Developmental Disabilities Network Journal, Volume 2, Issue 1

DEVELOPMENTAL DISABILITIES NETWORK JOURNAL, VOLUME 2, ISSUE 1

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ABOUT THIS JOURNAL

This journal disseminates high-quality research and evaluation about the multiple systems that serve individuals with disabilities and their families. Central to these systems is the "Developmental Disabilities Network," a group of federally designated programs in each U.S. state and territory that provide advocacy, training, research, and service focused on the unique needs of people with disabilities and their families. This journal specifically highlights programs, practices, and policies that encourage the full inclusion of people with disabilities in communities and all aspects of public life.

If you have questions about submitting a manuscript or becoming a reviewer for this journal, please contact the editorial office at editor.ddnj@usu.edu.

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EDITORIAL: INCREASING ACCESSIBILITY IN ACADEMIC PUBLISHING AND UPCOMING INITIATIVES

Matt Wappett

[Editorial: Increasing Accessibility in Academic Publishing and Upcoming Initiatives Upcoming Initiatives PDF File](#)

Matthew Wappett, Editor-in-Chief

Perhaps the most rewarding aspect of producing this journal is the opportunity that it provides us to see all the great work that is happening right now. It has been incredibly humbling to read and review all the submissions that have come in over the past year and a half. It has provided us with an unprecedented glimpse into the innovations and outstanding work that is occurring across the Developmental Disabilities Network. I would like to thank everyone who has contributed articles, helped review, or been involved in any other aspect of the editorial process on this issue of the Developmental *Disabilities Network Journal (DDNJ)*. From reviewing to editing we could not make this journal work without the tireless efforts of our staff and our contributors.

The last issue of *DDNJ* was entirely focused on the impact of the COVID pandemic on individuals with disabilities and the programs that serve them. This issue also includes a few additional articles about the impact of COVID that we could not include in the prior issue, but it also includes a wide variety of other reports from the field on multiple timely issues including health promotion, sexuality education, advanced care planning, and more. The work reflected in all the articles in this issue demonstrates the broad engagement of the Developmental Disabilities Network across the lifespan and the multiple systems that support individuals with disabilities and their families.

This issue also includes the second installment of the history of UAP/UCEDD programs, with a specific focus on the impact of UCEDD programs on some of the important disability policy issues in the 1980s and 1990s. This article is one of the last projects that Marv Fifield was working on before his passing in 2015. Marv was a pioneer in the disability field and had an incredible impact on the direction and development of the UCEDD network. Marv also worked with Senators Hatch and Kennedy to help shape the direction of the ADA and the DD Act reauthorization in 2000. We are excited to publish this segment of Marv's legacy, co-authored and edited by his son, Bryce Fifield, who has also been instrumental in the development and expansion of UCEDD programs in Utah, Idaho, and North Dakota. Both Marv and Bryce have been fixtures within the DD Network for almost

50 years, which gives them a unique, big-picture perspective on the development of the UCEDD system. We are honored to publish this important, but often overlooked, history in this issue.

Podcast Launch

We are also excited to announce that we will be launching a new podcast to accompany the DDNJ. The podcast is called *DDNJ Author Insights* and will include interviews with authors from the latest issue of the journal. Each episode will be structured as a conversation with the authors and will provide a more informal approach to the author's article...but it will also include some fun, behind-the-scenes insights on the process of designing, implementing, analyzing, and writing up their work. We want to acknowledge that authors are people too, and we want to help our readers gain a better understanding of the many voices who are working in the field today.

The launch of this podcast is part of our ongoing commitment to increasing the accessibility of the journal for a wider readership. We recognize that it is important to present our information in a wide range of media and hope that this podcast will help provide another alternative to access the information within the *DDNJ*. Not everyone has the time to sit down and read an entire article these days, and more and more people are choosing to get their information through

podcasts and audiobooks. The launch of this podcast means that you can access the *DDNJ's* content while you are on the go, and you can share it more readily across social media and other online platforms.

The first episode of our podcast will be coming out in early November 2021 and will include an important conversation with Dr. Heather Church and Dr. Jacqueline McGinley, two of the authors on the article entitled: "Advance Care Planning Within Individualized Care Plans: A Component of Emergency Preparedness" in the most recent issue of DDNJ. We felt that this article was a perfect representation of the type of work that we like to highlight in the *DDNJ—research* with immediate, real-world applications! Drs. Church and McGinley share some poignant stories and timely insights that really shift the way that we think about transition planning for older adults with disabilities.

Our plan is to release one episode per month, beginning in November 2021. Please take some time to check out the podcast when it comes out and please be sure to share it with your friends and colleagues.

AUCD Conference on Accessibility in Academic Publishing

We are also thrilled to announce that we will be participating

in a session at the upcoming 2021 AUCD Conference about increasing accessibility and inclusion in academic publishing. This session will be led by the editors of the *Review of Disability Studies* published out of the UCEDD in Hawaii, the *Journal of Rehabilitation* published out of the Sonoran UCEDD in Arizona, and the *Developmental Disabilities Network Journal* published out of the UCEDD in Utah. These three journals hope to move the dialogue about inclusive information dissemination forward over the next few years.

Over the past 20 years, the field of Participatory Action Research (PAR) has created models and practices for integrating individuals with intellectual and developmental disabilities (I/DD) into the research design, implementation, and analysis process. However, individuals with I/DD are often overlooked when it comes to the information dissemination and publication process. Most research articles are still geared towards academics and professionals and remain inaccessible to the subjects who participated in the research. Additionally, the peer-review process for most academic publications in the disability field still rely upon graduate students and researchers and does not include the voice or perspective of self-advocates and family members.

Our AUCD conference session will discuss some of the methods used by the editors of three academic journals to include people with disabilities in the review and publication process. For example, the editors of these journals include individuals with developmental disabilities on their editorial

boards, recruit writers with intellectual and developmental disabilities to submit editorials or other articles that highlight their experience and expertise, and articles in the *DDNJ* must include a "plain language" summary or a video abstract to make the content more accessible. Some of these journals also include individuals with developmental disabilities and their family members in the peer-review process. For example, the *DDNJ* strives to have each submission reviewed by at least one content expert and one individual with a disability or a family member of an individual with a disability. This process ensures that these journals are publishing content that reflects the perspectives and needs of people with disabilities and their family members.

The purpose of our AUCD session is to share some strategies and methods that support the inclusion of individuals with I/DD in the academic publication and dissemination process. This session will explore and help redefine how people with disabilities are included in the publication and peer-review process. The editors who are driving this conference session have an unwavering commitment to accessibility and inclusion in all aspects of the review and publication process and are interested in facilitating a broader conversation within the publishing community about how we can do better. Our hope is that this conversation will help define a new standard that can be used by other disability-oriented publications to ensure that the perspectives

of people with disabilities are more fully included in the research and publication process.

We would like to invite you, our readers, to join us for this important discussion at the 2021 AUCD Conference. If you are unable to attend the conference, or if you would like to share your ideas about increasing the accessibility of the publication process, please feel free to contact us at editor.ddnj@usu.edu.

Equity, Diversity, & Inclusion Special Issue

Last, but certainly not least, we are excited to announce that our next issue (Volume 2, Issue 2) will be a partnership with the AUCD Multicultural Council (MCC) and will be focused on issues surrounding the implementation of equity, diversity, & inclusion (ED&I) initiatives in DD Network programs. Over the past year and a half, there has been an exponential increase in focus on addressing diversity issues within the social services, but there have been targeted initiatives within the UCEDD, LEND, IDDRC, DD Council, and P&A networks to increase cultural responsiveness and inclusion. Similar initiatives are also underway within Independent Living programs and Parent Training & Information (PTI) programs. Therefore, we felt that it would be an ideal time to share some of the lessons, findings, and perspectives from the field on what works when implementing ED&I efforts.

Our Spring 2021 issue was a collaboration with the AUCD Council on Research & Evaluation (CORE). We were thrilled with the response and quality of the submissions that were received. We will be following a similar process for this second special issue on ED&I initiatives. Our plan is to put out a call for abstracts within the next month (October/November 2021). We would then review abstracts in early December to decide which articles we would invite for full submission. Full articles would be due 3-4 months afterwards. These articles would also be reviewed again by our editorial board and MCC members to ensure that they are on target for the focus of the special edition, and we would hope to have the special issue out in March/April 2022.

Watch for our call for abstracts, and please submit an abstract for consideration in this special issue. We are looking for broad representation across programs and populations and we would like to highlight the great work you are doing within your states and programs.

In Conclusion

Finally, we would like to thank you for taking time to read the research and perspectives published in the *DDNJ*. Information does not make a difference unless somebody consumes it and uses it to make the world a better place, so we are grateful to you for your interest and effort to read our journal. If you have

questions, concerns, or feedback please feel free to contact us at editor.ddnj@usu.edu.

Sincerely,

Matthew Wappett, Ph.D.

Editor-in-Chief

Developmental Disabilities Network Journal

THE ORIGINS OF UNIVERSITY CENTERS ON DEVELOPMENTAL DISABILITIES: SECOND GENERATION EXPECTATIONS AND GROWTH

Bryce Fifield and Marvin G. Fifield

Abstract

Part two of a two-part publication tracing the

evolution of University Centers for Excellence in Developmental Disabilities. Originally University Affiliated Facilities evolved into University Affiliated Programs on disabilities. Early expectations outlined by President Kennedy's Committee on Mental Retardation grew as funding for disability services and programs became available. Key legislation, program developments and organizational decisions are described for the time frame of 1970 through 2000.

Plain Language Summary

This article describes the origins of disability-related programs at U.S. universities. The idea for these programs came from a committee set up by President John F. Kennedy in 1962. This committee included stakeholders who wanted to improve the lives of people with disabilities. These programs would help people with disabilities through research, service, and training. This article describes key decisions that shaped the identity of these programs. These university programs were originally known as University-Affiliated Programs (UAP). They were later renamed University Centers for Excellence in Developmental Disabilities (UCEDD).

This is the second of a two-part publication describing the origins, evolution, and growth of programmatic expectations of University Centers for Excellence in Developmental Disabilities (UCEDDs). These programs were originally conceived as University-Affiliated Facilities (UAFs) and were intended to focus the expertise of the academic community on the needs of people with disabilities and address recommendations made in the Report of the President's Panel on Mental Retardation[1] (1962). The network of university programs has grown to include 67 UCEDDs and Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs in the U.S. and its Territories. UCEDDs and LENDs are different programs with differing funding streams and purposes. However, both are located at Universities or Medical Schools/Teaching Hospitals. Together, they comprise the UCEDD Network, despite their differing funding authority.

[1]The term "Mental Retardation" is used because that was the terminology of the time and was used in the official legislation, correspondence, and advocacy literature. Over time, this term has taken on pejorative connotations and has been replaced with the more generic term of "developmental disability."

These programs are hosted in a variety of academic institutions, organized with a wide variety of administrative structures, and serving a wide spectrum of disabilities. Over

its 55-year history, the UCEDD network has evolved along with a web of disability stakeholders, sometimes by design, sometimes by neglect, sometimes out of necessity, and sometimes in desperation. Describing this diversity and the key events that have influenced this evolution is challenging. It is difficult to present a linear description of events that are intertwined, often parallel, and frequently cyclical. It is often impossible to attribute key decisions to particular individuals or events.

As described in Part 1 of this publication (M. B. Fifield & Fifield, 2020), UCEDDs evolve. They have been known as University-Affiliated Facilities (UAFs), later University-Affiliated Programs (UAPs), in the legislation as University Centers for Excellence in Developmental Disabilities education, Research and Services (UCEDDERS), and most recently rebranded as University Centers for Excellence in Developmental Disabilities (UCEDDs). UCEDDs have grown up with other parts of the disability community including, protection and advocacy organizations, state councils on developmental disabilities, service provider networks in the public and private sectors, advocacy groups, federal and state oversite agencies, legislation providing services, treatment, and benefits for people with disabilities, and the consumer network of people with disabilities and their families. This publication describes the evolution of the UAF/ UAP/ UCEDDRS/UCEDD network during the 1980s and 1990s.

Second Generation University Affiliated Facilities (UAFs)

The Developmental Disabilities Act, authorized in 1970 and funded in 1972, introduced many substantive changes in the expectations of UAFs. However, it was not until the passage of other major disability legislation in rehabilitation and education, and after the first reauthorization of the Developmental Disabilities Act in 1975, that the second-generation expectations for UAFs began to solidify. P.L. 94-103, The Developmentally Disabled Assistance and Bill of Rights Act, not only extended but made several revisions to the DD program. The 1975 amendments authorized the three major components of the DD system: (a) state Developmental Disabilities Planning Councils (DDPCs); (b) Protection and Advocacy (P&A) agencies; and (c) University-Affiliated Facilities (UAFs). The new amendments also expanded the definition of developmental disabilities to include autism and learning disabilities. States were required to spend at least 30% of their formula grants on de-institutionalization.

Of particular importance to the UAF network was Section 145(e) of the 1975 Amendments, which authorized special project grants and earmarked no less than 25% of each year's appropriation for "projects of national significance." This provision provided approximately $12 million for projects of national and regional significance by which many of the

recommendations of the President's Panel could be implemented.

Projects of national significance were awarded for up to 3 years through an open competition. UAFs were expected to compete with all other eligible applicants. However, this source of support was particularly important to UAFs for it provided the first funding within the DD program from which UAFs could seek support for the program elements they were mandated to provide (i.e., exemplary services, interdisciplinary training, technical assistance, and dissemination). Section 145(e) was important to the UAF network by providing additional fiscal support to launch projects addressing issues of the day and state-of-the-art techniques.

In 1978, the DD Act was again reauthorized by the Comprehensive Rehabilitation Service Administration Construction Act (PL 95-602). These amendments mandated a functional rather than a categorical definition for developmental disabilities, which again changed the size and nature of the population the DD program was to serve. By 1978, core funding provided through the DD Act was described as *seed money* to help UAFs pursue other sources of support to provide the programs expected of UAFs.

Following the 1978 amendments, the Developmental Disabilities Division (DDD), the federal agency charged with managing the UAF program, undertook new initiatives and encouraged UAFs to apply for funding to address aging, technology, dual diagnosis, urban and rural area/poverty

projects, minorities, advocacy, case management, early
intervention, and transition into employment. UAFs were also
expected to use core support to seek other sources of funding
(i.e., Office of Special Education, Rehabilitation Services, state
funding, and Title XX) to provide mandated program
components.

In contrast, funding provided to UAFs from Maternal and
Child Health (MCH) was for the training of health
professionals. This support was available only to UAFs located
in medical centers and was independent of developmental
disabilities core support. MCH training funds were not
considered leveraged support, nor were these funds to be used
to obtain other funding.

From a fiscal standpoint, the most significant legislation
that emerged during the 1970s was not the DD Act, but the
1973 Vocational Rehabilitation Act (P.L. 93-112) and the
landmark Education for All Handicapped Children Act (P.L.
94-142), which was signed into law in 1975. The
Rehabilitation Act contained Section 504, which prohibited
discrimination because of disability in federally assisted
programs and became the foundation upon which future
disability rights legislation would be based. P.L. 94-142 held
that all children, regardless of disability, had the potential to
learn and had a right to a free and appropriate public
education in the least-restrictive environment and provided a
structure for funding services to school-aged children.

The Vocational Rehabilitation Act and Education for all

Handicapped Children's Act significantly influenced UAFs because they included programs for training, program development, model services, technical assistance, and research. These Acts were seen by most UAFs as sources of federal funding that could help them address DD-mandated program components. Farlee et al. (1976) pointed out that UAFs were among the most aggressive applicants to submit proposals to the Bureau of Education of the Handicapped (BEH) and the Rehabilitation Service Administration (RSA), even though UAFs faced complications in securing such support.

Co-mingling of funds from other federal programs was encouraged by the Developmental Disabilities Act. However, other federal agencies operated under regulations that did not encourage leveraging or co-mingling of federal support. Requests for proposals (RFPs) from BEH and RSA focused on specific objectives and applications did not extend beyond the purpose of their authorizing legislation to address interdisciplinary training or other DDD initiatives. These placed applications submitted by UAFs in an awkward type of competition. Furthermore, personnel in the BEH continued to view UAFs as medically oriented programs (Dr. Jasper Harvey, personal communication, 1976). To circumvent this bias, UAFs often submitted their grants to BEH through their university departments of special education or state agencies. Special Education and Rehabilitation review panels often did not know when they were reviewing applications from UAFs,

a situation which many UAF directors felt improved their chances of approval.

Most funding from education and rehabilitation was provided through time-limited, competitive proposals. To survive on such funding, the proposals submitted by UAFs had to receive high-ranking scores and they had to compete every 3 years. Not all UAFs or satellite UAFs were able to sustain a successful grant writing effort in such a competitive environment. During the late 1970s and 1980s, at least 18 programs that had been recognized as UAFs withdrew from the national network.

UAF Satellites

The UAF provisions of the 1975 DD Amendments included language permitting existing UAFs to expand programs by establishing satellite centers. Satellites were seen as a way of expanding UAF services at reduced cost and providing better control of the numbers and status of the UAFs entering the network (M. G. Fifield, 1976), although a lively debate emerged in defining whether a UAF satellite was a clinical extension of the host UAF in the same state or a free-standing center in another state (M. G. Fifield, Moss, & Landeen 1976). The DDD only approved the four UAF satellites located in states other than the host UAF as free-standing centers. For the next decade, when funding was available, the satellite provision

was interpreted as the preferred way of bringing new programs into the network.

The feasibility study for a UAF initially required the host UAF to conduct the study in conjunction with the DDPC of the receiving state. In practice, most of the feasibility studies were done by an interested group of faculty members from a university wishing to establish their own UAF. From the early 1980s on, the role of the host UAF became less and less significant, and the commitment and support from the DDPC increased in importance.

Since satellite programs quickly responded to the needs of their state and to available federal initiatives, they basically became new UAFs (Davidson & Fifield, 1988). When it was determined a satellite could meet the requirements of a full UAF, DDD encouraged them to apply. This increased core funding by approximately $50,000. The difference between the expectations of a full UAF and a satellite UAF was not particularly clear, but the interdisciplinary training program component was the most difficult expectation for new programs. Most UAFs could find funding for outreach training and technical assistance through subcontracts with state agencies; however, establishing an interdisciplinary training program with core courses on campus without MCH support or a large continuing service base was very difficult for most satellite programs. Consequently, many UAF satellites remained satellites for many years.

Impacting Generic Service Systems

The Developmental Disabilities Act was not meant to replace the support provided to individuals with disabilities from other human service programs. The Act focused on provisions that created changes, filled gaps, coordinated, and in other ways changed the generic service system so they could better accommodate the needs of individuals with developmental disabilities (Boggs, 1971). Common to each component of the DD system (DDPC, P&A, and UAFs) was the expectation that they would impact other service systems by:

1. The developmental disabilities state planning councils through state planning, awareness activities, and stimulation grants.
2. The protection and advocacy agencies through legal recourse and advocacy activities.
3. The UAFs through training, technical assistance, exemplary services, and dissemination.

Other techniques used to ensure greater impact included a required state fiscal match, and in the case of UAFs, the expectation of leveraging resources.

Local Match

The amount and nature of the required local match was an

important issue negotiated during the hearings in 1969 and 1970 (Boggs, 1971). During the UAF construction phase, a local match was not only required, but the amount of local match was one criterion for approval. Mayeda (1970) reported that approximately 49% of the costs for the construction phase was provided locally. P.L. 91-517 required a 25% match on all programs. This requirement was maintained in subsequent reauthorizations and was also required of recipients of grants offered by state developmental disabilities planning councils. The local match requirement was patterned after the vocational rehabilitation legislation and was intended to facilitate a federal/ state partnership in carrying out the purpose of the legislation (Boggs, 1971).

Leveraging DD Resources

Leveraging was not expected from other programs authorized by the Developmental Disabilities Act. However, leveraging resources was clearly implied in the guidelines for UAF core funding and the funding level in the first appropriation that became available in 1972. Throughout the 1970s, staff members of DDD and UAFs nurtured hopes that additional developmental disabilities program monies would be appropriated. Such was not to be the case. Thus, the core grant for administration and operation was increasingly viewed as seed money to be used to obtain funding from other sources to provide the interdisciplinary training, exemplary services,

and other mandated program components. Since it was also expected that UAFs would use their resources primarily to meet the needs of individuals with developmental disabilities, the impact of DD core funding could be increased several times in a UAF that aggressively sought and obtained other sources of support. This leveraging concept was consistent with the recommendations of the President's Panel on Mental Retardation, which had recommended that funding should be provided from several sources.

The UAFs that received MCH training support had an ongoing source of program support. However, it was not always easy for them to use their support to meet the expectations of both MCH and the DDD. MCH expectations remained focused on training for health personnel, clinical services, and leadership; whereas the ADD initiatives shifted with changing priorities of successive administrations. Applications for ADD funding submitted by MCH-funded UAFs were often criticized because they continued to provide the clinical programs that MCH required.

Difficulty Generated by Leveraging

Successful leveraging of additional resources is dependent upon what other sources of support are available, the eligibility of the UAF to compete for such sources, as well as the success of the UAF in writing winning grant proposals. In addition to these conditions, leveraging also has other problems. With

each new funding source, additional expectations were generated. Satisfying the many stakeholders in a UAF with funding from many sources was a difficult requirement. This was made even more difficult by the need for annual DD core applications and quarterly reports of DD-required activities. A frequent complaint of the UAF directors was that DD core support, which often represented a small portion (as little as 5 to 20% of the UAFs operating budget), exerted an inordinate influence over the total program (Farlee et al., 1976).

Leveraging also generated problems in reporting results and accomplishments. Some UAF sources of support objected to the UAF reporting their funding as leveraged. Furthermore, leveraging resources were often administered differently or reported through multiple channels within the university making them difficult to track, compare, or acknowledge. Leveraging sometimes created a no-win situation. For example, if the UAF was successful at obtaining non-DD support that served a much broader population, such as grants from Education or Rehabilitation, they were open to criticism from the DD community for focusing too much effort on other individuals with disabilities and not doing enough for those with developmental disabilities.

In 1978, President Carter reorganized the Department of Health, Education, and Welfare, elevating the Department of Education to a cabinet level and creating the Department of Health and Human Services (HHS). The Office of Special Education and Rehabilitative Services (OSERS) was

established within the Department of Education. In this reorganization, Social and Rehabilitation Services was replaced by the Office of Human Development Services (OHDS) within the Department of Health and Human Services, and the Rehabilitation Program moved to OSERS. DDD stayed in HHS reporting to OHDS. Later, the Division name was changed to the Developmental Disabilities Office (DDO) and still later to the Administration on Developmental Disabilities (ADD).

Federal Evaluation Studies of the UAF Network

As the UAF network grew, concerns for evidence of their effectiveness, accountability, and impact were raised. Between 1969 and 1983, seven separate studies were undertaken to determine the effectiveness and impact of the UAF network. Table 1 provides data on each of these studies, the initiating agency, who conducted the study, major findings, and recommendations.

Table 1 Evaluation Studies of UAPs

Date	Initiated by	Conducted by	Major findings	Major recommendati...
1969	Select Committee on Mental Retardation	Assistant Secretary of HEW	• Federal support principally from • Children's Bureau • Services limited to the health field • Not all UAPs qualify for training monies	• Earmark f... from appropria... federal age... for trainin... core supp...
1970	SRS	Mayeda	• UAPs operating at 20% capacity due to lack of federal funding • The experimenting with new programs • 90% of funding from MCH	• Facility is needed • Needs to b... new phase... • 300 per ye... UAP for c... program support • Regional programs

Date	Initiated by	Conducted by	Major findings	Major recommendati
1976	HEW	George Tarjan, Chairperson, Long-range Planning Task Force	• UAPs have implemented each of the original program concepts (i.e., IDT, continuum of care, change agents) • Established standard of excellence • Suggested performance criteria	• Greater precision i defining U mission • Establish a national network w both core program support fr federal sou • Change th name • Establish topical or regional ce • Strengthen relationshi with state programs • Accreditat
1978-80	P.L. 95-602 UAF Standards	David Phoenix, PI, Systems Research and Development Corporation	• Draft of standards prepared	• Field testi implemen

Date	Initiated by	Conducted by	Major findings	Major recommendati
1978-79	Senate Sub-Committee on the Handicapped	Controller General	• Funding from numerous sources, no fixed pattern • Vague mission	• Establish a national p • Establish measurem criteria • Develop u UAF guid
1980	ADD	Henney, PI E.M.C., Inc.	• UAFs are an important part of the national program	• Develop program c
1983	ADD	Elizabeth Boggs, Chair, UAF Ad Hoc Workshop on University Affiliated Facilities	• Diversification • Funding from various sources	• Improve standards quality, sit reviews an panels • Cooperati the federal • New initia

The first study was conducted by the Select Committee on Mental Retardation to identify the barriers and problems UAFs were experiencing in becoming operational. The second study was undertaken under a special contract with Tadashi

Mayeda to evaluate the network and make recommendations concerning further expansion. The major findings of these studies are summarized in Table 1.

The third effort to evaluate the federal investment in the UAF network was initiated by the Secretary of HEW in 1975, who awarded a contract to The American Association of University Affiliated Programs (AAUAP)[3] for a comprehensive evaluation of the UAF Program. This contract consisted of two parts: (1) the collection of descriptive data on UAFs (Farlee et al., 1976), and (2) an analysis and report from the *Long-Range Planning Task Force* convened for the purpose of reassessing the original UAF concept and making recommendations for the future (Tarjan & and the UAF Long-Range Planning Task Force, 1976). The Long-Range Planning Task Force was chaired by Dr. George Tarjan, who was the Vice-Chair of the 1962 President's Panel on Mental Retardation and actively participated in developing the concept of UAFs. The Task Force also included Dr. Elizabeth Boggs and Dr. Robert E. Cooke, who participated on the President's Panel, as well as directors of consumer and professional disability organizations, directors of UAFs, and other leaders in the disability field. After analyzing the data prepared by Farlee and reviewing other data, the Task Force concluded:

[3] In 1973 the name of the organization was changed from

AUAF to AAUAP with new bylaws and incorporated in the
State of Delaware.

...experience with the UAF Program in the period
following the implementation of P.L. 88-164 has validated
each of the original program concepts stated by the 1962
panel: training in models exemplifying a continuum of
care, interdisciplinary training, UAFs as change agents, and
incremental implementation, testing the UAF concept. (p.
4)

The final section of the Task Force report provided
recommendations for funding agencies, Congress, AAUAP,
and individual UAFs. Of particular importance were
recommendations concerning restructuring government
participation in the program around the concept of core
support and lead agency responsibility.

The task force finds no realistic alternative to multiple
federal funding of the UAFs in view of the wide range
of needs of developmentally disabled persons, the
interdisciplinary approach required by the range of needs,
and the categorical nature of most federal programs.
Indeed, these considerations provide justification for a
more vigorous effort to expand the base of the UAF
program support rather than one to consolidate all
funding in one agency. (p. 32)

The recommendations of the Task Force's Report were clear,

precise, and specific. They were referred to repeatedly by AAUAP, in negotiating with MCH, DDD, and in testifying before Congress. However, there was no systematic effort from the administration or Congress to implement the recommendations, even though some were adopted either in legislation or administrative procedures and initiatives several years later.

Two years after the Long-Range Planning Task Force had completed its study, Senator Randolph, Chairman of the Senate Subcommittee on the Handicapped, requested the Controller General to conduct a comprehensive evaluation of the total developmental disabilities program including the UAFs. Following a year of field work in which an extensive study was made of a sample of seven UAFs, the report was published February 20, 1980. The UAF section of this report pointed out that from the beginning, the UAFs were funded from numerous sources with no fixed pattern, with vague mission statements, and varying guidelines.

> This has placed facilities in a precarious "can't win" situation...trying to serve too many organizations. (p. 95)

The report recognized the complexity of UAFs, the lack of measurement criteria, and pointed out that HEW had not issued guidelines for UAF programs, developed specific regulations to make them accountable, or established national policies or strategies for them. The recommendations provided

by the Controller General (1980) were consistent with the three previous UAF evaluations.

In addition to the evaluation of the total DD program requested of the Controller General, the 1978 DD Amendments directed the Secretary to develop and promulgate program standards to evaluate UAFs. To address this requirement, ADD awarded a contract to develop such standards to Systems Research and Development Corporation. Systems Research utilized the AAUAP membership criteria as its foundation and undertook the initial work of convening panels, designing criteria of compliance, and procedures for collecting evaluation data. However, this contract was terminated as concerns about the growth of the federal budget superseded interest in standards, and efforts were directed to curtail the growth and expansion of UAFs (Frances Lynch, personal communication, 1981).

As part of an ADD technical assistance contract, Henney (1981) analyzed the data UAFs submitted quarterly in progress reports and prepared a report on his findings. This study reported very little that was not contained in earlier UAF evaluation studies. However, it did identify the evaluation points that were later placed in the UAF database and appeared in future UAF program criteria.

The Doldrums

In 1981, President Reagan followed up on his campaign

promise by introducing a program for economic recovery focused on cutting federal spending. Much of this was included in the Omnibus Budget Reconciliation Act (OBRA) of 1981. This legislation resulted in budget cuts in many domestic programs and several large, multipurpose block grants, which changed priorities and the role of federal agencies in addressing the needs of persons with disabilities (Braddock, 1986). Special centers that required continuous federal core funding were identified as prime targets for discontinuation, and efforts to curtail the growth and expansion of UAFs received special attention.

In the early 1980s, plans to cut back the UAF Program and/or eliminate the national network entirely were under consideration (Senator Orrin Hatch and Assistant Secretary Hardy, personal correspondence, 1981). During these austere times, UAFs had few strong advocates. The State Developmental Disabilities Planning Councils, Protection and Advocacy Agencies, and professional organizations were busy protecting themselves and could not afford to defend a competing program. Constituency groups, which had provided strong support for UAFs in the 1960s, were likewise concerned with continuing support for de-institutionalization, educational provisions, and a more equal distribution of federal income maintenance support. The perceptions these groups had of UAFs was that they were medically oriented programs operating in academic institutions and pursuing research and services that were

difficult to relate to the needs of consumers of disability services or the agencies responsible for serving them on a day-by-day basis (Bob Gettings, Edward Sontage, and Fred Weintrop, personal communication, 1982). One federal administrator described the UAF program as seen by its critics as follows:

> UAFs are like dinosaurs, with large medical appendages not addressing the real needs of the developmentally disabled. If allowed to multiply they could consume much of the federal budget. Yet, if they are killed, they would cause a terrible stink. The hope is, that by feeding them a few bales of hay periodically they would get hungry and go away. (Doris Harr, personal correspondence, March 1978)

In 1982, Dr. Jean Elder the newly appointed Commissioner of the Administration on Developmental Disabilities, asked the Assistant Secretary, Dorcus Hardy, to delay plans to reduce or eliminate the UAF Program until she had studied the situation. During the summer of 1982, Commissioner Elder appointed the Ad Hoc Workgroup on the UAF Program to make recommendations concerning the role and future of UAFs. Dr. Elizabeth Boggs, an original member of President Kennedy's Panel on Mental Retardation, chaired the workgroup that included consumers and service providers.

