training of the professional, but is a matter of whether the prognosis of the diagnosis includes the possibility of improvement or restoration. In many medically complex diagnoses or chronic diseases, restoration of prior functioning is not a reasonable goal.

Medical Complexity/Complex Chronic Disease

Complex medical conditions are emergent, persistent and substantially debilitating. Complex chronic disease (CCD) conditions involving multiple morbidities that require the attention of multiple health care providers or facilities and possibly community (home)-based care. A patient with CCD presents to the health care system with unique needs, disabilities, or functional limitations (Sevick et al., 2007).

The medically complex population should be familiar to life care planners. The International Academy of Life Care Planners definition of a life care plan: "The life care plan is a dynamic document based upon published standards of practice, comprehensive assessment, data analysis, and research, which provides an organized, concise plan for current and future needs with associated costs for individuals who have experienced catastrophic injury or have chronic health care needs [emphasis added]" (IARP International Association of Rehabilitation Professionals, 2021).

Like many in the healthcare field who practice life care panning, physical therapists work with patients with spinal cord injury symptoms of hypertonicity/spasticity, autonomic dysreflexia, and neuropathic osteoporosis. Other example diagnoses and symptomology are: Acquired brain injuries with behavioral/cognitive issues, spasticity/tonal imbalances, and seizures; burns with tissue frailty, contracture, and chronic pain; chronic pain with Co-occurring mental disorders (e.g. depression, anxiety) and pharmacological concerns.

Common Skilled Therapy Modalities and Interventions

When making physical, occupational or speech therapy recommendations in a life care plan, the scope of services that comprise that therapy are not usually explored and de-

Table 1

Key Differences Between Restorative and Maintenance Therapies

Restorative	**Maintenance**
Absence of severe chronic disease or disability that limits rehab potential	Chronic disease or disability is at the forefront in limiting rehab potential
Clear incident of onset	Often less clear incident of onset
Potential to regain prior level of function	Not expected to regain pre-injury/illness level of function
Objective/measurable improvement is anticipated in all areas addressed (e.g. transfers, pain, strength, balance etc.) and in a reasonable and generally predictable period of time. Short-term and long-term goals as established accordingly	Improvement is not anticipated. The goal is to maintain the patient's practicable level of function and/or slow deterioration. Goals are established accordingly.
Higher frequency and shorter duration (e.g. 2-3 x week for 6 weeks)	Lower frequency and much longer duration (e.g. 2-4 x month for 12 months)
Discharged with a home exercise program that the patient can perform independently or with assistance of an unskilled caregiver	Home program cannot be safely and effectively carried out by the patient or unskilled personnel
Upon reaching goals and discharged, the patient is stable	Decline is probable without continuation of skilled care

fined. Without an understanding of the proper scope of those recommendations, it is difficult to know if skilled or unskilled services are reasonable or necessary. Certain interventions and modalities can, by their nature, only be exclusively, safely and effectively delivered by a skilled therapist, while others may be carried out by non-skilled personnel provided that they have received the proper training. Assessment, evaluation and clinical decision-making, however, must be carried out by a skilled therapist. The skilled therapy interventions below are primarily physical and occupational therapy interventions.

Deep Heat

Deep heat modalities include ultrasound, shortwave diathermy (SWD) and microwave diathermy (MWD). Ultrasound is, however, the most used deep-heating agent. The ultrasound machine converts electrical energy into acoustic energy via the piezoelectric effect. SWD and MWD convert electromagnetic energy to thermal energy. Thermal energy (high temperature; heat) provides pain relief, increase in local blood flow, metabolism, and elasticity of connective tissues. The non-thermal effects of ultrasound may improve or repair soft tissue injury, slowing the inflammatory response and protein synthesis, while modulat-

ing membrane properties. Phonophoresis (Sonophoresis) is the use of ultrasound to drive medications into and through skin (PM&R Knowledge Now, 2016). Deep heat modalities have a number of contraindications and there is substantial risk of burns and tissue damage if done incorrectly; therefore, they must always be applied by a skilled therapist.

Iontophoresis

Iontophoresis is the use of a specialized electrical stimulation machine and electrodes or plates to deliver a medication through the skin barrier (PM&R Knowledge Now, 2016). Similar to phonophoresis, this is always a skilled modality.

Vestibular Rehabilitation Therapy (VRT)

Vestibular Rehabilitation Therapy (VRT) is a specialized form of therapy intended to alleviate both the primary and secondary problems caused by vestibular disorders. It is an exercise-based program primarily designed to reduce vertigo and dizziness, gaze instability, and/or ease imbalance and the propensity for falls. VRT begins with a comprehensive evaluation. Patients are seen by a licensed physical or occupational therapist with advanced post-graduate training (Vestibular Disorders Association (VEDA), n.d.).

Manual Therapy Techniques

The International Federation of Orthopedic Manipulative Physical Therapists (IFOMPT) defines manual therapy techniques as: "Skilled hand movements intended to produce any or all of the following effects: improve tissue extensibility; increase range of motion of the joint complex; mobilize or manipulate soft tissues and joints; induce relaxation; change muscle function; modulate pain; and reduce soft tissue swelling, inflammation or movement restriction" (Physiopedia 2021). Physical therapists select, prescribe, and implement manual therapy techniques when the examination findings, diagnosis, and prognosis indicate use of these techniques to decrease edema, pain, spasm, or swelling; enhance health, wellness, and fitness; enhance or maintain physical performance; increase the ability to move; or prevent or remediate impairment in body functions and structures, activity limitations, or participation restrictions to improve physical function. Manual therapy techniques may include the following: manual lymphatic drainage; manual traction; active release techniques; instrument assisted soft tissue mobilization; trigger point therapy; massage of connective tissue massage or therapeutic massage (e.g. cross-friction, myofascial release); mobilization of spinal and peripheral joints (thrust and non-thrust manipulation); soft tissue mobilization; dry needling; neural tissue mobilization; active range of motion (AROM); active assisted range of motion (AAROM); or passive range of motion (PROM)(APTA Guide to Physical Therapist Practice, 2021).

With the exception of range of motion, all of the above techniques require the skills of a trained therapist, However, even ROM requires skill in circumstances where there is risk for fracture, abnormalities in muscle tone, or when graded resistance or assistance is required.

Neurological Physical Therapy

Neurological Physical Therapy is a form of therapy that is focused on working with people who have a type of neurological disorder or disease. The types of neurological diagnosis treated by this form of physical therapy may include traumatic brain injury, ALS, Alzheimer's disease, cerebral palsy, Parkinson's disease, multiple sclerosis, stroke, or spinal cord injuries (Disabled World, 2017).

Some common neurorehabilitation techniques are NDT/Bobath, movement therapy/Brunstrum, PNF/Proprioceptive Neuromuscular Facilitation, and sensorimotor/Rood. The implementation of any of these approaches requires extensive training and clinical skill (Ideas for OT, n.d.).

Therapeutic Exercise

Therapeutic Exercise is the systematic performance or execution of planned physical movements or activities intended to enable the patient or client to remediate or prevent impairments of body functions and structures, enhance activities and participation, reduce risk, optimize overall health, enhance activities and participation, reduce risk, optimize overall health, and enhance fitness and wellbeing" (APTA Guide to Physical Therapy Practice, n.d.). Common Types of Therapeutic Exercise include: strengthening exercises, usually performed with heavier resistance and fewer repetitions (e.g. 8-12 repetitions); endurance exercises engage large muscle groups over a longer period of time, in the area of 50 to 60% VO2Max to achieve greater cardiovascular endurance; flexibility exercises achieved through stretching and movement; and, balance and coordination exercises that focus on maintaining an individual's center of gravity.

The effectiveness of therapeutic exercise is undeniable, however it must be properly dosed to be safe and effective. The exercise prescription generally follows the FITT pneumonic:

- F- frequency: number of days per week
- I- Intensity: low, moderate or vigorous
- T- Time: minutes per session for endurance exercise
- T- Type: endurance, strength, flexibility or some combination (APTA Guide to Physical Therapy Practice, n.d.).

Proper exercise dosing and periodic progression and/or modification of an exercise program requires clinical skill. Frequently a home-exercise program or aspects of a home-exercise program can be carried out by the patient or under the supervision of a trained caregiver. However, there are instances when that is not safe. A common example would be when prescribing dynamic balance exercises to a patient with high fall risk and osteoporosis. In order to be effective, balance exercises need to be of a difficulty that translates into a 25% failure rate. Failure equates to a loss of balance sufficient to cause a fall. Another example would be in the case of an individual that suffered a SCI and has severe lower extremity spasticity requiring tone reducing techniques in order to stretch effectively.

Common Unskilled Therapy Interventions

Range of Motion

Range of motion interventions include basic passive, active assistive or active range of motion that do not require careful modulation of resistance or assistance, inhibition or facilitation of movement.

Therapeutic Exercises

Therapeutic exercises include a home exercise plan that has been prescribed by a therapist and identified to be safe and effective without the continuous need for skilled intervention. Periodic reassessment would still be necessary for modification of the plan.

Superficial Heat

Commonly used superficial heat modalities include hot packs, heating pads, and paraffin bath. They are used to increase the temperature of the skin, fat, blood vessels, nerves, and increase circulation and provide pain relief.

Cryotherapy

Cryotherapy means ice or cold application. Ice is believed to control pain by instigating local anesthesia. It also decreases edema, nerve conduction velocities, cellular metabolism, and local blood flow.

Walking Program

A walking program is an independent or supervised ambulation program that may be prescribed by a medical professional. May entail use of an assistive device and self-monitoring of vital signs such as heart rate. Not to be confused with gait training that is a skilled intervention that may include facilitation or inhibition of certain movement patterns and manual, verbal and demonstrative cueing to allow for or improve functional gait.

Frequencies of PT Delivery

Restorative Frequency and Duration

According to CMS, The frequency refers to the number of times in a week the type of treatment is provided. Where frequency is not specified, one treatment is assumed" (Medicare Benefit Policy Manual, n.d.). Duration is defined as "the number of weeks, or the number of treatment sessions, for THIS PLAN of care" (Medicare Benefit Policy Manual Chapter 15 – Covered Medical and Other Health Services, 2003).

In traditional/restorative therapy, frequencies are of high intensity: 2, 3, 5 times per week and duration is of low intensity, or 4, 6, 12 weeks. When determining traditional therapy frequency and duration medical professionals often fall into scheduling habits; consequently, life care plans commonly have recommended frequencies such as: 3 times a week for 4 weeks or 2 times a week for 8 weeks. These often-used frequencies and durations do not always reflect the specific treatment needs of the individual. Therefore, when possible it is helpful to refer to clinical practice guidelines or established protocols when recommending

the frequency and duration. An example would be physical therapy following total shoulder replacement with a frequency of: 3 times a week for 12 weeks (The Ohio State University Wexner Medical Center, n.d.).

However, this specificity is not always possible especially with diagnoses that are not acute or clearly defined, such as late effects of CVA or exacerbation of low back pain. In those instances, the clinical judgement of a treating therapist or physician would be most helpful, and a range is often useful, such as two-to-three times a week for four-to-six weeks.

Regardless of diagnosis, acuity, age, symptomatology etc., when recommending a restorative course, it is imperative to keep in mind that objective/measurable improvement is anticipated in all areas addressed and in a reasonable and generally predictable period of time. Once goals are met the patient is discharged.

Maintenance Frequency and Duration

Unlike traditional/restorative therapy, maintenance therapy frequencies are of much less intensity: 1 time week, 1 time every two weeks, 1 time month and duration is of high intensity; for example, 26 weeks/year, 50 weeks/year, or 12 months/year.

Unfortunately the vast majority of therapists and physicians are unfamiliar with maintenance therapy; consequently, when consulted their recommendations will almost invariably mirror a restorative therapy prescription despite the fact that the patient is not expected to improve, is medically complex, and will regress functionally and otherwise if not provided with skilled care. Providing educational resources specific to maintenance therapy often proves helpful.

The Maintenance Therapy Benefit as Law; CMS & Jimmo v. Sibelius

Health care in the United States is heavily influenced by the Centers for Medicare and Medicaid Services (CMS). CMS is a part of the Department of Health and Human Services and provides health coverage to more than 100 million people through Medicare, Medicaid, The Children's Health Insurance Program and the Health Insurance Marketplace.

Medicare is the ultimate collateral source, spending $799.4 billion in 2019 or 21% of total National Health Expenditures (CMS Centers for Medicare & Medicaid Services, 2019b).

As a result of its enormous scope, CMS and specifically Medicare is a major driver of healthcare policy. When CMS changes or clarifies a policy/regulation it influences the rest of the market. This was clearly demonstrated following the January 24, 2013 settlement agreement in the case of Jimmo v. Sebelius, in which the plaintiffs alleged that Medicare contractors were inappropriately applying an "improvement Standard" in making coverage determinations (CMS Centers for Medicare & Medicaid Services, 2021b).

The settlement resulted in a clarification of the maintenance therapy and skilled nursing policy for Medicare beneficiaries which:

- Defined skilled maintenance therapy and skilled nursing
- Repudiated the improvement standard
- Clarified that maintenance is not limited to specific diagnosis

- Clarified that there are no specific time limitations to care.
- Stated that diagnosis of dementia or altered cognitive status does not preclude care
- Applies to multiple settings: home health, outpatient, skilled nursing facilities
- Stated that the beneficiary must require skilled services that are reasonable and necessary (CMS Centers for Medicare & Medicaid Services, 2019a).

The settlement agreement mandated that CMS update its provider manuals and mount an educational campaign for contractors, adjudicators, providers, and suppliers. Despite these efforts the vast majority of clinicians are still unaware of maintenance therapy as an option for their medically complex patients that are not expected to improve. While therapists understand intuitively the benefit of skilled care for this population, they do not realize that the services are covered and reimbursable. All too often these patients are discharged once they fail to improve or plateau; consequently, they deteriorate.

Use of support care staff to supplement maintenance therapy

When establishing a care plan or making recommendations in a life care plan, it is extremely important to take into consideration and utilize the resources/supports available to the individual. Individuals in need of a life care plan by definition have experienced catastrophic injury or have chronic health care needs. Nearly always they require attendant care in some capacity to assist with activities of daily living (ADls), functional mobility etc. When establishing and carrying out a maintenance course of therapy it is appropriate for the therapist to train the caregiver/s in performance of the aspects of the home program that can be safely and effectively carried out by a non-therapist. The caregiver/s may be a home health aide, CNA, massage therapist, personal trainer, family member etc. Frequently the individuals themselves can perform aspects of the program once properly trained such as basic ROM exercises. In these cases the skilled therapist would come in periodically to provide skilled hands-on care and provide the clinical judgement necessary to evolve the program based on their reassessment of the individual and their function and needs. It is also important to keep in mind that agency CNA/home health aide turnover is very high, averaging 64.3% in 2019 (down from 84% in 2018) necessitating frequent retaining of support care staff (Home Health Care News, 2020).

Choosing the Appropriate Frequency, Restorative or Maintenance

When recommending a maintenance vs. traditional therapy frequency some key questions should be asked and answered in order to determine the appropriate course:

a Is the person being evaluated medically complex?

b Are they expected to improve (e.g. regain their prior level of function) in a reasonable amount of time?

c Does the necessary treatment require the skills of a therapist to safely and effectively carry it out?

d Is it probable that the person being evaluated will regress functionally without ongoing skilled therapy?

Table 1 above can be referenced for a list of key differences in these approaches.

For those individuals that would benefit from maintenance therapy it is probable that during certain periods during their life span they will also need periodic courses of restorative care. Life care plans should account for these occurrences. An example would be an individual with a cervical spinal cord injury that requires a maintenance course of physical therapy of 40-60 visits per year and develops heterotrophic ossification at the hip requiring surgery. Following surgery, he will need a restorative course of therapy (e.g. 3 times a week for 6 weeks). Once he achieves his goals with restorative therapy, he and his caretakers would revert back to the maintenance therapy frequency.

Conclusion

Historically, maintenance therapy has been poorly understood and severely underutilized by the medical community, but hopefully this is changing. Therapy is a frequent and vital component of the majority of life care plans. Most individuals who need a life care plan have chronic conditions resulting from injury or illness and are medically complex. Establishing the correct frequency of future therapy is critical for this population. Maintenance skilled therapy is critical in halting or slowing decline and keeping individuals out of the hospital, maximizing, and stabilizing function and improving overall quality of life.

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IARP-Florida

The members of ***IARP-Florida***
would like to express our appreciation
to the editors and contributors to the
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Your hard work and expertise
result in a wonderfully comprehensive journal,
making our profession better with each edition.
Thank You!!

IARP Rehabilitation Disability Case Management Section Status Report: A Year-In-Review

Greetings IARP Members,

The RDCM board consists of our chair, Sara Shugars who has been an amazingly effective leader making our meetings very productive, yet still enjoyable. Kim Nortz is our Secretary, who is a great idea person, like Michael Fryar and Aleesha Luke, who serve effectively as Board Members at Large. These board members' commitment and follow-through, coupled with their great personalities have made it a pleasure to work with them and be their representative to IARP.

The RDCM committee has been very productive this year expanding our board, reaching out to our section on the listserve, and hosting interactive webinars.

We have hosted two very successful webinars:

- *"Post-Concussion and Chronic Headaches: Case Study Review and Discussion"*; presented by Sara Shugars and Kim Nortz
- *"Neurosurgical Case Discussion: From ICU to RTW"* presentation by Dr. Allan D. "Tripp" Nanney III, Neurosurgeon, hosted by Sara Shugars

Our upcoming goals for 2022, include developing Ergonomic specialists as a new membership group into the RDCM section. RDCM representatives will be attending future ergonomics seminars and national conventions to present the benefits and value of IARP/RDCM membership and recruit new members.

Based upon feedback from our members, we will also develop an interactive webinar regarding vocational placement services.

We will also focus on increasing the information and value of interaction on RehabConnect to build the RDCM community and our value to each other.

As always, the RDCM board members will continue to focus on recruiting tenured and young professionals to fill RDCM Board Member at Large positions, as well as Finance, Education, and Membership and Marketing Committee openings.

If you are interested in volunteering one to two hours a month on teleconference calls to assist in the education and interaction of RDCM members, please contact any of us:

Sara Shugars: sara@shugarsconsulting.com
Edward Steffan: epsteffan@epsrehab.com
Kim Nortz: knortz@wcf.com
Michael Fryar: fryar1976@hotmail.com
Aleesha Luke: aleesha@lukevr.com

Best wishes from the RDCM board for a safe, healthy, productive, and prosperous year!

Edward P. Steffan, M.S., C.R.C., L.P.C.
Representative to the International Association of Rehabilitation Professionals

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Evolution of Life Care Planning with Technology

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Abstract

When the concept of life care planning was introduced in the 1980s, only certain technology-based tools were available to the general public and life care planning practitioners. During the last 30 years as life care planning evolved, so too did the role of technology-based products. During this time, workplaces adopted the personal computer, as well as internet, email, and cellular telephones. This adoption of advanced technology improved the life care planner's efficiency and delivery of services in a competent and ethical manner. During the COVID-19 pandemic, enhanced technology including the use of video conferencing, has assisted with the restrictions of social distancing and the safety of evaluees. This article reports findings from a 2020 survey of 100 life care planners who responded to five questions about the role of technology in their life care planning practice.

Keywords: life care planning, technology, software, COVID-19

Any discussion of technology in life care planning must examine the roots of life care planning as a professional discipline. It is well-known that life care planning emerged as a result of the work by Frederick Raffa, economist, and Paul Deutsch, psychologist, in the 1970s (Weed, 2019), and by the early 1980s, the concept of life care planning was introduced in *Damages in Tort Actions* (Deutsch & Raffa, 1982). Since that time, there have been multiple articles written, tens of thousands of life care plans developed, numerous life care planning conferences held, and several textbooks written about life care planning as a practice area. Like all disciplines, life care planning tools reflected the times in which the field emerged.

A review of reports from the United States Census Bureau regarding the percentage of American households with computers starts the timeline in 1984, two years after *Damages in Tort Actions* was published. Based upon data collected through the Current Population Survey in 1984 (the first time that data about computer use was reported), 8% of American households had a computer and 59% of the people in those households reported that they were learning how to use the computer (Ryan, 2018). Contrast this to the 89% of American households that reported having a computer during the last round of data collection in 2016 (Ryan, 2018). The availability of personal computing changed how work was performed in almost all disciplines, and this is true of life care planning.

A review of early life care planning publications revealed statements such as "The biggest aid to the rehabilitation professional during the research phase of the life care plan will be the telephone" (Deutsch & Sawyer, 1994, A-7), reflecting the tools available to life care planners at the time. As computing technology became more accessible in the United States, this transitioned was reflected in life care planning publications. The first edition of the *Life Care Planning and Case Management Handbook* (1999) included a 28-page chapter entitled "Technology and Life Care Planning," where it was noted, "Most life care planners will be using the Windows 95 operating system by Microsoft, Inc." (Thomas, 1999, p. 411). In that chapter, there was an explanation of email, which was noted to be "in the early stages of development" (Thomas, 1999, p. 414). To provide a cost summary for items contained in a life care plan, the options of using a calculator or programs such as Excel or Lotus were referenced (Thomas, 1999, p. 409). In a 2001 International Academy of Life Care Planning (IALCP) *Academy Letter*, Paul Amsterdam wrote, "Many life care planners use mail order catalogs or some Internet sites to get prices for wheelchairs" (Amsterdam, 2001, p. 1). In this same Academy Letter, a section was found entitled Research *Websites for Life Care Planners*. By 2002, the IALCP Academy Letter (McCollom, 2002) reflected that the IALCP maintained a website.

It is clear that as computer technology was emerging, some of it was being incorporated into the practices of life care planners. The personal computer, eventually equipped with internet access, obviously became available to life care planners, as did other industry-specific technology tools, some of which were developed by rehabilitation professionals, to address other needs within a life care planning practice. This included computer-based programs that provided medical coding information; computer programs that provided access to aggregated healthcare-related costs; and computer programs that generated the actual life care plan report. Martino (2007) emphasized that computer programs could help to save time when preparing life care plans although the programs could not analyze and interpret the data. These tools emerged as the field of life care planning was developing and healthcare costing became increasingly complex.

For example, until the 1970s, which was essentially the same time that the concepts of life care planning were formed, the Diagnosis-Related Group (DRG) coding system did not exist (Busch, 2017). It is doubtful that any of the early life care planners could have anticipated the complexity that exists in 2020 medical coding and healthcare reimbursement systems.