The Ad Hoc Workgroup reviewed the history and the mission of UAFs. They studied the funding pattern, evidence of productivity, and federal expectations. In 1983 they issued their report containing many recommendations, which

included further improvement of standards, quality assurance, and expanding relationships with state and local service systems. The report again called for cooperation at the federal level. Recommendations to the ADD for managing UAFs included:

1. Three-year core grant cycles,
2. Discretionary funds for new initiatives,
3. Priorities for establishing new programs

Most of the recommendations of the Ad Hoc Workgroup on UAFs had been addressed in some form by previous studies. What appeared to be different about Dr. Boggs' report (Boggs, 1983), was that it was commissioned by the ADD, and the recommendations focused on things for which the ADD was responsible and capable of doing without waiting for consensus from other federal agencies or an executive decision from the Secretary. As a result, many of the recommendations of the Ad Hoc Workgroup were implemented in-house by the ADD.

The New Wave

The findings and recommendations of the Ad Hoc Workshop for UAFs convinced Commissioner Elder that the UAF program could *lead the field of service to the developmentally disabled* (DDD, 1972, p. 2) by providing leadership for the

changes and new initiatives the administration wished to pursue.

First, the application review process for UAFs was strengthened by including a rigorous peer-review process. UAF applications that did not meet expectations were placed on a partial funding cycle. A site visit was scheduled, sponsored by the ADD, with team members made up from colleagues of other UAFs, state and federal program administrators, administrators of constituency organizations, and an ADD staff member. The procedures to be followed in conducting site visits were adapted from those established by the AAUAP in its consideration of membership. The ADD site visit provided a direct onsite evaluation of compliance with ADD expectations and included technical assistance and recommendations for program improvement. Problems were noted and corrective action plans were required. UAFs not able to comply with expectations were placed on probation, and when appropriate changes were not evidenced, funding was terminated, and the program moved to another university (Davidson & Fifield, 1992).

Second, responding to the recommendation that the ADD should be more proactive, three new UAF initiatives were pursued: employment, adult services, and services to minority populations. However, rather than simply assigning UAFs to undertake these initiatives with or without start-up funding, the ADD administrative staff were assigned an active role working directly with the UAFs. Commissioner Elder

undertook an aggressive campaign to relate these initiatives to constituency groups and to bring the DD system together to plan, report, and support one another in addressing these new initiatives. By 1985, Dr. Elder had demonstrated that UAFs could serve as the vehicle by which the initiatives of the administration and the needs of persons with disabilities could effectively be addressed, and there was no longer talk of reducing or eliminating the UAF program.

Out of the Doldrums

The language of the 1984 amendments to the Developmental Disabilities Act (P.L. 98-527) addressed several of the recommendations of the *UAF ad hoc workshop*. Overall, the new amendments brought the DD network closer together. UAF directors were placed on state developmental disabilities planning councils and new provisions were added, reflecting increased responsiveness to consumer and constituency groups. The 1984 amendments identified desired consumer outcomes such as independence, productivity, and community integration. In response, an aggressive effort was undertaken by UAFs to develop criteria by which consumer outcomes could be identified and reported (Guralnik, 1991). The minimum core grant to UAFs was increased to $150,000, and new appropriation language included authorization for additional satellite UAFs.

Changes were also taking place within the AAUAP. For

years, the AAUAP had focused much of its effort on helping individual UAFs to survive. Annual meetings usually centered on discussions of appropriations legislation and other potential sources of program support.

Responding to the Boggs report (1983), the AAUAP committed itself to becoming increasingly proactive. An electronic mail and message system was established within the network, and efforts to expand relationships with consumers and other professional organizations were undertaken. In 1985, a series of position papers were developed addressing concepts of interdisciplinary training, special purpose UAFs, early intervention services, relationships with MCH, and services to adults with disabilities. These became topics of discussion and were later used in drafting legislative provisions.

When Dr. Bill Jones accepted the Executive Director position of the AAUAP, these efforts were moved into high gear. Close relationships were forged with other professional and consumer organizations. The association established the Consumer Organization Liaison Committee as a standing committee with membership from the leadership of the Washington-based consumer organizations. The issues and concerns of consumer organizations became AAUAP initiatives. Some of these included expanding training in epilepsy, early intervention, and expanding activities to address direct consumer outcomes. All of AAUAP's position papers, initiatives, and planning documents were systematically reviewed and commented on by the Consumer Organization

Liaison Committee members. These efforts helped forge common objectives and a united legislative agenda. This further strengthened the role of the AAUAP and the Consortium for Citizens with Developmental Disabilities (CCDD).

Since the beginning of national constituency disability organizations (National Association for Retarded Children in 1950, United Cerebral Palsy Association in 1948), some form of a legislative liaison, coalition, or consortium has brought these groups together to promote desired legislation. UAP leadership and staff have joined in this effort since the middle 1960s. The first Executive Director of the AAUAP (then AUAF) was Cynthia Sturdevant, who had been very active with the NARC. Subsequent AAUAP executive directors continued this effort—some more vigorously than others. Over time, the CCDD (now the Consortium for Citizens with Disabilities, CCD) has played substantial roles in helping to shape legislation and national policy affecting the disability community. The CCD includes representation from over 120 professional and consumer organizations whose common concern is legislation provisions that improve the lives of people with disabilities. Senate and House committee members look to the CCD to promote consensus among its members regarding new legislative language and provisions. Although not always possible, there is little doubt that the greater the consensus between the CCD members, the higher the probability of favorable legislative outcomes. Dr. Jones not

only made this a priority but also took on a leadership role in researching provisions, developing position papers, and arbitrating differences among the membership.

During the 1980s, the leadership and faculty of UAFs began taking an increased role in responding to and shaping disability legislation at the national level. Many programs were developing areas of expertise related to employment, rehabilitation, education, and early intervention. Much of the research data about employment models for people with disabilities that would eventually find its way into the professional literature was developed in employment projects located in UAFs. Thus, the directors of these projects were called upon to provide testimony and to join with constituency groups in promoting supported employment in the Rehabilitation Act (Kiernan, 1986).

Similarly, by 1986 sixteen UAFs had ongoing early intervention initiatives and provided data needed to support proposed legislation in this area. Several UAF directors and faculty members were asked to provide descriptive data and report on model early intervention programs. Two years later, when hearings on the Technology-Related Assistance Act for Individuals with Disabilities were held, UAF faculty with pilot projects in technology were again called upon for testimony (M. G. Fifield, 1988.

The 1986 legislative session was particularly successful in addressing new initiatives for people with disabilities. Under the leadership of Senator Lowell Weiker, Chairman of the

Subcommittee on the Handicapped, and Senator Hatch, Chairman of the Senate Committee on Labor and Human Resources, supported employment provisions were added to the 1986 Amendments to the Rehabilitation Act, and early intervention provisions for infants and toddlers became Part H of the Education for All Handicapped Children's Act. As these provisions were crafted and negotiated, representatives from UAFs played prominent roles.

Emerging Expectations of Second Generation UAFs

The expectations of the second generation of UAFs that emerged in the late 1970s and mid-1980s occurred during a period when major transformations were occurring nationally and in the developmental disability field. The five UAFs that entered the network between 1975 and 1978 were very much like the first generation UAFs. After 1978, five UAF satellites entered the network, and three UAFs were established at a different university after another UAF program in the same state had been discontinued. In addition, four programs were considered part of the UAF network, but were not fully recognized either by the ADD or MCH: New Mexico, Mississippi, Ohio University, and Winthrop College in South Carolina.

Some of the most significant expectations of second generation UAFs were those placed on their host universities.

During the 1960s and early 1970s, the advantages of a UAF to a university were apparent. These advantages included the possibility of a facility in which to conduct clinical research, preservice, interdisciplinary training, and leadership—all activities highly valued and consistent with the expectations of universities. Throughout most of the 1970s, UAF faculties and host-university administrators remained hopeful that additional construction funds would be appropriated. When the construction authorization was repealed in the 1978 Reauthorization, the hope for construction faded.

Between 1976 and 1987, the expectations for the sponsoring universities for UAFs became increasingly explicit. These expectations included academic appointments for the Director and key staff, space to house an expanding program, leveraging of outside resources, and the anticipation that in the future the UAF would be asking for and receiving state-appropriated funding.

Such commitments were not easily negotiated with university administrators; consequently, it was increasingly difficult to convince university administrators that they should sponsor a UAF. In some cases, it was these very expectations that caused some UAFs to drop from the system (Ken Dumars, personal communication, 1985). Other UAFs sometimes went through considerable restructuring in an effort to find a good fit within their host universities.

Other expectations for UAFs that emerged during the second generation included those concerned with developing

and maintaining close relationships with the state Developmental Disabilities Planning Council and the state service agencies; working on systems change; and conducting outreach training, technical assistance, and service programs in community settings.

The activities to address these expectations are not closely associated with the traditional roles of university faculty. Clearly, the second generation UAF faculties, staffs, and directors were expected to spend a significant amount of time off -campus working with agencies and individuals in community settings.

Second-generation UAFs tended to represent either the center-based clinical model or the community-based model, which focused less on direct services to clients. Many of the new UAFs that began operating in the 1980s were structured so that the bulk of their activities were embedded in the community rather than in a clinic or hospital setting. The differences between these models seemed to be widening, driven to a large extent by the sources of their support. In May of 1976, there were 39 recognized UAFs; 21 reported they had MCH training support. The Department of Education, through the Bureau of Education of the Handicapped, provided the second largest source of support for UAF programs (Farlee et al., 1976). The largest single source of support for UAFs, however, remained from MCH but was available to only 22 programs (Farlee et al., 1976).

Fiscal data, which includes sources and the amount of

funding obtained and how such funds were spent, is among the most important program information available. Each UAF collects and maintains such data. However, collecting comparable and defendable data across the UAF network, or fiscal support and expenditures, is complicated by reasons of leveraging and organizational structure in individual UAFs. Leveraging creates many reporting problems, not only because of the variety of sources of support but also how partial support is separated out, how such funding is managed, and what portion of it is used for UAF activities. Furthermore, each university has its own way of determining cost centers and attributing sources of income. Major components counted as part of the UAF may also be counted as components of other university units. The relationship between such units and the UAF varies between universities. For example, some MCH training grants are clearly administered by the UAF. At other universities, the MCH training grant is administered by a unit only loosely connected to the UAF.

At times, major components like research and training centers, health or education institutes, engineering centers, or special training programs were developed by the UAF but later reassigned or gradually taken over by another university administrative unit. Furthermore, it is not uncommon for a university to assign a special institute, research, or technical assistance program like a center for the gifted, substance abuse, or aging to be administered by the UAF rather than to

establish another administrative unit. The activities and the fiscal data on such as reported depends largely on each UAF's definition and criteria. Consequently, fiscal data, at best, are estimates. Two of the seven UAF evaluation studies systematically collected and reported UAF fiscal data. Other UAF evaluation studies collected information on selected sources of support. However, it was not until 1987 that an ongoing systematic effort was undertaken to collect and report UAF fiscal data.

By the middle 1980s, the MCH training expectation no longer dominated most of the UAF training activities. Other funding sources had been found to support interdisciplinary training, and other strategies to address the training requirement had been devised, including greatly expanded outreach training. Rather than MCH and non-MCH UAFs, there were UAFs with MCH programs and UAFs that did not have MCH funding but may have had other program support from the Office of Special Education, Rehabilitation Service Administration, National Institute on Disability and Rehabilitation Research, or state sources.

The 1987 DD Act Amendments

Even before the 1987 legislative session began, the leadership of the AAUAP and consumer organizations were working together to develop new provisions. Table 2 identifies the most significant changes in the UAP[4] program contained in the 1987 DD Act reauthorization.

[4]Throughout the remainder of this paper, University Affiliated Programs (UAP) will be used both in the present and past tense.

**Table 2 Changes in the UAF Provisions of the 1987
Amendments of the Developmental Disabilities Act**

Provision or language	Significance
Name change	University Affiliated Facilities were no longer facilities, but Programs (UAPs).
New UAPs were a priority	Both authorization and appropriation legislation provided for new UAPs in unserved states. This provision was strongly supported by the National Association of Developmental Disabilities Councils (NADDC).
Training initiatives: • Staff training to service aging developmentally disabled individuals • Staff training for direct service providers • Staff training for early intervention services	The most important new UAP provision was the training initiatives. This was the first time that DD funding was provided to UAPs to meet their training expectations.
Increase in core support	This was a small increase but reflected renewed confidence in the need for and the relevance of UAPs.
Ongoing support for the UAP database	This provision permitted an ongoing collection of comparative data reflecting the national impact of the UAP network and the development of a national profile of productivity.

Perhaps as important as the changes themselves, was the support for the provisions provided by disability consumer organizations, particularly members of CCDD. This reflected a change in the way UAPs were perceived by consumer organizations and the role they would be expected to play in the future. Core support for UAPs was increased, new UAPs in unserved states were made a priority, and the training initiatives provided the first ongoing DD program support.

One of the most significant changes was in the name of the program. The program name had been a frustration almost from the start. The term *facility* had always been misleading and required lengthy explanations. Changing the official name to *University Affiliated Program (UAP)* helped, but, of course, did not fully solve the communication problems. With such significant provisions in the new amendments, the conditions were in place for a new generation of UAPs.

Third Generation UAPs

Consumer-outcome expectations for UAPs emerged in the 1980s starting with the 1984 Amendments to the DD Act. However, it was not until the 1987 Amendments became law that these additional expectations began to be addressed by programs through their core grants and additional funding sources. Consumer-outcome expectations, quality and impact indicators, provisions that increased consumer involvement

and participation, and opportunities for state councils and
UAPs to work together received considerable attention.

Expanded Relationships Between DDPCs and UAPs

Section 122 of the 1987 Amendments to the Developmental
Disabilities Act called for a comprehensive review and analysis
of the effectiveness and consumer satisfaction of
developmental disabilities services provided or paid for by
federal funds. Under this section, each state council was
required to undertake and submit to the governor and state
legislature a written report of such a study. Furthermore, the
ADD was required to compile the state data and submit a
composite report to Congress. This requirement was referred
to as the 1990 Report and involved an extensive national
evaluation study requiring the collection of descriptive and
consumer satisfaction data (Jaskulski et al., 1990).

At the national level, the research, design, and data analysis
for the 1990 report was subcontracted to the UAP faculty at
Temple University. Many state councils asked their UAPs to
help them meet the requirement of the 1990 Report. In many
states, the Council subcontracted the study to the UAP. In
other states, the UAP was given the responsibility to prepare
their state report or undertake major components of the work
involved. In most states, this was a very positive and supportive

initiative and represented an expanded relationship between the state planning council and the UAP.

UAP Program Standards

Early drafts of the 1970 DD Act and the 1975 Amendments called for UAP standards and/ or accreditation. However, when the laws were signed, standards were included in overall evaluation efforts with the entire DD program, which was contracted to the EMC Institute, Inc., in Philadelphia under the direction of Dr. Irwin Schpok.

By 1976, chaffing under criticism that UAPs had no common level of quality, the AAUAP undertook the task to develop association membership standards. Dr. Herb Cohen, Director of the Rose Kennedy Center, chaired this committee and utilized the criteria first published by DDD in 1972 (DDD, 1972). The membership standards derived from this effort identified three membership levels—full, associate, and affiliate. The standards included an application that required documentation of compliance and made provisions for verification during site visits.

Included in the 1979 Amendments to the Developmental Disabilities Act, Section 122(a) directed the Secretary to establish by regulations UAP standards that reflected the special needs of persons of various ages with developmental disabilities. In addition, the Secretary was directed to include

performance standards related to each of the mandated UAP
activities.

To develop program standards for UAPs, the DDD
contracted with Systems Research and Development
Corporation located at Research Triangle in North Carolina
to develop program criteria for UAPs. This effort was led by
Mr. David Phoenix, who started with the membership
standards developed by the AAUAP and the suggested
guidelines for measuring program acceptability included in the
Long-Range Planning Task Force for UAFs Report. Systems
Research Corporation proposed program criteria, submitted
them to consensus panels, and made them ready for field
testing in 1979.

It was difficult to determine how serious Congress was
about UAP program standards, even though they were
mandated in the authorization legislation. The
Appropriations Committee did not provide sufficient funding
to develop the standards, let alone to implement and monitor
them. Also, the only funding provided UAPs by the
Developmental Disabilities Act was the discretionary funds
to be used for administration and core support. The funding
UAPs obtained to provide mandated interdisciplinary
training, exemplary service, dissemination, and technical
assistance programs did not come from ADD, but from other
federal and/or state funding agencies. In effect, the authorizing
language directed the Secretary to develop performance
standards that would tell UAPs how they could use the

funding they had obtained from grants and contracts awarded from other agencies.

With the passage of the Omnibus Budget Reconciliation Act of 1981, which combined the reauthorization of several disability programs and proposed further reductions in funding, work on the development of UAP performance standards was tabled. Between 1981 and 1984 little was done to further develop UAP standards or program criteria.

The 1984 DD Amendments (P.L.98-527) again required the Secretary to develop and promulgate UAP standards. However, as recommended by Dr. Boggs, rather than subcontracting this task, as was done earlier, it was assigned to Marjorie Kirtland, then Deputy Director of ADD. Following 1.5 years of work, on November 20, 1987, the first program standards for UAPs were published in the *Federal Register* (1987).

Although program standards were now established, as prescribed by law, provisions to implement, monitor, and determine compliance were not in place. Furthermore, the published standards were based on the second generation UAP expectations contained in the 1984 and earlier reauthorization amendments. By the time they appeared in the *Federal Register*, the 1987 DD Amendments were already enacted in P.L. 100-146 and included many changes in the expectations of UAPs, which were not part of the standards.

A system to implement UAP standards was proposed during the AAUAP annual meeting in October 1987 by Ray

Sanchez, Director of ADD's Division of Program Planning
and Development. The proposed system was called the
Quality Enhancement System (QES) and was endorsed by
UAP directors and the ADD. The QES included a new
application process, review panels, and site visits. Over the next
few years, cooperation between the ADD and members of the
AAUAP developed five documents designed to sequentially
implement the QES (Davidson & Fifield, 1992).

1. Guidelines for the Development and Maintenance of
    Quality University Affiliated Programs (Davidson &
    Fifield, 1988).
2. Handbook for Conducting University Affiliated
    Programs Site Reviews and Self-Assessments (M. G.
    Fifield, Davidson, Garner, & Stark, 1989).
3. Technical Manual on University Affiliated Program
    Core Functions (Golden, 1990).
4. Revisions of the UAP Continuing and Competitive
    Core Grant Application.
5. National Information Reporting System for University
    Affiliated Programs (Pappas, 1990).

Accompanying the National Information Reporting System
for UAPs was the *UAP Data Collection, Reporting, and
Utilization Manual* (Pappas, 1990). This manual culminated
almost 15 years of work in developing and implementing a
network-wide data reporting system (Guthrie, 1976; Pappas,

1990). This effort started in 1976 with Don Guthrie of the
Neuro-Psychiatric Institute at UCLA. From that time
forward, a variety of efforts to collect and report data about
UAP activities were launched. Sometimes these efforts were
supported with funds from MCH and sometimes with funds
from the ADD. Both agencies expressed a need for
information about UAP activities, but the agencies differed in
the types of data they wanted, the definitions and collection
methods that needed to be developed, and the formats for
reporting the data. Consequently, each effort to gather data
about individual UAP activities across the network became
increasingly complex and controversial.

It was not until the DD Amendments of 1987 that a
consistent approach to data collection and reporting was put
into place. This system was designed primarily around ADD
data needs. Like other data collection efforts, it was criticized
and challenged from the start, because common definitions
and data collection mechanisms were difficult to agree upon,
and self-report measures were used. It was viewed primarily
as descriptive and always putting the program in the most
favorable light.

Systems Change

The data UAPs collected as part of the national information
reporting system was to be submitted by each UAP to the
ADD and to MCH (Training and Client Services) in an

annual report. In addition, the report called for information that documented activities and yearly accomplishments in addressing consumer outcomes, meeting the needs of minorities and underserved populations, leveraging, and systems change. Although leveraging non-ADD resources and systems change have always been an ADD expectation of UAPs, this was the first-time accomplishments in these areas were to be reported. These data points articulated the programmatic expectations of the ADD.

The AAUAP undertook the task of analyzing the data reported and combining and grouping it to reflect the impact that the UAP network had nationally. Because of the nature of the data reported and the diversity within the UAP network, the report was primarily descriptive and explained the scope of the UAP network rather than specific accomplishments. Systems change became the heading for activities designed to impact and improve the developmental disabilities service delivery system. Initially, UAP systems change activities focused on core functions; however, following the 1984 DD Amendments, UAP faculty were expected to advocate and promote the purposes and the values expressed in the Developmental Disabilities Act and its amendments.

Among the changes brought about by the 1987 Amendments was renewed interest in establishing a UAP in every state. Between 1987 and 1994, each annual appropriation included additional funding to support new UAPs or satellite UAPs. States could apply either for a satellite

or a full UAP, based on what they felt would be their best presentation to the review panel. Twenty new UAPs were admitted to the network between 1987 and 1994—five were satellites, and 15 were full UAPs. By 1993, seven satellite programs had become full status UAPs.

Competition between universities in unserved states for their UAP was often fierce. This in-state competition was handled by the ADD by providing either a consortium or multi-campus UAP or having each interested university submit a competitive proposal and selecting the proposal that they felt was the strongest.

Consortium or Multi-Campus UAPs

Between 1972 and 1984, multi-campus UAPs were not encouraged by the ADD. The history of multi-campus centers was not encouraging because competition between universities had been much more common than cooperation and few multi-campus UAPs had survived. Out of the six multi-campus, first-generation UAPs, Kansas was the sole survivor. The others either separated into independent UAPs or one was dropped as another unit took the leadership. However, after the 1987 Amendments, intra-state university competition for the designated UAP resulted in divided loyalties. To resolve this problem, a consortium or multi-campus program was an obvious compromise, and several were submitted and approved, including Arkansas, Texas, New Mexico, and New Hampshire.

The satellite and host UAP models were another version
of a multi-campus unit. This model had not been any more
successful than the multi-campus UAPs in the same state.
Satellites that were successful separated as soon as possible
from their host and became full UAPs.

Competitive UAP Proposals

When universities within the same state were unable to work
out a consortium or a multi-campus program, in-state
university competition was handled by the ADD encouraging
each university to submit its own application and let the ADD
review panel identify the winning proposal. Competing
universities in Texas, North Dakota, and Oklahoma were
submitted and awarded following this procedure. A selection
was made in Texas and a year later in North Dakota. A year
later, Oklahoma submitted an acceptable consortium-type
application.

Specialized services are still being offered and the health
components of UAPs have remained. The 1993 UAP survey
also asked directors to identify the legislation that has exerted
the greatest impact on their programs. The programmatic
impact of legislation has depended primarily on the funding
it provides any specific UAP, and the cumulative effects of
important legislation are reflected in the difference between
legislation reported as important by first generation UAPs and
third generation UAPs.

The programmatic implications of new federal initiatives

and interests are also determined by the longevity of the elected or appointed decision maker. Federal administrators often want to leave their stamp of influence on the programs they direct. Initiatives generated by such well-intentioned directors are frequently changed with the next appointee. The frequency with which this has occurred in ADD has caused some UAP directors to become wary about taking on new initiatives until it is clear whether the new initiative is to be a long-term emphasis or a flash in the pan.

At this point in time, third-generation expectations are coalescing around expanded consumer empowerment and involvement in UAP planning and operations, responsiveness to state needs, and an expanded community rather than university focus. Technical assistance and outreach training is replacing the expectation of core interdisciplinary preservice training. Third generation UAPs seem to be state focused rather than a national or regional resource program as envisioned in the 1970s (Tarjan & the UAF Long-Range Planning Task Force, 1976).

Overarching Themes in the Evolution of UAPs

In examining the historical, descriptive, and survey data drawn together for this study, several overarching themes emerge. Three themes in particular have had significant impact on the evolution of the UAP network: the diversity and changing

nature of the expectations of UAPs, the imperative to respond to consumer needs, and the role of values in developing programs.

Diversity

In 1962, the Panel's Report to the President pointed out that mental retardation was a complex problem requiring bold, creative approaches on many fronts. The UAP implementation legislation reflected such creativity and diversity, by design and sometimes by neglect.

University-Based

Inherent in our nation's university system are expectations of academic freedom, critique and challenge by colleagues, and technology transfer. Traditionally, it has been the nation's universities that have conducted the research leading to new scientific discoveries and to the development of new social theory and policy. It is the expertise found among university faculty that our society looks to for new initiatives, studies in organization systems, and fact finding. Perhaps the most unique feature of our nation's universities is their diversity. They are organized differently, funded from multiple sources, and bring together scholarship and scientific expertise from diverse fields.

By locating the proposed developmental disabilities

programs in universities, the UAPs evolved in many different directions determined by their location, the strengths and interests of the host university faculty, as well as the mission and goals of the university. Different UAPs reported to different administrative units and were composed of different program components. Each of these influences affected the evolution of UAP programs in different ways and added variety, comprehensiveness, and multiple perspectives to the disability field.

Expectations of Administrative and Supervisory Agencies

UAPs have been established by more than one federal agency. The first centers were established through a construction program for service and training clinics that already existed supported by Children's Bureau. The Division of Mental Retardation, which first administered UAPs, was renamed several times. In addition, it has been placed under several different federal administrative organization structures and has had a large number of directors, commissioners, or appointees acting in that capacity. As often happens, the agendas and interests of the second administrative echelon's directors, commissioners, or associate directors has also influenced the expectations of UAPs.

Over the past 30 years, the agency administering the UAP shifted from an agency focusing on health to Social and

Rehabilitation Services (SRS), then to the Office of Human
Development Services (OHDS), and more recently to the
Administration on Children and Families (ACF). Even when
specific directives were not passed down to the ADD, UAPs
were encouraged to apply for discretionary funding to the
secondary echelon agencies, and UAPs have undertaken
projects in Aging, Head Start, Foster Care, Special Needs
Adoptions, Family Support, and Employment.

In addition, the interests of an appropriately placed
legislator sometimes established or added significantly to the
program support of selected UAPs. Even though such
legislative favoritism was viewed as *pork*, UAPs so favored had
to compete for renewal, and many developed exemplary
programs.

Influence of Diverse Funding Sources

The studies undertaken to evaluate UAPs, summarized in
Table 1, repeatedly called for a common mission and a
common source of funding. The fact that these
recommendations were not implemented, although troubling
at the time, has become a major source of diversity. Individual
programs interpreted the UAP mission in line with their own
strengths and sought support from different sources. Each
agency from which a UAP was successful in obtaining funding
had its own set of expectations and objectives.

Because of their need to rely on many sources of funding,

legislation other than the DD Act has influenced the evolution of priorities, expertise, and capacity of UAPs. Not only does the impact of funding from other non-DD Act legislation for each UAP generation differ, but certain UAPs have pursued funding, programs, and opportunities made available under certain legislation at the expense of other opportunities. For example, health legislation has had a greater impact on first generation UAPs than on second generation programs. For other programs, the influence of rehabilitation and education legislation is greater than the health legislation, and even greater in many instances than the DD Act itself.

Discretionary Funding with Short-Term Competitive Grants

Most UAPs have obtained the majority of their fiscal support through competitive grants awarded generally for a 2- to 5-year period. In many cases, UAPs have competed with each other for these grants. Thus, there were winners and losers and programs and services offered by UAPs reflect this success/failure ratio.

Programs funded under time-limited federal grants have a side benefit in that they require successful applicants to be current with the literature and best practices. Success in obtaining competitive grants requires the applicant to demonstrate the very characteristics UAPs were expected to exemplify. The fact that so many UAPs have survived and even

thrived, reflects not only resourcefulness, but the merits of each individual program.

Consumer Participation

The disability field has been responding to consumer pressures since the early 1960s. Even before then, it was the National Association for Retarded Children (NARC) that carried the momentum for services and programs and the legislation that has supported them. President Kennedy, himself, was a consumer. One of the important precedents set by the President's Panel in 1962 was that of strong consumer participation. Later consumer members of the President's Committee on Mental Retardation and members of consumer organizations played an important role in the implementation legislation. Boggs (1976) reported that the leadership of the President's Committee shifted from professionals to consumers during the early 1970s. The Developmental Disabilities Act of 1970 expanded the role of consumer participation and state planning councils with consumer membership. Each subsequent reauthorization of the Developmental Disabilities Act has increased and strengthened consumer participation.

All UAPs were required to establish an advisory or policy committee. Until the late 1980s, most had a single advisory or policy council with representation from consumers. During the last half of the 1980s, representatives from consumer

organizations and members of the DDPCs were encouraged as consumer representatives. More recently, the ADD has encouraged UAPs to place primary consumers on their boards and councils. Expanding and effectively empower consumer participation in the leadership and management of UAPs continues to be a growing trend over the last decade.

The Americans with Disabilities Act (ADA)

Public Law 101-336 was signed by President Bush on July 26, 1990. The ADA, which extends federal civil rights protections to all Americans with disabilities, has been described as the most significant disability legislation of the decade and it has added a great deal of strength to the consumer-empowerment movement. Although this legislation impacts **all** individuals with all types of disabilities, not just those with developmental disabilities, and as such, was much more general than the Developmental Disabilities Act, UAPs as a part of the disability field, were expected to both comply and facilitate university and state compliance of the ADA and to work with public and private organizations on compliance issues (Seelman, 1993). The ADA initially provided opportunities for UAPs to seek funding to provide technical assistance, develop training materials, conduct seminars, and for UAP staff to take training themselves in the implementation of ADA provisions.

One of the outcomes of the ADA has been a significant
increase in the interaction between UAP faculty and staff and
representatives of disability organizations, particularly those
concerned about individuals with mobility impairments and
individuals with vision and hearing loss.

Such groups have not traditionally been a service
population of UAPs. People from these organizations and
consumers with such disabilities have been added to many
UAP policy and advisory boards and to specific projects. This
not only increases consumer representation but expands UAP
efforts to better address the needs of these disability groups.

1990 Amendments to the Developmental Disabilities Act

P.L. 101-494 was signed into law 1 month after President Bush
signed the ADA. These amendments used the same language
as the ADA and reflected increased sensitivity to disability
rights, values, and consumer empowerment. Consumer
outcome measures (i.e., independence, productivity, and
integration) were defined and the core functions of UAPs were
grouped under three headings: (a) interdisciplinary training
(although not defined, it was to provide training for parents,
professionals, paraprofessionals, students, and volunteers); (b)
demonstration of exemplary services and technical assistance;
and (c) dissemination of findings.