Life Care Plan Interviews

Historically, life care planning documents have emphasized the importance of conducting an interview with the evaluee and/or their family members (Weed, 1999; Weed & Berens, 2010; Weed & Berens, 2019; Weed & Field, 2012). Weed and Owen (2018, p. 15) note,

> Observing or interviewing the client/evaluee at their place of residence not only is typically more convenient for the client/evaluee, but also will provide more information. An on-site tour will help identify and inventory equipment, supplies, environmental and transportation needs.

The in-home interview also allowed the life care planner to observe the individual in their home environment; to observe the behaviors of caregivers in the home; and to document accessibility issues in and around the home. However, there has been little written in the life care planning literature about technological tools that can be utilized to complete the interview.

While the advantages of conducting in-home visits are outlined above, this approach is not always followed. Some life care planners conduct evaluee interviews at their offices or other professional settings which then do not provide the life care planner the opportunities identified above.

Any form of in-situ evaluation is also likely to involve travel costs for one party which can include airfare, mileage, lodging, meals, ecological impacts, etc. There is likely to be billable time charged by the professional for their travel and if an evaluee requires a companion as well as durable medical items or other support that can make travel difficult and add expense.

A concern about the life care planner being present in the home of the evaluee that has become increasingly pertinent over time, is the environmental impact of travel. According to the EPA (2020), transportation was responsible for 28% of greenhouse gas emissions in 2018.

With the onset of the 2020 global COVID-19 pandemic, disease transmission issues have also been raised when considering in-home assessments of evaluees. Life care planners often work with individuals whose health status is fragile, and there is the inherent risk of disease transmission for any participating party from public exposure, such as when traveling or by unwittingly transferring germs to another party in face-to-face interview. After the spread of COVID-19 began, consideration of how to conduct evaluee visits was undertaken.

Given the current access to technology that enables remote assessment, questions about how life care planners can best use these tools to complete life care planning procedures is being considered. Historically, in life care planning, there was discussion of conducting virtual visits at the 2002 Life Care Planning Summit, 18 years prior to the spread of COVID-19 and in a time when many of our now widely-available technology tools simply did not exist. Discussion of life care planners utilizing video conferencing tools was first introduced by Weed and Berens (2010, p. 864) when they note, “The value placed on the face-to-face meeting is so significant that the life care planner and others will pay premium prices for reliable video conference software and hardware.”

In 2020, due to the COVID-19 pandemic, many businesses increased their use of Zoom and other video conferencing platforms, and many life care planners switched to or increased their use of virtual home visits. At the 2020 International Association of Rehabilitation Professionals virtual conference, rehabilitation professionals (including life care planners) who attended one presentation were surveyed on this topic. Forty-two percent (n=72) of respondents (n=170) noted that 91-100% of their assessments were being conducted via remote/ tele- assessment after the onset of the COVID-19 pandemic, while prior to COVID-19, only 3% (n=6) of respondents (n=170) conducted 91-100% of their assessments remotely. In this sample of rehabilitation professionals, 40% (n=67) of total respondents (n=166) conducted 0% of their assessments remotely prior to the onset of COVID-19, while only 5% (n=9) reported conducting 0% of their assessments remotely after the onset of COVID-19 (M. Hildebrandt, personal communication October 9, 2020). It is noted that while 170 individuals responded to the first question, only 166 responded to the second question. Like many other businesses, this shows a significant shift in how rehabilitation professionals were accomplishing their work prior to and following the onset of COVID-19.

When considering whether or not to use videoconferencing tools for evaluee assessment, each individual life care planner must consider the manner they determine is best to complete their interview. First, the objectives of the in-person home visit must be clearly identified. To achieve the purposes outlined above, the life care planner who uses this tool must be comfortable observing how the individual functions in their environment via videoconferencing. The life care planner can note and assess equipment already in use by videoconferencing. It is possible to get a visual representation of the individual’s home through such means. However, some life care planners may not feel comfortable collecting their interview data through technology and may prefer to appear in-person. Additionally, some evaluees may not have

technology available to accomplish remote interviews. Some individuals with disabilities may have difficulty using such technology, including individuals with verbal impairments. All of these factors must be considered by the life care planner.

As all life care planners are bound by a Code of Ethics through life care planning credentialing bodies and/or their primary professional Code of Ethics, consultation of these codes can also be an important step in consideration of how to complete evaluee interviews. For example, the Commission on Rehabilitation Counselor Certification (CRCC) Code of Ethics (2017) requires that rehabilitation counselors avoid harming those we work with and require that we use procedures that have empirical or scientific foundation (6a). For review of remote assessment studies, the reader is referred to Appendix B that includes an extensive bibliography developed by Dr. Mary Barros-Bailey, which provides resources for determination of efficacy of tele-assessment. Additionally, based upon communication with the International Commission on Healthcare Certification (ICHCC), the body that issues the Certified Life Care Planning credential, this agency approves the practice of virtual life care planning visits with the evaluee (B. May, personal communication, December 29, 2020).

Changing Use of Technology in Disability-Related Work

Long before the 2020 outbreak of COVID-19 in the United States, agencies that provide services to individuals with disabilities were beginning to deliver services through technology rather than in the person's home or in the professional's office. Certain technologies had historically been used for tasks such as report preparation. Increasingly, a number of agencies have adopted videoconferencing technology to conduct meetings with individuals with disabilities. For example, while telehealth services were used by agencies who serviced individuals with disabilities in rural communities prior to COVID-19, such services have been needed by many more individuals with disabilities in other locations during COVID-19.

The adoption of technology-based tools has also occurred within the United States Social Security Administration (SSA). Only 15 years ago, vocational experts working in Social Security disability adjudication hearings were mailed paper copies of the files of claimants. With time, that evolved into compact discs (CDs) being mailed to the vocational expert, and, by 2020, this same data is accessed in almost all cases through an electronic records program managed by the Administration. Prior to COVID-19, many Social Security Disability adjudication proceedings throughout the United States evolved from in-person hearings to administrative law judges appearing remotely by video conferencing capabilities.

The Veterans Administration (VA) was a leader in utilizing internet-based telehealth and by 2013, the VA noted that more than 600,000 veterans had been treated via telehealth care (United States (U.S.) Department of Veteran Affairs (VA), 2020a). The Connected Tablet program was established at the VA in 2016, and a VA study found that veterans had "high levels" of satisfaction with virtual care, missed fewer appointments, and found the access to be easy and convenient to use (U.S. Department of VA, 2020b). In 2018, the VA had accomplished more than 1 million video telehealth visits using VA Video Connect (U. S. Department of VA, 2019). More than half of the visits were accomplished remotely for veterans living in rural areas and more than 100,000 veterans used mobile devices (i.e., cell phones or personal computers) to access the VA Video Connect application (U. S. Department of VA, 2019). In 2018, a federal rule allowed practitioners, regardless of the state in which they were licensed, to cross state lines to assist veterans through telehealth (U. S. Department of Veterans Affairs, 2018). Today, VA virtual services include mental health, educational counseling, vocational rehabilitation and employment services, and treatment across state lines (U. S. Department of Veterans Affairs, 2020c). Hence, the VA health care providers are increasing access to care through video technology for veterans throughout the country (U.S. Department of VA, 2020c).

Impact of COVID-19 on Use of Technology

With the rapid spread of COVID-19 throughout the United States, many employers moved employees home to work remotely to contain the spread of the virus. Employers who provide disability-related services were no exception. This impact was felt from local developmental centers that provide daily services for people with disabilities to the United States Supreme Court, who heard oral arguments via telephone for the first time in history in May 2020, with the public listening through a live audio feed (Coyle & Scarcella, 2020). The November 2020 Supreme Court oral arguments were also held in this same manner (Coyle & Scarcell, 2020). Notably, however, the Supreme Court has expressed intent to resume in-person proceedings when it is deemed safe to do so.

Not only did the U.S. Supreme Court conduct proceedings virtually, so did many state courts. On March 24, 2020, the North Dakota Supreme Court was one of the first of a number of state supreme courts to hear oral arguments through videoconferencing applications (National Center for State Courts (NCSC), 2020). In addition, since COVID-19, remote depositions have been taking place through the use of Zoom, Skype, Webex, or other videoconferencing providers (Keenan & Strongman, 2020).

In 2020, with the COVID-19 pandemic, the Social Securi-

ty administration began to offer claimants telephone hearings to avoid delay in processing Social Security disability claims with many claimants participating by telephone in their own homes. According to the National Center for State Courts (NCSC, 2020), judges began to use videoconferencing at unprecedented levels, and there have been discussions that the use of technology tools may continue after the pandemic in order to save time and money.

In March 2020, vocational rehabilitation counselors (VRCs) employed by the U.S. Department of VA began working remotely, and these VRCs were requested to communicate with veterans electronically, via telephone, and virtually through the tele-counseling program (U. S. Department of Veteran Affairs, 2020c). In September 2020, the VA announced their partnership with Apple to provide veterans who qualify with "cellular-enabled" iPads so they could easily access virtual care (U.S. Department of Veterans Affairs, 2020b). To promote telehealth services, the U. S. Department of Veterans Affairs (2020d) provides apps that require "secure identify authentication" and secure messaging to assist the veteran to manage their health care, and the veteran is cautioned to only use password-protected devices, to not save medical records on a public computer, and to avoid using public Wi-Fi (U.S. Department of VA, 2020d).

Martin (2020) reported that the larger commercial insurance payors including Blue Cross Blue Shield (BCBS), Aetna, Cigna, and United Healthcare covered telemedicine visits in their healthcare plans. At the onset of the pandemic, medical practitioners were able to use FaceTime, Skype, Zoom, or any two-way audio-visual device. The Office of Civil Rights (OCR) which enforces Health Insurance Portability and Accountability Act of 1996 (HIPAA) did not want practitioners to use "public facing communication service" like Facebook Live, Twitch, or TikTok (American Medical Association (AMA), 2020). According to the AMA (2020) practitioners were encouraged to notify patients of potential security risks and to secure business associate agreements (BAAs) with telehealth vendors to make sure that the software platform was secure for any online meetings and these agreements outlined the responsibilities to maintain protected health information (PHI). For mental health providers, there are software vendors with full encryption security who can assist with managing and maintaining records, scheduling, keeping notes, and telehealth appointments (Cottone & Tarvydas, 2016). Only with time will it become evident which providers return to in-person based service delivery and which continue to incorporate technological tools into service-delivery models.

With the shift of some disability-related service provision toward the use of technology-based tools by psychologists, physicians, nurse practitioners, and counselors, surveying life care planners to see how they were conducting their services in 2020 was proposed. Specifically, questions about the use of technology in life care planning practice and how evaluee interviews were being conducted were researched.

Methodology

In order to answer the research question, *How are life care planners using technology?* A five-question survey about technology and life care planning was developed by the authors. Survey questions are attached in Appendix A. Survey questions were informed by the anecdotal experience of the authors who, because of the 2020 outbreak of COVID-19, were using technology in different ways to accomplish life care planning tasks during the COVID-19 pandemic. Life care planners were asked to respond to the survey, and responses were collected for a period of 30 days, between August 16, 2020 and September 16, 2020. The survey link was disseminated through the IALCP section discussion group, which at the time had 499 members. The survey was also shared through the International Commission on Healthcare Certification listserv.

Results

A total of 100 responses were collected during the data collection period. Respondents' years of experience in life care planning ranged from one month to 45 years, with the mean number of years in life care planning reported at 18.52 and the median reported at 20.05 years. Responses to each of the remaining four questions are discussed below.

Responses to *Question 1: Do you use life care planning software in preparation of your life care plan reports/ tables?* included 100 responses with 75 individuals indicating "no". Of the 25 individuals who responded affirmatively to using life care planning software, specific programs identified included Active LCP (3), LCPStat (8), FormPro, Excel(2), Word (3), WordPerfect, MDS, "proprietary", LCP for Word, Advocate, Maniha software, Fluent, and Prolaw.

Responses to *Question: 2: Do you conduct home visits/ evaluee interviews virtually?* included 100 responses with 72 individuals responding that they did conduct virtual visits and 28 saying they did not. To the follow-up question, *If yes, what percentage of the time?* 62 responses were received. The percentage of time in these responses ranged from 1 to 100 percent, with an average of 69.87 percent of the time and a median of 90 percent of the time.

Responses to *Question 3: Prior to the COVID-19 outbreak, did you conduct home visits/ evaluate visits virtually?* included 96 responses, 30 of which were "yes" while 66 individuals responded "no".

To *Question 4: Please check other technology that you use in the life care planning process?* a total of 81 responses were received. When asked about "other technology" used in the life care planning process, survey choices includ-

ed Dragon Dictate, Costing Database, ProQuest or other literature database, All of the above and Other. Response counts included 59 individuals who used costing databases; 14 who used Dragon Dictate; 15 who used ProQuest or other literature databases; and 3 who responded that they used all of the above. For open responses in the 'other' category, responses included: Pub med (2); online facility databases; MD guidelines; Apple dictation and Access database; AHD (2); "proprietary", "custom templates" or "company specific"; Physicians' Fee Reference (PFR); FairHealth; Context 4Healthcare; Medscape; FormPro; LCPStat (2); Zoom; Custom Pro Law; Word tables; Google shopping; AT databases; GoodRx; case management contacts, state and federal websites; and vendor cost database.

Discussion/ Analysis

A review of the above data indicates that life care planners are readily using technology in their life care planning practice but are doing so in various ways. In this sample, 75% (n=100) of life care planners reported that they did not use life care planning software in preparation of their life care plans. This may be in part due to the cost of such software, which may be cost-prohibitive for some life care planners, particularly those with smaller or newer practices. Others may be unfamiliar with the types of software available to life care planners.

In addition to life care planning software, life care planners were asked about other technology used in their life care planning practices. Overwhelmingly, the most often-cited tool used by life care planners included costing databases (used by 73% of individuals who responded to this question, n=81). Literature databases were also commonly used by life care planners, with both ProQuest and PubMed mentioned. The widespread use of these tools may be explained by presentation of these tools at life care planning conferences and advertising in life care planning materials. Additionally, obtaining costing data has been reported by life care planners as a major practice challenge (Owen & Wilkins, 2019), and costing databases help to overcome this barrier by providing cost-related data in an efficient manner.

In this same sample of life care planners, the majority of respondents indicated that they conducted virtual home visits with evaluees. However, over two-thirds of the respondents indicated that they did not conduct home visits virtually prior to COVID-19. While many newer life care planners were trained in an era when videoconferencing was widespread, and discussion of remote assessment is now part of life care planning training (M. Barros-Bailey personal communication December 3, 2020), other life care planners who were trained in an era when computers were less available may be less comfortable adopting such technology. A review of life care planning documents notes that telehealth as a method of service delivery is not mentioned until 2019 in the fourth edition of *Life Care Planning and Case Management Handbook* (Weed & Berens, 2019), while the cost of videoconferencing is discussed in comparison to the cost of travel for face-to-face meetings in the 2010 third edition of *Life Care Planning and Case Management Handbook* (Weed & Berens, 2010). With the spread of COVID-19, however, all life care planners were forced to evaluate the best method of service delivery during these changed circumstances. It is beyond the scope of this manuscript to predict what percentage of life care planners will change their technology use after COVID-19.

Like all technology, the pros and cons of using videoconferencing platforms to conduct evaluee interviews must be considered. For example, using such technology removes the risk of illness transmission to the evaluee. However, it may not be appropriate for some individuals based upon their disability-related limitations or their particular evaluation. Use of such technology has become standard for some programs and agencies that provide disability related services including the Social Security and Veteran's Administration, who both plan to maintain use of remote video conferencing post-COVID-19.

As life care planners evaluate the use of such technology in their practices, further discussion in the community is warranted on this topic as each life care planner determines on a case-by-case basis the efficacy and appropriateness of available approaches, the cost and inconveniences of issues such as travel, and risk of illness transmission relative to the value of the activity of face-to-face meetings. Future discussion of this issue may be a timely topic for the next Life Care Planning Summit.

Limitations

The data collected in this research were not collected randomly, and the authors relied upon self-report by life care planners to accurately report their use of technology in their practices. The sample contained 100 respondents, but demographic data were not collected on the respondents; therefore, whether these 100 respondents are representative of the population of life care planners cannot be determined. As such, it is unknown if life care planners who responded to this survey were principally trained as nurses, rehabilitation counselors, physicians, etc. Life care planners were not queried about their satisfaction in their use of technology when performing life care planning tasks. Life care planners were not queried about the number of life care plans completed annually or the venues in which life care plans were prepared. While extensive resources have been reviewed for efficacy in remote assessment, none were reviewed specific to life care planning, and this is recommended as a further area of study. Based upon these factors, follow-up research is

recommended.

Conclusion

Life care planners have always considered the tools available to them in their practices. Whether using a telephone to collect costing data or fax machines to send communication to healthcare providers, life care planning service delivery has also been a reflection of the era. In the 1980s and 1990s, when many life care planners were trained, the internet was not used, there were few cellular telephones in circulation, and videoconferencing tools were not accessible to the majority of people. As such, the literature in life care planning often cited the use of in-home visits where the life care planner traveled either by car or plane to conduct an in-home interview with the evaluee.

With time, individuals and agencies who provide disability-related services have changed how they have delivered these services and have incorporated the use of technology to improve accessibility and efficiency in service provision. This is also true of life care planners. In this research, 100 life care planners provided information about how they use selected technology in their life care planning practices. The use of life care planning software, costing databases, and virtual evaluee visits were all reported in this sample. While differences were seen in how life care planners use technology, it is indisputable that technology has changed the practice of life care planning. As evidenced-based research supports the use of such technology, we can expect continued evolution of life care planning practices. It is important for life care planning organizations to recognize changes in life care planning practices as they occur.

Appendix A
Life Care Planning & Technology Survey

1. Do you use life care planning software in preparation of your life care plan reports/ tables?
   - Yes
   - No
   - If Yes, what _____

2. Do you conduct home visits/evaluee interviews virtually?
   - a. Yes
   - b. No
   - c. If yes, what percentage of the time? _____
   - d. If yes, what platform do you use (e.g., FaceTime, Skype, Zoom, etc.)

3. Prior to COVID-19 outbreak, did you conduct home visits/ evaluee interviews?
   - Yes
   - No

4. Please check other technology that you use in the life care planning process.
   - Dragon dictate
   - Database consultation for costing
   - ProQuest or other literature review database

5. How many years have you worked as a life care planner?

Appendix B
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BIBLIOGRAPHY OF TELE-ASSESSMENT RESOURCES

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Selected Training

APA: https://www.apa.org/topics/covid-19
PAR: https://www.parinc.com/Resources/Training-Portal
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IARP Forensic Section Committee Annual Report: A Year-In-Review

The 2021-22 IARP Forensic Section Board is comprised of the following members and respective positions:
Chair – Mitchell Schmidt
Chair-Elect- Tricia Oakes
Secretary – Liz Kattman
Representative to IARP Board- Dana Beining
Member at Large – Celena Earl (Representative to Education Committee)
Member at Large – Deborah Hilby (Representative to Legislative and Government Affairs Committee)
Member at Large – Jarrod Perry (Representative to IARP Finance Committee)
Member at Large – Jason Purinton (Representative to Membership and Marketing Committee)

The Forensic Section Board meets monthly for IARP committee and activity updates and development and implementation of forensic-focused information, resources, programs and events. This year, the IARP Forensic Section board members created and put forth an earnings capacity methodologies survey. The results of the survey were recorded and are in the final process of being analyzed and tabulated.

We also continued our tradition of supporting the IARP Young Professionals group by providing current professional resource books to designated members of this group. These complementary books support YoPro members' professional development in the practice of forensic vocational rehabilitation. These resource books were provided to the designated members via direct parcel delivery in 2020 and 2021, as the IARP Annual Conference was presented virtually.

In the late summer and early fall of 2021, members of the IARP Forensic Section Board spearheaded centralizing a scholarship process for selected members to attend the IARP Annual Conference.

The IARP Forensic Section Board looks to 2022 with the following priorities:

- Present the earnings capacity methodologies survey results in a journal article and IARP webinar.
- Facilitate and attend a virtual 'meet and greet' event via Zoom for Forensic Section members. We plan to hold this event in spring 2022.
- Continue to supply the Young Professionals group with books and other materials to help them develop a forensic practice. We are looking forward to providing these resources directly to interested YoPros who attend the 2022 IARP Annual Conference.

Dana Beining, MS, CRC, LPC
Representative to IARP Board

Mitchell Schmidt. M.Ed., CRC. ABVE/D, LPC
Forensic Section Chair

The Rehabilitation Professional, 29(3), pp. 129–146

Parenting Decisions and Disability: What Rehabilitation Counselors Should Know

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The purpose of this qualitative study was to gain a better understanding of the experiences of parents raising a child with a disability. The researcher collected qualitative data through multiple interviews with parents who had children with disabilities. The results of this study indicated that parents perceived that both the parent and child had needs that were not being met and found ways in which they were empowered to make certain parenting decisions. Three major themes emerged from the data: 1) desire to protect, 2) the influence of medical professionals, and 3) a sense of passive hope for their children and other families. Parents shared what appeared to be lacking was sufficient education and emotional support to help them channel their loving energy into setting higher expectations for their children. They needed help to effectively plan for and reach developmental milestones, and support for confidence in their child's abilities to afford them opportunities to take control of their own lives. Several recommendations were suggested to help rehabilitation professionals better support parents raising children with disabilities.

Keywords: Parenting, disability, parenting decisions, children with disabilities

Parenting a child with a disability is not always an easy task. Each disability comes with a unique set of challenges, and both parents and children need to find the most effective ways to deal with them. Researchers have found that parents often assume added responsibilities to make their disabled child's life as easy as possible, and that parents did not require as much accountability or behavioral autonomy from them as they would a typically developing child (Sanders 2006, Locke et al., 2012).

Sanders (2006) indicated that parents and care providers of children with disabilities may overprotect these children with the intent of shielding them from harm; however, this emphasis on safety also limits the children's exposure to difficult situations, which prevents them from learning from failures and experiencing the increased sense of self-efficacy that comes with surmounting challenges. When caring for a child with a disability, parents, as well as others within the child's support system, tended to shift their focus more heavily onto managing various aspects of the disability rather than on the child's overall quality of life (Sanders, 2006).

Traditionally, the treatment of children with disabilities has emphasized management of the physical aspects of the disease, and physicians measure treatment efficacy primarily by means of physical improvement (Centers for Disease Control and Prevention, 2020; Holmbeck et al., 2002) However, several researchers have shown that this approach to disability management tends to lead to overprotection rather than fostering autonomy and encouraging independence (Cappelli et al., 1989; Hartlage & Green, 1972; Holmbeck et al., 2002; Segrin et al., 2015). Though well intentioned, this

overprotective approach can promote delays that affect many if not all areas of a child's life, including education and employment. As a result, overprotected children may fail to develop the necessary behavioral, social, communicative, functional, occupational, and basic academic skills necessary to succeed in school, live independently and lead full, well-rounded lives.