The language of the 1990 DD Amendments reflected some

subtle, yet meaningful, changes in the expectations of UAPs. Preservice training, model service programs, research, and leadership activities typically associated with universities were de-emphasized. The expectations emphasized included community-based training, optional services, technical assistance, and dissemination. The 1990 Amendments also provided three new training initiatives: (a) positive behavior management programs, (b) assistive technology, and (c) training needs determined by the UAP in consultation with the state planning council. The criteria for approving UAP applications for both training and core funding included competency- and value-based training and peer reviews, including site visits.

In 1992, ADD included consumers as members of the panels that reviewed UAP core and training grants. The comments of panel members on evaluation forms reflected their concern for language that was politically current; indicated value-based programming; and showed principles, priorities, and implementation of ADA and consumer empowerment. In July 1992, a special institute was sponsored by the ADD to train a group of consumers to serve as members of UAP site visit teams. From that time forward, a trained consumer has been included as a member of each UAP site visit.

Values-Based Programming

National policy reflected in federal legislation is not always based on objective data (Seekins & Fawcett, 1986). Congressional hearings are often staged, with witnesses carefully selected and coached to provide testimony supporting the values and provisions congressional leadership have already determined to promote in legislation (Weatherford, 1985).

In the disability field, reaction to intolerable conditions in large congregate state institutions triggered the de-institutionalization movement (P.L. 91-517). Renewed concern for human dignity was translated into the *Bill of Rights* provisions of the Developmental Disabilities Act and the Protection and Advocacy Program (P.L. 94-103). In more recent reauthorizations, service philosophies, including family support, community-based services, and consumer outcomes became legislative language and new program initiatives.

Over the past five decades, many such value-based provisions have been added to various reauthorizations of disability legislation (i.e., free and appropriate education, least-restrictive environment, consumer responsive, reasonable accommodation, essential job elements, and presumed eligibility). The 1994 Amendments to the DD Act (P.L. 103-230) added a list of eight value or policy principles under Part A, General Provisions, Section 101, Findings, Purpose, and Policy. These policy principles address the values and

beliefs concerning the capability and participation of individuals with disabilities and family members, respect for individual and cultural differences, the benefits of services and supports provided in an individual manner, and the advantages of integration and participation.

To many in the disability field, the term "inclusion" has evolved to reflect the combination of desired outcomes from support and service programs. Perhaps at the broadest level, inclusion emphasizes the need to change the environment and remove societal barriers to better accommodate the person with disabilities rather than changing the individual. More recently, independence and productivity, integration, least-restrictive placement, and other similar values have been encompassed under the term "inclusion." However, defining, measuring, and balancing inclusion with other values has been more difficult.

Early in the 1990s, professional organizations and consumer groups rallied around the concept of inclusion. The CEC called for a policy on inclusive schools in community settings. Special debates and consensus panels were convened to develop such a policy. By the middle of 1993, inclusion seemed to be the clarion call within the disability field. UAPs in Maine and Massachusetts had changed their name to reflect their commitment to community inclusion. The AAUAP established a special committee on inclusion and undertook efforts to assess and encourage commitment to inclusion within the network. However, different individuals and

groups in the disability field defined the term "inclusion" and applied it quite differently. On a continuum, this could range from a conservative interpretation that considers it one of many options, to a very liberal definition in which inclusion is a right, and the choice of something less than full inclusion is not acceptable (Burke & Grannon, 1994).

1994 Amendments to the Developmental Disabilities Act

By 1993, as the hearings started on the reauthorization of the Developmental Disabilities Act, opposition to the deinstitutionalization provisions were expressed by the Voice of the Retarded (VOR), a national organization representing many parents and family members with loved ones living in institutionalized settings. In effect, institutionalization is the opposite of inclusion, and VOR was concerned that inclusion was being interpreted to supersede choice, options, and family support rather than describing the environment in which supports were to be offered. VOR, along with representatives from the deaf community and several organizations representing learning disabilities, expressed concern that many considered inclusion as the ultimate value. They pointed out that inclusion was a placement, not a program decision. Its emphasis could lead to placement without support and could be trading effective treatment for such placement.

This opposition delayed congressional agreement on the

language and the provisions of the 1994 Amendments to the
DD Act for over 6 months. When the 1994 Amendments were
passed by both houses and signed by President Clinton on
April 7, 1994 (P.L. 103-230), the resulting language did little
more than try to accommodate both extremes, and in doing
so, called attention to the fact that how inclusion was defined
and implemented would be a major policy debate in future
reauthorization legislation.

As the new millennium began, the UAP network was well
established. Individual programs were established in every state
and territory of the nation. Programs were located in a wide
range of research universities, teaching colleges, medical
schools, and teaching hospitals. Some UAPs were multi-
campus consortia operations, while some operated outside of
formal academic structures. Funding for the network
continued to come from the MCH programs to operate
clinical LEND programs and from the ADD for broader
community-based programs. The national association of
UAPs underwent significant restructuring and was rebranded
as the Association of University Centers on Disabilities
(AUCD), which pursued a broad range of disability initiatives,
not just serving the interests of the constituent programs.

In 1976, the UAF Long-Range Planning Task Force
concluded that the original UAF concept was sound and that
it was in meeting a significant social need (Tarjan & the UAF
Long-Range Planning Task Force, 1976). The original
concepts have matured over the past 6 decades. In response and

along with the evolution of the disability community, UAFs have evolved into programs and more recently into University Centers on Disabilities (UCEDs). Their funding and activities are highly diverse and collectively impact the lives of millions of people with disabilities and their individual social and community networks. In many planned, unplanned, and unexpected ways, the current network of programs is successfully addressing the needs of the disability field as originally outlined by the President's 1962 panel.

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ADVANCE CARE PLANNING WITHIN INDIVIDUALIZED CARE PLANS: A COMPONENT OF EMERGENCY PREPAREDNESS

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Advance Care Planning Within Individualized Care Plans: A Component of Emergency Preparedness PDF File

Abstract

Federally legislated Medicaid requirements for recipients with intellectual and/or developmental disabilities (IDD) to have a person-centered plan (PCP) do not specifically state that advanced care plans (ACP) be a component of the plan. However, coronavirus disease 2019 (COVID-19) has provided a salient reminder of the importance of incorporating ACP within the PCP for people who have IDD. As demonstrated by situations arising from COVID-19, emergencies and crises can dramatically alter access to care for people with IDD. This paper synthesizes results from an environmental scan related to ACP for adults with IDD. Findings suggest that the use of ACP, particularly when such planning processes result in the delineation of roles and documentation of preferences, can be helpful in mitigating the impact of these crisis situations on the person with IDD and their caregivers.

Plain Language Summary

People with a disability who receive services from the government for their disability have to have a written plan about their life. Plans for the future do not

need to be part of this written plan. However, with the COVID-19 pandemic, we see more emergencies that cause big changes to the lives of people with disabilities. During big events like this, it can be helpful to have plans for the future written down. In this paper, we look at what is known about planning for the future for adults with disabilities. We make suggestions to improve these plans so people with disabilities and their caregivers feel more prepared during a crisis.

Keywords:

Advance care planning, intellectual & developmental disabilities, person-centered plans, caregiving, end-of-life, decision-making, emergency planning

Health policy, planning, and practice often fail to meet the needs of people with intellectual and/or developmental disabilities (IDD), especially in response to unforeseeable emergencies (Nygren & Lulinski, 2020). An example of this is the coronavirus disease 2019 (COVID-19) pandemic (Avalere Health, 2020; Courtenay & Perera, 2020; Hughes & Anderson, 2020; Willner et al., 2020). Throughout the COVID-19 pandemic, public policy has often failed to adequately support people with IDD and their caregivers

(Center for Public Representation, 2021). The ongoing pandemic has revealed the necessity of emergency planning and also the longstanding absence of it in the lives of people with IDD (Miceli, 2020).

More specifically, COVID-19 has provided a salient illustration of the need to integrate advance-care planning within the mandated person-centered planning process for those receiving Medicaid home- and community-based services (HCBS). Implementation science demonstrates that capacity building using evidence-based frameworks in health care and public health settings are requisite to influence policy and achieve funding to enable effective evidence-based service provision (Metz et al., 2015; National Institutes of Health, 2019; Pollastri et al., 2020). Identification and articulation of the measures and practices necessary to guide an emergency response in the service of people who have IDD on an ongoing basis is needed in order to ensure policy and funding, which enable effective responding to these emergencies. This is particularly so in the face of population-level emergencies, whereby there are competing demands for public resources to respond to the emergency.

In this brief, we contend that advance care plans (ACPs) are integral to the maintenance of care and services during unanticipated crises, and, as such, warrant inclusion in requisite person-centered plans (PCPs), which may also be known as life-care plans (LCP). For brevity, they will be referred to as PCPs throughout this paper. Drawing upon a

human rights perspective, we offer recommendations for policy and practice that harness lessons learned from the COVID-19 pandemic to ensure that the person-centered planning process attends to emergency preparedness, including advance-care planning for people with IDD and their caregivers. We argue that doing so prior to emergency situations increases the likelihood of maintaining principles of independence, participation, care, self-fulfillment, and dignity when such circumstances do arise.

Advance-Care Planning for People with IDD

Advance-care planning is defined as the development of a care plan in preparation for when one's diminished capacity prevents decision-making for oneself (Perkins & van Heuman, 2018). Considerations reflected in an ACP may include: (a) wishes for one's future, (b) residential decisions, (c) financial considerations, (d) occupational and recreational preferences, (e) supportive measures to facilitate daily living and life-course transitions, and (f) maintaining a social support network (Arc Center for Future Planning, 2016). ACP tends to result in a better-informed care during crises—especially when it is completed as a collaborative process, informed by key stakeholders, and reflective of the values and priorities of the person for whom it is being completed (Arnold et al., 2012;

Bigby et al., 2015; Heller & Caldwell, 2006; Heller & Kramer, 2009).

ACP is distinct from the more generic ACP process that people who have IDD complete with their care team in that the focus on the LCP tends to be on arrangements within the context of day-to-day living. Conversely, ACP specifically accounts for decision-making in unforeseeable crises and emergencies. Unlike LCP, the focus of ACP often includes consideration for palliative care, funeral and burial, as well as transition of care following incapacitation of caregivers.

Where PCPs aim to facilitate autonomy and life satisfaction experienced by the person with IDD, completion of the ACP process tends to result in better-informed care during both individual and population-level emergencies and crises. This is especially so when it is completed as a collaborative process, informed by key stakeholders, and reflective of the values and priorities of the person for whom it is being completed (Arnold et al., 2012; Bigby et al., 2015; Heller & Caldwell, 2006; Heller & Kramer, 2009). Resource allocation to the ACP process is crucial to effective implementation of services in emergencies and crises.

Yet, few Americans have completed ACPs, with Yadav et al. (2017) estimating that only about one-third of Americans have these plans in place. Healthcare providers, who are arguably well-positioned to initiate conversations regarding ACPs, reported avoidance of this process because of the discomfort and difficulties these emotionally laden conversation can evoke

(McEnhill, 2008). For people without disabilities, Voss (2017, 2019) indicated a trend toward increased use of advance directives, particularly among people with IDD with serious illnesses. However, many people within the disability community remain reluctant to participate in the ACP process because of concerns of misuse of the plan to rationalize withholding of care (Center for Public Representation, 2021; Johnson, 2010). The COVID-19 pandemic appears to have exacerbated these fears.

Family Caregivers and Future Planning

Less than a one-half of maternal caregivers between the ages of 58 and 87 years of age reported completing ACPs for their children with IDD (Freedman et al., 1997). Parents of adult children with IDD cite a lack of options available, indecision, and frustration navigating obstacles as reasons for delaying or forgoing the ACP process (Taggart et al., 2012). Among the most significant of barriers was parents' deep-seated fear of a future when they could no longer provide care for their children (Haley & Perkins, 2004; Marsack-Topolewski & Graves, 2020). However, an ACP educational program was found to alleviate parents' planning challenges. A study of this intervention found that the prospect of planning became less intimidating when caregivers had access to opportunities to become familiar with ACPs (Heller & Caldwell, 2006).

Informal caregivers (i.e., unpaid and/or family caregivers) can abruptly become disabled or unable to provide care, requiring coordination of care for themselves as well as their loved one with IDD (Kuper et al., 2020). In situations that require informed consent from the caregiver, sudden changes in the caregivers' capacity can affect decision-making and care arrangements for the individual with IDD (Alexander et al., 2020). A pre-existing ACP delineating transfer of decision-making and emergency care can help to alleviate burden during times of emergencies. Providing care and meeting the needs of people with IDD throughout the COVID-19 pandemic provides a salient example of an unanticipated circumstance that could require provision of alternative care arrangements on short notice.

Learning from the COVID-19 Pandemic

Because of the unexpected impact of COVID-19, families and people with IDD have encountered significant challenges (Hughes & Anderson, 2020). While some of these disruptions have been mitigated by technology, the ongoing pandemic has resulted in statewide closures of needed resources, services, and supports (Avalere Health, 2020; Hughes & Anderson, 2020; Rose et al., 2020). A nationwide survey, administered to 1,600 community service providers for people with IDD, found that as a result of COVID-19:

- 68% of service providers were forced to close,
- 52% of remaining services had to increase spending for staff overtime, and
- 57% of providers struggled to adequately staff services, such that they were sometimes unable to offer them (Avalere Health, 2020).

In response to the COVID-19 pandemic, medications had to be modified in some cases to address hyperarousal and anxiety resulting from extreme, ongoing, and uncontrollable changes (Hughes & Anderson, 2020).

Global circumstances arising from the early months of the COVID-19 pandemic illustrate how a novel virus with no cure or treatment can impact the delivery of care. Emergencies require caregivers to respond and adapt to new realities (e.g., lockdowns and physical distancing measures, interruptions to supply chains, caregiver attrition). These realities influence and limit when, how, where, and what care can be delivered. Regardless of availability of formal caregiver support, family caregivers were often expected to navigate challenging circumstances while balancing other life responsibilities (Grier et al., 2020). While COVID-19 yielded many unexpected challenges, caregivers who had engaged in ACP may have been able to minimize disruptions in care.

Emergency Preparedness: A Human Rights Perspective

Members of the United Nations (UN) have responded to the recommendations of international institutions, such as the World Health Organization (WHO) and the International Association for the Scientific Study of Intellectual Disabilities (IASSID), to prioritize policy development, capacity building, and research to support adults who have IDD as they age (Evenhuis et. al., 2000; Hogg et. al., 2000; Thorpe et al., 2000). The guiding principles informing these initiatives are similar to those adopted by the UN General Assembly in the United Nations Principles for Older Persons (resolution 46/91), as well as those identified in the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2012). These include: (a) independence, (b) participation, (c) care, (d) self-fulfillment, and (e) dignity. Unfortunately, the abstract nature of these characteristics makes them challenging to quantify and generalize across populations. These challenges have been exacerbated by the pandemic, which has made it not only difficult to measure adoption of these principles but also posed unrelenting challenges to enacting policies that uphold them.

Service closures and physical distancing requirements resulted in innumerable people who have IDD losing access to essential services; thereby, increasing the burden on many families to provide care (Avalere Health, 2020; Rose et al.,

2020). However, little regard is devoted to the condition of the individual or the family's ability to meet those needs. The extant research on ACP with people who have IDD has focused on planning in the absence of a global pandemic. Emergent knowledge suggests that PCPs were often insufficient in articulating ACPs during this particular emergency situation (Miceli, 2020). When systems fail to adequately prepare for or have difficulty enacting policies in the wake of foreseeable unforeseen events, the climate exists where it can become increasingly difficult to uphold the guiding principles of independence, participation, care, self-fulfillment, and dignity.

Discussion

Given the inevitability of emergencies, people with IDD will need to maintain access to care and support throughout unexpected situations. Planning is needed to manage potential changes that affect people with IDD, family caregivers, and service providers. COVID-19 has provided a particularly salient illustration of an emergency situation that could have benefited from the intentional and widespread integration of ACP within the PCP process. Given the increased likelihood of people with disabilities, including those with IDD, to be infected and/or die from the virus, a pressing need exists to maintain continuity of care in such emergency situations

(Pineda & Coburn, 2020). An ACP can help mitigate these challenges, along with others related to care and service access.

Medicaid now requires that each individual receiving services through the HCBS waiver have a PCP (U.S. Department of Health and Human Services [USDHHS], 2015). This rule change provides a prime opportunity for considering ACP. As the PCP process must be completed at regular intervals, the ACP can be updated to reflect changing caregiver arrangements and planning for emergencies. This process can also build familiarity and comfort with planning across the lifespan. Incorporating ACP into the PCP as a standard practice can serve to alleviate distress on the part of the person with IDD, family caregivers, and health care providers when crises arise.

The UNCRPD offers guiding principles that can inform the enactment of policies and practices for the integration of ACP in the PCP process. Yet, the focus of UNCRPD is on the home and family, particularly the rights of people who have IDD and caregivers to children with IDD. There is no provision made for family caregivers of adults who have disabilities. Lifelong disabilities, however, do not end upon entry to adulthood. Frequently, access to supports familiar to the person with a disability and their family are offered to children through the school. With the transition to adulthood and exit from the school system, these supports cease to be available. As such, alternative supports and plans need to be put in place.

In a community-based care setting, which seems to be the service model of choice among UN member nations, failure to account for adults who have disabilities and those who assist or care for them may hamper their ability to benefit from the principles articulated in the UNCRPD. The absence of such considerations can create perilous scenarios for both the caregivers and persons with IDD in emergency situations. When these scenarios are not accounted for in health policy, mechanisms to adapt to such circumstances are limited.

Family caregivers have experienced these challenging circumstances throughout the COVID-19 pandemic, such that many have reported defeat, anxiety, and depression (Willner et al., 2020). Some family members, particularly in the case of older adults with IDD, have found themselves incapacitated and requiring emergency care services for themselves as well as people with IDD (Rose et al., 2020). Family caregivers have had to become nimble when identifying and accessing alternative support services during the pandemic. Where barriers to care arise, it is the role of the relevant professionals to assist the parent or family member to identify what options exist to meet the needs of their loved ones. Emergency planning can be incorporated within the person-centered planning process. The knowledge that this has been accounted for and is likely to reflect the individual's values and needs, can serve to alleviate parental fear for the future—a previously identified barrier to engaging in the planning process.

Building ACP into the PCP process provides an opportunity for the person with IDD to develop familiarity with transitions and changes to routine that can arise from emergencies and crises. A documented plan for navigating emergency situations, specifying who will be responsible for fulfilling various roles and needs, can ensure more accountability in and effective delivery of care and support in spite of foreseeable unforeseen circumstances. Accounting for dietary preferences and restrictions, behavior management protocols, and individual values/ priorities can ease disrupted circumstances. Accounting for finer details, such as end-of-life planning, can also ensure that one's values and priorities can/ will be upheld. This has become particularly important during the COVID-19 pandemic when caregivers and surrogates were often prevented from being present with the person with IDD through the changed circumstances.

Service providers can help their clients plan for emergencies by engaging people who have IDD and their families in the ACP process. The PCP process, a required element for those receiving Medicaid-funded services, is an ideal setting for discussing and documenting ACPs. Doing so may help to ensure that individuals with IDD, as well as their family and members of their care team, understand what to expect and know how to minimize disruptions as crises emerge.

Recommendations for Practice

1. Systematically desensitize the anxiety associated with ACP by incorporating it within the regularly scheduled person-centered planning process, allowing people with IDD and their families regular exposure to practical and supported discussions about relevant arrangements when no emergency or crisis is imminent.

2. Embed and regularly update stress mitigation strategies within the PCP documents, accounting for foreseeable unforeseen circumstances, such as emergencies and crises, which may necessitate temporary or permanent alternations to care arrangements.

3. Ensure that a mechanism for keeping current features within the PCP documents, such that it will serve to maintain a semblance of stability across alternate care arrangements (e.g., dietary preferences and restrictions, favored pastimes, fears, preferred clothing, and/or comfort items, etc.).

4. Formalize and implement plans to rehearse emergency responses (e.g., alternate care accommodations, communication of the need for alternate care, etc.) regularly so that alternate care circumstances are not foreign to the care recipient at the time of crisis response.

5. Include alternate care providers in the rehearsal process, thereby achieving role clarity, identify possible challenges, and resolving any issues that may arise prior

to the eventuality of an emergency or crisis situation.

Conclusion

In general, people are hesitant to engage in the ACP process. This is particularly so among people who have IDD and their loved ones. However, having an ACP is especially important among this population, as it can facilitate safe and effective responding to emergency situations. The current COVID-19 situation, worldwide, has provided a salient example of how people with IDD have been impacted by unforeseen loss of access to services and sudden changes to their care and living arrangements. The effect has been, in many situations, circumstances that compromise one's ability to live in ways consistent with principles of human rights for both those who have disabilities, including IDD, and people who are aging (i.e., people with IDD and/or their family members). Developing an ACP, within the context of a PCP, a plan that is legislated for updating at regular intervals, can facilitate a clear approach to support and care consistent with one's values when emergencies arise.

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DAILY LIFE EXPERIENCES OF FAMILIES OF PEOPLE WITH DISABILITIES DURING COVID-19 PANDEMIC

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Daily Life Experiences of Families of People with Disabilities During COVID-19 Pandemic PDF File

Abstract

Background

For people with intellectual and developmental disabilities (IDD) and their families, COVID-19 has introduced additional challenges including significant disruptions to daily life and increased risk in accessing services and supports. Understanding how families are adapting and navigating through the crisis is critical to inform ongoing supports as the pandemic continues and beyond as there will likely be ongoing changes in service and support delivery both directly and indirectly related to COVID-19. The purpose of this study was to survey families in one Midwest state in the U.S. to document experiences during COVID-19 with a focus on understanding how families are navigating current and new support needs related to general health and wellbeing, decision making, support needs, and access to services for their children with IDD.

Method

An online survey was used to study 372 family members or caregivers who supported people with IDD across the life course. Results were analyzed descriptively to capture the experiences of families of children with IDD

based on the type of questions for the overall
sample as well as for each of the four age groups
representing key life course transitions (0-4,
5-17, 18-21, and > 21).

Results

Across the life course, families and caregivers
reported challenges from COVID-19
impacting several areas of daily life, including
health and wellbeing, decision making, changes
in support needs, challenges obtaining supports
and services, and managing challenges. Across
the ages, almost one third of the sample
reported more support needs for behavioral or
emotional needs and almost 20% reported
having trouble in supporting the increased
needs. Further, a majority of family members
in this study described fewer opportunities for
important daily activities, including decision
making and physical activity.

Conclusions

Families of children with disabilities reported
increased support need for their child with a
disability during the pandemic.
Recommendations for planning for supports
and services are provided.

Plain Language Summary

This study asked families about their experiences during COVID-19. Families and caregivers described challenges that affected their daily life. Many people said they needed more behavioral or emotional supports. Many people said they had trouble accessing supports they needed. Most family members said there were fewer opportunities for their children to make decisions. This paper includes ideas for how services and supports can be improved.

Background

The COVID-19 pandemic has introduced signifcant disruptions throughout the world and necessitated rapid and ongoing changes in the lives of all people, including families and children (Patrick et al., 2020). The long-term impacts across multiple domains of health and functioning are unknown. For people with intellectual and developmental disabilities (IDD) and their families, COVID-19 has introduced additional challenges, including significant disruptions and increased risk in accessing services and supports to meet needs across multiple life domains (e.g., daily living, health, education, social; Eshraghi et al., 2020; Houtrow et al., 2020; Summers et al., 2021). For example, early in the pandemic, Neece et al. (2020) reported that

families of young children with IDD experienced decreased access to essential services, struggled to fill the gap, and dealt with significant concerns about the long-term impacts on education and social engagement opportunities. Work is needed to better understand the ongoing impacts of COVID-19 on people with IDD and their families across the life course. Specifically, there is a need to better understand the impact of COVID-19 on the day-to-day experiences of children, youth, and adults with IDD as well as the impacts on support needs and access to supports and services. Understanding how families are adapting and navigating through the crisis is critical to inform ongoing supports as the pandemic continues and to plan for ongoing changes in service and support delivery both directly and indirectly related to COVID-19 (Camden & Silva, 2021). As such, the purpose of this study was to survey families in one Midwest state in the U.S. to document experiences during COVID-19 with a focus on understanding how families are navigating current and new support needs related to general health and well-being, decision making, and access to services for their children with IDD. We specifically targeted developing a better understanding of the day-to-day life and experiences of families with children with IDD across the life course.

Method

Survey Design and Delivery

The survey used in this study was developed through an existing collaboration between a university research center focused on disability, a statewide self-advocacy group, and a statewide parent advocacy group. The project team was working together, prior to COVID-19, on state-wide system change initiatives in education and adult services for children, youth, and adults with IDD, and quickly pivoted to identify and address issues that emerged in March 2020 with the first stay-at-home orders being issued in the state. The project team met using virtual technology to brainstorm and develop the domains and items for the survey. The draft was then refined and shared with other self-advocates and family members from community organizations. These stakeholders reviewed the items and provided feedback on applicability (i.e., does the item apply to the experiences of people with IDD and their families during the pandemic) and accessibility (i.e., is the item easily understood). Items on the survey asked questions about general well-being (e.g., How are you doing during the pandemic? How is your child doing during the pandemic?) and health (e.g., Has your child's physical activity level changed? How are you and your family staying safe?), as well as decision making (e.g., Has COVID-19 changed the opportunities your child has to make decisions?). Families

were also asked to rate changes in support needs (e.g., My child has needed more support for their behavior) and identify areas where there were challenges with accessing supports (e.g., finding enough support workers, getting to doctors appointments, accessing masks or other personal protective equipment [PPE]). A variety of question formats were used, including yes/no, scaled response, and open-ended questions. For example, questions about family member perceptions of the well-being of their child with a disability were rated on a Likert scale (1 being "Poor" and 5 being "Very good"), while questions regarding challenges with supports and services allowed respondents to select all relevant answers (e.g., "Difficulty with support workers showing up, Difficulty finding enough support works"). General demographic questions were also included. The survey closed with an open-ended question asking families/caregivers about their experiences and the strategies they would share with other families managing COVID-19.

The survey was disseminated to family members by project partners through emails to listservs and via social media platforms maintained by multiple partner organizations, including the state's Family Training and Information Center, University Center on Excellence on Developmental Disabilities, Council on Developmental Disabilities, the statewide self-advocacy group for adults with IDD, and Protection and Advocacy System. The survey was disseminated in May of 2020 and remained open for 1 month.

This time period was targeted as this was a time, particularly in the Midwest state where the survey was disseminated, when public health safety measures related to COVID-19 were beginning to be modified and reduced yet there was great uncertainty about the most effective ways to promote health and safety, particularly in vulnerable populations introducing greater need for individual decision making about health and safety.

Sample

In total, 372 family members or caregivers completed the survey. They supported people with IDD across the life course. We organized the sample into four age groups based on differences in service delivery and supports (i.e., 0-4, 5-17, 18-21, 22 and older). See Table 1 for the breakdown of the sample. The largest age group was the school-aged population (45.4%), and our smallest sample was young children aged 0 to 4 (4.3%). The sample was distributed across urban, suburban, rural, and remote settings, with roughly half of the overall sample living in suburban settings. The majority of the family members who completed the survey had children, youth, and adults who had ID or ID and ASD, although a smaller subset had ASD only or other developmental disabilities. The school-aged sample contained the largest proportion of participants who had children with ASD only. Except for the youngest age group, the majority received Medicaid-funded supports

and services. The overwhelming majority of the sample was White/European American and non-Hispanic. Overall, the demographics of the sample reflected the relative racial and ethnic composition of the Midwest state where the survey was administered, but Hispanic and African American groups were underrepresented relative to their absolute percentage of the state population. See Table 2 for a breakdown of the survey results by age and other relevant demographics (location, type of disability, race/ethnicity, etc.).

Table 1 Children, Youth, and Adults with Disabilities Whose Parents/Caregivers Completed the Survey

Age of child or adult	*n*	%
0-4	16	4.6
5-17	165	47.4
18-21	49	14.1
Over 21	118	33.9
Missing	1	.3

Table 2 Demographic Data Broken Down by Age Ranges

	Overall		0-4		5-17		18-21		> 21	
Demographic	n	%	n	%	n	%	n	%	n	%
Place										
Urban	54	15.5	2	12.5	20	12.1	8	16.3	24	20.3
Suburban	195	55.9	7	43.8	100	60.6	29	59.2	58	49.2
Rural	89	25.5	7	43.8	38	23.0	10	20.4	34	28.8
Remote	9	2.6	0	0	6	3.6	2	4.1	1	.8
Missing	2	.6	0	0	1	.6			1	.8
Parent or caregiver										
Parent	321	92.0	16	100	152	92.1	48	98.0	105	89.0
Caregiver	26	7.4	0	0	12	7.3	1	2.0	13	11.0
Missing	2	.6			1	.6	0	0	0	0
Disability										
ID	102	29.2	4	25.0	25	15.1	17	34.7	56	47.5
ASD	92	26.4	4	25.0	60	36.4	11	22.4	16	13.6
ID_ASD	97	27.8	0	0	44	26.7	15	30.6	38	32.8
Other[a]	58	16.6	8	50.0	36	21.8	6	12.2	8	6.8
Receives Medicaid-funded supports										
No	104	29.8	8	50.0	72	43.6	16	32.7	8	6.8

Yes	242	69.3	8	50.0	93	56.4	33	67.3	108	91.5
Missing	3	.9	0	0	0	0	0	0	2	1.7
Race										
African American	8	2.3	1	6.3	6	3.6	1	2.0	0	0
White	315	90.3	10	62.5	145	87.9	45	91.8	114	96.6
Asian	5	1.4	0	0	3	1.8	0	0	2	1.7
> 2 races	12	3.4	3	18.8	7	4.2	0	0	2	1.7
Other	3	.9	0	0	2	1.2	1	2.0	0	0
Missing	6	1.7	2	12.5	2	1.2	2	4.1	0	0
Hispanic										
No	321	92.0	10	62.5	150	90.9	45	91.8	115	97.5
Yes	20	5.7	5	31.3	12	7.3	1	2.0	2	1.7
Missing	11	3	1	6.3	3	1.8	3	6.1	1	.8

[a]"Other" includes mental health disability, learning disability, visual impairment or blindness, hearing loss, physical disability, speech language disability, and/or traumatic brain injury.

Analysis

To descriptively explore the experiences of families of children with IDD, we calculated descriptive statistics (e.g., frequencies,

means, standard deviations) based on type of questions for the overall sample as well as for each of the four age groups. Open-ended questions were reviewed for key themes; exemplars of family experiences are shared to contextualize findings.

Results

Health and Well-Being During COVID-19

Table 3 presents the descriptive findings for items asked of families/caregivers for overall health and well-being during COVID. Eighty-four percent of families and caregivers in this study reported that they were doing average or better during the pandemic, although more families and caregivers reported below average well-being in the school-age (5-17) age group. Interestingly, parents/caregivers tended to report that their child with a disability was not doing as well (74% reported their child was doing average or below) during the pandemic, perhaps reflecting differences in child and parent experiences.