Cultural and societal responses associated with disability and raising a child with a disability are often informed by the medical model of disability. Our society predominantly operates from the medical model perspective of disability, driven by diagnosis. A physiological difference, impairment or injury are viewed as deficits or a failure of a bodily system (Goodley, 2016). The central focus of this model lies in its location of disability as an individual problem (Swain et al., 2003). The goal is to fix what is "wrong" with the individual. Therefore, solutions are focused on fixing, normalizing, and cure even when the impairment does not cause pain or illness. Individuals are viewed as abnormal, less-than, weak, and incapable. Corrective surgeries, therapies, interventions, and devices are imposed by medical professionals (Goodley, 2016). This perspective leads people to believe that disability is inherently a bad thing that needs to be eliminated (Vash & Crewe, 2003). People with disabilities have been explained as divine punishment, karma, or moral failing which leads to responses like shame, pity, fear, and avoidance. In an attempt to rid disability from society, people with disabilities have been euthanized, institutionalized, and sterilized (Goodley, 2016). Culture, religion, and the individualistic approach tend to reinforce the dominant medicalized view of disability.

There is a need for researchers to explore this area further to develop new approaches towards effective parenting strategies for improving family interactions and involvement with their children (Holmbeck, et al., 2002, Segrin et al., 2015). For children of any ability level, access to necessary opportunities to develop behavioral autonomy is vital to success. Consequently, it would appear to be important to encourage parents, and other individuals interacting with the child daily, to learn specific styles and practices that nurture the skills required for independence and maturation.

Researchers have shown that parenting style is one of the most important family variables in a child's psychosocial development. Cappelli et al. (1989) found several significant correlations between overprotection and poor psychosocial functioning in children with cystic fibrosis. Similarly, Hayden et al. (1979), Holmbeck et al. (2002), and Bayu & Kusmariyatni (2019) found that overprotection levels were higher for parents of children with spina bifida, and this was associated with lower levels of preadolescent decision-making autonomy, which, in turn, was associated with more externalizing problems. These findings have been consistent across the available literature regardless of the type of physical disability the child experienced. Adults treated children with disabilities differently from their peers and, as a result, children with disabilities did not have the same life experiences.

Purpose

Available literature has established a correlation between parenting style and social maturity and the negative impact it has had on children with disabilities. However, the literature currently does not address the question of *why* parents make choices that overprotect their child and limit their development of autonomous functioning. The results of the present investigation provided a better understanding as to why this correlation exists and may help professionals find new ways to encourage parents to allow their child more independence. With added support, families may learn to embrace positive change and ensure their child has opportunities to cultivate their social skills which help increase overall autonomy and therefore independence (Mirabile et al., 2018). Furthermore, this study provided a deeper understanding of the dynamics associated with raising children with disabilities, which in turn addresses the 'what', 'how' and 'why' associated with the choices parents make in raising their children with disabilities.

Terms and Definitions

Autonomous Functioning

Behaviors associated with a child's ability to be more independent, or display autonomy have continued to define the overall construct of autonomous functioning. Research suggests behavior that is more autonomous has numerous positive outcomes for children as they grow and express increasing levels of maturity (Roth et al., 2007). When autonomous, individuals experience their behavior as self-endorsed and congruent with their values and interests.

Social Maturity

Maturity is defined as an individual's ability to respond to their environment in an appropriate manner; this response is generally learned rather than instinctive. Maturity also encompasses being aware of the correct time and place to behave in a certain manner and knowing when to act appropriately, according to the circumstances and the culture of the society one lives in (Wechsler, 1950; Beebe et al., 2000). When an individual is socially mature their behavior is in accord with standards and norms for a person of that age.

Parenting Style

Parenting style is a predominant factor in socialization because it is within the family circle that social learning begins and the first social contact is established (Pringle, 1951; Javady, & Zeinali 2019). Several characteristics determine the processes through which parenting style influences child development, including but not limited to values and goals parents have in socializing their children; the parenting practices they employ and the attitudes they express toward their children. Different parenting styles affect a child's degree of socialization and maturity.

In the face of disability, parents utilize different dimensions of parenting to cope with the situation. One such dimension is parental control and restriction versus allowing autonomy. Parental control refers to extensive regulation of the child's behaviors and actions, autocratic parental decision-making, overprotection, and giving instructions to the child about how he or she should think or feel. The presence of a physical disability often causes parents to be more restrictive and many parents allow their child less autonomy (Aran et al., 2007). Although an overprotective parenting style often comes from a place of love and the desire to keep a child out of harm's way, there are many unforeseen negative consequences.

Independence

Traditionally, independence is defined as a person's evolution from a state of dependent childhood to an independent adult identity based on the achievement of developmental milestones (Valentine & Skelton, 2007). Oftentimes disability tends to be understood as reliance on others, and as a result, these individuals are not seen as independent (Friedman & Owen, 2017). Disability studies scholars examine disability and independence as a social construct, rather than a physical characteristic. Consequently, one's physical abilities or developmental milestones do not determine the presence or absence of independence. These scholars use the term "independent" to indicate someone who has taken control of their life by choosing how their life is led, rather than what the person can do without the help of others (Thomas, 2004).

Researcher Identity

The researcher was born with Cerebral Palsy, an experience the researcher shared with the participants' families. The researcher's mother will be the first to tell you that she did not initially know anything about raising a child with a disability—she raised the researcher as she would any other child.

This mindset illustrates the premise of how the researcher grew up and demonstrates the viewpoint that guided the researcher from a young age. Until the researcher became older, they were not aware that they were different.

With personal experience, the researcher was able to capture the participants' stories more vividly and was more sensitive to the difficult subject matter. With this in mind, the researcher was careful to ask neutral interview questions and ask clarifying questions with the intent of understanding participants' perspectives, rather than sharing their own thoughts and experiences in order to avoid bias.

Research Questions

This study explored parenting styles and attitudes as they related to raising a child with a physical disability. Three questions guided this investigation:

(a) What factors did parents feel influenced them in 1) making parenting decisions about their children with disabilities that involved questions about autonomy vs. protection and 2) the expectations they had for their children?

(b) How did parents perceive that they modified their childrearing approaches and expectations for their children with disabilities?

(c) How did parents feel they could have been better supported through the process of raising their children with disabilities?

Method

With approval from an Institutional Review Board, the researcher collected qualitative data using grounded theory. Grounded theory refers to a set of systematic inductive methods for conducting qualitative research aimed toward theory development. The term grounded theory denotes dual referents: (a) a method consisting of flexible methodological strategies; and (b) the products of this type of inquiry. Increasingly, researchers use the term to describe methods of inquiry for collecting and analyzing data. As an exploratory method, grounded theory is particularly well suited for investigating social processes that have attracted little prior research attention, where previous research is lacking in depth or where a new point of view on familiar topics appears promising (Milliken, 2010). Through multiple interviews, parents of children with disabilities were asked questions about their experiences parenting a child with a disability, how they perceived their parenting approaches have shifted since their child's diagnosis, what they envisioned for their child's future and what, if any, further information would have been helpful in adjusting to their child's disability.

Participants

Participants were parents of children attending the Children's Clinic of Southern Arizona. All families resided in Arizona and came from similar, working class sociocultural backgrounds. The lead researcher's requisite knowledge and understanding of the cultural values related to disability helped to successfully reach data saturation. This clinic serves children all over southern Arizona for both general pediatric care as well as children with disabilities. Parents included in the study were those of children whose disability was primarily physical, meaning any disability or chronic disease that left the child with a physical impairment such as not being able to walk, trouble with movements, and seizure disorders.

Table 1
Participant Characteristics

Parental Role	Child's Age	Child's Gender	Child's Diagnosis	Siblings
Mother	17	Female	Spina Bifida	No
Mother	11	Male	Friedrick's Ataxia	Yes
Grandmother	17	Female	Dwarfism	Yes
Mother	7	Male	Spina Bifida	Yes
Mother	13	Female	Spina Bifida	Yes
Mother	17	Male	Spina Bifida	Yes
Mother	18	Male	Cerebral Palsy	Yes
Mother	18	Female	Cerebral Palsy	Yes

Design and Procedure

Recruitment

The sampling methods were a mix between convenience and non-probability sampling. Non-probability sampling as Merriam (2009) describes it was most appropriate, as generalizability is not a goal of qualitative research. This method was purposeful because the researcher sought to understand a given population and used a criterion-based selection to create a list of attributes essential to the study to find a unit matching the list (Merriam, 2009). With this in mind, selected families were those that were able to best answer the research questions.

There were several factors to consider when determining sample size, including the purpose of the study, feasibility, the goals of the researcher, and the amount of data useful for the goal of achieving saturation. The researcher stopped data collection once data saturation was reached which included 12 participants (Seidman, 2019).

Procedure

The researcher conducted semi-structured interviews to examine the feelings, thought processes, challenges and overall life experience surrounding parenting a child who has a physical disability. Parents were asked a series of guiding, open-ended questions to help provide an in-depth account of their experiences. The questions helped ascertain how parents viewed their child and treated him or her as compared to their other children, if applicable. The interview also included questions related to parents' feelings about certain situations and asked them to recall difficult decisions they have had to make, the thought process behind those decisions as well as the feelings, positive or negative, that influenced those decisions. The personal nature of these questions allowed the researcher to explore everyone's experience to gain as much information as possible and be open to any previously unidentified constructs or factors to inform the research questions sufficiently.

Data Analysis

The researcher transcribed all interviews and observation notes for further analysis. Data was analyzed using what Merriam (2009) described as a "constant comparative method whereby the researcher constantly compares within the study the data being collected, comparisons are constantly made within and between levels of conceptualization until a theory can be formulated" (p. 200). In this way, the analysis and coding of the data produced higher-level themes, concepts, and assertions. This process began with assigning reasonable codes, categories, and themes suggested by the first instance of narrative text or other observations. In coding the data, the researcher followed a grounded approach (Corbin & Strauss, 2011). The researcher explored the data openly with no preconceived notions.

Limitations of the Study

One notable limitation in this study relates to the use of a convenience sample. The researcher only collected data from one site and therefore the findings may not be representative of the general population. Thus, transferability of study findings may be limited. Study bias of the researchers may also present a limitation; however, all possible precautions were taken to ensure data remained subjective.

Results

In response to interview questions, the researcher identified several themes and subthemes related to each research question following data analysis. Data illustrates the main themes of 1) desire to protect, 2) the influence of medical professionals, and 3) a sense of passive hope for their children and other families are shared.

A Parents Desire to Protect Their Child and Keep Them Safe

A common theme throughout every interview was all parents' worry that their child's disability would have negative consequences in the child's everyday social life and interactions. These concerns led them to protect the child more than a typically developing child out of concern for their safety and a desire to shelter their children from pain or scrutiny. Parents expressed several fears that contributed to feeling this way and created a greater sense of responsibility to protect their child and how those concerns manifested in everyday interactions and reactions in their own lives.

For example, several parents discussed concerns about bullying in public and in school directly related to their child's disability. One of the parents, feared other children would bully her son because he can be hard to comprehend, "Right now my biggest worry is bullying because there are a lot of people who make fun of him and don't understand him." Another parent shared these concerns but was hopeful that, as her son ages and his peers mature, the situation could improve, and he will have more friends. "They make fun of my son. I know he wants to go to college . . . and at this point and my hope is that if he does get involved in a college that the bullying will stop."