Table 3 Overall Health and Well-Being During COVID

	Overall			0-4		5-17		18-21		> 21	
Question	n	%	n	%	n	%	n	%	n	%	
How are you doing during the COVID19 pandemic?											
Very good	27	7.7	2	12.5	8	4.8	2	4.1	15	12.7	
Above average	100	28.7	4	25.0	36	21.8	15	30.6	45	38.1	
Average	165	47.3	6	37.5	81	49.1	30	61.2	48	40.7	
Below average	42	12.0	2	12.5	29	17.6	2	4.1	9	7.6	
Poor	14	4.0	2	12.5	11	6.7	0	0.0	1	.8	
Missing	1	.3	0	0.0	0	0.0	0	0.0	0	0.0	
How is your child with a disability doing during the COVID19 pandemic?											
Very good	25	7.2	2	12.5	10	6.1	6	12.2	7	5.9	
Above average	64	18.3	4	25.0	27	16.4	6	12.2	27	22.9	
Average	153	43.8	4	25.0	71	43.0	25	51.0	53	44.9	
Below average	80	22.9	5	31.3	40	24.2	10	20.4	25	21.2	
Poor	26	7.4	1	6.3	17	10.3	2	4.1	6	5.1	

Missing	1	.3	0	0.0	0	0.0	0	0.0	0	0.0
How have your child's physical activity levels changed during COVID19?										
More activity	48	13.8	0	0	34	20.6	8	16.3	6	5.1
less activity	240	68.8	11	68.8	110	66.7	32	65.3	87	73.7
No changes	60	17.2	5	31.3	21	12.7	9	18.4	25	21.2
Missing	1	.3	0	0.0	0	0.0	0	0.0	0	0.0
How has your child's diet changed during COVID-19? My child easts...										
More than usual	99	28.4	2	12.5	55	33.3	12	24.5	30	25.4
Less than usual	40	11.5	2	12.5	20	12.1	5	10.2	13	11.0
About the same	209	59.9	12	75.0	90	54.5	32	65.3	75	63.6
Missing	1	.3								

My child doesn't have enough to do.									
Yes	142	40.7	4	25.0	64	38.8	24	49.0	49	41.5
I am worried about me getting sick									
Yes	96	27.5	4	25.0	49	29.7	13	26.5	30	25.4
I am worried about my family members or child getting sick									
Yes	216	61.9	11	68.8	95	57.6	29	59.2	80	67.8

A large majority of families reported less physical activity for their children during the pandemic and slightly less than half reported diet changes. A large minority of families (40.7%) also reported their children did not have enough to do, particularly for the 18-21 sample (49%). While a quarter to one third of family members and caregivers reported worrying about getting sick themselves, much higher numbers reported worrying about this for this child, ranging from 60% to 69% of the sample.

Decision Making During COVID-19

Table 4 provides information on how families/caregivers have supported their child to engage in decision making about what to do during the day during the pandemic and if there have been changes. A large majority of families (72.5%), but particularly families with school-age and adult children (65-77%), felt opportunities to make decisions had been restricted because there were fewer opportunities to go places, although a small minority (slightly less than 10%) felt their children were making more decisions.

Table 4 Decision Making During COVID

	Overall		0-4		5-17		18-21		> 21	
Question	n	%	n	%	n	%	n	%	n	%
How do you support your child with a disability to decide what to do during the day?										
Child decides on their own	67	19.2	2	12.5	32	19.4	17	34.7	16	13.6
I give my child choices on what to do and they decide	123	35.2	4	25.0	65	39.4	15	30.6	39	33.1
My child has developed a routine, and that works well for them	117	33.5	5	31.3	48	29.1	16	32.7	48	40.7
I decide what my child will do	35	10.0	5	31.3	20	12.1	1	2.0	9	7.6
Missing	7	2.0	0	0.0	1	.6	0	0.0	6	5.1

Has COVID-19 changed the opportunity your child has to make decisions? Choose one.									
I make more decisions for my child now	28	8.0	2	12.5	16	9.7	6	12.2	4	3.4
My child makes the same amount of decisions as before	66	18.9	7	43.8	26	15.8	10	20.4	23	19.5
Because we can't go to as many places, there are fewer opportunities to make decisions	253	72.5	7	43.8	123	74.5	32	65.3	91	77.1
Missing	2	.6	0	0.0	0	0.0	1	2.0	0	0.0

Changes in Support Needs During COVID

Table 5 provides an overview of changes in support needs reported by parents/caregivers. Across the ages, more than one third of the sample reported more support needs for

behavioral (35%) or emotional (32%) health and one fourth reported concerns with changes in social skills. Over 20% reported having trouble supporting their child because of increased needs. This was particularly pronounced for young children (44% reported increased behavioral support need and 19% reported increased emotional support need) and school-aged children (43% reported increased behavioral support need and 37% reported increased emotional support need).

Table 5 Mean Changes in Support Needs During COVID

	Overall		0-4		5-17		18-21		> 21	
Statement	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%
My child has needed more support for their behavior	123	35.2	7	43.8	71	43.0	12	24.5	32	27.1
My child has needed more support for their emotional needs	113	32.4	3	18.8	61	37.0	15	30.6	34	28.8
I am having trouble supporting my child because of increased support needs.	71	20.3	6	37.5	44	26.7	7	14.0	14	11.9
I am concerned with the changes in my child's social skills	93	26.6	5	31.3	53	32.1	11	22.4	24	20.3

Challenges in Supports and Services

Table 6 reports on challenges families and caregivers identified with supports and services during COVID-19. Twenty percent

of the sample reported challenges with finding support providers, with a higher percentage of families of school-aged children having difficulty (27%). Fifteen percent of the sample also reported having trouble getting a mask or other PPE. A minority of participants reported difficulty with support workers showing up (8.3%) and difficulty getting to doctor appointments (9.2%). We attempted post-hoc comparisons to investigate differences in challenges accessing supports and services between participants receiving versus not receiving Medicaid-funded services; however, the sample size and number of people reporting challenges in supports and services were too small to be analyzed.

Table 6 Mean Challenges with Supports and Services

	Overall		0-4		5-17		18-21		> 21	
Statement	n	%	n	%	n	%	n	%	n	%
Difficulty with support workers showing up	31	8.3	1	6.3	18	10.9	2	4.1	10	8.5
Difficulty finding enough support workers	76	0.4	3	18.8	44	26.7	9	18.4	20	16.9
Having trouble getting to doctor appointments	32	9.2	0	0.0	15	9.1	7	14.3	10	8.5
Having trouble getting a mask or other equipment to protect me or family members	55	15.8	1	6.3	26	15.8	9	18.4	19	16.1

Managing Challenges

Responses to the open-ended question about strategies families/caregivers would share with other families to navigate COVID-19 highlighted several key issues. While we did not

ask specifically about supports received from schools, many participants with school-aged children described experiences (both positive and negative) related to supports received from schools during remote education. Multiple family members described struggling with getting supports from their schools. One family member stated *"People who have immunocompromised children need more support through their school district. The schools are not wanting to help as much and just brush us off."* Another family member noted a need for more support as *"Being [my child's] special education teacher/ PT/OT/Adaptive PE and Speech Teacher while working and caring for other siblings has been incredibly challenging."* Another family highlighted the importance of a team approach to education during remote learning: *"I insisted the school support with teachers and paras working with my child to accomplish her work using Zoom. This has been THE reason she has been able to complete schoolwork."*

Family members of adults with IDD focused on the significant difficulties in accessing paid, well-trained supporters who could assist with activities and maintain health and functioning during the pandemic. For example, one parent wrote *"I only survived once I got some good personal care attendants. It was hard to train them quick.... But now I can rest. It takes a village."* Another parent noted the significant difficulties associated with organizing supports remotely when their child lived outside the home and worries about what would occur beyond the pandemic.

My son lives in an apartment and receives residential supports through a provider organization. We are doing his grocery shopping, buying in bulk, and coaching by phone on meal preparation as he has been in lock-down for the past 10 weeks. He is in the HCBS wait list and pays [out of pocket] for his supports, including job coaching. We have reduced his level of services, so he does not run out of money in his trust. He has been on the wait list for 5 years and there's little hope that relief will come anytime soon. My greatest concern right now is that Congress has not appropriated any relief for direct support staff who are underpaid and underappreciated already. Then what will happen to support services my son and others rely on?

Another family who received paid supports noted the changes in their roles and the emotional toll.

Our adult son lives in a group home, but we talk with him multiple times daily, visit outside his house and wave and talk briefly through his house window. Even though he doesn't live with us, we still bear much of the responsibility for his care and well-being, and in Covid-19, of course, we worry about him lots! Because of his quarantine, we are unable to be with him, or to bring him to our home overnight weekly as we have done as a routine before. Covid 19 has been very hard on our son emotionally.

Across the life course, families emphasized the role of routines and creating meaningful opportunities to focus on choice and decision making, including embedding these opportunities within activities in the home—like cooking and eating. One family highlighted their focus on keeping *"a routine around*

simple things. Give [the child] as many small choices as possible embedded in their routines. Eat healthy." Another noted,

> *I focus on things she likes. For example, she likes cooking. I let her choose a recipe and we talk through what is needed and I give her the time she needs to make something. I am nearby if she has questions or needs assistance. I put together her own recipe book and I will give it to her on her birthday.*

Another central area that families emphasized was the importance of technology. For those who had access, using technology to maintain communication and support was critical: *"If you have access to internet, suggest your child use FaceTime or Zoom to have instant face-to-face communication with friends and family."* For some parents of adults in residential settings, such technology provided the only means of interaction available. One family member noted, *"My daughter is living in an apartment with residential support, so my direct input is limited to phone calls, emails, and video chat."* One family whose child received day services emphasized the critical role of a virtual program offered by their adult child's day service,

> *My child's day service has developed an online virtual program, he Zooms with them Mon-Fri from 10:00 a.m.-3:00 p.m. His behavior has improved as a result of them implementing this, he loves the interaction with day service staff and with his friends.*

However, some families expressed concern about the

limitations of technology. For example, one family member noted, *"Now we literally are home all day every day and he is not getting any stimulation other than computer/iPad,"* while another said that therapy via video chat was *"not ideal."*

Discussion

This article reports the results of a survey of family members in one Midwest state in the U.S. designed to understand how families are navigating current and new support needs during the COVID-19 pandemic. The survey sought to understand the day-to-day experiences of families during COVID-19 related to general health and well-being, decision making, support needs, and access to services for their children with IDD. Below we highlight implications of this research to inform planning as the pandemic continues and in the future.

Overall, family members reported being concerned about the health and well-being of their child with a disability. Over 30% of family members and caregivers reported an increase in behavioral and emotional support needs and noted difficulty obtaining needed supports and services during the pandemic. These numbers were highest for school-aged children, perhaps suggesting the significant and negative impacts of the rapid pivot to remote learning. A national survey found that 14% of families with children with and without disabilities reported an increase in behavioral support needs for their children (Patrick et al., 2020); therefore, our finding suggests that the

impacts on children with disabilities may be even more pronounced. It is possible that youth with disabilities may be even more vulnerable to the social isolation and decreased supports that resulted from the pandemic. Ongoing planning to provide supports for families during the pandemic and beyond must more systematically consider how to build meaningful, individualized approaches for people with disabilities. It must also consider access and comfort with technology and student support needs. For example, schools and community organizations must build and test protocols that anticipate increased behavioral and emotional support needs when in-person supports are not an option.

Further, a majority of family members in this study described fewer opportunities for important daily activities, including decision making and physical activity, which has been reported in other studies (Neece et al., 2020). These findings tended to be more pronounced for families of school-aged children with disabilities. Related to decision making, the pandemic has increased the complexity of every-day decisions for all people. For example, a trip to the grocery store during the pandemic requires considerably more planning (e.g., planning for the time of day with the fewest number of people, using PPE, ensuring safe social distancing in the store). This increased complexity may be why family members report making more decisions for their child or adult with a disability during the pandemic, which could reflect that many people with disabilities did not have the experience and supports

needed to navigate the complex decision-making context necessary to promote their health and safety during the pandemic. This finding highlights the importance of supporting people with disabilities to make decisions early in life, so they have the experience and supports needed for more complex decision making related to health and safety during a pandemic, and other times, such as during transition from high school to adult life (Shogren et al., in press). Further, this finding emphasizes the need for plain language supports needed for people with IDD to fully participate in decision making regarding safety, such as explanations of the precautions (masks, social distancing).

Regarding technology-based supports and comments made by families and caregivers, it is important to first note that a limitation of this survey was that it was only distributed online; therefore, we only reached families who had access to technology. As such, their comments may not generalize to other families and their children with disabilities who have limited access to technology or the internet. Of the respondents, however, open-ended comments did suggest that technology played a key role for some families, although it clearly did not fully address the range of support needs. This suggests that while technology can be a valuable form of support for some and for some situations, it cannot fully address all of the support needs of people with disabilities. Further, when considering technological solutions, consideration should be given for the support the person with

IDD may require from family members to take advantage of
social or daily supports being offered virtually. Individualized
planning is needed to determine effective methods of support
provision when face-to-face interaction is not possible as well
as the role of technological supports as opportunities for face-
to-face interaction reemerge. If remote delivery of supports is
needed, remote supports should be practiced on a regular basis
during "normal" times to support people with disabilities and
their families to learn the technology and prepare for virtual
supports.

In summary, this article highlights experiences of families
of children with disabilities during a critical period during the
COVID-19 pandemic and provides insight into how families
navigated existing and new support needs for their children
with IDD in daily life. While this study adds to the literature
on the experiences of families of children with disabilities
during the pandemic, we should note that it represents one
time point early in the pandemic. Ongoing and longitudinal
work is needed to better understand short- and long-term
impacts on support needs. Further, more work needs to be
done to compare and contrast experiences accessing supports
and services for those receiving Medicaid-funded services
versus those who do not.

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PARENTS' BELIEFS REGARDING SHARED READING WITH INFANTS AND TODDLERS

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Parents' Beliefs Regarding Shared Reading with Infants and Toddlers PDF File

Abstract

Parent beliefs about reading to young children—and

factors related to such beliefs—affect a child's reading skill. But little is known about parent beliefs about reading to infants and toddlers. To fill this gap, three University Centers for Excellence in Developmental Disabilities (UCEDDs) studied 43 English- and Spanish-speaking parents of children 9-18 months of age. The three UCEDDs were working on a project to create a children's book that had tips for parents about how their 1-year-old learns and grows. The UCEDD study survey asked about parent beliefs regarding reading to young children (4 questions) and factors related to those beliefs (2 questions). Parents were also asked to give feedback about the book. Nearly all parents agreed that children should be read to as infants and that this helps children develop reading skills. Most (62%) parents said it was "very common" for friends and family to read with children of this age. Parents said that reading the board-book together was useful for "promot[ing] language," "help[ing] my baby's development," and "help[ing] my child speak." More research like this can identify ways to help parents of young children develop reading skills.

Plain Language Summary

Reading books with young children helps them

learn to read. What parents think about how children learn to read affects what they do to help children learn to read. There is not much information about this topic in parents of infants and toddlers. This paper reports on a study by three UCEDDs helping to create a children's board-book. The UCEDD study surveyed 43 parents of 9- to 18-month-old children. The UCEDD study also tape-recorded what parents said about reading the board-book with their children. Most parents agree that reading to infants is the right thing to do and that it helps them become better readers. Parents thought the board-book would help their child's language and speech.

Introduction

A child's home literacy environment (HLE) predicts later literacy (Farver et al., 2013; Lancy, 1994; Sulzby & Teale, 1991). The HLE encompasses activities, resources, and attitudes (Bracken & Fischel, 2008; Burgess et al., 2002; Frijters et al., 2000; Weigel et al., 2006a), They include print-focused (e.g., providing names and sounds for letters), book-directed, non-print focused (e.g., shared book reading), and joint attention activities (e.g., caregiver-child conversations; Bracken & Fischel, 2008; Schmitt et al., 2011). HLE measures are predictive of children's later literacy outcomes, even

adjusting for demographics (Gottfried et al., 2015; Tamis-LeMonda et al., 2019; Van Steensel, 2006; Weigel et al., 2006b).

Shared book reading is the most commonly studied HLE activity (Roberts et al., 2005)—its timing, quantity, and quality impact school readiness (Cates et al., 2017; Raikes et al., 2006). Furthermore, parents/caregiver (hereafter parents) HLE *beliefs* affect subsequent HLE *behavior* (DeBaryshe, 1995; Landry & Smith, 2007). Parents' literacy beliefs are influenced by factors including culture, socioeconomic status (SES), parents' own reading ability, interest, and experiences. Some cultures encourage conversation with children during infancy, others not until they are perceived to be old enough to understand and respond (Hoff, 2006). In one study, just one third of U.S. immigrant Latino families reported that children under 5 years old could understand an explanation of text; 5 years of age was identified as "*la edad de la razon*" (age of reason; Reese & Gallimore, 2000).

Poverty can compromise school readiness—65% of all fourth graders in the U.S. are not proficient readers vs 79% of those who are low-income (National Center for Education Statistics [NAEP], 2019). Children from lower income backgrounds are read to less, hear fewer total words and less different words, and have fewer literacy resources (Huttenlocher et al., 2007) Still, parental beliefs about literacy development can mediate the effects of these demographics upon literacy outcomes (Rowe et al., 2016; Zajicek-Farber,

2010). However, research on parents' literacy beliefs has focused on White, higher SES parents of children aged preschool or older (Hammer et al., 2005; Hart & Risley, 1995; Perry et al., 2008; Reese & Gallimore, 2000). Several dissertations have examined the literacy beliefs among parents of color for very young (i.e., below preschool-age) children (Donohue, 2009; Edwards, 2008). A more recent qualitative study found that low-income African-American and Puerto-Rican parents were highly attuned to the importance of the HLE for their preschoolers, but had less explicit understanding of specific strategies to use (Sawyer et al., 2018).

To address the gap in research on literacy beliefs among parents of infants and toddlers, we conducted a study of parents of 9- to 18-month-old children. We incorporated this Parent Beliefs about Early Reading ("PBER") study into a larger U.S. *Learn the Signs, Act Early* (Centers for Disease Control and Prevention [CDC], 2020) related project funded by the Association of University Centers on Disabilities (AUCD) and the Centers for Disease Control and Prevention (hereafter referred to as the CDC project). The goal of this project was to develop a board book for 1-year-olds and their parents to complement existing books for 2- and 3-year-olds children This book—*Baby's Busy Day: Being One is So Much Fun!*—was designed with content on developmental milestones and parenting tips to promote and monitor development to complement existing books for 2- and 3-year-old children and their parents (CDC, 2020; Harrell, 2019).

The goal of this PBER study was to provide exploratory data on parents' (a) beliefs about reading with young children and (b) factors that might influence those beliefs (see the Appendix for the PBER survey items).

Methods

Settings

The CDC partnered with AUCD to select the following three UCEDDs from which the PBER study sample was recruited:

- University of Minnesota UCEDD—recruited from two childcare providers, the Minnesota State Fair, an Early Head Start, and local community events. At the Minnesota State Fair, the Early Head Start, and the community events, families of young children were approached by study staff.
- University of Indiana UCEDD—recruited from libraries throughout Indiana as well as childcare providers and local agencies serving Spanish-speaking individuals.
- Rose F. Kennedy UCEDD (Bronx NY) —recruited from: (a) an Early Head Start program serving predominately Spanish-speaking parents and their 1- to 4-year-old children; (b) the Infant-Parent Court Project, which provides trauma-informed care for parents and

their children aged birth to 3 years; and (c) Einstein/ Montefiore employees.

This study was approved by the institutional review boards of all sites. Participants completed consent forms in English or Spanish, depending upon their preference.

Eligibility

Study participants were drawn from the CDC project (n = 67), for which parent eligibility criteria were (a) age > 18 years, (b) spoke and read in English or Spanish, (c) was the primary caregiver for a 9- to 18-month-old child, (d) did not work with children with developmental delays, and (e) did not have a child who was evaluated for developmental delays. CDC project participants who completed PBER items prior to dyadic observations (see Figure 1) were included in this study.

Data

The larger CDC project collected and analyzed parent data regarding initial and revised versions of *Baby's Busy Day* in English and Spanish. These data included: (a) Survey—with questions on demographics, *Baby's Busy Day*, and PBER (6 items); (b) Observational—site staff structured ratings completed during dyadic (parent-child) reading of *Baby's Busy Day*, and (c) Debrief—semistructured interview(s) and/or

focus group(s) immediately after dyadic observations. See
Figure 1 for study flow. The PBER items regarding parent's
beliefs about reading to young children (4 items) and factors
that may influence those beliefs (2 items) were developed by
New York staff. Spanish-speaking participants were
interviewed by Spanish-speaking study staff.
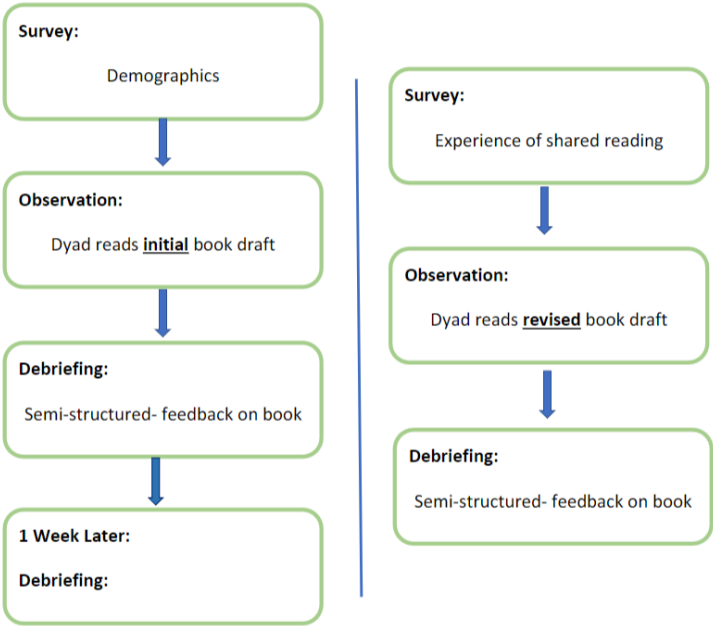
Figure 1 CDC Evaluation Protocol: Round 1 (left) and
Round 2 (right)

Demographic and PBER survey data are presented as n and
%, as appropriate. Debriefings at the New York site were
audiotaped and transcribed (Indiana and Minnesota were
unable to audiotape debriefings). New York staff reviewed the

transcriptions for quotes that were most illustrative of the PBER items. These qualitative debriefing data are presented alongside the relevant PBER survey data in the Results section. Note, bracketed text was added to improve the clarity of quotes.

Results

Participant Demographics

As shown in Table 1, most of the participants (n = 43) were female (93%) and > 30 years (72%). Just over half identified as Hispanic/Latino (51%), had a college degree (54%), and an annual income > $30,000 (56%). A higher proportion of Indiana and Minnesota participants spoke English as a primary language, did not identify as White or Hispanic/Latinos were > 30 years, and had incomes > $30,000, compared to New York participants.

Table 1 Parent/Family Demographics

Participant demographics	Indiana ($n = 5$)	Minnesota ($n = 17$)	New York ($n = 21$)	Total ($n = 43$)	%
Parent age					
< 30 years	2	0	10	12	28
>30 years	3	17	11	31	72
Parent gender					
Female	5	14	21	40	93
Male	0	3	0	3	7
Race					
Asian	0	1	0	1	2
Black/African American	0	0	2	2	5
White	5	14	3	22	51
Other	0	0	12	12	28
Prefer not to answer	0	1	2	3	7
Missing	0	1	2	3	7
Hispanic or Latino origin					
Yes	1	2	19	22	51
No	4	15	2	21	49

Education					
Less than college degree	2	2	13	20	47
College degree or higher	3	15	8	23	54
Annual household income					
Below $30,000	1	0	9	12	28
Above $30,000	4	17	5	24	56
Prefer not to answer	0	0	7	7	16
Main language spoken at home					
English	4	15	8	27	63
Spanish	1	2	13	16	37

Parent Beliefs (4 items)

As shown in Table 2, nearly all parents (93%) affirmed that parents should start reading with children during infancy (birth-12 months). Debriefing data found that many parents reported reading with their 9- to 18-month-old children a few times per week or "everyday" and that reading was "a standard part of [their] bedtime routine." Several affirmed the value of reading age-appropriate books with children of this age. One

stated that *Baby's Busy Day* was "at the same level of stories I usually read with [my child]" and another responded that the book was "a good gift for a 1st birthday."

Table 2 Parents' Beliefs About Reading with Children 9-18 Months

Survey items	Indiana	Minnesota	New York	Total	
				n	%
At what age should parents start reading to their children?					
Infancy (birth-12 months)	5	17	18	40	93
Younger toddler (12-24 months)	0	0	3	3	7
Older toddler (24-36 months)	0	0	0	0	0
Preschooler or older (3 years or older)	0	0	0	0	0
Some parents think reading to children at this age helps them learn how to read when they are older. Do you agree?					
Agree	5	15	17	37	90
Neither agree nor disagree	0	2	1	3	7
Disagree	0	0	1	1	2

How necessary is it to read books with a child at this age (about 9-18 months)?					
Very	5	14	18	37	88
Somewhat	0	3	2	5	12
Not very	0	0	0	0	0
Do you have time to read to your child as much as you would like to?					
Yes	4	8	8	20	48
Sometimes	1	6	12	19	45
No	0	3	0		

Similarly, 90% of parents believed that shared reading with children of this age helps them learn to read when they are older. Qualitative comments reflect parents' awareness of the value of pre-literacy skills. Parents stated that reading *Baby's Busy Day* with their children was useful for "promot[ing] language," "help[ing] my baby's development," and "help[ing] my child speak." Parents described the book's size and materials as encouraging their child's involvement in reading: (a) "[I] like that it's a board book and that it's a size that a child can hold on to. He was more interested in picking up the book and playing with pages;" and (b) "They like books where they can touch things…textures, noises, things that can

interact with." Parents appreciated the "Parent Tips"—brief suggestions to involve children during reading in order to promote development, provided in each page spread. One parent said "...when you have a baby, they don't give you a manual...and when you're reading books they don't say 'point to something so baby understands'...so I thought it was pretty awesome that it has those points [Parent Tips]."

Nearly all (90%) parents affirmed the necessity of shared reading with 9- to 18-month-old children. Parents noted that they had "books like this [*Baby's Busy Day*]" or the "same level of stories" (Spanish) at home. Varied reasons were offered to support their stance (e.g., reading teaches children different skills and promotes quality time between parent and child). Several parents referred to *Baby's Busy Day* as a "tool for child development" because by mimicking characters in the story, children could learn skills like "recogniz[ing] body parts" and "get[ting] herself dressed." Additionally, one parent commented, "My favorite was page 7 where the baby hugged the sister.... I would like to see my two daughters hug like that." Two parents emphasized reading together was a way for parent and child to bond. They enjoyed that *Baby's Busy Day* encouraged children "to participate with me" and "made reading time more interesting for us to spend quality time together." Just under half (48%) of parents reported having enough time to read their children.

Factors That Might Influence Beliefs (2

items)

When asked about reading practices of their friends and family, 62% responded that reading with 9- to 18-month-old children was very common and approximately 36% of participants responded somewhat common (Table 3). Over 90% of parents reported that they personally enjoy reading.

Table 3 Factors that Influence Parent's Beliefs with Children 9-18 Months

Survey items	Indiana	Minnesota	New York	Total n	%
How common is it for your friends and family to read books with a child at this age (about 9-18 months)?					
Very	3	12	11	26	62
Somewhat	2	5	8	15	36
Not very	0	0	1	1	2
Do you enjoy reading (e.g., magazines, books, online articles)?					
Yes	5	17	17	39	93
Sometimes	0	0	3	3	7
No	0	0	0	0	0

Discussion

Shared reading from infancy promotes emergent literacy skills. Yet less than half of 0- to 5-year-old children are read to daily (Data Resource Center for Child and Adolescent Health, U.S. 2018). even fewer from low-income families (National Center

for Education Statistics, n.d.)– falling short of the Healthy People 2020 target (Office of Disease Prevention and Health Promotion, 2020). Thus, we conducted a study of literacy beliefs among parents of young children in three states from diverse backgrounds. Nearly all parents endorsed reading to a child before their first birthday, and that reading to children aged 9-18 months helped them learn to read. Yet, just under half of parents feel like they have enough time to read.

Overall, respondents' beliefs align with the emergent literacy paradigm, which values reading aloud to children starting from birth. Our study did not ask about reading behaviors, but we note that parents who supported this paradigm were more likely to practice behaviors consistent with it (e.g., providing reading materials and demonstrating reading and writing; Bingham, 2007; Lynch et al., 2006). Given that experiences and environment influence their literacy beliefs and behaviors, it is notable that nearly all respondents affirmed the value of reading with very young children. Finally, nearly all respondents enjoyed reading. Parental enjoyment of reading and their self-efficacy as a teacher was related to their literacy beliefs and their child's motivation to read (Baker & Scher, 2002; Bingham, 2007). Therefore, respondents' enjoyment of reading may be associated with their beliefs about early onset of parent-child reading and the importance of reading with infants to their emergent literacy skills.

The study has strengths and limitations. A key strength is

exploration of this topic in an under-studied population (i.e., parents of very young children). Additional strengths include a sample that was drawn from three states and that was racially, ethnically, and socioeconomically diverse—including 51% Hispanic/Latino. Further, the qualitative data provides useful context for the survey responses. Key limitations include a small, nonrepresentative convenience sample. In addition, embedding our PBER study within the larger CDC project limited the ability to obtain more detailed and nuanced data. For example, survey items focused on shared book reading, rather than other literacy-promoting activities, given the CDC project focus on developing *Baby's Busy Day*. Additionally, as the CDC project sought feedback on a book about developmental milestones, this may have influenced respondents' perceptions of shared reading and development.

Nevertheless, our findings serve as an important starting point for more research on literacy beliefs of parents of infants and from diverse backgrounds and geographic locations. Parental literacy beliefs are a critical component of the HLE and can mediate the effects of parent characteristics such as education on literacy outcomes (Cottone, 2012; DeBaryshe, 1995). Therefore, future research should focus on how parental beliefs about reading with young children influence parental literacy behaviors and children's literacy outcomes.

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COMMUNITY CONVERSATIONS: FINDING SOLUTIONS TO INCREASE EMPLOYMENT FOR INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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Community Conversations: Finding Solutions to Increase

[Employment for Individuals with Intellectual and Developmental Disabilities PDF File](#)

Abstract

This study describes the implementation and findings of a pilot community conversations event in the state of Oregon to identify innovative solutions to under- and unemployment experienced by individuals with intellectual and developmental disabilities (IDD). The event was facilitated in partnership with the University of Oregon UCEDD, local Arc chapter, and other relevant community stakeholders. A total of 36 diverse individuals (e.g., school personnel, business owners, individuals with IDD, and caregivers of individuals with IDD) participated in a two-hour community conversations event about how to improve employment opportunities for those experiencing IDD. Participants engaged in discussions about solutions to employment challenges and completed a pre-post event survey about their experience at the event. Results from the survey and future considerations for additional community conversations are discussed.