In addition to bullying, parents expressed concerns about how the public reacts to disability in general, wanting to shelter their children from negative reactions in the public sphere. Parents expressed concern about children not being treated or viewed like their peers. Society has many different views of disability and parents expressed those reactions can be frustrating, and they wanted to help their children through those experiences. For instance, one parent felt that people treated her son differently because of his disability.

> One of the biggest things, when we are out socially, is he does absorb a lot of attention from people . . . they stop us when we are walking and try to pray for him. It is just a lot of unnecessary attention that I know is coming from a place of love, but it is very difficult because he is not being treated equally.

Parents shared that often people were unsure as to how to react to their children, so they needed to be there to oversee interactions.

> Some people do not know what to say or do. I think they are just afraid. A lot of people do not know how to approach my son. You know, they stare, or they look at him—they do not feel comfortable enough to go up to him.

As part of protecting their children, parents expressed that they did not let their children be alone or do things independently. The parents made sure there was always someone there to assist him or her physically or in social situations to ensure the child's safety. There was a constant desire to keep them safe, which in turn affected how parents treated them. Several parents admitted to being more protective of their child with a disability because their disability affected their ability to handle a lot of things on their own. As one parent expressed,

> I want to protect him, as a parent, that is what any parent wants for their child, especially when their child has a disability, because they are very gullible. I do not know if that is the right word. They are easy prey because they want to be very understanding and very giving, and people use them for that.

In general, parents felt their children with disabilities were more susceptible to harm and did not have the tools necessary to protect themselves. They needed constant monitoring and looking after because their social skills oftentimes were not up to par with their peers. One parent felt these characteristics created somewhat of a cycle for her daughter. She saw her daughter as more gullible and less socially aware but also said that she probably became that way from being protected constantly and never being left alone to adapt to situations herself. The following transcript from an interview demonstrated her thoughts:

> Parent: We do not leave her with caregivers that we do not know. We must totally trust them before they are left with her. I have a fear of her getting hurt and she's very gullible, and she knows that. She knows that she's gullible. And she is easily swayed by people that she believes their stories and can be taken in and she knows that. So, we're careful.
>
> Interviewer: Why do you think that is?
>
> Parent: Because I think she has been so protected; she has always had adults around her. She's never been exposed to the lies that people will tell to get their way. She's never really learned to be savvy.

The Influence of Medical Professionals

Several parents discussed the influence of the information given by medical professionals as well as the experiences the parents themselves had surrounding their child's diagnosis. These factors all had an impact on parental attitudes toward disability and, in turn, how they made decisions concerning their children.

Medical Advice and Communication

The parents who were interviewed had regular interactions with medical professionals. The interviews made it clear, through the responses to several questions, that information that came directly from the doctor had significant influence over a parent's behavior or actions toward their children. Every disability had different experiences attached to it, and each doctor handled conditions somewhat differently. Nevertheless, the interviewees exhibited some similarities and influences to consider when they received the prognosis of a disability before their child was born. In most cases, parents expressed high levels of fear because the doctors or nurses did not provide adequate information. When information was provided, disability was often framed as a negative characteristic aligning with the medical model of disability. It was up to the parents themselves to draw their own conclusions, and in many cases, do their own research.

One parent recalled being very afraid because, after getting very little information from her doctor, she attempted to fill in some of the gaps on her own. Her research – and lack of expertise – led to her becoming inundated with frightening information that was not necessarily accurate. She noted,

> Reading on the internet is really scary. That was not the best route to go. By the time I got to the specialist, I had already figured out that she would be born with spina bifida. I just was more wanting to know what that would mean for her because the internet scared the heck out of me. I was not sure what that meant.

While in some cases the parents agreed the doctor gave more information, in certain cases that backfired in a way because they were given the worst-case scenarios. Doctors told many parents to expect the worst. Some were told to expect a very low quality of life. Additionally, doctors told some parents to prepare themselves to say goodbye to their new child. This instilled a great deal of fear in parents and set up an expectation that their child was not going to have a typical upbringing, or in some cases going to survive at all. One parent said "I was told not to expect much. It was sad. They said he would not have a normal life, he would not walk, or talk" Another parent recalled a similar experience**,** "the specialist kind of laid it on rough. He was like she'll never walk. She might have a mental disability. Most likely, your marriage will be ruined because it's harder to raise a kid with a disability." For these parents, setting lower expectations for their child started before they even had a full understanding of their capabilities.

Along with presenting parents with a diagnosis, some doctors discussed terminating the pregnancy as an option because of the hardships that lied ahead, assuming the parents were incapable or unwilling to raise a child with a disability. Three of the parents interviewed recalled experiences in which doctors not only presented termination as an option but also why it may be a wise choice. Another participant recalled the conversation with her doctor,

> Interviewer: He asked, do you want to terminate?
>
> Parent: We were like no, that's not even an option. We were given the option to terminate. He was pretty negative. Once I told him pretty firmly that, no, that wasn't a choice for us, he was a little more supportive. Even things like he wanted me to get an amniocentesis and he wanted to see if she had any other "genetic abnormalities" he called them.

One of the other parents described how her doctor discussed termination once he realized there was going to be an abnormality with the pregnancy, "the doctor kind of mentioned something about that there were always alternatives for my daughter, if she wished to pursue them since the baby was going to have something wrong with her at birth." Parents were warned multiple times about the difficulties they would face, as well as medically advised not to have high expectations.

Throughout the interviews, many parents expressed frustration over the information medical professionals had provided for them. They felt either that they were not given enough or accurate information to best support their child. Many parents wished that the doctors had been more optimistic and given them hope throughout the process of receiving a diagnosis. One parent said, "I just wish that she would have been a little more optimistic and given me a little more hope and not such a limited view. Just hope—that's all I needed." Parents generally wanted to feel more supported by their doctors. In addition to support, some felt that medical professionals should have been more responsible in providing them with resources that could help them prepare for this alternative parenting experience that provided its own set of difficulties. One parent shared an example:

> There are resources out there, but nobody knows where to go to because schools and other agencies do not want to tell you because they do not want to risk having to share money or they do not want to have to search for things—they do not want to get off their butts. It's frustrating because they don't want to have to do the work. I wish I knew better.

In addition, parents expressed that most of the information doctors and professionals provided them was medical as opposed to practical. Doctors did not help support the parents in terms of information that would help in day-to-day life or discuss things parents should be considering. Their chief concern was always medical. In turn, parents were given no guidance on approaches to allowing more inde-

pendence or what to consider when forming expectations for the child throughout the development process.

One parent remembers feeling overwhelmed and wishing she had more to go off after talking to her doctors:

> Pretty much they just give you basics, and then there's books that I got and started reading, kind of to know what exactly cerebral palsy was and knowing how it affects the muscles and things like that. It was up to me to figure out how that information applied to my son.

Again, another parent echoed with a similar experience in talking to the doctors, "you got this very medical viewpoint, but nothing about my kid as a person."

Personal Experiences Surrounding the Child's Disability

The medical aspect of the disability evoked many emotions in parents that were often difficult to process. Often to cope with the feeling of a lack of control, parents took on added responsibilities to attempt to exert control, in this way impacting the attitudes they had towards their children. Parents discussed how they were responsible for tending to their children's' emotional needs surrounding medical issues. Parents felt an added sense of responsibility to support their children specifically because of their disabilities. They felt there was an additional level of need from their children because the associated medical issues were very complex and frightening. Parents felt that by having more of a presence they could "provide more of an explanation and ease fears."

Parents went through many emotions after their child was born with a disability, and the diagnosis significantly affected their view of the future. In discussing this throughout the interview process, parents reflected on how their parenting approach shifted. For example, one parent spoke about how she felt when her son was diagnosed. "I felt like I had let him down, but I had to put that in the back burner because the only way that he can succeed is if I am strong for him."

Several parents shared similar feelings of guilt and a sense of loss because the disability was unexpected. One parent stated, "you just think that they're going to be healthy, that they're going to be ok, everything's going to go well. And you hope for that. But you don't really think that this is going to happen. I didn't."

Several parents expressed that they had felt overwhelmed by the amount of information they were flooded with in the beginning of their disabled child's life. Moreover, the idea they could not handle everything the child was going to need was overwhelming. As such, their parenting approach was more hands-on from the beginning because the level of responsibility extended to so many additional areas. As one parent noted,

> my biggest fear was probably not being able to fulfill everything, I mean all her needs. Or getting all the, especially the medical attention that she needed. She was fragile. It was so scary because I thought how am I going to go home, or wherever I was going with her. I was afraid. Because you see her in the hospital, she has all these tubes, the IV, and everybody has seen her. Very overwhelming.

Adding to feelings of being overwhelmed, the experience of having a child with a disability and starting that journey was very traumatic for some of the parents. In most cases, doctors considered the child medically at risk postpartum, adding not only to the level of stress parents were experiencing but also reinforcing the notion that it was the obligation of the parents to constantly monitor their child from day one. As a result, parents chose to take on more responsibility and remember traumatic experiences from the day their child is born:

> I almost lost him at 16 weeks, so they stitched my cervix, and I was on bed rest, and he still came early. He was born not breathing, so they had to resuscitate him, and it took some work to get him back to breathing, so before then, I really did not know, but once he was born, I did not leave his side.

Another parent also spoke about how worried she was once her daughter was born and how the traumatic experience largely shaped her interactions with her daughter:

> She was born in DC, so I left the hospital without my baby, because she was transported here like four hours after she was born. I had to give my permission over the phone to a doctor to perform a surgery. I mean can you imagine, they're asking me 'do you give me your permission to perform a surgery' and I'm not with her. Like, I'm never leaving her again. It was a shocking thing.

The severity of these experiences had a lasting impact on many parents, indeed shaping the decisions they continued to make concerning their child moving forward.

A Sense of Passive Hope for Their Children and Other Families

Throughout the interviews, parents expressed the desire for their children to live a full life. Often, when asked to elaborate, parents shared that a full life consisted of the child becoming more independent and less reliant on their guardians. Each parent indicated a hope that their child would continue to progress and find their independence as they developed. Despite such hope as a guiding force and general optimism among parents, children did not always actively engage in becoming more independent. Parents believed there were other factors that would help their child become more self-sufficient without having to work continuously towards that overall goal.

Several interviews concretely illustrated a disconnect between parents' desires for children's' independence, and the behaviors that foster independence themselves. Many parents expressed hopes and desires for their children to be independent, less reliant, live on their own, find jobs, go to school, etc. Those expressed desires did not always translate in ways that would indeed foster such independence because, in those same families, the children relied heavily on their parents. One parent contained her desire for her daughter to find independence one day, but at the same time acknowledged she would never leave her daughter alone for fear that something would happen to her. She also told the interviewer on several occasions that her daughter was "gullible" and had "never been exposed" to difficult situations. Those same situations, for most teenagers, help foster a sense of autonomy and self-reliance (Ryan et al., 2006).

In most cases where parents expressed a desire for their child to have more independence, they also acknowledged that they were not at that point in their lives. For instance, one participant acknowledged that her son, who was 18 years old, could have been living independently. While she wanted that for him, she felt he still had a lot more to learn before he would be able to do so successfully. She illustrated this more fully:

> Well, I wouldn't want him to be anywhere else. He has a good home; he has his own room, his own bathroom. He just lives in our house, and I felt like if I kept him at home and was able to continue to give him the care that he needed, that that would benefit him in the long run.

She maintained a paradox in that she shared such things, but at the same time expressed her desire to see him independent someday. Another parent purveyed a similar outlook, whereby she encouraged her granddaughter to pursue her dreams and be independent but at the same time declared**,** "She still relies on me for a lot of things, and between me and my husband we help her with most of her daily living."

Many parents also found hope in their religion and held beliefs that a higher power would not only protect their child but also guide them to a better place in life. For some, they felt as though the support they gave or did not give the child was not going to dictate the child's level of independence – that independence was up to God. In essence, parents felt their children's fate was already decided. As one parent explained:

> Her being more and more independent. We have a hope. We believe that, and in the Bible, that it talks about a time when sickness and death and pain and all that stuff will be no more through God's kingdom. And so, we do believe that there is going to be a time when she'll get out of the wheelchair. She'll be healed and live an easier life. That's what the Bible promises.

Several other parents shared the belief that if it were God's will for their child to be independent, it would happen. This belief helped them to place their child's future in the hands of God, thereby decreasing their own share of responsibility to behave in ways that promote independence. Several parents expressed having a level of faith was extremely helpful in allowing them to feel less overwhelmed by their child's disability. One parent expressed that being able to put their faith in God was a lifesaver. "As a Christian person, it's understanding more and just being willing to help. It's just you have to do what you have to do, and you have to learn a lot of things, and help in every way possible." The parent said that, even in moments of despair within her family, their faith saw them through.

For several families, though the idea of independence was ideal, the process of their child achieving it seemed daunting. Many had the hope for it in some vague future, but few seemed able to fully accept the personal accountability to see it through or make the process more manageable for their children. Several parents relied on external services to promote their child's independence. In their own minds, they had given their child all the resources they could, with the hope that those services would foster independence. Parents felt they had "done their job" in giving their dependents everything they needed – including services which would be enough to make children be independent and flourish. As one parent noted, "when she was younger I did everything the doctors told me to, she has been receiving all of the services we were supposed to sign up for in order to help her move forward."

Most of the interviewees talked about independence as a future goal but did not express concrete plans for reaching that goal. When asked where they saw their child or their hopes for the future, the most important piece was happiness. That was their biggest hope—even if happy did not necessarily mean independent or self-sufficient. As one participant said, "I just want to see him enjoying himself. If he's not married, he might have an aide, but whatever he's doing, I just want to see him enjoying life." Two other parents both declared they would take it one day at a time, and as long as their child was happy, everything else would fall into place.

Many of the above comments reflect the dominant medical model framework of disability where the focus lies on fixing the individual through services and surgeries. There was also an over emphasis on independence meaning doing things alone rather than looking for ways for the child to be in control of their care. Parents wanted their child to achieve independence but often shared language that reinforced negative stereotypes and misconceptions surrounding the disability community often and consistent with the medical model (Swain et al., 2003). Other parents seemed to focus on the idea of happiness as a goal but there was a lack of discussion on how happiness would be achieved.

Developmental Milestones

When talking about expectations, several interviewees identified different areas where their approaches toward their child with a disability shifted, triggered by their children attaining specific developmental milestones. For example, in some cases their expectations changed over time. Parents expressed that as their child got older and they had more of an idea as to the challenges their child was facing, their anticipations shifted. One parent said there were considerations she had to entertain for her son that most parents did not need to think about for their children:

> That plays a part in how much to expect for him, you must plan for worst case scenarios and kind of have a situation for that, but it's hard to. At the same time, we kind of live this life that anything could happen. It's in the cards for us, whatever it is. We don't expect a lot because things are very unpredictable.

Several parents likewise noted unpredictability as a factor contributing to their inability to set many expectations, citing the fact that they couldn't control the unknown.

While parents in this study recognized that their children were not always reaching typical developmental milestones, they noted their expectations shifted in favor of manageability according to their child's individual needs. One parent described the nature of this process,

> It's kind of a day-by-day thing. He [my son] expresses that he wants to do DJ-ing and stuff like that . . . We haven't really talked about him living independently. We try to give him as much independence at home as we can; we are realistic.

For several parents, having other children in the home who were siblings highlighted when their child with a disability was achieving typical developmental milestones – or when they were not. Recognition of failure to achieve the same developmental milestones as their siblings led parents to alter their own expectations and decisions about parenting.

Some parents said they had the same expectations for all their children, with or without disabilities, while others admitted they had changed their parenting approach depending on the child. One parent stated "the expectations are different. I have higher [expectations] for her [sibling] than I do him, just because I know that she can do more things without assistance than he can. it's so different with both kids."

Two parents also admitted to treating their children without disabilities differently and holding them to higher expectations.

> Raising my children, and my granddaughter and my children, and yes, for the other children, for her sister—I expected them to do more than their sister. She gets very tired. She tires easily. It seems to be it takes a lot of energy to get up and go to school, and then do her homework, and get ready for bed, and all of that, and eat.

Another parent also discussed how she did not expect as much from her son compared to her other children because he had been through so much that she wanted to give him a break and make living easier.

One of the other important milestones discussed in the interviews was socialization. Many children of the parents interviewed had not reached appropriate social milestones because of their parents' reluctance to let them socialize independently. Parents said they had to make sure their children were okay, noting that there were many more factors to consider in social outings than with typical children, "because you know for a fact, when you're taking him somewhere, you're going to have to be there the whole entire time, making sure that the safety's there."

Every parent in this study expressed some level of concern around their disabled child's socialization and everything they needed to consider with regard to social activities. While many children grew into independently participating in outings and social events, the parents shared that they felt they needed to be present if their child was to remain safe. One explained,

> A lot of additional considerations make it a lot harder. Definitely. We went to Cancun, and it was wonderful, but you have to think in your head, are we going to be able to get a shuttle to the hotel that will fit a wheelchair, how is that going to be through customs, can we take his medication, what happens when we are at the beach, what kind of rooms do they have, are they handicapped accessible. It's just a lot more planning and we need to make sure he's ok.

When discussing typical developmental milestones, the interviewer also asked about dating habits for any children who were in their teens. Specifically, each parent was asked whether mom or dad had discussed dating with their teenager and how and if they approached the conversation. Most parents said either they did not discuss it or that the subject had not come up; and tried to avoid answering the question. An interviewee provided an example of this:

> No, not really dating. He went to prom with a girl when he was going to school at ASDB. He has a couple of girls that like him at the day program. He hasn't really gone out on a date, per se, with a girl. He goes out with the guys and has guys' night out and stuff like that, but we haven't really done any of the dating.

Other parents described that their teenagers had not expressed interest in dating yet, so the conversation had so far been absent. When discussing her daughter's dating habits, One said she had not discouraged dating and had always been open to talking to her daughter. However, she considered her daughter would have different experiences than most girls her age because of her disability, "she

has some idea of dating and I have been, I mean it hasn't happened yet, but yeah I try to guide her, because for her it will be different."

Assistance vs. Independence: The Struggle with When to Push, When to Assist, When to Let the Child Try Independently, and Child Involvement in Decision Making

When asked about what parents expected as their child continued to grow, parents had different expectations for the future. They were able to tell the researcher what their expectations for their child were, but there were some discrepancies between whether those desires were realistic. One participant knew what her son wanted to do but also did her part to ensure that his goals were what she considered achievable. She stated, "he wants to be a Vet Tech, he started out wanting to be a doctor, and that started you know, he works in the summers with animals, he volunteers his time, and they work with other kids that are disabled." Another seemed to have high expectations for her daughter and said, "I would like for her to progress and be more proactive both in word and in actions, events that would be good for her, and just to help her grow both physically and mentally." Nevertheless, this parent is like so many other parents struggling with when to push and when to assist or let children try things on their own to be more active in making decisions about the future—especially when emotions were challenging to navigate. As she explained "the emotional part, I think is a little harder when you see the hurt. I just try to help her deal with it. Try to help the best way I knew how to make her feel that it was going to be okay.

Most parents shared that they struggled in this way and aired on the side of giving more support rather than letting their child figure out a difficult situation on his or her own. This was due at least in part to a lack of surety with regard to when it was appropriate to push them. There was also the added emotional burden that came with medical uncertainty, and some parents did not provide the freedom for their children to address indecision on their own because of the added emotional stress associated with making decisions or the possibility of making the wrong choice.

Additionally, a parent shared that she also had a difficult time making some decisions because she wanted her son to develop as typically as possible and reach milestones like his peers, but she struggled with wanting to offer more support. She shared, "How much do I push? How much should I push? Am I making the right decision to not be on him as closely as I was? Those are very hard choices to make." Some parents expressed that they consciously tried to offer their child more opportunities to make decisions and communicate about desires and needs. This fostered and encouraged independence. As one of them said,

> Now with her being a teenager I think that we do it together. I tell her what I have heard or, what is going on. What I need to kind of respond to? I ask her what she would like to do, or if she has input. I think we make decisions together now, whereas when she was younger, of course, I made all the decisions.

Still, even with more decision-making power, most parents were conscious of still being involved in all major decisions concerning their child.

Parents' Recommendations and Hope for Others

Parents expressed recommendations for others in similar situations. In certain cases, not having appropriate resources influenced their parental approaches. For example, several parents said that if they had mentors to help guide them, they would have made different parenting decisions. According to the parents interviewed in this study, having other parents who had gone through the same thing to share resources and offer support would have made a significant difference in their parenting approaches. Seeing how other parents handled similar situations would have given these parents ideas as to how they could handle their own situation. As for their children, the parents shared that it would have helped their children to interact other individuals with disabilities and may have acted as a motivating factor to help them continue to push themselves. Several participants confirmed this need for a role model, "like a mentor, a peer to peer, there to help and give advice."

Other parents described how helpful it would have been to have additional resources. Parents shared that access to parental resources was crucial in both encouraging independence of their children and relieving pressure from parents by helping them not second-guess their decisions or worry as much about when to push versus offer assistance. They shared the desire to have better resources available to prepare their children to be more independent. One parent stated, "there were various resources that I should have had. See, that's the key word. Everything's 'should have.' I was told transportation wasn't available when it actually was. And that hinders his independence, too. It did. It really did." Awareness of supports and different ways to encourage independence was key for several interviewees, and they mentioned promoting such awareness would likewise help many parents going through the same struggles:

> Well, I guess if they gave classes, I think, to parents, maybe. If the kids are in the NICU for a long period of time, if they offered classes that they can take that kind of explained a little bit more about now and in the future, what's going to happen. I think that could help you and maybe give you some kind of counseling to prepare you for what's going to be . . . the outcome, once the babies leave and you're the one taking care of them. I think that would be helpful.

Some parents said that once they found the ability to advocate for their children, they pushed more for their children and fought for them to reach their full potential. One parent discussed this:

> I think most every professional normally helps parents, and they cover as much information as they can. I think just reaffirming parents that there is the help there, if they need it, you know. Not to be afraid to ask for it . . . always be your own advocate.

Some parents found that advocacy was a driving force in their ability to go about ensuring that their child had rights and could become typical contributing members of society. This nevertheless has its own difficulties. Because it can be exhausting to constantly advocate, parents expressed the importance of finding a balance – not just for themselves, but also for their children. The importance lay in finding a balance for one's children, given all the "extra things" they needed to deal with. Another parent illustrated this point:

> From a mom, I am a part of a lot of special needs groups and a common theme is making sure that we create some sort of balance for our kids academically and socially. Just trust your kid. They are going to drive that force for you, and they may not be the best student, but they might be the best friend that someone is looking for. That is, I think, the most important advice I can give someone that's starting out in this world.