Plain Language Summary

This paper describes a gathering of community members who worked together to find a solution to employing individuals with disabilities. Individuals from a Northwest community planned a community conversation event. This event allows for brainstorming solutions to a problem. Brainstorming occurs by bringing together different people with diverse viewpoints. A facilitator supports brainstorming and conversations. The facilitator also takes notes so members of the event can focus on finding solutions to a problem. Over 30 people participated in this event. The event planners placed people at different tables based on their roles in the community. This allowed for people to meet and listen to diverse voices. Each table included a teacher, family member, employer, and self-advocate. Our self-advocates had an intellectual or developmental disability. Researchers helped plan the event and support community members. The research team evaluated the event to help the community members collect and analyze data. This paper presents a description of the event and findings from the event. Data collected from this event suggest that community conversations are a positive catalyst to change. Participants enjoyed

meeting other members in their communities. Participants also appreciated a group of diverse individuals working together to solve a problem.

Individuals with intellectual and developmental disabilities (IDD) experience higher rates of unemployment, underemployment, and segregation in employment settings than typical adults and those identified with other disabilities (e.g., learning disability, orthopedic impairment; Wagner et al., 2003). The discrepancy in rates of employment is staggering; only 19.3% of individuals with disabilities are employed compared to 66.3% of those who do not experience a disability (Bureau of Labor Statistics, 2020). Statistics for individuals with IDD are even more discouraging, with estimates of employment for this population as low as 10% (Butterworth & Migliore, 2015). These discrepancies highlight an inequitable reality for individuals with IDD and underscore the importance of efforts to close the employment gap and improve integrated and competitive employment outcomes. Educators and policymakers continue to work diligently to help close the employment gap through their respective means, yet much work remains.

Educator Practices

Mandated by the Individuals with Disabilities Education Improvement Act (IDEA, 2004), educators are required to

implement transition planning for all individuals with disabilities to prepare them for employment, postsecondary education, and independent living. Educators implement a variety of classroom-based practices that are supported by research and promote positive postschool outcomes (Mazzotti et al., 2014, 2016; Test et al., 2009) and integrate transition-related skill development into academic content (Rowe et al., 2015). Some practices, including involvement in vocational education, work-based learning, and development of self-determination skills, are identified as predictors of positive postschool employment outcomes (Rowe et al., 2015; Shogren et al., 2014, 2015; Wehmeyer et al., 2006, 1996).

Work-based learning and paid work experiences for individuals with IDD provide an opportunity for employers to develop positive attitudes toward hiring and supporting individuals with IDD within their businesses. Positive attitudes and interactions with individuals with IDD are an influential factor in increasing employment rates for individuals with disabilities (Unger, 2002). However, discrimination and negative attitudes towards individuals with IDD persist and may lead to employment barriers (Livermore & Goodman, 2009). One approach to reducing discrimination and stigma is increasing positive interactions between education and employment sectors that support training and real-world experiences for individuals with IDD (Flippo & Butterworth, 2018). Unfortunately, the formation and

facilitation of strong relationships between the education and employment sectors are complex and challenging.

Policy Initiatives

The drastic differences between the employment rates of individuals with and without IDD are the result of a long history of segregation, maltreatment, stigma, and discrimination (Fleischer et al., 2012). In response to the historic disability rights movement, some protections from discrimination were instituted for those with disabilities (see Section 504 of the Vocational Rehabilitation Act of 1973). Additional landmark legislation has been passed and amended since 1973 to reduce discrimination and increase the inclusion of individuals with disabilities within society (e.g., American with Disabilities Act, 1990; IDEA, 2004). Because of the persistent under-employment and unemployment of individuals with disabilities, legislation has been enacted to support skill development and increase employment readiness for individuals with disabilities (e.g., IDEA, 2004; Workforce Innovation and Opportunities Act, [WIOA] 2014). Other national initiatives focused primarily on improving employment outcomes for individuals with IDD include Employment First. The Employment First initiative, both a philosophy as well as a policy, purports that employment in the general workforce should be the first and preferred option for individuals with IDD and that public funding should

prioritize this over other alternatives (Office of Disability Employment Policy, 2020). This initiative acknowledged the years of segregation and subminimum wage often found in sheltered workshops or at employment sites with waivers to pay individuals less than minimum wage. It also guarantees competitive wages for individuals with IDD in inclusive and integrated work settings. While Employment First has taken root in several states throughout the country, it has yet to receive national sponsorship (Association of People Supporting Employment First, 2020).

Community Conversations

Even with the implementation of evidence-based practices in special education environments, national policies and funding for services to prepare young adults with disabilities for employment, and good intentions, there continues to be chronic unemployment and under-employment of individuals with IDD (Lipscomb et al., 2017). To improve these outcomes and reduce perceived barriers, the education system and employment sector must work together to ensure a seamless transition to employment. Achieving these outcomes necessitates involving all relevant stakeholders, including employers, educators, and members of the community. To date, research has primarily focused on how education systems can better prepare individuals with IDD for employment with little to no emphasis or input and involvement from employers

during transition planning (Riesen & Oertle, 2019). All relevant stakeholders must be included in developing policies and practices moving forward to help identify innovative strategies for overcoming systemic barriers to employment for individuals with IDD.

One strategy to bring multiple stakeholders to the table is community conversations, an asset-based approach to solving community-based problems (Carter & Bumble, 2018). The purpose of community conversations is to bring together an interdisciplinary group of individuals who typically may not have a chance to interact and provide them an opportunity to identify innovative solutions to pervasive problems within their community (Carter et al., 2009). Swedeen et al. (n.d.) identified four core principles of community conversations.

1. All communities possess unique opportunities, connections, resources, and relationships;
2. Members within each community are the experts on the most pressing challenges, the most viable solutions, the strategies that will work best, and the most effective ways to enlist others in support of change;
3. Any group of community members who come together – no matter how well-connected each individual already is – will learn about new resources, connections, and ideas by interacting with others who share different viewpoints and have different life experiences; and
4. Real change that lasts is most likely to come when ideas

are based on locally feasible strategies and approaches. (p. 4)

There have been several occasions in which community conversations have been used to identify barriers and formulate solutions that individuals with disabilities face regarding employment. According to emerging research, community conversations may be an effective strategy to begin to address issues of unemployment and underemployment by identifying unique barriers found in their community and finding local solutions for individuals with IDD (Bumble et al., 2017, 2018; Dutta et al., 2016; Molfenter et al., 2018; Trainor et al., 2012).

The task of preparing individuals with IDD for integrated and inclusive employment cannot fall solely on educators (Flippo & Butterworth, 2018). A collaborative approach, including multiple agencies and community stakeholders, is imperative to support successful transitions for individuals with IDD. Community conversations has the potential to be a springboard for increased engagement and collaboration within a community with the ultimate goal of reducing the employment gap for individuals with disabilities; thus, creating a more equitable community (Bumble et al., 2018).

Study Purpose

Because of the potential positive impact of community

conversations on employment for individuals who experience IDD, a community group in Oregon piloted a community conversations event. This particular event was designed according to established research with considerations for the unique needs of the specific community of focus (see Swedeen et al., n.d.). The purpose of this evaluation was to demonstrate how a collaboration between a University Center for Excellence in Developmental Disabilities (UCEDD), community organizations, and community members came to fruition in an attempt to improve community-based employment opportunities for individuals with IDD. This manuscript outlines the development of an evaluation partnership and presents data from the pilot implementation of community conversations. We specifically address the following evaluation questions.

1. What are the perceptions of community members toward employment barriers and opportunities for individuals with I/DD in the community?
2. What were the perceived outcomes of the community conversations event?
3. What were the overall facilitator and participant perceptions of the community conversations event?

Method

Procedures

The University of Oregon Institutional Review Board reviewed our application to evaluate the implementation of the community conversations event and deemed the research as exempt. To capture as much information from the small pilot event, the authors utilized both quantitative and qualitative approaches to provide a robust understanding of the event's process and impact. All participation in data collection activities (i.e., pre-post surveys, open-ended responses, facilitator feedback) were anonymous and voluntary. There were no incentives provided to participants for completing the surveys or interviews.

Successful implementation of a community conversations event necessitates the commitment of a group of community stakeholders with a mission to identify solutions to a pervasive issue in their community. A UCEDD sponsored guest lecture by Dr. Erik Carter on outcomes of individuals with IDD and community conversations, sponsored by the University of Oregon's UCEDD, was the impetus for the pilot event. After the guest lecture, an initial group of community members in attendance came together and agreed to work to implement a local community conversations event.

The Community Conversations Planning team (CC team) utilized the *Community Conversations Practical Guide*

(Swedeen et al., n.d.) to inform the planning and implementation process. The CC team worked through steps suggested by Swedeen and colleagues including (a) choosing a focus for the event, (b) choosing questions that will be asked to the participants, (c) finding support for the event, (d) finding a venue and creating a comfortable space, (e) deciding on a date and time, (f) recruiting and marketing, and (g) choosing and training table facilitators.

Inspired by previous work to understand and begin to address employment inequities in other communities, the CC team chose to focus on employment for individuals with IDD for the first community conversations event. Once a focus was selected, the CC team came to consensus on what two questions would be asked at the event. The CC team also identified when the event would be. The community conversations event was scheduled 8 months after the initial team meeting to coincide with the National Disability Employment Awareness Month celebrated by the Office of Disability Employment Policy. In addition, a gathering space at a local community church was identified as the event site.

During twice-monthly meetings, the CC team continued to use the community conversations practical guide to provide directions on logistics (i.e., where and when) and procedural considerations (i.e., accessibility issues and event participant make-up). Funding for the event was also discussed during CC team meetings and a need for funding to implement event activities was determined. Initial funding was made possible

by sponsorship from the University of Oregon UCEDD. Additional funding was acquired after members of the CC team were awarded a Better Together grant sponsored by the Oregon Council on Developmental Disabilities (OCDD). Funds from both the University of Oregon UCEDD and Better Together grant were used to purchase all food, drinks, and supplies (i.e., disposable plates, napkins, utensils) needed to serve dinner to the large group. These funds were also used to hire a caterer with autism to provide dinner for the event, allowing the event to serve as a successful example of inclusive employment.

Last, because the event was planned as a pilot to inform future community conversations, CC team members created a means for evaluation. Evaluation procedures included a review of previously conducted evaluation surveys (i.e., Carter et al., 2012), identification of event activities that needed evaluative questions, and the creation of new additional survey items that were not already used in previous research. A pre-post evaluation survey was created to examine changes in participant perceptions before and after the community conversations event, as well as facilitator perceptions on what occurred at their table.

Setting and Participants

The CC team planning meetings convened in person at the University of Oregon. Meetings were held approximately twice

per month leading up to the community conversations event and lasted 60 minutes. The location for the community conversations event (i.e., a community church) was selected for the following reasons: (a) it was accessible for mobility devices, (b) it had a large meeting room to hold up to 50 participants, (c) technology capabilities to project presentation materials were available, and (d) it had an accessible kitchen to prepare, cook, and serve dinner at the event.

Community Conversations Team

Team members included family liaisons from the local Arc chapter, associates with the local developmental disability services office, representatives from a local job training organization, members of a disability-focused technology firm, a transition technical assistance provider for local school districts, and higher education faculty and researchers. The CC team members were the drivers of the implementation of the community conversations event and the process and impact evaluation. Because the event was facilitated by community members and designed specifically for the community, the authors would like to acknowledge that the CC team and facilitators worked together to write this manuscript.

Community Conversations Facilitators

Table facilitators were recruited for each table at the event and

included four doctoral students from special education and school psychology and two research associates from the University of Oregon. The table facilitators participated in a 2-hour training created for the event by CC Team members that included (a) the purpose of a community conversations event; (b) expectations for table facilitation (i.e., read the community conversations questions to their table, keep conversations progressing and on topic, assure all participants at their table have a chance to participate, and take detailed notes); and (c) management of event logistics (e.g., rapport building with table participants, mediation if a challenge arises, time management, and note taking).

Community Conversations Participants

The CC team came to consensus that a wide range of community representation was desired at the event and each table, with an understanding that it was impossible to include all the relevant community stakeholders. During planning meetings, the CC team decided representatives from the following community sectors would be recruited: (a) school personnel who work with transition-age youth, (b) a business representative who employed a person experiencing IDD, (c) a business representative who had not employed an individual with IDD, (d) personnel from a community agency that works with individuals with IDD, (e) a caregiver of a young adult with IDD, and (f) a self-advocate (i.e., a young adult with IDD). The CC team engaged in purposeful recruitment

(Palinkas et al., 2015) to ensure equitable numbers of representatives were present at the event and in each facilitated discussion group. Recruitment of participants began by reaching out to personal and local networks to advertise and invite participants from the different stakeholder groups. Recruitment methods included sending emails, making phone calls, and inviting business owners in person. A total of 36 participants attended the event (six participants at six tables). Of note, there was not equal representation of participant groups at the event. Because of over representation, some tables had either more school personnel or community provider personnel. In addition, the sample size per group shown in Table 1 and 2, do not accurately describe the full sample. This is because the original intention for this community conversation was for evaluation purposes. Only data from participants who consented to have their data aggregated as part of a study are presented below.

Measures

To evaluate the event, the CC team and facilitators administered multiple measures to collect evaluative data that would inform any future event iterations. Measures were used to collect information on (a) participant perceptions of the event and (b) facilitator perceptions of the event. Measures collected data via Likert-type rating scales and questions with an open-ended response option.

Participant Perceptions

The CC team and facilitators reviewed and adapted a published community conversations evaluation measure (see Carter et al., 2012) to capture participant perceptions of employment barriers and opportunities for individuals with IDD. The pre- and post-event survey consisted of six items with a 4-point Likert-type response option from 1 (i.e., Strongly Disagree) to 4 (i.e., Strongly Agree). Pre- and post-event survey items are listed in Tables 1 and 2 in the Results section.

An additional seven items (see Carter et al., 2012) were included in the post-event survey to capture participant perceptions of the event. These additional items also had a 4-point Likert-type response option from 1 (i.e., Strongly Disagree) to 4 (i.e., Strongly Agree). Post-event survey items are listed in Table 2.

The post-event survey also provided an opportunity for participants to respond to three open-ended questions. These questions included: (1) *What idea was the best that you heard during tonight's community conversations?* (2) *If I were asked what recommendations I had for improving the quality of this evening, I would suggest...,* and (3) *I wish the following people from our community had been present at tonight's event...* These questions helped us understand how to make the next community conversations event more effective.

Facilitator Perceptions

The six table facilitators were asked their perceptions of the event in a thirteen-item post-event survey. Facilitator perceptions were captured by ten items with a four-point Likert-type response option from one (i.e., Strongly Disagree) to four (i.e., Strongly Agree). Example items in the facilitator evaluation included: *The people at my table provided actionable or innovative solutions to the first and second questions, Participants were engaging with each other during the table discussions,* and *I felt that this event was able to capture the solutions to the problem as it was meant to do.* Facilitators were also asked to answer three open-ended response items that included: *What other voices needed to be heard in the community conversations? Are there any cultural concerns (e.g., location, disability) that were not addressed that needed to be in this community conversations? How do you suggest improving this event?*

Data Analysis

Our evaluation utilized quantitative data analysis for the Likert-type scale surveys and qualitative data analysis for open-response questions. Because of the small number of participants and the survey's limited sensitivity to change, descriptive statistics (e.g., means and standard deviations) were calculated to analyze facilitator and participant quantitative

data. Basic thematic coding was used to identify overarching themes from facilitator notes and any written responses from open-ended responses by participants (Miles et al., 2013). Because of the limited number of participants, a deep examination of meaning and generalization from the data was not tenable. Instead, the authors reviewed notes and responses in detail to determine if any inductive themes were salient across participants.

Results

Perceptions of Employment Barriers and Opportunities

Data from pre- and post-event surveys were designed for evaluative purposes to explore participant's perceptions of employment barriers and opportunities for individuals with IDD. No hypotheses were identified prior to the CC event regarding the effect the event may have on participant attitudes. Table 1 provides pre- and post-event comparisons by type of participant. Means from pre- and post-event survey data suggest that, overall, participants did not believe (i.e., "disagreed") there were many opportunities for youth with disabilities to work in the summer months (M_{pre} = 2.23, M_{post} = 2.23, $n_{\textit{pre and post}}$ = 30). Participants also disagreed that employers were generally positive about hiring individuals with disabilities in the summer months (M_{pre} = 2.44, n_{pre}

= 29; M_{post} = 2.24, n_{post} = 31). In addition, on average, participants were not agreeable to the statement "strong partnerships between schools and employers currently exist in my community" (M_{pre} = 2.41, n_{pre} = 27; M_{post} = 2.94, n_{post} = 31).

Table 1

Pre- and Post-Event Participant Perceptions of Employment Barri

	Many employment opportunities exist in my community for youth with disabilities in the summer months		Employers in my community are generally positive about hiring youth with disabilities in afterschool or summer jobs		Employers in my community may need help learning how to support youth with disabilities on the job		Strong partnerships between schools and employers currently exist in my community	
Participant	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Self-Advocate								
Mean	33.3	33.3	3.00	3.000	3.67	4.00	2.67	3.00
Sample	3	3	3	3	3	3	3	3
Caregiver								

	Many employment opportunities exist in my community for youth with disabilities in the summer months		Employers in my community are generally positive about hiring youth with disabilities in afterschool or summer jobs		Employers in my community may need help learning how to support youth with disabilities on the job		Strong partnerships between schools and employers currently exist in my community	
Participant	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Mean	2.00	1.71	2.28	2.25	3.71	2.88	2.33	2.13
Sample	7	7	7	8	7	8	6	8
Business Hired								
Mean	2.00	2.17	2.23	2.00	3.80	3.67	2.00	1.83
Sample	5	6	4	6	5	6	4	6

	Many employment opportunities exist in my community for youth with disabilities in the summer months		Employers in my community are generally positive about hiring youth with disabilities in afterschool or summer jobs		Employers in my community may need help learning how to support youth with disabilities on the job		Strong partnerships between schools and employers currently exist in my community	
Participant	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Business Not Hired								
Mean	2.0	2.0	3.0	2.0	3.5	4.0	1.5	2.5
Sample	2	2	2	2	2	2	2	2
School Personnel or Agency								

Participant	Many employment opportunities exist in my community for youth with disabilities in the summer months		Employers in my community are generally positive about hiring youth with disabilities in afterschool or summer jobs		Employers in my community may need help learning how to support youth with disabilities on the job		Strong partnerships between schools and employers currently exist in my community	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Mean	2.23	2.33	2.38	2.25	3.77	3.67	2.67	2.33
Sample	13	12	13	12	13	12	12	12
Total								
Mean	2.23	2.23	2.44	2.24	3.73	3.77	2.41	2.94
Sample	30	30	29	31	30	31	27	31

Note. 1 = Strongly Disagree, 2 = Disagree, 3 = Agree, 4 = Strongly Agree.

Participants were also asked about their perceptions of their community. Regarding the community's ability to support youth with disabilities in employment, participants on average did not believe that this was a strength of the community (M_{pre} = 2.73, n_{pre} = 30, M_{post} = 2.74, n_{post} = 37). Participants, on average, also disagreed with the idea that community leaders believed it was important to improve employment for individuals with disabilities (M_{pre} = 2.83, n_{pre} = 30, M_{post} = 2.70, n_{post} = 30). Finally, participants were asked whether employers needed help learning how to support youth with disabilities on the job. On average, participants agreed that employers needed to learn how to support youth (M_{pre} = 3.73, n_{pre} = 30; M_{post} = 3.77, n_{post} = 31). Table 2 provides data from the post-event survey across participant role.

Perceived Outcomes

The post-event survey that was given to attendees at the event provided an opportunity to reflect on the event and their feelings about being included in community conversations. Table 2 provides post-event data across participant roles. On average, when asked about aspects of the community, participants were more likely to disagree with the statement *"I learned about resources, opportunities, or connection in my*

community that I previously did not know about" (M_{post} = 2.97, n_{post} = 30) and were more likely to agree with the statement, *"The conversation this evening improved my perceptions of the capacity of our community to improve work outcomes for youth with disabilities"* (M_{post} = 3.06, n_{post} = 31). Participants were also asked to respond to statements about employment. On average, participants agreed that *the conversation will contribute to better employment opportunities for youth with disabilities in the community* (M_{post} = 3.17, n_{post} = 30), and they agreed that they *were able to identify things they could do to enhance employment opportunities for youth with disabilities in the community* (M_{post} = 3.10, n_{post} = 30). Additionally, participants responded favorably to statements about the event. For example, on average, participants agreed with statements *tonight's conversation was a valuable investment of my time* (M = 3.60, n = 30), and *tonight I met people I could work with in the future* (M = 3.67, n = 30).

Participants also voluntarily answered open-ended responses to help the CC team understand innovative ideas that emerged during the event. Depending on their role, participants had different reflections on innovative ideas that came from the community conversations. Participants from a business background, whether they had employed an individual experiencing IDD or not, felt it was important to help *"educate employers about the benefits and resources available to support them and the employee"* and that *"having job agencies get together to get advice/new ideas"* and *"going to*

employer community groups to educate" would be beneficial strategies for the community to engage in Business participants also felt it was important to improve the dissemination of information, indicating that there should be *"more information sharing among all support organizations."*

School personnel also discussed finding innovative ways to connect young adults with IDD to businesses. Suggestions included the use of *"video resumes"* (i.e., a video documentation of skills and interest to demonstrate workplace competence to employers) to help youth demonstrate skills desired by businesses. Other discussion items included *"improving transportation"* and using *"ride shares"* as a means to reduce transportation barriers to get students to work. Making connections with businesses was also emphasized with participants recommending a *"focus on business outreach, business partnership program," "educating business owners/ employers of benefits to their company hiring adults with disabilities,"* and that *"**we** need to educate employers about people with disabilities and not be afraid to hire and include them into their business."*

Table 2
Post-Event Participant Perceptions of Event

Participant	Tonight, I learned about resources, opportunities, or connections in my community that I did not know about	Tonight's conversation will contribute to better employment opportunities for youth with disabilities in my community	I was able to identify things I could do to enhance employment opportunities for youth with disabilities in my community	The conversation this evening improved my perception of the capacity of our community to improve work outcomes for youth with disabilities
Self-advocate				
Mean	3.33	3.33	3.33	3.67
Sample	3	3	3	3
Caregiver				
Mean	2.88	3.00	3.00	2.63
Sample	8	8	8	8
Business hired				

Participant	Tonight, I learned about resources, opportunities, or connections in my community that I did not know about	Tonight's conversation will contribute to better employment opportunities for youth with disabilities in my community	I was able to identify things I could do to enhance employment opportunities for youth with disabilities in my community	The conversati[on] this eveni[ng] improved my perception of the capacity o[f] our communit[y] to improv[e] work outcomes for youth with disabilitie[s]
Mean	2.83	3.17	3.00	3.00
Sample	6	6	6	6
Business not hired				
Mean	3.50	3.50	4.00	4.00
Sample	2	2	2	2
School personnel or agency				
Mean	2.91	3.18	3.00	3.08

Note. 1 = Strongly Disagree, 2 = Disagree, 3 = Agree, 4 = Strongly Agree.

Parents or caregivers of a person with IDD also appreciated the idea of businesses who had employed a person with IDD mentoring other businesses indicating that *"business mentorships, presentation to business groups, having a central hub of information and creating a universal packet for potential employers"* would be viable strategies. Caregivers also believed that *"creating a PR campaign for business"* would be a benefit to the community.

Participant Feedback on Event Implementation

Participant Perceptions

After the event, participants answered two open-ended prompts to help the CC team understand how to improve future community conversations. Participant responses from the open-ended prompt, *"If I were asked what recommendations I had for improving the quality of this evening, I would suggest...,"* were reviewed for salient themes. One theme that emerged across multiple participants was to have more representatives from local businesses involved in the next event. Some participants felt that there was plenty of representation of individuals from the disability community (i.e., special educators, service providers) and not enough

representation from employers, which would have allowed for more diverse conversations and perspectives. The second theme that emerged focused on the logistics of the event. Participants believed that the acoustics in the event space was too loud, making it difficult to hear other members at their table. This suggests that a bigger room for the event where tables could be spread out and distribute sound more evenly would have been beneficial. Third, some participants asked for more opportunities to hear from self-advocates, indicating *"more share outs from self-advocates about their experience highlighting popular job activities."* One self-advocate even asked for more discussion time to share with their table members. Finally, many participants who responded to the prompt were very pleased with the outcome of the event and requested more time to connect, sharing *"it was great! More discussions of questions with everyone."*

Overall, participants responded to the prompt *"I wish the following people from our community had been present at tonight's event..."* consistently across roles and communicated they wanted more businesses that have and have not hired individuals with IDD present at the community conversations event. Some participants identified certain types of employers they desired to be at the event: *"some large employers"* or *"rural business leaders."* Other participants felt it was important to have more agencies involved including the local Chamber of Commerce, Vocational Rehabilitation Services, Developmental Disability Services, and local government.

Facilitator Perceptions

For a more robust evaluation of the event, the CC team felt it was important to gather participant perceptions as well as perceptions of the table facilitators. Table facilitators were asked to respond to 10 statements on a 4-point Likert-type scale from 1 (i.e., Strongly Disagree) to 4 (i.e., Strongly Agree) about their experience at the event. Responses included: *"The people at my table provided actionable or innovative solutions to the first and second questions"* (M_{Q1} = 3.60, n_{Q1} = 6; M_{Q2} = 3.80, n_{Q2} = 6). Facilitators, on average, agreed that *"Everyone had the opportunity to provide input"* (M = 3.80, n = 6), *"Participants were engaged with each other during the conversation"* (M = 3.80, n = 6), and *"The event was able to capture the solutions to the problem it was meant to do"* (M = 3.20, n = 6). Facilitators were more likely to disagree with the statement, *"The individuals at their table learned something from the opening presentation [by a self-advocate]"* (M = 2.80, n = 6).

Facilitators also rated, on a scale of 1 to 3 (i.e., 1 = shorter, 2 = right amount of time, and 3 longer), that they believed the event could be shorter (M = 1.80, n = 6). Finally, facilitators were asked to reflect on their role and training. The facilitators, on average, agreed that they *"Were accurately able to summarize in their notes the participants ideas and thoughts"* (M = 3.60, n = 6) and *"Were able to keep the conversations at their table focused on the two community conversations*

questions" ($M = 3.40$, $n = 6$). The responses to the final item suggested, on average, that the facilitators agreed that *"The facilitator training provided good guidance for the event"* ($M = 3.80$, $n = 6$).

Discussion

The purpose of this event description and evaluation was to provide an example of how to create and implement a pilot community conversations event collaboratively. A second purpose was to provide a summative process and impact evaluation of the event with the hope to aide in the future implementation of other community conversations. There were a few key results worth discussing, including (a) participant emphasis on having more business representation at the event, (b) the positive impact a diverse network of participants can have on the event, and (c) the need for a strong collaborative planning team.

The resounding desire to have more representatives from local businesses at the event was clearly communicated, which aligns with similar findings to a previously conducted community conversations event (Bumble et al., 2018). The CC team intended to have much higher representation of business and during the planning period ran into many barriers recruiting employers to participate. Because of these difficulties, the CC team had to edit the two small group discussion questions to discuss how to encourage the

involvement of more business representatives in future events. This allowed for tables to discuss solutions rather than focusing on the low number of business representatives at the event. Some solutions included business-to-business peer mentorship and education. A common sentiment communicated throughout the table discussion was that businesses need to know how to talk with other businesses. For example, participants suggested that businesses that have successfully hired an individual with IDD should be encouraged to share their positive experiences, an important first step in starting to dispel myths and address any implicit bias. Some participants suggested that businesses have a responsibility to understand the benefits of hiring individuals with IDD and that more outreach to businesses around the Employment First initiative and other policies that support the competitive employment of individuals with IDD may be necessary.

Second, while the business perspective may have been underrepresented, data from the event suggest that the use of community conversations may be a tool to help individual's network and identify innovative solutions to problems, affirming the event's intended purpose. A common saying from the disability rights movement, *"nothing about us without us,"* reminds practitioners and researchers that the voice of all individuals must be included in these discussions of that change and solutions will not come without the voice of individuals with disabilities. This is a pivotal point, as the

community conversation must be centered around the individuals in which we are working to support. Without centering conversations around disability and listening to the voices of individuals who experience disability, there is a great risk of continuing exclusionary practices.

Expanding the participant network and diversifying representation at each table allowed for distinct ideas and perspectives to be heard concerning the complex issue of under-employment and unemployment of individuals with IDD. Some of the more widely endorsed suggestions (e.g., ride share ideas to help with transportation to work) came from self-advocates, which indicates the value of incorporating those experiencing disability into these events. To address potential bias and break down barriers to employment, some participants promoted video resumés.

Finally, the overall positive perceptions from participants can partially be attributed to the strong collaborative community conversations planning team. In any event, success comes from a group of committed individuals who are willing to pool resources together to create an opportunity for an inclusive, solution-focused event.

Limitations

There were a few limitations to the pilot community conversations event. First, the limited number of participants made it difficult to generalize findings. The sample size also

prevented the ability to conduct repeated measures analysis to statistically evaluate mean differences of participant responses. The second limitation pertains to missing data. The completion of pre- and post-event assessments was voluntary, preventing data collection from all participants at both timepoints, which also explains different sample sizes. Third, while the goal was to have a balance of participant roles at each table, there was an underrepresentation from the business community, even when multiple recruitment methods were used. This could potentially bias and skew the conversation while missing more employer voice. Finally, while there was representation of self-advocates at every table, only three self-advocates completed the pre-post survey. To ensure full participation of self-advocates, structures should always be in place to evaluate our practices and design them to be accessible for all. Part of our facilitator's directions were to support self-advocates in completing the pre-post assessment if they consented to do so. A limitation is the uncertainty of whether self-advocates did not complete the survey because (a) the pre-post survey was inaccessible to them, or (b) they made a decision to decline to participate.

Future Considerations

As Carter and Bumble (2018) indicated, community conversations have many promising elements including: (a) involvement of new voices, (b) identification of localized ideas,

(c) a solution focused framing to a complex problem, (d) building awareness, and (e) a shared commitment to solving a problem. Findings align with other community conversations events that have focused on employment issues for individuals with IDD (see Bumble et al., 2018). Parallel findings include solutions focused on: (a) enhancing inclusive workplaces such as educating employers about disability-specific employment supports (e.g., funding mechanisms for job coaching or other accommodations), (b) undertaking community-wide efforts like transportation services to ensure individuals with IDD can access work on time with any needed supports, and (c) strengthening school/transition services such as inclusion of agencies during transition planning and more work-based learning opportunities. These parallel findings begin to illuminate that while community conversations focus on local solutions, similar barriers to employment persists across communities. Gathering more data on specific barriers and solutions that are identified within community conversations may provide guidance on the formation of more national solutions.

Another similar finding was the smaller representation of the business sector at this pilot community conversations (Bumble et al., 2018). Without having employers at the table, a very important stakeholder perspective is lost and not heard. Findings from this community conversation suggest that participants were not agreeable that work was available for individuals with IDD in the community. There was also

consensus that employers needed to be educated on employing individuals with IDD, which is a similar finding to Bumble and Carter (2020). Ensuring opportunities to gain employer perspectives on what they do and do not know may be a critical first step. Also finding optimal times for employer participation is important so that it may be more feasible to attend future community conversations. Reflecting on this community conversation, we may consider surveying businesses on event logistics (e.g., best day/time and location). It may behoove groups implementing similar events to first survey employers to identify how to better encourage participation.

Implications for Future Practice

One common implication for future research found across studies (Bumble et al., 2018; Bumble & Carter, 2017; Carter et al., 2012) includes suggestions for how to generalize solutions identified within community conversations into community practice. Community conversations are solution-focused but little information is available on what, if anything, is changed in the community following the event. Future iterations that involve this methodology should have plans to follow-up with attendees as part of the study to gather information on if and what changed because of their experience with the event. Learning of changed behaviors or connections that were made as part of the event could help (a) inform how to make a

replication of the event more effective, and (b) provide details to future attendees about what community conversations are and what are expected outcomes are for attending. The CC team believed this was the first step in a long process toward change. After pilot implementation, additional stakeholders have been identified to participate in future conversations, recruitment strategies have been revised to increase participation of stakeholders that were underrepresented and plans for additional funding and collaboration started so another successful community conversation can take place. Moving forward, the CC team understands that educators, employers, and policy makers must communicate and collaborate so employment opportunities are available for all, not just some. Creating inclusive community conversation opportunities with agents of change (e.g., policy makers, and business leaders and owners) is a pivotal next step for our community and providing equitable employment opportunities for individuals with IDD.

Conclusion

The use of community conversations to discuss common challenges in the disability community is a powerful tool to bring together a variety of individuals to begin to troubleshoot pervasive problems of practice. Understanding that the problem of under- and unemployment is a community issue that can only be solved through collaborative and coordinated

action to allow for innovative solutions that meet local needs. We encourage communities to identify a specific issue and implement their own inclusive, solution-focused community conversations event.

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COLLEGE STUDENTS' KNOWLEDGE OF AND OPENNESS TO STUDENTS WITH AUTISM SPECTRUM DISORDER

Louis W. Turchetta and Valerie Ryan

College Students' Knowledge of and Openness to Students with Autism Spectrum Disorder PDF File

Abstract

College students with autism spectrum disorder (ASD) face challenges due to limited understanding

of this condition. This study investigates college students' awareness of and openness to peers with ASD using an educational intervention. Data were analyzed via a pre–post survey design with two groups. Factorial analysis of variance showed no significant differences between groups. However, a Wilcoxon signed-rank test revealed significant differences in the treatment group's ranks on the openness scale and knowledge scale between pre- and post-intervention surveys. Findings yielded small (openness) and large effect sizes (knowledge) as expected. Brief educational interventions in required courses can thus potentially enhance students' knowledge and engender positive future interactions with students with ASD.

Plain Language Summary

College students with autism spectrum disorder (ASD) face many social challenges. These difficulties stem from limited understanding of the disorder among students and staff. Peers' responses may influence the academic and social success of students with ASD. This study measured college students' awareness of and openness to students with ASD. An educational intervention was performed. No significant changes were found between groups'

scale scores and time of survey. However, the intervention group's pre- and post-intervention scale scores differed significantly. Results show the value of educational interventions. Providing brief autism-focused education in college courses may enhance students' knowledge. This familiarity could promote positive interactions with peers with ASD.

Autism spectrum disorder (ASD) affects an individual's capacity for social cognition and communication. Students with ASD represent a growing segment of postsecondary education; an estimated 44% of high school graduates with ASD go on to attend a 2- or 4-year school (Jackson et al., 2018). Concerningly, however, students with ASD have substantially lower completion rates (i.e., between 20% and 40%) than neurotypical students 5 years after graduation (White et al., 2016). A consistent increase in the enrollment of students with ASD underscores the need to better understand these individuals (VanBergeijk et al., 2008).

The social acceptance of students with ASD at the postsecondary level is an essential aspect of their transition to adulthood (Anderson et al., 2018). A crucial barrier facing college students with ASD is a lack of understanding of this condition (Underhill et al., 2019) from both peers and instructors. Exclusion or generally unreceptive attitudes can render the college environment less hospitable to students with ASD (Gelbar et al., 2015). In particular, peer rejection can

contribute to depression, aggressive behavior, and attrition among this population (Harnum et al., 2007). Families of college students with ASD frequently rank adequate support for social functioning above academic support (Camarena & Sarigiani, 2009). In fact, social support represents one of the most crucial components of college success (Gelbar et al., 2015). Many college students with ASD have cited others' understanding of their diagnosis as a major obstacle (Nevill & White, 2011).

Theoretical Framework

Medical Model

Two popular theoretical frameworks describe disability from divergent points of view. Historically, most educational institutions have assumed a conventional medical model perspective, which stresses an individual's functional limitations (S. R. Jones, 1996). This model frames disability as a personal experience in which rehabilitation is necessary to alleviate associated challenges. More specifically, this model depicts students with ASD as having social or developmental shortcomings that interventions are designed to address (Nevill & White, 2011). The medical model suffers from numerous deficiencies with respect to inclusion.

Social Construct Model

The second and more recent approach to defining disability describes the concept as a social construct, effectively expanding the disability framework to include all people (Denhart, 2008). This model posits that disability is socially constructed rather than purely individual. Viewing disability through this lens allows for greater appreciation of diversity in the classroom (Strange, 2000). This more inclusive framework also encourages changes to environments, thinking, and beliefs to address challenges facing people with disabilities.

The social construct model also enables institutions to craft interventions intended to improve the surrounding environment for students with ASD (Matthews et al., 2015). Interventions designed to target the environment rather than the individual may yield notable impacts; environmental improvements are especially relevant to the retention and advancement of college students with ASD (Matthews et al., 2015; Nachman & Brown, 2020; Strange, 2000).

Importance of Typical Peer Attitudes

Peers' attitudes toward students with ASD may greatly influence these students' academic and social outcomes. For example, the degree of social connectedness perceived by students with ASD is related to the attitudes of their neurotypical peers (Jackson et al., 2018). Peers can profoundly affect young adults' self-concept, social skills, academic

achievement, motivation, and future outcomes (Wertsch, 1985).

Students with ASD continue to struggle on college campuses, and services that promote social functioning (e.g., coaching or peer mentoring) are not required by law (Brown & Coomes, 2016). Students may also lack the social skills necessary to effectively self-advocate and often choose not to disclose details about their disability (D. R. Jones et al., 2021). Students with ASD cite social challenges as being among their greatest hurdles on college campuses; a lack of awareness among peers seems to be one of the most critical areas of need in supporting students with ASD (Anderson et al., 2018).

Typical students may misconstrue certain ASD-related behaviors, such as a lack of eye contact or misinterpretation of social cues, as reluctance to make connections. Research on perceptions of atypical behaviors in the ASD population suggests the importance of environmental change in fostering acceptance (Underhill et al., 2019). College students tend to view such behavior more negatively when it is not tied to a diagnostic label such as ASD (Brosnan & Mills, 2016; Butler & Gillis, 2011). Giving neurotypical students the means to identify and support peers with ASD may lead to greater understanding and inclusion. Additionally, raising awareness of ASD could enable neurotypical peers to better recognize associated behaviors and view them more favorably (Gillespie-Lynch et al., 2021).

Importance of Advocating for Greater Awareness

Awareness programs can potentially reduce stereotypes and stigma about students with ASD (Van Hees et al., 2015). Efforts to increase awareness of ASD may lead to improved understanding of students with the condition (Griffith et al., 2012). Raising awareness of ASD is consistent with interventions modeled after social construct theory (Matthews et al., 2015) and supported by the Interagency Autism Coordinating Committee's (2020) strategic plan for ASD research. Furthermore, greater awareness of ASD among typical college students and faculty could improve the experience of students with ASD by reducing isolation and dropout (Griffith et al., 2012).

Promoting awareness of students with ASD in community college settings is especially important; these students are twice as likely to attend community college than a 4-year institution (Snyder et al., 2016). Students with ASD may attend community college in greater numbers for various reasons, including affordability, lower admissions requirements, accessibility, an emphasis on teaching over research, and smaller classes (Ankeny & Lehmann, 2010).

Students with ASD and their families have long advocated for campus support such as peer mentoring and ASD awareness programs. These programs may ease the transition for students with ASD (Camarena & Sarigiani, 2009). When

neurotypical peers exhibit high openness and acceptance of atypical behaviors consistent with ASD, students on the spectrum can prosper (Underhill et al., 2019). Maximizing awareness and acceptance among peers and faculty could, therefore, benefit all parties. ASD awareness education can be incorporated into relevant academic courses (e.g., introductory psychology) to enhance understanding among the general student body (Nevill & White, 2011). Yet studies examining efforts to improve the environment for students with ASD are scarce (Brown & Coomes, 2016), especially at the community college level (Shmulsky & Gobbo, 2019).

Aim of Study

This study sought to assess community college students' awareness (i.e., knowledge) of and openness to peers with ASD before and after an educational intervention. The intervention consisted of a 20-minute mini lesson on ASD created by the lead investigator and presented in his general psychology course. The mini lesson was designed to dispel common stereotypes and to promote an accurate understanding of ASD. Students' knowledge and openness were assessed before and after the lesson and compared to a control group of students in other general psychology classes who did not receive the lesson. Related implications and directions for future research to improve educational efforts in this area are provided in closing.

Method

Participants

Participants were recruited via email and verbal announcements from four instructors (including the lead investigator) teaching general psychology at the Community College of Rhode Island (CCRI). Students received extra credit for full participation. Specifically, to be included in the data analysis, students in the experimental group were required to complete pre- and post-surveys and attend the in-class educational intervention on ASD. Control group members were required to complete only the pre- and post-survey; they did not attend the mini lesson. Sixty students were initially recruited and completed the pretest; 44 also took the posttest. The final sample (N = 44) was somewhat evenly distributed in terms of gender (56.8% women, 43.2% men). Participants were between 18 and 48 years old (M = 21.5 years). In terms of ethnicity, 58% of participants identified as White/European, 7.4% as Black, 2.5% as South Central American, 22.2% as Other Latino, 8.6% as multiracial/multiethnic, and 1.2% did not say.

Procedures

Participants completed an identical pre- and post-test including two surveys that respectively measured knowledge

of ASD and openness to people with ASD. All surveys were administered through Google Forms before and after the in-class educational intervention. Participants were assigned to either the treatment or control group based on course enrollment. Those who attended the lead investigator's class received the 20-minute mini-lesson, whereas students in other general psychology courses did not (i.e., control group).

Intervention

The lead investigator created the mini lesson and delivered it in his general psychology course. The lesson consisted of PowerPoint slides along with brief videos, including publicly available video clips depicting the perspectives of students with ASD. In terms of the lesson's learning objectives, the intervention group was expected to be able to (a) define ASD; (b) describe aspects of the identification, intervention, and prognosis for individuals with ASD; (c) understand differences in how people with ASD may express empathy and emotion; and (d) describe how the behavior of individuals with ASD can sometimes be misunderstood.

Timeline

The experimental and control groups completed an identical posttest 1 week after the intervention. During the informed consent process, students who agreed to participate in the study were randomly assigned an ID with which the lead

investigator could verify and match their pre- and posttest scores for data analysis. Personally identifying information was kept separate from participants' responses.

Ethical Considerations

Study participation was voluntary, and all potential participants (i.e., across courses in which the study was advertised) could complete a comparable alternative assignment for extra credit if they desired. The lead investigator completed required trainings on human subjects research and received study approval from CCRI's Institutional Review Board.

Instruments

The first survey was designed to evaluate participants' openness to individuals with ASD. The survey included a vignette along with seven questions developed by Harnum et al. (2007). A second survey, a knowledge assessment, was administered simultaneously during the pre- and posttest; this assessment was developed by Stone (1987), adapted by Heidgerken et al. (2005), and used in a study regarding college students' knowledge of autism (Tipton & Blacher, 2014). Both measures are provided in the Appendix.

Data Analysis

We adopted a between- and within-groups pre–post design involving two 2 × 2 factorial analyses of variance (ANOVAs). A mixed design was employed to determine whether scores on the openness scale and knowledge scale differed by group (treatment vs. control) and time of survey (pre- vs. post-intervention). We also used the Wilcoxon signed-rank test to determine whether significant differences existed in the treatment group's ranks on the openness scale and knowledge scale between pre- and post-intervention surveys. The alpha level was 0.05. All analyses were conducted in R version 3.4.3 (R Core Team, 2017).
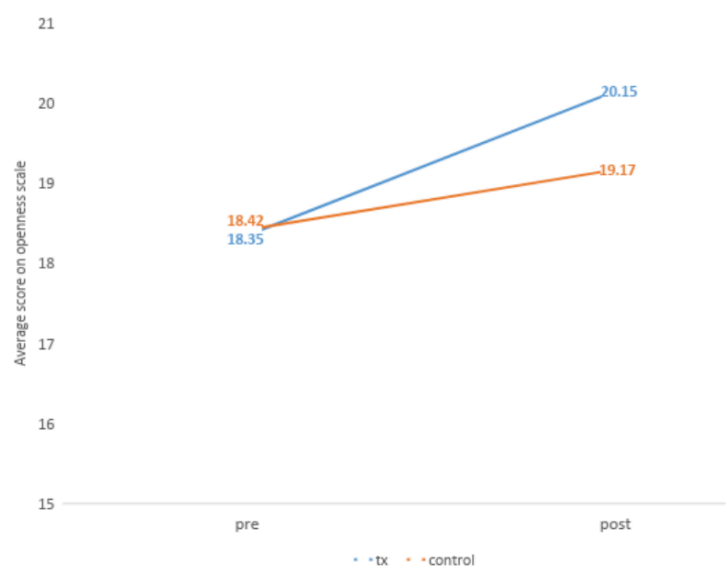
Results

Figure 1 *Plot of Treatment and Control Groups' Pre- and Post-Test Scores on Openness Scale*

The Wilcoxon signed-rank test indicated statistically significant differences in pre- and post-test ranks on the treatment group's openness scale ($Mdn_{\text{pre-test}}$ = 19 vs. $Mdn_{\text{post-test}}$ 21.5; V = 27, p = 0.01) and knowledge scale ($Mdn_{\text{pre-test}}$ = 35 vs. $Mdn_{\text{post-test}}$ = 40; V = 46.5, p = 0.03). The ranks were significantly higher for the post-tests versus the pre-tests. Students in the treatment group thus apparently held more favorable attitudes toward, and were more knowledgeable about, people with ASD following the informational mini lesson.
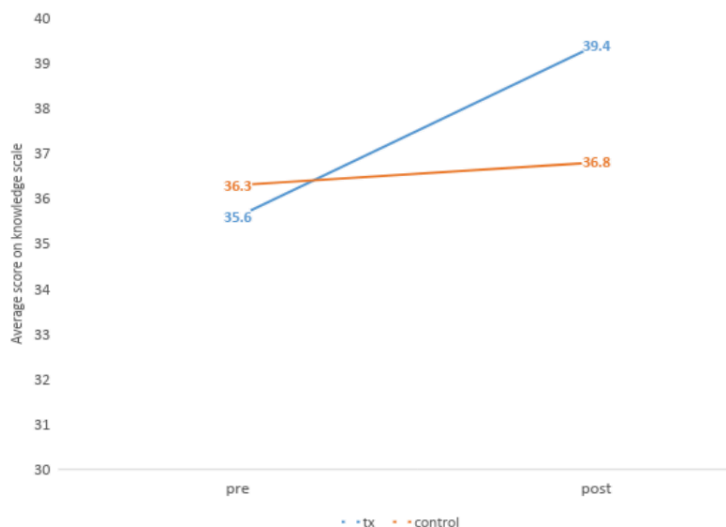
Figure 2 *Plot of Treatment and Control Groups' Pre- and
Post-Test Scores on Knowledge Scale*

The Wilcoxon signed-rank test also yields an effect size, Cliff's delta (d). This measure was small for the difference between the treatment group's pre- and posttest scores on openness ($d = 0.19$) but large for the difference between their scores on knowledge ($d = 0.48$). The large effect size associated with knowledge indicates that this variable was substantially influenced by the intervention. The small effect size associated with openness indicates that the intervention was substantially less influential on this variable.

Discussion

The intervention showed promising results, as students' knowledge and openness each improved in the treatment group. The lack of statistically significant interactions and main effects in the factorial ANOVAs may be due to two factors: (1) a small sample size and (2) non-normally distributed data. There were only 20 participants in the treatment group and 24 in the control group, resulting in little power to detect significant effects. The Wilcoxon signed-rank test, a non-parametric test analogous to a dependent samples t test, was, therefore, a better candidate for analyzing these data.

The statistically significant results of the Wilcoxon signed-rank test suggest an expected large effect size for change in knowledge and an expected small effect size for change in openness. Tests of factual knowledge often show large gains after an educational intervention (Gillespie-Lynch et al., 2021). Scholars have also found that implicit attitudes, such as openness, may be more resistant to awareness training (D. R. Jones et al., 2021). Research on implicit attitude change highlights the quantity or amount of contact as the most critical element for change (Gardiner & Iarocci, 2014). Knowledge or explicit awareness of the need for change is typically the first stage in a change process. The transtheoretical model of change asserts that when attempting to change behavior, attitude change through consciousness raising or promotion of awareness is usually the first step

(Prochaska & Norcross, 2001). Our findings imply that awareness initiatives, such as a mini lesson in a general psychology class, can substantially improve knowledge and marginally improve openness in typical students. These results are consistent with those of Van Hees et al. (2015), who reported large increases in knowledge and modest increases in openness after an educational intervention.

Furthermore, consistent with Gillespie-Lynch et al. (2021), openness did not change substantially; however, educational interventions may initially help students to understand individuals with ASD. An educational intervention and initial improvement in explicit knowledge could serve as a prerequisite for positive future interactions. More specifically, before considerable gains in openness can be realized, typical students may first need knowledge in addition to multiple opportunities to be in the presence of students with ASD over extended periods and with repeated exposure.

Limitations

The limitations of this research include its small sample size and uncertainty regarding the retention of participants' gains in knowledge and openness after post-measures were collected. Additionally, students who chose to participate in this study for extra credit may have fundamentally differed from those who opted not to take part.

In the future, researchers could recruit a larger sample size

and adopt a follow-up design to determine whether any increases in participants' scores have lasting effects. Scholars can also examine the impacts of intervention programs on student populations who have already received ASD education.

Conclusion

Ideally, subsequent research and interventions combining education and other best practice measures (e.g., peer mentoring) could increase students' extent of positive exposure to and experiences with ASD, possibly enhancing openness over time. Students with ASD may particularly benefit from policies that incorporate awareness education into introductory coursework for all students.

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PROMOTING INCLUSION OF ADULTS WITH DISABILITIES IN LOCAL FITNESS PROGRAMS: A NEEDS ASSESSMENT

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Abstract

Fit-Pals (pseudonym) is a university-based, service-learning program with a mission to prepare adults

with disabilities to engage in lifelong physical activity. We conducted a needs assessment to evaluate recent programmatic partnerships with community-based fitness organizations. We aimed to (1) evaluate organizational perceptions of Fit-Pals' partnership efforts, and (2) identify perceived organizational needs to improve inclusion practices. Representatives from each of our seven partner organizations participated in an online survey, follow-up interviews, and a stakeholder meeting. A thematic analysis of survey and interview responses highlighted areas for programmatic growth related to training in disability awareness and fitness accommodations, and improved communication across all partnership levels. Our stakeholder meeting further identified gaps between advocacy for disability inclusion and awareness of actionable steps to effectively enact this within organizations. Drawing from the literature, we discuss Fit-Pals' efforts to increase the capacity of our community partners to support members with disabilities.

Plain Language Summary

Fit-Pals is an exercise program for adults with disabilities. In our program, adults with disabilities go to activity classes with a college student "buddy."

The two buddies go swimming or do yoga or other exercise together. In the past, fitness buddies exercised alone at the university recreation center. Now, fitness buddies go to activity classes with other people in their community. We want to know if this change was a good idea. So, we did a "Needs Assessment." We talked to people leading the community activity classes. We asked what they liked about Fit-Pals. We asked how we could help them make their classes better for adults with disabilities.

Our needs assessment had three parts. First, we asked people to answer questions in an online survey. Eight leaders from community activity programs did the survey. Second, we met for in-person interviews to ask more questions. We asked what they liked and disliked about Fit-Pals. We asked what they wanted to change. Third, we invited community leaders to lunch. Fitness buddies and Fit-Pals staff also came to lunch. We talked about what we learned from the survey and interviews. Together we planned how to make Fit-Pals better.

We learned everyone likes that we match fitness buddies together. Activity leaders said they do not always know how to help adults with disabilities but they want to learn. They also want everyone in Fit-Pals to talk more to each-other. Our plan is to help fitness buddies and activity leaders work together.

> Fitness buddies are going to teach activity leaders about adults with disabilities. They are going to be role models. We hope others learn from us. We hope others make programs like Fit-Pals. We want all activity programs in the community to include adults with disabilities.

There is a recognized need to promote life-long physical activity among adults with disabilities (AWD). In Oregon, approximately 1 in 4 AWD are not engaging in routine physical activity (Oregon Office on Disability and Health, 2012). Inactive AWD are 50% more likely to experience chronic health conditions, such as heart disease and diabetes, compared to physically active AWD (Carroll et al., 2014). In Oregon, AWD are more likely to experience obesity, and self-rate their health as poor, compared to peers without disabilities (Oregon Office on Disability and Health, 2012). Collective efforts are needed to empower AWD to adopt healthy, active lifestyles, and thereby offset these observed health disparities (UDHHS, 2005, 2018).

The present research reports on the redesign and evaluation of Fit-Pals, a university-community partnership towards increasing the inclusion of AWD in community-based physical activity programs (note: we are using a pseudonym for our program to protect confidentiality). Physical activity is characterized by routine participation in recreation and fitness programs fostering enjoyment, health, and wellness (Cooper

et al., 1999; U.S. Department of Health and Human Services [UDHHS], 2005, 2018). AWD engaging in routine physical activity can experience improved cardiovascular fitness, muscular strength, balance, and self-rated quality of life (Bartlo & Klein, 2011). Yet, fitness facilities in Oregon are largely inaccessible when evaluated against the Americans with Disabilities Act (ADA) guidelines (Cardinal & Spaziani, 2003). Furthermore, AWD self-report substantial social and structural barriers to physical activity opportunities within their communities (Rimmer et al., 2004; 2005). Barriers reported by AWD include a lack of social support and community acceptance within fitness organizations (Buffart et al., 2009). Additionally, fitness organizations often have limited policies and promotional efforts targeting AWD, and staff report limited knowledge or awareness of inclusive fitness practices (Bodde & Seo, 2009; Cardinal & Spaziani, 2003; Temple, 2007). In the present study, we sought to identify barriers and create an action plan for improved inclusion of AWD within our own Fit-Pals program.

Program Overview

Based in Oregon, Fit-Pals is a university-based service-learning program with a mission to prepare AWD to engage in lifelong, community-based physical activity. Fit-Pals serves 20-25 AWD each academic semester. Undergraduate student volunteers are

paired with an AWD participant as an "exercise buddy" and provide instructional support during weekly activity sessions.

In 2017, a Fit-Pals board member, and parent of an AWD participant, raised concern that our Fit-Pals' program structure did not align with its stated mission. At that time, participant and volunteer pairs were meeting one-on-one, twice per week, at the university student recreation center. The student recreation center is not open to the public and did not enable non-student AWD participants to access the facility outside scheduled session times. This raised concerns that AWD were not being prepared with knowledge, familiarity of community-based resources, and support systems that would lead to sustainable physical activity habits. Additionally, the Fit-Pals program model positioned undergraduate student volunteers as "experts or fitness trainers" responsible for developing and leading exercise programs without knowledge translation or input from the AWD participants. The high dependence on student volunteers further restricted program capacity to the availability of student volunteers for one-on-one pairing. As a result, AWD participants experienced extended periods of inactivity during academic breaks.

In 2018, Fit-Pals was redesigned to integrate AWD participants into community-based physical activity and group exercise programs, reducing university-influenced dependence. Fit-Pals partnered with local community-based fitness and recreation programs to promote inclusive environments within existing programs for swimming, strength and

conditioning, aerobics, and yoga. Fit-Pals' staff, including undergraduate student volunteers, were repositioned as direct supports for implementation of inclusive practices through education, resource sharing, advocacy, and research.

Research Aims

The present study aimed to evaluate Fit-Pals' programmatic changes and identify priority areas for continued growth via a community needs assessment. In 2019, we conducted a needs assessment guided by the Riley et al. (2008) three-step framework for supporting community fitness and recreation centers' adoption of disability-inclusive practices: (Step 1) *assess* facility inclusion and identify readily achievable barriers for removal within Fit-Pals partner organizations; (Step 2) *review* the inclusion report with a stakeholder committee and identify top priorities for programmatic and structural change; and (Step 3) develop *action* steps for removing barriers, increasing accessibility, and fostering inclusive cultures within community organizations (Riley et al., 2008). In this report we detail our evaluation process and share lessons learned. We intend for this transparency to support similar programs' applications and extensions of related efforts within their own communities.

Methods

Participants

Our community needs assessment sought to engage one to two respondents at each of Fit-Pals' seven partner organizations. These seven organizations included community pools and fitness centers, as well as studios that specialize in yoga, dance, and strength training. We contacted a community partner representative (CPR) at each organization with whom we already had established relationships and trust (Riley et al., 2008). These CPRs were recruited to participate in an online survey, a follow-up interview, and a stakeholder meeting. CPRs were asked to identify additional stakeholders from their organization to provide a more robust perspective of the organization—those identified were invited to participate. All CPR respondents were informed that participation was for program evaluation and optional. Table 1 reports general descriptions of CPRs and their level of participation.

Table 1:
General Description of Community Partner Representatives (CPR) Who Participated in Survey and/or Interview and Who Attended the Post-Assessment Stakeholder Workshop

Type of Organization	Partnership Agreement	CPR's Job Position	Survey	Interview	Stakeholder Workshop
Fitness Programs	Existing classes designed for AWD	A. Program Director B. Instructor	 √	√ √	√ √
Fitness Program	Open fitness with coaching staff support	A. Program Director	√	√	√
Fitness Program	All classes open	A. Program Director B. Instructor	 √	√ 	
Fitness Program	New class designed for Fit-Pals' participants only	A. Owner Instructor B. Instructor*	√ 	 	 √
Aquatics Program	All classes open	A. Program Director B. Instructor	√ √	√ √	 √

Type of Organization	Partnership Agreement	CPR's Job Position	Survey	Interview	Stake Work
Fitness Program	All classes open	A. Program Director B. Instructor	√	√	
					√
Yoga Program	All classes open	A. Owner/ Instructor	√	√	

* Affiliated with Fit-Pals (*Note: Fit-Pals is a pseudonym to protect anonymity*)

√ = participated

CPRs were incentivized to participate with customized, adaptive fitness resources including Fit-Pals merchandise, a bound copy of *Guidelines for Disability Inclusion in Physical Activity, Nutrition, & Obesity Programs and Policies: Implementation Manual* (Kraus & Jans, 2014), and the chance to win a raffle prize. The raffle prize was the choice of enrollment in ACSM/NCHPAD Certified Inclusive Fitness Trainer webinar series or an inclusive fitness/aquatics equipment basket. The funding for incentives was provided, in part, by a Community Engagement Grant from the local University Center for Excellence in Developmental Disabilities (UCEDD).

This study was approved by the University Institutional
Review Board (IRB) for the protection of human subjects.

Design

Step 1: Inclusion Assessment

Figure 1 illustrates the three-step approach (Riley et al., 2008)
taken to evaluate Fit-Pals. In *Step 1* we assessed CPRs'
perceptions of Fit-pals partnership, inclusion strategies, and
current/ anticipated needs to further support the participation
of AWD within their programs. A mixed-method approach
was taken. CPRs were first invited to complete an online
survey (Qualtrics CoreXM Survey Software; Version 01/19/
2019, Provo, UT). The development of multiple-choice and
Likert-scale survey items was informed by existing survey
mechanisms (e.g., Accessibility Instruments Measuring Fitness
and Recreation Environments [AIMFREE], Rimmer & Riley,
2004), and prior literature (Casey et al., 2010; Riley et al.,
2008). Additionally, the authors' drew on their experience
running Fit-Pals as a guided estimation of what topics would
be relevant to CPRs (Maxwell, 2012). Invitations to
participate in the survey were distributed through direct emails
from the Fit-Pals coordinator (first author).

The fit-pals needs assessment design with three different steps.

Figure 1

Fit-Pals' Need Assessment Approach

As an extension of Step 1, CPRs were invited to participate in follow-up interviews. Efforts were made to recruit at least one CPR from each partner organization to reach saturation of perspectives (Yeo et al., 2003). Preliminary survey results informed the development of a semi-structured interview guide. When applicable, open-ended prompts, alongside reference to survey responses from CPRs, were used to facilitate in-depth discussion of key topics. Interviews were conducted in-person by the first author, who had a prior relationship with participants as Fit-Pals' program coordinator (Riley et al., 2008), along with at least one note-taker. Interviews were recorded and transcribed using Spext 4.0 software (Spext Labs Inc., Berkeley, CA).

Planned Analysis for Step 1

First, a descriptive analysis of the online survey data was planned. The 10-member research team examined frequency counts across survey items to identify response patterns. Second, an inductive qualitative analysis of interview transcripts was planned. As such, no *a priori* hypothesis or themes were generated. Researchers developed codes in a three-step process: (1) initial code generation, (2) group consensus and synthesis of initial codes into a code book, and (3) transcription analysis using the generated code book. Coding was organized using ATLAS.ti 8.3 Mac software (Scientific Software Development GmbH, 2019). This reiterate approach, including revisiting survey results, was

taken to ensure a robust understanding (Silverman, 2015) of the data was reached. Discussion continued until a group consensus was met on the convergent themes within the data. Table 2 illustrates example themes generated from survey and interview data.

- Staff/instructor training
- Disability awareness campaigns
- Equipment sponsorship or recommendations
- Liaison with disability groups
- ...