Discussion

Some key interventions could significantly improve the support of parents, their children with disabilities, and the family to help children reach their full potential.

1. *Parents would benefit from programs provided by rehab counselors specifically designed to support and prepare them once they have learned of their child's disability diagnosis.*

The major barriers to implementing these types of programs are funding and public policy. To effectively influence public policy and funding decisions, rehabilitation professionals will need to advocate more heavily for our profession, the contributions we can make to rehabilitation, and the consumers we serve (Patterson & Joseph, 2009). We need to accept that part of our responsibility as professionals in this setting is to become advocates and take steps towards influencing public policy and decision-making on a larger scale for the disability community.

2. *Therapy teams should include a rehabilitation professional who is available to help parents navigate the process of raising of a child with a disability to help parents feel more supported and prepared.*

Presently, professionals are giving parents medical information about the child that does not include practical implications that would help encourage independence or foster autonomy. Rehabilitation

counseling as a profession needs to hold greater value to the public and other professionals as we continue encouraging equality for individuals with disabilities. Rehabilitation counselors' scope of practice goes beyond providing people employment services to also include provision of mental health support and family integration through the provision of independent living services. A rehabilitation counselor's knowledge, skills, and service delivery are comprehensive and applicable to almost any group, including people who do not meet the definition of having a disability. It is essential that rehabilitation professionals fully communicate expectations and encourage parental involvement in the rehabilitation process. This type of approach will challenge the idea that all of responsibility falls on services providers. Parental involvement can also help ensure children learn the skills necessary for independence early on.

3. *For children specifically, it would be beneficial to teach the skills necessary to socialize as part of the rehabilitation process early in the child's life.*

This would require taking our approach beyond the medical perspective to one that is well rounded and comprehensive to rehabilitation, including but not limited to counseling services that specifically encourage and help navigate independent living. This shift in services to encourage the independent living philosophy from an early age could be made possible by increased funding to children's services within Centers for Independent Living. Policy reform is necessary to introduce supports within school systems, so teachers have the skills and knowledge necessary to encourage more independence, opportunities for socialization, opportunities for children to make their own decisions, and to work with parents as advocates to determine the best situation for the child.

Integrating the Independent Living Philosophy into the Rehabilitation Process

Individuals with disabilities have unique needs in a counseling relationship that counselors need to consider (Bent et al, 2002). It is vital to stress the importance of taking control and setting goals and expectations that encourage typical development because individuals with disabilities typically do not have the autonomy to make these types of decisions (Sanders, 2006; Locke et al., 2012). It is imperative that a child with a disability always has an opportunity to make an informed choice, and that professionals and parents respect their autonomy and judgment (Holmbeck et al., 2002). Integrating this type of philosophy into the rehabilitation process is one way we can strive to avoid inherent biases against people with disabilities.

Below are additional recommendations for rehabilitation counselors to help shift the dominant cultural response to disability and expectations of children/clients with disabilities including:

- Acknowledging the difficulties of controlling biases that are unconscious and automatic. By examining our own biases and perceptions about disability we can avoid perpetuating stereotypes and misconceptions faced by people with disabilities.
- Self-monitoring: continuously self-monitor your perceptions, judgments, behavior, decisions, and actions for the influence of implicit biases.
- Accountability: hold yourself responsible for the negative influence that implicit biases have on your perceptions, judgments, behavior, decisions, and actions
- Learning and centering the experiences of people with disabilities. Getting to know people within the community and learning from their experience while engaging in positive meaningful relationships can help build new positive associations and reduce stereotyping.

Rehabilitation counselors should adopt the Disability-Related Counseling Competencies (DRCC) endorsed by the American Counseling Association (ACA) Governing Council in 2019. The purpose of the document is to encourage counselors to implement best practices, increase understanding, and assist people with disabilities (Chapin et al., 2018). With this in mind, rehabilitation counselors should seek to move beyond diagnosis and focus on quality of life to facilitate independence and autonomy. This is consistent with the belief that everyone should be supported in living life to their full potential. For

children with disabilities, it is vital for rehabilitation services to start as a child rather than waiting until adulthood. To achieve this, we must recognize the relationship among all areas of the child's life, including social, physical, emotional, cultural, and vocational aspects.

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IARP Membership & Marketing Committee Annual Report: A Year-In-Review

Mike Rosko- SSVE
Jason Purinton- Forensic Section
Nick Choppa- LCP
Hantac Chang- Young Professionals Section

Dear IARP Members:

Before I review 2021's goals and accomplishments, I would like to thank Tony Morin for his many years of service and dedication as the director to the Membership & Marketing Committee. I had the pleasure of serving as the VRTS Representative to the Membership & Marketing Committee and worked directly with Tony for a couple of years. His commitment to IARP and this committee was truly inspirational and his efforts were greatly appreciated. I would also like to thank our past and current committee for your hard work to ensure we have met and continue to meet our goals.

The primary goal of the Membership & Marketing Committee has been to grow our membership in all areas of IARP. However, to increase our membership and market IARP to individuals, organizations, and academic institutions, we needed to finalize and distribute materials explaining the benefits of joining IARP and informational content on this wonderful organization to the sections and chapters of IARP. We have uploaded the documents for easy access for our chapter and section leaders to distribute to their respective groups.

As the director of this committee, I have encouraged more participation from each section and chapters to engage in a membership campaign by way of increasing our organizational membership, academic partnerships, student members and individual professional members. With the help of the Young Professionals and local chapters, direct contact to each college and university throughout the country was made, which lead to speaking engagements in graduate level rehabilitation courses.

Lastly, we implemented a new IARP Awards Campaign this year and are focused on continuing to improve and streamline the Awards process for the upcoming 2022 Awards Campaign.

Our current priorities include reviewing the feedback received from companies and colleges/universities and implementing necessary changes to the Organizational Membership and Academic Partnerships to reflect additional opportunities and benefits for joining IARP. It is such a wonderful time to be a member of IARP and the Membership & Marketing Committee and we are excited to grow our membership and expand the benefits of IARP to rehabilitation professionals throughout the country.

Erin S. Bailey, CRC, ABVE

INTERNATIONAL ASSOCIATION OF REHABILITATION PROFESSIONALS

IARP Vocational Rehabilitation Counseling Coalition: A Year-In-Review

Dear IARP members,

The International Association of Rehabilitation Professionals (IARP) has been a part of the Vocational Rehabilitation Counseling Coalition (VRCC) since its inception in 2014. IARP member, Lynne Tracy, is the founding member of VRCC. VRCC was established for rehabilitation counseling associations to come together on issues vital to the continuation and advancement of the Rehabilitation Counseling community and profession. There have been other rehabilitation counseling coalitions in the past, but the coalitions have not lasted. The VRCC is the longest-standing rehabilitation counseling interest coalition. VRCC meets virtually once a month and in-person twice a year (except for 2020). Since 2014, an IARP member has been the facilitator of VRCC, and there has been at least one IARP member as part of VRCC. Currently, Elizabeth Watson and Lisa Byrne represent IARP on VRCC.

Although the member associations have changed throughout the years, currently VRCC has representatives from the following associations:

- American Board of Vocational Experts
- Commission on Rehabilitation Counselors Certification
- Council of State Administers of Vocational Rehabilitation
- International Association of Rehabilitation Professionals
- National Association of Multicultural Rehabilitation Concerns
- National Council on Rehabilitation Education
- National Counselor on Rehabilitation Education
- National Association of Service Providers in Private Rehabilitation
- National Counselors and Education Association
- National Rehabilitation Association
- National Rehabilitation Association Committee on Rehabilitation Accreditation
- National Rehabilitation Counseling Association

VRCC is designed for members to present rehabilitation counseling concerns of their member associations openly. Since 2014, the concerns of member associations have changed. Currently, VRCC is reviewing the newly released **Council for Accreditation of Counseling and Related Educational Programs (**CACREP) 2024 Standards Draft, and VRCC will be completing a written comment to CAPREP. The review's goal is to have a united response to the rehabilitation counseling concerns that member organizations can support. Other current matters of discussion include exploring the reality and possibility of the member organizations working together on lobbying efforts on mutual rehabilitation counseling legislation issues and the possibility of having a joint conference with member organizations.

IARP is proud to be part of the VRCC and contribute to the discussion of issues that impact the field of rehabilitation counseling.

Elizabeth M. Watson, MS, CRC, LCPC
Representative to the Vocational Rehabilitation Counseling Coalition

INTERNATIONAL ASSOCIATION OF REHABILITATION PROFESSIONALS

IARP Council of President's Annual Report: A Year-In-Review

Dear IARP Members:

IARP chapters play a vital role in the IARP members experience. Through participation in an IARP chapter, members get to meet and network with other members, attend chapter events and conferences, and develop lasting professional relationships. Every month, the Council of Presidents meets to discuss what has transpired over the month in each president's region. It provides the leaders of the chapters from 27 regions an arena to facilitate discussion about what has been working well and what resources can be used to improve operations and membership engagement within each region.

Monthly meetings support leaders who share the following principles with their board members to help facilitate:

1) Establishing and reviewing IARP's mission/philosophy/goals
2) Strategic planning to determine services and programs to offer the membership
3) Evaluating IARP services, programs, and operations on a regular basis

The Council of Presidents meetings provide the chapter leaders with a forum to share challenges and brainstorm ideas. Chapter presidents dedicate their time and expertise to help support the members of their chapters. This year, a sub-committee was formed to develop a handbook for new chapter presidents to assist in learning the policies and procedures to operate a chapter within the national association.

Goals for the upcoming year will focus on completing the operations manual for chapter presidents and to continue to meet to discuss chapter activities and share feedback from chapter members.

Evie Cowitz, BA, RRP, CCRC, CCLCP, CVRP, RTWDM
Chairperson of the Council of Presidents

INTERNATIONAL ASSOCIATION OF REHABILITATION PROFESSIONALS

VOLUNTEER ENGAGEMENT

LEGACY BOARD
Structure and Position Descriptions

PURPOSE

The IARP Legacy Board's purpose is to create opportunity for past leadership to utilize their expertise to have continued engagement with the board, committees, and events by advising, planning and providing strategic input where needed. This committee will be chaired by the immediate past president for a two-year term and will consist of an appropriate number of members determined to fulfill specific objectives. This group will provide feedback and direction on the development of the Board of Chancellors on an ongoing basis.

GOALS & EXPECTATIONS:

- Engagement success will be based upon participation in the Legacy Board throughout the year:
  - **GUIDANCE**
    Will provide feedback and insight into industry processes and purposes that will continue to support member recruitment and engagement.
  - **STEWARDSHIP**
    With a focus on member engagement, will work with staff and key board members to develop key stewardship actions. Will assess and edit as necessary for ongoing purposes.
  - **HISTORY**
    As key stakeholders, will maintain contact with appropriate past leaders of the organization through regular communication, establishment of system to honor tradition of service and connection with mentor/coach program.
  - **LEGACY**
    Develop and manage areas to help maintain IARP
- As we close out the first year of this group, we will look for feedback to help support the continued evolution of this board to facilitate continued growth through the development of meaningful engagement opportunities.

TIME COMMITMENT

This board will meet as needed (number and length to be determined by board at their first annual meeting) and serves as the oversight group for IARP's stewardship plan and other objectives as defined by the International Board of Directors and the Legacy Board. Legacy Board members are invited to participate in a minimum of two years with no limit to years of involvement and should plan to spend one - two hours per month working together.

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The Rehabilitation Professional & Journal of Life Care Planning: A Year in Review

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