Table 2
Example of Theme Generation from Survey and Interview Questio

General Topic	Survey Question Examples	Interview Questions Examples	Sample from Interview Transcript	Ge T
Satisfaction with Partnership	Indicate how satisfied your organization has been with the supports [Fit-Pals], has provided for each of the following. a. Recruited participants with disabilities b. Provided disability awareness training c. Provided one-on-one support staff/ volunteer d. Assisted in creating plans for individual modifications and accommodations e. … Response options: [1] very dissatisfied to [5] very satisfied; [6] didn't expect support; [7] don't know	How does your organization view the partnership now? Did the partnership not meet, meet, or exceed expectations? Did anything surprise you about what Fit-Pals programming offers?	*[15] "We are unsure about the range of accommodations we are responsible for. We are unsure what we are legally required to provide or the extent of accommodations that are feasible and needed"*	Comm

General Topic	Survey Question Examples	Interview Questions Examples	Sample from Interview Transcript	Ge... T...
Facilitators & Barriers	How have the following factors impacted the abilities of people with disabilities to engage in activities at your organization? a. Attitudes of community members b. Attitudes of staff c. Knowledge of staff about disability d. Staff/Instructor training e. ... Response options: [1] not helpful to [5] very helpful; [6] not needed; [7] don't know	What challenges to inclusion has your organization faced during this partnership? *[follow-up] The survey mentioned barriers of ... Can your share more about these barriers?*	*[7] "I think it is important that if we are building an inclusive community, we need to include people with disabilities. We want to build relationships and help facilitate community. [Fit-Pals] adds to our community."*	2 Be... Par...

General Topic	Survey Question Examples	Interview Questions Examples	Sample from Interview Transcript	Ge T
Needs	Indicate the extent to which your organization would find the following helpful to promoting the inclusion of people with disabilities: a. Staff/instructor training b. Disability awareness campaigns c. Equipment sponsorship or recommendations d. Liaison with disability groups e. … Response options: [1] not helpful to [5] very helpful; [6] not needed; [7] don't know	After talking with our stakeholders about the future of our program and based on their feedback, our goal is to eventually offer [Fit-Pals] as a transitional program for PWD to be less dependent on us, as a program, and more independent in navigating their own goals towards health and fitness. What tools and/or resources are necessary to support the above your organizations goals of inclusion?	*[19] "Obviously, there are me and other staff members to help facilitate workouts and give ideas too. But we are definitely limited in staff and [management] is very reluctant to keep adding staff [due to] financial issues going on right now, as I'm sure you can appreciate."*	8 Pa Sust

To improve the trustworthiness of data interpretations, member checking was conducted at the end of Step 1. CPRs were invited to review transcript excerpts deemed relevant for our analyses and provide feedback. Care was taken to clearly communicate with CPR participants that they were being invited to edit their responses or add additional comments to improve the representativeness of the data (Carlson, 2018; Koelsch, 2013). Participants could return feedback electronically or via hard copy. Nonresponsive participants received a follow-up email and were offered the additional option of providing verbal feedback over the phone (Carlson, 2018). All participants approved transcripts without any changes.

Step 2: Stakeholder Input

For Step 2, we sought stakeholder input on themes generated from Step 1. We held a post-assessment stakeholder workshop to identify priorities for programmatic changes. Stakeholders included CPRs, AWD participants, Fit-Pals' board members, and Fit-Pals' staff and student volunteers. Assigned seating at the workshop was planned to facilitate cross-stakeholder conversation. The incoming program coordinator (third author) facilitated a large group discussion to reach consensus on the accuracy of themes presented, as well as a consensus of which themes should be prioritized in the upcoming year.

Step 3: Action Steps

In Step 3, a plan for programmatic changes was developed. The priority themes identified by stakeholders in the stakeholder workshop (Step 2) were used to develop short and long-term action steps that would further support the improved inclusion practices within Fit-Pals community partnerships.

Results

Step 1: Inclusion Assessment

A total of 10 CPRs participated in Steps 1 & 2 (survey only = 2; interview only = 2; survey and interview = 6), with at least one representative from each of Fit-Pals' seven partners (see Table 1). The research team identified seven descriptive themes through reflection and reiterative discussion of surveys and interviews (see Table 2). We expand on these seven themes below, integrating evidence from the surveys and interviews. Fit-Pals staff's knowledge of the partnerships helped to contextualize, and further explore, CPRs perspectives on organizational levels needs for supporting inclusion.

Theme 1: Awareness and Knowledge of Fit-Pals

All survey respondents (n = 8) agreed that Fit-Pals' overall mission to "Build and support inclusive practices at community-based physical activity, fitness, and sport facilities" was clearly communicated. However, some CPRs reported Fit-Pals' specific program objectives, such as supporting AWD's engagement in lifelong physical activity within an inclusive community, were only somewhat communicated to the organization (n = 3).

During interviews, CPRs further acknowledged general awareness of the Fit-Pals' mission and affiliation with the University. They further identified Fit-Pals' provision of volunteers, helpers, or assistants as a core component of the program's services.

> [1] "[Fit-Pals is] a program that supports people with disabilities in community classes. [Volunteer assistants] are a great asset to [activity] instructors."

In the survey, six of the eight CPRs indicated that a core value of their organization was the "promotion of inclusive climates." Their survey responses further indicated that CPRs believe upholding this value is a joint responsibility shared with Fit-Pals' staff. Four of the eight CPRs expressed satisfaction with "Fit-Pals' development and implementation of specific adapted fitness classes." One CPR indicated that

their organization was "not expecting this service as part of the Fit-Pals partnership."

Theme 2: Benefits of Partnership

In interviews, CPRs expanded on the perceived benefits of the partnership for AWD and the community:

> [2] "[Fit-Pals] is a really good opportunity for people who need a bit more help in getting involved in more public activities, getting them out of the house to be more active."
>
> [3] "It's really fun with one [participant] who's been there from day one to see his progress. I mean, that is fun for everyone, but it's so cool. Like, exactly, it is inclusivity! These individuals are getting better just like you and I."p>

CPRs indicated in the survey that their organization was very satisfied with the support provided by undergraduate student volunteers (n = 6). The appreciation for volunteers was emphasized during interviews, for example:

> [4] "I have one young man in my class. He's kind of difficult to work with and [the university student volunteer] is just so good. She keeps encouraging him. She was having him do things I hadn't thought of, neither had anyone else."

Additionally, CPRs shared in interviews that the partnership benefited their organizational staff, commenting on how the opportunity to work with AWD and undergraduate student

volunteers improved their organization's capacity and staff comfort with teaching diverse groups of individuals.

> [5] "To be honest, it helps educate myself and our staff. It's easy to train athletes, it gets harder to train people with limitations and then people with disabilities. Training [Fit-Pals participants] makes us better coaches. [After a year of partnership], we now know what works well for them. We are [developing] our drop-down list in our minds, 'okay, let's try this, let's try that.' More experience has given us the ability to act on our feet."

CPRs further identified in the interviews how the inclusion of AWD in their classes raised disability awareness among community members and helped to build an inclusive climate within their organizations. Many CPRs identified Fit-Pals' mission to integrate AWD into community fitness programs as aligning with their organization's philosophy for inclusion, as exemplified by the following quotes.

> [6] "[Fit-Pals] shows people that [AWD] are able to participate and it gets people to see [AWD] out being part of the community as well, not just sequestered to a particular niche."
>   [7] "I think it is important that if we are building an inclusive community, we need to include people with disabilities. We want to build relationships and help facilitate community. [Fit-Pals] adds to our community."

Theme 3: "Best Fit" for Participant and Instructor

In interviews, many CPRs emphasized the need for collaboration between Fit-Pals, community partner organizations, and AWD participants when identifying "best fit" program options for AWD participants. CPRs further commented on the logistical challenges with implementing inclusive practices. CPRs characterized best fit program matches for AWD as those meeting the physical-ability level and expectations of the participant. This term was also used to reference the environment and AWD preferences for activity classes based on speed of instruction, noise level, culture, crowdedness, and/or time of day it is offered.

> [8] "But if somebody has a physical limitation then maybe a boot camp class might not be as appropriate [for them]. Given the type of class, [we] can talk about what's appropriate and what's not appropriate. But our philosophy is that anybody that walks into our classes knowing what's supposed to be happening in class should be able to participate and be successful with it."
>
> [9] "Everyone has their own journey that they go through during a yoga class, and I could see how if somebody wasn't able to follow that culture how that could be disruptive to other participants. But there is wiggle room within that, [and] maybe a faster flow class might be more appropriate for [Fit-Pals participant], as opposed to a therapeutic [class]. But we will have to see it on an individual basis."

During interviews, CPRs further discussed "best fit" in terms of specific instructors who were perceived to be more comfortable or had more experience working with AWD. Consistent with points later discussed in relation to theme 5, CPRs called for Fit-Pals to improve or more formally facilitate discussion between AWD, Fit-Pals' staff and program instructors to evaluate fit and accommodation needs.

> [10] "[One of our instructors] was a former occupational therapist. She's great and [teaches a class] geared towards strength training and not necessarily just cardio."
>
> [11] "I think some [instructors] are quite comfortable [working with individuals with disabilities], and others maybe not so much. That's probably a lot [to do with] individual experience and background."

Theme 4: Request for Disability Awareness and Inclusive Fitness Training

In the surveys, all eight CPRs reported that organizational staff were somewhat to very knowledgeable and comfortable working with AWD in fitness settings. However, five CPRs indicated that their organization would find disability awareness and inclusive fitness trainings very helpful, such as adopting and designing physical activities for individuals with disabilities and communication techniques. Six of the eight CPRs indicated that Fit-Pals should provide the training as part of the program's service. Only one survey respondent reported that their organization had provided additional

disability awareness training to their staff in response to partnering with Fit-Pals.

During interviews, CPRs were enthusiastic about opportunities for trainings and had several ideas to share.

> [12] "Maybe something like a manual, or something like that, for facility owners with more general information about what typically works [for people with disabilities in fitness settings]."
>
> [13] "[We'd like to learn more about] adapted certifications. We don't even know if those [certifications] exist, where they are located and how much they cost."
>
> [14] "I would love to have an afternoon symposium with everyone getting together and just talking about [adaptive strategies].... We don't know where to start, to be totally honest with you [in terms of education], so just having access to people who are experts [would be helpful]. We are more than willing to learn and ready to learn."

Theme 5: Communication

CPRs indicated in the survey that there was a high level of uncertainty around the roles and responsibilities of those involved in the partnership, as there was no concise agreement among the CPRs on the services provided by Fit-Pals. CPRs expanded on this theme in interviews, highlighting that Fit-Pals' expectations of organizational staff in implementing inclusive strategies were vague.

> [15] "We are unsure about the range of accommodations we are responsible for. We are unsure what we are legally

required to provide or the extent of accommodations that
are feasible and needed."

[16] "[It would be helpful] if [a] representative from
[Fit-Pals] came to [a] staff meeting and explained a little
bit more about what the objectives are. I think [the facility
staff] want to be helpful, but maybe aren't always sure
[how] to be helpful. I'm not sure what their role should be
in terms of providing direction or that sort of thing."

In interviews, CPRs also raised concern about the high
variability in the preparedness and knowledge of Fit-Pals'
undergraduate student volunteers who accompanied AWD
participants.

[17] "A challenge is the [student] volunteer[s] themselves.
We've had some who come in and [say] 'I got this.' [So we
think] 'Okay cool, go for it.' Then others, they['ve] got the
deer in the headlights look."

[18] "If the [student volunteer] could maybe have a
meeting with [the AWD participants'] family/ caregiver.if
there's somehow [a] way you could get a little information
[on the participant it could help the student volunteer be
successful]."

Theme 7: Partnership Sustainability

The final theme reflected CPRs concerns around the logistics
and feasibility of maintaining support for AWD during
summer months without Fit-Pals. In the survey, only one CPR
reported their organization provided one-on-one support for
AWD, separate from the services provided by Fit-Pals. When

prompted in interviews to identify what was needed to support AWD outside of Fit-Pals, and without university volunteers (e.g., during summer months or academic breaks), CPRs deferred the responsibility of inclusive programming to Fit-Pals volunteers, interpreting their organization's role as [19] "mostly just providing a space...[and] a nice safe environment" CPRs also noted staffing as a primary limiting factor to sustaining Fit-Pals-related programming over summer months.

> [20] "Obviously, there are me and other staff members to help facilitate workouts and give ideas too. But we are definitely limited in staff and [management] is very reluctant to keep adding staff [due to] financial issues going on right now, as I'm sure you can appreciate."

During interviews, CPRs reiterated that individual fit and needs were important when considering the feasibility of AWD participants attending their programs during the summer, unaccompanied by university volunteers.

> [21] "It just depends, the ability of people to be independent doing it because we are not really in position to provide more resources."

Step 2: Stakeholder Input

The seven themes described above were shared with our stakeholders during a 2-hour workshop meeting at a local

community center. A total of 38 stakeholders attended the workshop, including CPRs representing Fit-Pals' seven partnerships, AWD participants and their caregivers, Fit-Pals' board members, and Fit-Pals' program staff members and volunteers.

The facilitated group discussions led to a consensus among stakeholders that the seven themes and interpretations shared above were representative of Fit-Pals' programming and partnership needs. Stakeholders at the workshop further identified two themes as priorities for continued program development: (1) education/training to create enabling environments within community fitness programs (i.e., theme 4); and (2) improved communication between AWD participants, CPRs, and Fit-Pals' program staff to ensure equitable collaboration (i.e., theme 5). Stakeholders further emphasized the need to empower AWD participants to contribute to decisions around program logistics, determining best fit program options, and inclusive solutions for instructors.

Step 3: Action Steps

In response to the stakeholder workshop, Fit-Pals' leadership implemented an action plan to improve (1) cross-stakeholder communication and (2) disability training for student volunteers and organization staff. Two undergraduate intern positions were created to oversee communication and the

development of new volunteer training materials. To improve transparency and communication, training materials for volunteers included introduction guides and communication protocols, program expectations, and step-by-step instructions for participation at each organization. Additionally, CPRs received resources on fitness tools and common considerations when developing fitness plans for AWD. Based on stakeholder feedback, Fit-Pals also prioritized self-advocacy development among AWD participants, facilitating opportunities for individuals with disabilities, and their families, to conduct accessibility assessments at the facilities they utilize and provide consultation for programmatic changes. Fit-Pals has maintained open lines of communication with CPRs to further identify opportunities for support and training.

Discussion

Overall, stakeholders expressed positive responses to their organization's partnership with Fit-Pals, and to Fit-Pals' efforts to integrate AWD into existing community physical activity programs. Our findings indicate that CPRs are committed to disability inclusion and value Fit-Pals' impact on their program culture and their instructors' professional development. However, most CPRs acknowledged limited organizational capacity to implement disability inclusion strategies. CPRs expressed hesitation and concern for programming logistics when pressed during interviews about expanding their

inclusive practices. This tension highlighted a disconnect between advocacy for inclusion and adoption or implementation of inclusive practices.

CPRs appear to be cognizant of the gap between advocacy and practice, given one of the priority themes identified by stakeholders was need for more training and information sharing. Encouragingly, addressing these priorities will target instructor knowledge, community acceptance, and social support barriers, that are frequently reported by AWD within the literature (Bodde & Seo, 2009; Buffart et al., 2009; Rimmer et al., 2004; Rimmer et al., 2005; Temple, 2007). Moreover, buy-in from CPRs was evident and suggests high community engagement towards improving the health of AWDs in our community. Community engagement has been shown to reduce health disparities among disadvantaged populations, such as AWD (O'Mara-Eves et al., 2015; Wallerstein & Duran, 2006) and is an important outcome from this study.

We designed our needs assessment to first focus on community partners, but our stakeholders stressed the need to simultaneously empower AWD participants. Rimmer and Rowland's (2008) dyad model illustrates how "creating enabling environments" and "empowering individuals" jointly support the adoption of healthy lifestyles among AWD. One of Fit-Pals' AWD participants stepped forward as a leader in our stakeholder workshop. His voice became valuable in the evaluation and development process, attending and presenting

our needs assessment outcomes at the Association of University Centers on Disability annual conference as a self-advocate (Ross et al., 2019). Moving forward, we recommend including self-advocates as decision makers at all stages of program development, implementation, and evaluation.

Lessons Learned and Implications

Several outcomes and lessons learned from our needs assessment can inform others' efforts towards building partnerships for inclusive community-based fitness. First, communication with stakeholders, and a shared investment in the mission, is critical. Fit-Pals' programmatic growth depended on our capacity to talk with our stakeholders. It was a Fit-Pals' board member, and parent of an AWD participant, who first raised concern that Fit-Pals lacked community integration. Then, it was "champions" at each Fit-Pals' partnership facility that fueled program growth and opportunities for inclusive programming. These champions raised concerns about communication that may have hindered Fit-Pals' effectiveness. We found that our open and repeated dialogue during the needs assessment (survey, interview, stakeholder workshop) increased CRPs willingness to collaborate and learn about sustainable programming for AWD.

We also learned that our stakeholders shared a value for inclusion, but voiced uncertainty around how to put that into

action. This sentiment is echoed in research, where developing a concrete action plan focused on physical, financial, and societal barriers to an inclusive environment is a recognized step to building organizations' capacity for effective inclusion (Riley et al., 2008; Stinson et al., 2020). This needs assessment allowed our team to connect with our stakeholders by providing them a voice in the reconstruction of the Fit-Pals' program. Their voice not only improved their investment in the program and in inclusion, but also allowed us to understand and adapt the program to their true needs. The buy-in from CPRs was instrumental in executing Fit-Pals' action plan from Step 3. We recommend elevating the voices of stakeholders in planning through stakeholder or advisory board meetings.

The community organizations that participated in our needs assessment perceived their partnership with Fit-Pals as adding to their organizations' communities and as having a positive impact on the well-being of AWD participants. These positive attitudes, however, did not always translate into effective practice within partner organizations. This is consistent with prior research wherein fitness centers low in physical and social accessibility compliance often self-identified as "accessible" (Arbour-Nicitopoulos & Ginis, 2011). In other words, there is a disconnect between an organizations' intension to be inclusive and accessible, and the impact on AWD experiences. The CPRs supported inclusion in their organizations; however, they communicated that they

innately deferred the responsibility of inclusive programming to Fit-Pals and the volunteers. We learned that they interpreted their organization's role as the "host" for Fit-Pals' programming and participants. The stakeholder meeting was an important first step to fostering a shared ownership of inclusion and inclusive fitness programming. Future research needs to identify ways to support full adoption of inclusion in community fitness programs. The field would also benefit from interventions that teach and support community fitness centers in incorporating inclusive practice in their existing and new programming, as opposed to only offering segregated programs or only viewing inclusion as the responsibility of outside organizations.

Limitations

The interpretation of our needs assessment was considered with potential limitations in mind. First, there is risk of social desirability bias because CPRs were recruited based on preexisting partnerships and professional relationships with the first author as program coordinator. CPRs may have expressed positive perspectives in an effort to protect the existing partnership or program reputation. Second, Fit-pals staffs' dual role of participant-researchers lends potential for confirmation bias, wherein we self-identified positive perspectives on the partnership to affirm our program decisions. Several triangulation methods were used to improve

the trustworthiness of our data interpretation, including iterative discussions with Fit-Pals' staff and volunteers to contextualize CPRs shared perspectives, member checking, and inviting feedback at the stakeholder meeting. Notably, CPRs participating in this study represented varying levels of organizational leadership, including program directors, activity class instructors, and business owners, ensuring that multi-perspectives were considered in identifying partnership needs and priority growth areas.

Conclusion

By detailing our three-step evaluation process, we hope our needs assessments can serve as a model for other organizations looking to examine their current community partnerships. Our needs assessment, guided by Riley et al. (2008), (1) assessed inclusion in partner community programs and their perceptions of Fit-Pals' role, (2) followed up with stakeholders to ensure results were interpreted correctly and the most important themes were identified, and (3) designed and implemented actions steps for program improvement. Utilizing this model allowed researchers to pinpoint specific opportunities to increase or add programmatic support. Stakeholder buy-in remains critical to the success of our community partnerships moving forward. Similarly buy-in from community partners allowed them to start viewing their organization as the one responsible for implementing inclusive

practices. Fit-Pals has planned ongoing assessments to continue monitoring community partner needs and plans to adjust program supports as needed.

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TESTING A WELLNESS INDICATORS MEASURE FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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Abstract

Background and Purpose

People with intellectual and developmental disabilities (IDD) often have health and wellness issues that are not as good as people without disabilities. States are required to monitor health and wellness for people with IDD who use many disability services. However, there are few ways to monitor wellness between states or at different points in time. In this study, we share a new model that states may use to monitor wellness of people with IDD.

Methods

We used data from a survey called the National Core Indicators (NCI) to develop this model. First, we developed the model using our state's data. Then, after we found a model that worked well, we tested that model using the National Core Indicators from the entire U.S.

Results

Our final model worked well in both our state NCI

data and the national NCI data. This is important because policies at both levels can affect the services that people with disabilities can use. Our model had three parts: heart health, mental health, and behavioral wellness. These are described more in the paper. We also used statistics to test some factors that might predict outcomes related to heart health, mental health, and behavioral wellness. Age, sex, where someone lives, and level of intellectual disability were all good predictors of all three categories of wellness that we studied.

Implications

The model of wellness that we developed worked well but should be tested using data from other individual states. It is very important to know about health and wellness right now since the services people with disabilities can use are changing in many states. We think our model can help planners and advocates understand how services affect wellness in a way that is easy to compare from state to state and at different points in time.

Plain Language Summary

Background and Purpose

People with intellectual and developmental disabilities (IDD) often health and wellness that are not as good as people without disabilities. In this study, we share a new model that states may use to monitor wellness of people with IDD.

Methods

We used data from a survey called the National Core Indicators (NCI) measure health and wellness. We tested this model in Virginia and in the entire United States.

Results

Our final model worked well in both our state NCI data and the national NCI data. This is important because policies at both levels can affect the services that people with disabilities can use. Our model had three parts: heart health, mental health, and behavioral wellness.

Implications

> The model of wellness that we developed worked
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> advocates understand how services affect wellness in
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The health challenges of people with intellectual and developmental disabilities (IDD) have been a focus of international attention since the early 2000s (Krahn & Fox, 2014). In 2012, two national IDD groups, The Arc and the American Association on Intellectual and Developmental Disabilities (AAIDD), produced a joint policy statement highlighting the need for policy and practice changes to address health care access and health disparities among individuals with IDD (AAIDD, 2012). As community living has replaced institutions for people with IDD, the need for community-based healthcare has increased, as has the need to monitor access to quality healthcare (Krahn et al., 2009; Krahn & Fox, 2014).

Despite the increased attention on health outcomes for people with IDD in recent years, there have been few attempts to measure wellness for people with IDD in a way that enables monitoring of system performance across time or across service systems, which vary from state to state. The current study seeks to fill this need by proposing an empirical model for

measuring wellness, which was developed from National Core Indicators-In Person Survey (NCI-IPS) data at the national level and in one pilot state.

Measuring Health and Wellness Outcomes

There have been a number of attempts to measure health status and outcomes specifically for people with IDD, including the NCI-IPS and the Personal Outcome Measures (POM) from the Council on Quality and Leadership. The NCI-IPS includes objective measures of health (utilization of preventive and primary care) as well as a subjective measure (self-reported health status). The POM also incorporates subjective ratings of health, utilization of services, organizational supports, and health behaviors (Friedman et al., 2019). Aggregated data from the POM has been used as a measure of provider quality, while NCI-IPS data are typically used to monitor outcomes at the level of the state IDD system.

One commonly used way to track system performance at the state level is the NCI-IPS, which is widely used across states. Previous research using the NCI-IPS has highlighted IDD system performance on objective measures of health such as body mass index (Stancliffe et al., 2011), meeting physical activity recommendations (Stancliffe & Anderson, 2017), and accessing preventative care (Bershadsky et al, 2014).

Prior literature has identified a number of challenges to

measuring state IDD system performance related to the health and wellness of people with IDD. Though we have known for some time that people with IDD experience inequitable access to services, including preventative and health promotion services (Krahn et al., 2006; Whittle et al., 2018), there has been less consensus on how to track and measure health-related outcomes systematically across states or within states over time. This may be, in part, due to the absence of high-quality, merged datasets that enable such tracking, while also accounting adequately for service costs (Bonardi et al., 2019; Dinora et al., 2020). Ecological challenges of using measures developed based on national data in individual state contexts (and vice versa) have also contributed to challenges in measuring health outcomes for people with IDD across states (Cheng et al., 2020). Additionally, use of population-based data to study health outcomes for people with IDD can be constrained by differing definitions of disability in different surveys and difficulty identifying people specifically with IDD in population-based study samples (Havercamp et al., 2019).

Physical Health

It is well established that people with IDD experience poorer physical health outcomes than people without disabilities (e.g., Anderson et al., 2013; Krahn et al., 2006; Reichard et al., 2011). Higher rates of co-occurring conditions, vulnerability to health risk behaviors, and lack of access to preventative

healthcare and health promotion services contribute to shorter life expectancies and higher rates of mortality for manageable and preventable conditions (Krahn et al., 2006).

Rates of chronic conditions among people with IDD vary by study because of differing samples, methods of gathering data, and the type of data collected (Haveman, et al., 2010), but are generally reported to be equivalent to or higher than rates in the general population (Dixon-Ibarra & Horner-Johnson, 2014; Erikson et al., 2016; Haveman, et al, 2010). Analysis of the National Health Interview Survey (NHIS) from 2002 to 2011 found that adults with IDD were significantly more likely to experience diabetes, cardiovascular conditions, and respiratory conditions compared to adults without IDD (Fujiara, et al., 2018). Analysis of Medicaid claims found that 73% of beneficiaries with IDD had at least one chronic condition (Reichard et al., 2019). Compared to beneficiaries without disabilities, those with IDD had higher rates of diabetes, chronic kidney disease, chronic obstructive pulmonary disease (COPD) and cardiovascular disease (Reichard et al., 2019).

Mental Health

People with IDD often have high rates of mental health diagnoses, stress, and inadequate emotional support (Esler et al., 2019; Havercamp & Scott, 2015; Krahn et al, 2006; Scott & Havercamp, 2014). A recent analysis of NCI-IPS data found

that 44.8% of respondents had at least one co-occurring psychiatric diagnosis and 53.5% were taking at least one psychotropic medication (Esler et al., 2019). Specifically, 22.9% of respondents had a mood disorder, 14.3% had an anxiety disorder, 9.8% had a psychotic disorder, and 6.1% had a different mental health diagnosis (Esler et al., 2019). These categories were not mutually exclusive, and 16.4% of respondents had two or more mental health diagnoses (Esler et al., 2019). The exact prevalence rate of co-occurring mental health diagnoses in people with IDD varies by study. For example, Reichard et al. (2019) found that 59% of Medicare beneficiaries with IDD had at least one mental health diagnosis, while Scott and Havercamp (2014) reported a prevalence rate of 36.6%.

Accurate diagnosis and effective treatment of mental health conditions may be complicated by communication challenges, atypical presentations of mental illness, and lack of access to providers with knowledge of IDD (Krahn et al., 2006). A study in Massachusetts found people with IDD were more likely than the general population to utilize the emergency department for mood and anxiety disorders, suggesting that the treatment available in the community is inadequate or inaccessible (Lauer et al., 2019). Additionally, while adequate emotional support is associated with significantly lower rates of mental health diagnoses (Scott & Havercamp, 2014), 30% of respondents to the NCI-IPS reported inadequate emotional support (Havercamp & Scott, 2015).

Behavioral Challenges

Research suggests that challenging behavior is distinct from mental health in people with IDD (McCarthy et al., 2010). Some researchers (Painter et al., 2018) have suggested that behavior may be an atypical presentation of mental illness, particularly for individuals with more significant disabilities. Other authors (Bowring et al., 2019; Davies & Oliver, 2014) have found mixed evidence for correlations between mental health and behavioral challenges and concluded that the two concepts have a complex relationship that is not yet well understood. Scott and Havercamp (2014) found that 45% of NCI-IPS respondents needed support for challenging behavior. A more recent analysis of NCI-IPS data found that 23.2% of respondents specifically needed support for self-injurious behavior (SIB) and that support for SIB is significantly associated with needing support for disruptive or destructive behavior (Bradley et al., 2018). Challenging behaviors are associated with lower levels of social support, friendship, community participation, satisfaction, choice, rights, and employment for people with IDD (Bradley et al., 2018; Scott & Havercamp, 2014). Psychotropic medications are frequently used to treat nonspecific challenging behaviors, without a formal diagnosis or behavior plan (Bradley et al., 2018; Esler et al., 2019; Krahn et al., 2006).

Study Objectives

The aim of this study was twofold: (a) to confirm a three-factor (cardiovascular, mental health, behavioral health) model of wellness in a large national random sample of people with IDD who use state-funded services, and (b) to explore the relationship among wellness indicators and socio-demographic characteristics.

Method

The methods summarized in the following sections were reviewed and approved by the Institutional Review Board at the authors' affiliated university.

Design and Procedure

Development of the Wellness Indicators model emerged out of initial work with state-level NCI-IPS data as part of a larger study to investigate relationships between Medicaid service expenditures and outcomes for people with IDD in Virginia. For an accounting of the results of the state-level analysis, readers may refer to the authors' open science website (Bogenschutz et al., 2021). The authors wished to design a method that could provide a more nuanced way for state IDD systems to measure wellness than had been developed previously from the IPS and found good fit with this present

model, based on Virginia's data. Subsequently, the researchers obtained the 2017-2018 NCI-IPS national dataset from its owners and tested the model against that national sample to assess fit.

Overview of State Study

Since measuring outcomes for people with IDD is often challenged by ecological issues (outcome models derived from national data often have poor statistical fit with a particular state's data and vice versa), we wanted to create a model of wellness outcomes that would be statistically suitable for use in both national and Virginia contexts. To do this, we first decided to use our state's NCI-IPS data to develop and test a model of wellness outcomes.

Initially, the wellness indicators were developed using the Virginia NCI-IPS data via an iterative item-selection process that accounted for the ordinal and/or categorical nature of the NCI-IPS scale items used. We started with all relevant items included and a single latent wellness factor. We then eliminated items based on low factor loadings (< .40 in standardized units) and subsequently grouped items into two and then three latent factors (cardiovascular health, mental health, and behavioral wellness), which was the solution we found that demonstrated the strongest model fit and parsimony. A full accounting of this process may be found

on our project's Open Science Framework website, which includes full output and code (Bogenschutz et al., 2021).

Data Source

Data for this study came from the NCI-IPS, a collaboration of participating states, the Human Service Research Institute, and the National Association of State Directors of Developmental Disabilities Services. NCI-IPS is a voluntary effort by public IDD agencies to measure and track their own performance; thus, the overall goal of the NCI-IPS project is to track state system-level performance, not necessarily to account for individual-level outcomes. A central component of NCI is the In-Person Survey (IPS; formerly known as the Adult Consumer Survey). The NCI-IPS is a nationally validated instrument administered face-to-face by trained interviewers to adults (18 years and older) who use at least one public IDD service (in addition to case management). The IPS gathers information about an individual's general demographics, physical and behavioral health, and a range of personal outcomes. NCI-IPS results from the background section of the 2017-2018 survey were the basis for the analyses in this study. The background section of the IPS is completed using administrative records supplemented by information from the person's case manager. The specific wording of questions that were used as the basis for our analyses may be found on the project's OSF website (Bogenschutz et al., 2021).

Though not used in this study, the NCI-IPS also has two sections that are administered face-to-face with participants with IDD. Section I requires responses directly from the person with IDD and includes questions in a number of subjective domains, such as service satisfaction, safety, friendships, rights, home living, and employment choices. Section II may be answered by the person with IDD or by their proxy if needed. This section contains questions that may be answered objectively, including items about topics such as community inclusion, rights, choices, and service access.

Variables

The Wellness model was constructed from three clusters of NCI-IPS variables, all of which came from the background section of the NCI-IPS dataset from 2017-2018. The background section is completed using administrative records prior to administration of the IPS and is typically completed by a case manager. These variable clusters were selected because, based on face validity, they are indicators of basic wellness that are available in the NCI-IPS and were initially developed as factors for our model via a pilot using one state's IPS data (Bogenschutz et al. 2021). Initially, we tested the feasibility of other variables as potential wellness indicators but found them to have poor fit with the state's data; thus, they were removed from the final model.

Mental Health

Four variables were selected for inclusion in the mental health factor: (1) presence of mood disorder (e.g., depression, bipolar disorder, etc.), (2) presence of an anxiety disorder (e.g., obsessive disorders, panic disorders, etc.), (3) presence of a psychotic disorder (e.g., schizophrenia, etc.), and (4) presence of another mental illness or psychiatric diagnosis.

Cardiovascular Health

Similar to the mental health variables, the cardiovascular health indicators represented presence or absence of particular health conditions in the background section of the IPS. The variables that we used were: (a) presence of cardiovascular disease (e.g., coronary heart disease, angina), (b) presence of diabetes, including Type 1 and Type 2, (c) presence of high blood pressure, and (d) presence of high cholesterol.

Behavioral Wellness

Finally, a cluster of variables was used to indicate an individual's behavioral wellness and support needs. There were six variables in this subscale: (1) noted behavioral challenges (e.g., aggression, self-injurious behaviors, pica, etc.); (2) whether the person has been prescribed medication for a behavior modification purpose (e.g., stimulant, sedative, or beta-blocker to treat ADHD, aggression, self-injurious

behavior, etc.); (3) whether the individual has a current behavior plan; (4) support needs for self-injurious behavior; (5) support needs for disruptive behavior; and (6) support needs for destructive behavior. All of these variables could be addressed through the NCI-IPS background section.

Sample

In 2017-2018, a total of 25,671 people with IDD took part in the NCI-IPS, including the background section. Adults with IDD from 35 states and the District of Columbia were represented in the 2017-2018 dataset. Participating states were asked to establish a random sample that would reach a threshold of 95% confidence level and 5% margin of error which, for most states, was at least 400 individuals. Sample sizes varied from 331 (VT, WY) to 8,279 (CA). Sampling methodologies varied slightly from state to state. For example, some states used a stratified random sampling method. All states included a random sample of adults with IDD who used at least one state-funded service in addition to case management.

The mean age of respondents in the 2017-2018 national survey was 42 years and the sample was 59% male. The racial composition of the sample was predominantly White (67%) with respondents identifying as African American (16%) and Latinx (10%) also comprising a notable portion of the sample.

In Virginia, sample demographics largely mirrored the national trends, based on a 2017-2018 sample size of 809.

Analysis

Data analysis for our national study included three phases, all using Mplus Version 7.11 (Muthén & Muthén, 2017). First, confirmatory factor analysis (CFA) was used to test the relative fit of a series of competing factor models of wellness. Consistent with recommended approaches for validating CFA models (e.g., Brown, 2014; Kline, 2015), we tested our preferred, three-factor model that emerged from our state-level model building (as described above) to a one-factor model that constituted a plausible alternative factor structure. We also tested several alternatives to obtain the best-fitting model for the pattern of item loadings on each factor, again in accord with methodological guidance (Brown, 2014; Kline, 2015), to obtain the model with the best balance of fit and parsimony. Data analysis was conducted using Mplus Version 7.11 (Muthén & Muthén, 2017) with the mean- and variance-adjusted weighted least squares estimator (WLSMV) for all models. This estimator allows for the use of robust standard errors to account for possible violations of the multivariate normality assumption common to most structural equation modeling (SEM) models. To explore missing data patterns, Little's (1988) test was used to determine whether the data could be assumed missing completely at random (MCAR).

The results of this test suggested that the data could not be treated as MCAR, thus requiring estimation procedures that are more robust to missing data. Overall, rates of missingness were quite low for most survey questions, with results reported for more than 90% of individuals for all items used. The lowest response rate was 92.9%, for the item pertaining to high cholesterol. To address any potential bias because of missing data, we compared the results generated by our preferred WLSMV estimator to a model that used full information maximum likelihood (FIML) via the MLR estimator in Mplus. Our results did not differ significantly in terms of magnitude or statistical significance regardless of the choice of estimator.

Assessing Model Fit and Parsimony

The mean- and variance-adjusted weighted least squares estimator (WLSMV in MPlus) and Satorra and Bentler (2001) scaled chi-square (S-B χ^2) were used to examine model fit for all CFA models. In addition to the S-B χ^2, we also used the comparative fit index (CFI), standardized root-mean-square residual (SRMR), and root-mean-square error of approximation (RMSEA) with a 90% confidence interval to assess model fit. We adopted Hu and Bentler's (1999) guidelines for assessing acceptable model fit, which include CFI $\geq$ .95, SRMR $\leq$ .08, and RMSEA $\leq$ .06.

Results

Developing the Wellness Model: Descriptives and Correlations

Table 1 reports descriptive statistics and cross tabulations for each of the variables used in our analysis. Table 2 presents item-level polychoric correlations between all items used in this study. Polychoric correlation was used in order to determine the strength of association between the variables because all variables were ordinal in nature with two or more categories (Jöreskog, 1994; Olsson, 1979). This approach is especially preferred when conducting CFA with ordinal variables composed of less than five categories (Rhemtulla et al., 2012), which is often the case when working with NCI data.

Table 1 Descriptive Characteristics of the Analytic Sample

Variable	Category	%	*n*
Cardiovascular disease	1	93	22,609
	2	7	1,749
Diabetes	1	88	21,653
	2	12	2,866
High blood pressure	1	78	18,922
	2	22	5,338
High cholesterol	1	81	19,189
	2	19	4,476
Mood disorder	1	68	16,577
	2	32	7,740
Anxiety disorder	1	71	17,229
	2	29	7,028
Psychotic disorder	1	69	16,782
	2	31	7,400
Other mental illness	1	90	21,417
	2	10	2,427
Behavioral challenges	1	88	21,482
	2	12	2,801
Behavior medication	1	78	18,472

Variable	Category	%	*n*
	2	22	5,281
Behavior plan	1	72	17,588
	2	28	6,737
Self-injurious behavior	1	79	19,755
	2	17	4,206
	3	4	1,105
Disruptive behavior	1	59	14,215
	2	31	7,426
	3	10	2,489
Destructive behavior	1	72	17,413
	2	22	5,263
	3	6	1,373

N = 25,667.

Items included in this work were initially selected from the NCI-IPS primarily based on their face validity. As demonstrated in Table 2, the items for this analysis had several distinct patterns of association, with a number of individual correlations in the .30 – .70 range. Moving from left to right in Table 2, the first four items (Cardiovascular Disease to High Blood Pressure) compose our hypothetical Cardiovascular Health construct, the next four items represent Mental

Health, and the last six items represent our Behavioral Wellness construct. Within each of these clusters, higher correlations are observed, suggesting that the items may fit well into three separate but related constructs. Overall, no items demonstrated universally weak correlations below .10, and no items demonstrated universally large correlations above .80 that may hinder the detection of distinct and interpretable factors.

Table 2 Polychoric Correlations Among Variables

Variable	1	2	3	4	5	6	7	8
1. Cardiovascular disease	—							
2. Diabetes	0.25	—						
3. High blood pressure	0.37	0.53	—					
4. High cholesterol	0.32	0.51	0.62	—				
5. Mood disorder	0.10	0.18	0.16	0.20	—			
6. Anxiety disorder	0.09	0.09	0.07	0.11	0.58	—		
7. Psychotic disorder	0.01	0.02	-0.03	0.02	0.47	0.46	—	

Variable	1	2	3	4	5	6	7	8
8. Other mental illness	0.10	0.10	0.09	0.11	0.44	0.27	0.45	—
9. Behavioral challenges	0.10	0.16	0.20	0.20	0.45	0.34	0.39	0.44
10. Behavior medication	-0.02	0.01	-0.01	<.01	0.44	0.38	0.73	0.43
11. Behavior plan	0.02	0.04	0.01	0.04	0.41	0.34	0.70	0.30
12. Self-injurious behavior	-0.04	-0.03	-0.09	-0.07	0.28	0.30	0.71	0.28
13. Disruptive behavior	0.01	0.01	-0.03	0.01	0.38	0.36	0.70	0.31
14. Destructive behavior	-0.02	0.02	-0.05	-0.02	0.38	0.33	0.72	0.34

Investigating Alternative Factor Structures

Having examined the polychoric correlation matrix and found it conducive to factor analysis, we then used CFA to investigate the factor structure of the selected items. The initial working hypothesis was that the items would best be represented by three latent factors, Cardiovascular Health, Mental Health, and Behavioral Wellness, as had been confirmed in our state-level IPS analysis (described above). To confirm this, we first tested a model that included all items in one latent factor (a plausible rival hypothesis), then tested our preferred three-factor model. For each class of model, we compared a tau-equivalent model with a congeneric model in order to represent the underlying item loading patterns most accurately.

Four separate CFA models were tested. Model fit and parsimony statistics are available in Table 3. Model 4, the three-factor model with congeneric item loadings, demonstrated the best model fit and parsimony according to the guidelines suggested by Hu and Bentler (1999). In contrast, the one-factor model with tau-equivalent items demonstrated the worst fit and parsimony. Chi-square difference tests were significant for the comparisons between models 1 and 2, 2 and 3, and 3 and 4, respectively (all $ps < .001$). Therefore, the three-factor model with congeneric items appears to be the most accurate representation of the underlying constructs among

the models we examined. This model also demonstrated excellent model fit and parsimony, with CFI, TLI, and RMSEA values all within the accepted thresholds for strong model fit. A path diagram representing model 4, the best-fitting model that was tested, can be found in Figure 1.

Table 3 Model Fit and Parsimony Statistics for Competing Models of

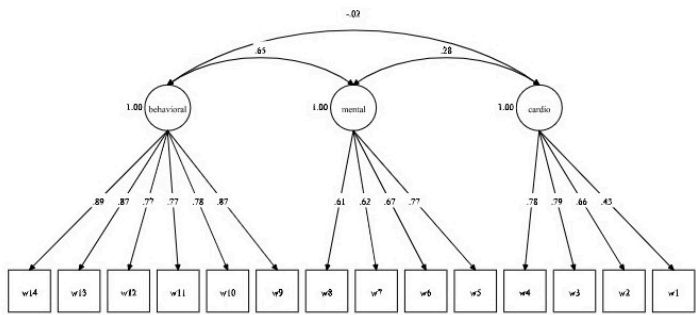| Model #	Model description	S-B χ2	df	p	CFI	TLI	RMSEA	90% LB
1	1 Factor model w/ tau equivalent items	49747.66	90	< .001	0.69	0.69	0.15	0.15
2	1 Factor model w/ congeneric items	19938.15	77	< .001	0.88	0.85	0.10	0.10
3	3 Factor model w/ tau equivalent items	4026.88	85	< .001	0.98	0.97	0.04	0.04
4	3 Factor model w/ congeneric items	2176.65	74	< .001	0.99	0.98	0.03	0.03

$N = 25,667$ for all models.

Figure 1 Wellness Confirmatory Factor Analysis for National
Data

Note. Items are numbered in the order they are presented in
Table 2. All indicated correlations and path coefficients are
significant (p < .05) except for the correlation between cardio
and behavioral health difficulty (p = .13). Estimates are
presented as standardized coefficients. S-B $\Diamond\Diamond$2 (74) =
2176.64, p < .001; RMSEA = .033, 90% CI [.032, .035]; CFI
= .99; TLI = .98; WRMR = 4.27. N = 25,477.

Testing the Wellness Model: Factor Correlations and Regressions

Factor Correlations

Correlations among the three wellness factors are shown in
Table 4. All factors were significantly and positively correlated,
however the relationships between latent factors varied in
strength. The correlation between mental health difficulty and
cardio health difficulty was small to medium in size using

Cohen's (1988) guidelines, while the correlations between mental health difficulty and behavioral health difficulty, and behavioral health difficulty and cardio health difficulty, were large in size.

Table 4 Correlations Among Latent Measures of Wellness, National Data

Measure	1	2	3
1. Mental health difficulty	1	—	—
2. Cardio health difficulty	0.295***	1	—
3. Behavioral health difficulty	0.745***	0.677***	1

N = 20,398.***p <.001.

Personal Characteristics and Residential Contexts

We included basic personal characteristics (age, gender, severity of intellectual disability) and place of residence, as predictors of wellness in one multivariate structural equation model (SEM) that included all three wellness factors as outcomes. Complete results are displayed in Table 5.

Table 5 Estimates for Wellness Regression Mod

Variable	Mental health difficulty model				Cardio health difficulty model			
	B	SE	z	p	B	SE	z	p
Group 4-6	-0.171	0.033	-5.139	<.001	-0.189	0.034	-5.519	<.001
Group 7-15	-0.161	0.057	-2.797	0.005	-0.103	0.055	-1.88	0.060
Live w/ Fam.	-0.995	0.031	-31.955	<.001	-0.157	0.033	-4.755	<.001
Live Ind.	-0.403	0.035	-11.619	<.001	0.093	0.035	2.67	0.008
Live w/ Host	-0.143	0.046	-3.082	0.002	-0.013	0.049	-0.253	0.800
Age	-0.003	0.001	-5.108	<.001	0.033	0.001	55.12	<.001
Female	0.099	0.019	5.22	<.001	-0.091	0.019	-4.786	<.001
ID Level 2	-0.069	0.022	-3.158	0.002	-0.144	0.022	-6.523	<.001
ID Level 3	-0.153	0.029	-5.207	<.001	-0.330	0.03	-11.106	<.001
ID Level 4	-0.506	0.037	-13.763	<.001	-0.516	0.036	-14.255	<.001

Note. Group 2_3 is reference category for residence. Male is
the reference category for gender. ID(1) is the reference
category for Level of ID. All coefficients are standardized and
interpreted in terms of standard deviation units. Fit statistics

for combined model: S-B Chi Squared = 3173.452, df = 195, CFI = .97; TLI = .96; RMSEA = .027 (90% CI [.027, .028]).N = 20,398.

Gender

Participants' genders significantly predicted all three wellness factors. Women were associated with lower levels of cardio and behavioral difficulty and higher levels of mental health difficulty. All three of these estimates were fairly small in magnitude, with approximately .10 standard deviations difference between women and men.

Age

Most participants in the national sample ranged in age from 26 to 58 years. The youngest participants were 18 years old and the oldest was 95 years old. The SEM model found age to significantly predict all wellness factors. Older participants were associated with lower levels of mental health difficulty and behavioral difficulty but higher levels of cardio health difficulty. All three of these estimates were small in magnitude, ranging from -.003 to .033 in standard deviation units for each 1-year increase in participant age.

Level of Intellectual Disability

Disability status was associated with all three wellness outcomes. With each level of intellectual disability going from

mild (ID level 1, the reference) to profound (ID level 4), mental health difficulty and cardio health difficulty decreased pointedly. Participants with moderate, severe, or profound ID were predicted to have more behavioral challenges and support needs than people with mild ID. The magnitude of these differences increased consistently from ID levels 2 to 4 for mental health and cardio health difficulty. For behavioral difficulty, moderate ID (ID level 2) was associated with the highest levels of behavioral difficulty.

Type of Residence

Residence type was found to be a relatively consistent predictor of wellness outcomes as well. Compared to those living in 2-3 bed group homes (the reference category), those living in all other settings were found to have lower levels of mental health difficulty. Further, those living in 2-3 bed group homes had higher levels of cardio difficulty compared to participants living in 4-6 bed group homes and those living with families. Participants living independently had higher levels of cardio difficulty than those living in 2-3 bed group homes. Finally, those living in 2-3 bed group homes had higher levels of behavioral difficulty compared to participants living in 7-15 bed group homes and those living with families, independently, or in sponsored residential housing.

Discussion

Extant literature suggests a longstanding pattern of poor wellness outcomes for people with IDD relative to the general U.S. population (Anderson et al., 2012; Krahn et al., 2006), yet researchers and policymakers have not previously developed a sound way to track wellness outcomes across state systems. This study developed and tested a novel three-factor model for understanding wellness for people with IDD who use Home and Community-Based Services (HCBS) waivers. The model's development was significant in that state-level data were used to develop the model, which was then tested using the national NCI-IPS dataset, with results showing strong fit properties in both the state and national analyses. This procedure is significant, not only because it is among the first efforts to systematically measure wellness using the IPS, but also because most measures that have been developed using the IPS have relied exclusively on either state or national data, but not both. Since both state systems and federal policy help shape the lives of people with IDD, it is critical that we consider how to measure system-based outcomes at both levels.

In 2016, about 20% of the 7.37 million people with IDD used state services to support their health and community living, accounting for over 1.4 million people nationwide (Larson et al., 2018). Many of the services and supports provided through state systems are funded via Medicaid programs, including HCBS. The Centers for Medicare and

Medicaid Services (CMS) requires the ongoing monitoring of wellness outcomes for people with IDD who use HCBS and other Medicaid-funded programs (CMS, n.d.). In order to meet this mandate, it is vital to have sound tools for measuring wellness at the system level. This study is among the first attempts to develop such a model that may be used to track wellness outcomes across state systems and offers the potential to be a useful tool for states to use to gain insight into how their services support the physical, mental, and behavioral wellness of people with IDD.

Tracking wellness outcomes may be particularly important at this point in time since the way in which many states are providing health and wellness supports for Medicaid beneficiaries with IDD is shifting rapidly. Notably, managed care approaches to Medicaid service management and provision are becoming more common and represent a major shift away from typical fee-for-service models of wellness service provision that have traditionally been offered to people with IDD. Having valid ways of measuring wellness will be essential for policymakers to monitor the effects of these changes and to help guide decision making about how their state systems support physical, mental, and behavioral wellness in the context of budgetary concerns. In this sense, using the wellness measures presented above may provide policymakers with a powerful new tool to use in quality assurance initiatives.

Future Directions and Limitations

While our model for measuring wellness outcomes using the NCI-IPS has strong properties based on national NCI-IPS data and the data of a representative state, it is important to note that state systems for supporting people with IDD vary. Thus, it is important to continue to test this model on individual state datasets before using it to track outcomes. While this study suggests that the model is likely to hold strong properties when applied in other state systems, checking suitability of the scale in other states and on additional sample cohorts is necessary, since sample characteristics may differ from state to state and from year to year.

Additionally, it is important to bear in mind that NCI-IPS samples are composed of people who use state-funded services, but that many people with IDD do not use any such services. We are unsure about how the model for measuring wellness that we have presented in this paper may or may not remain viable in samples of people with IDD who do not use state-funded services. Also, the variables we used to construct our model are all from the background section of the IPS, which is not based on self-response. Proxy reporting or data obtained from administrative records may have limitations, and self-reported health status may yield different results, especially for objective measures of health (Scott & Havercamp, 2019).

The wellness model is primarily intended to be used as a tool for tracking the performance of state IDD systems. In

order to optimize the utility of the model, in future research and evaluation applications, we recommend that it be used in conjunction with other factors that can help policymakers make data-driven decisions about their investments on behalf of people with IDD, including service usage profiles (including residential supports and employment supports, for instance), opportunities for personal decision making, and demographic factors. Additionally, variables in the NCI do not encompass all possible indicators of mental health, cardiovascular health, and behavioral wellness, so our model is consequently bounded in nature. Future research should include other sources of data, including subjective and self-reported measures of health.

Conclusion

Psychometrically sound measurement is fundamental to meeting CMS mandates for supporting the wellness of people with IDD who use HCBS and other state-funded Medicaid services. This article presented an empirically derived model for measuring physical, mental, and behavioral wellness for people with IDD, using the widely administered NCI-IPS. The resulting model may present states with an important new way to track wellness outcomes as part of their system-level quality assurance efforts, with the goal of understanding and addressing the relatively poor health outcomes that affect millions of people with IDD.

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TESTING THE EFFICACY OF LEADERSHIP FOR EMPOWERMENT AND ABUSE PREVENTION (LEAP), A HEALTHY RELATIONSHIP TRAINING INTERVENTION FOR PEOPLE WITH INTELLECTUAL DISABILITY

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a Healthy Relationship Training Intervention for People with Intellectual Disability. *Developmental Disabilities Network Journal, 2*(1), 19.

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Abstract

Leadership for Empowerment and Abuse Prevention (LEAP) is an abuse prevention intervention for people with intellectual disability. The purpose of this research was to evaluate the intervention's efficacy. Findings indicated no significant differences in scenario identification questions depicting acceptable or concerning situations. However, statistically significant improvements were noted in participants' depth of understanding, including their ability to correctly describe why a scenario was abusive or exploitative and what to do next when confronted with unhealthy situations. Limitations and implications for practice are discussed.

Plain Language Summary

LEAP is a training program for people to help them

have good relationships. We did research to see if LEAP helped people who came to training better tell the difference between good and bad relationships and what to do if they are in a bad relationship. We found that people did not get better at pointing out good and bad relationships, but they did get better at telling why a relationship was good or bad and what to do next if in a bad situation.

Background

The risk of abuse against people with disabilities, particularly people with intellectual disability (ID), has been well documented in the literature (Curtiss & Kammes, 2020; Harrell, 2012; K. Hughes et al., 2012). Abuse of people with ID often begins in childhood and continues throughout the lifespan (Catani & Sossalla, 2015). In a systematic review, Byrne (2018) cited abuse prevalence rates ranging from 14% to 32% for children and 7% to 34% for adults with ID.

Compared to people without disabilities and other disability groups, people with ID are at an increased risk of targeted violence and are more likely to experience abuse, neglect, and exploitation (Beadle-Brown et al., 2010; Office of Justice Programs, 2018; Smith et al., 2017). The majority of abuse perpetrators are known by and may be familiar to the person with ID and can include parents, intimate partners, extended family members, teachers, transportation drivers,

and paid service providers (Harrell, 2017; Stevens, 2012). Victims with disabilities do not always seek help, but when they do, they often face barriers including, inaccessible structures, programs, and service providers who are unequipped to work effectively with them and provide care (Malley, 2020; National Child Traumatic Stress Network [NCTSN], 2016). As a high-risk population that has been underserved in their communities, adults with ID would benefit from abuse prevention programming that is empirically validated and targeted to their specific needs (Bowen & Swift, 2019; Eastgate et al., 2011; Hickson & Khemka, 2016).

Evidence-Based Abuse Prevention Programs for People with Intellectual Disabilities

Over the past 15 years, there has been an increase in abuse prevention programs for people with ID with varying formats and types of evaluation. Systematic and scoping literature reviews of studies of abuse prevention programs for adults with ID show, however, that the majority of the programs focus on women with mild to moderate ID (Araten-Bergman & Bigby, 2020; Doughty & Kane, 2010; Lund, 2011; Mikton et al., 2014). Most programs are based on a theoretical framework, such as the social-ecological model, and incorporate skill development to increase participants' ability

to respond to abuse. These programs are characterized by verbal and textual learning methods and utilize cognitive, behavioral, or psychoeducational-based curricula. Many of the curricula address physical, sexual, and emotional abuse in addition to intimate partner, familial, and non-familial abuse. Most of the training sessions are held in person and led by trainers who do not identify as having a disability. Few programs involved people with disabilities, including those with ID, in their development. The literature generally lacks information on how programs are tailored to participants' needs. For example, how participants communicate, their support needs, and how curriculum components are adapted to the learning styles of participants. Additionally, participants' sociodemographics are largely missing except for ID category (mild, moderate, severe) and gender (Araten-Bergman & Bigby, 2020; Doughty & Kane, 2010; Lund, 2011; Mikton et al., 2014).

The evaluation designs in the literature cited above include satisfaction surveys, pre-post evaluations, and randomized control trials. The majority of the reviewed studies utilized a pre-post research design, and most did not include a qualitative component. Participant outcomes were typically assessed using self-reported questionnaires, and specific measures varied across studies. Most of the studies did not use a measure of incidents or frequency of abuse, and our review of previous studies indicated that only a few of the programs included implementation fidelity protocols (Hickson et al.,

2015; R. B. Hughes et al., 2020; Ward et al., 2012). Efforts to empirically validate abuse prevention programs for adults with ID pose difficulty because of the heterogeneity of the study population and challenges with the development of instrumentation and study processes that meet the comprehension needs of people with ID and allow for their full participation in research (Dryden et al., 2017; Kidney & McDonald, 2014). The small number of rigorously evaluated programs, along with the variation in outcomes measured across studies, has made it challenging to establish best practices in abuse prevention programming for this population (Araten-Bergman & Bigby, 2020; Doughty & Kane, 2010; Fisher et al., 2016; Mikton et al., 2014).

Within the body of literature on abuse prevention programs for people with ID, studies are lacking in several ways. Few programs are led or co-led by people with disabilities or include men. Also, little appears in the literature about program implementation fidelity or curricula that incorporate multimodal teaching strategies. Finally, many existing programs do not address varying support needs, especially within the context of research processes and instrumentation. To address some of the limitations of existing programs and research designs, and to best meet the needs of people with ID in our locale, the authors developed, implemented, and evaluated Leadership for Empowerment and Abuse Prevention (LEAP), an abuse prevention program for people with mild, moderate, and severe ID. LEAP utilizes multimodal

teaching and learning strategies, including adaptations for people who communicate through nonverbal means and is co-led by people with disabilities. The evaluation design incorporates video-based assessments to address the limitations of text-based questionnaires and includes an implementation fidelity process and measure.

Theoretical Framework for LEAP

This research aimed to test the efficacy of LEAP, an abuse prevention educational intervention for people with ID. The development of LEAP was informed by Social Cognitive Theory (SCT; Bandura, 1986, 1997). SCT describes how people acquire and maintain certain behavioral patterns and asserts that behavioral change depends on the interplay among the environment (i.e., the external world), people (i.e., beliefs, ideas, and feelings), and behavior (i.e., how people act). Figure 1 illustrates the SCT conceptual framework and its application to LEAP.
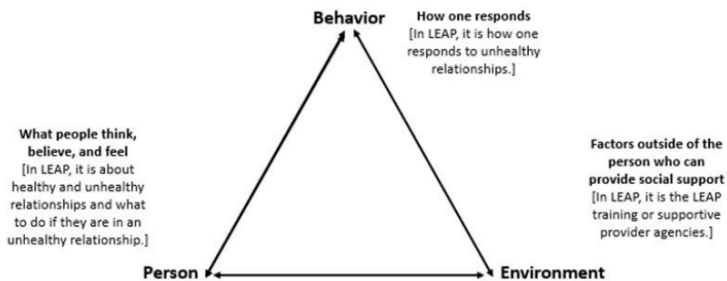

Figure 1 *LEAP Conceptual Framework*

According to SCT, people acquire skills and new behaviors by acting them out, being reinforced for their actions, and observing others. These direct and observed experiences influence behavior through expectations they create, including expectations about the ability to perform the behavior successfully and the consequences of the behavior (Bandura, 1986, 1997).

With SCT in mind, the LEAP intervention relies on vignette scenarios, role-playing, and group exercises for instruction. Participants learn by observing and discussing modeled behavior. LEAP is designed to strengthen participants' self-efficacy and self-confidence and is reinforced by a repeated empowerment statement.

The curriculum's theory of change (Figure 2) is focused on learning to differentiate between "healthy" and "unhealthy" relationships/situations, knowing how unhealthy relationships may lead to abuse, and how to respond when in an unhealthy relationship/situation. Accordingly, the curriculum targets a person's knowledge, feelings, and beliefs to influence behavioral outcomes.
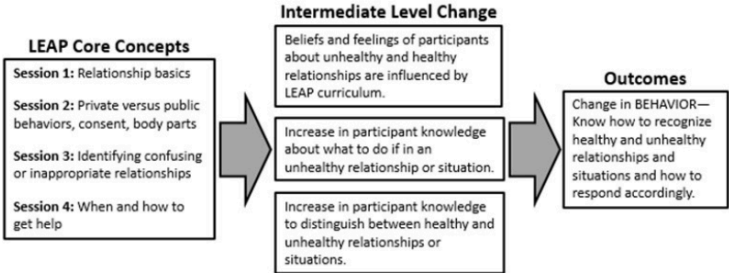

Figure 2 *LEAP Theory of Change*

LEAP Research Questions

Although awareness, prevention, and intervention programs have been developed to address the risks that people with ID face, there continues to be a need for quality research to demonstrate meaningful participant outcomes (Hughes et al., 2020; Mikton et al., 2014). Our research study addressed this gap by testing the efficacy of the LEAP healthy relationship intervention for people with ID. Research questions included the following.

1. Do LEAP participants increase their knowledge about healthy and unhealthy relationships after completion of the intervention?
2. Do LEAP participants better (a) distinguish between healthy and unhealthy relationships, (b) explain why they made their determination, and (c) identify a next step if the relationship is unhealthy after the completion of the intervention?

Method

All methods were reviewed and approved by the supporting university's Institutional Review Board.

Setting and Recruitment

This study used primarily quantitative methods to determine the effectiveness of the LEAP intervention using availability (purposive) sampling procedures. Research participants were recruited from 15 residential and community-based disability agencies providing day support and employment services to adults with ID in one Mid-Atlantic state. Participants in the study included adults diagnosed with ID who regularly attended the agency, were interested in participating in the LEAP intervention, and completed the consent process. Participating agencies agreed to provide space for the consent process, pretest and posttest, and four 90-minute weekly LEAP sessions. Eligibility for the LEAP study included the following criteria for participants: (1) must be between the ages 18-65 years; (2) identified as having an ID by a service provider, legal guardian, or family member; (3) ability to demonstrate an understanding of the study description and risks; and (4) ability to provide informed assent or consent. Consent and assent for research were secured from participants and legal guardians, as required.

Participants

All 109 LEAP participants were recruited from organizations and providers that specialized in serving people with ID. A representative from these organizations used administrative

records to report the personal characteristics of study participants. Sample characteristics, including age, gender, race, level of ID, guardianship, and residence type, are reported in Table 1.

Table 1

Demographics of LEAP Sample (N = 109)

Characteristic	*M*	*SD*	*N*	%
Age	34.3	13.5		
Gender				
Female			56	51.4
Male			52	47.7
Missing			1	0.9
Race				
African-American			32	45.7
Asian			3	2.8
Hispanic			1	0.9
White			31	44.3
Two or more races			5	4.6
Missing			3	2.8
Level of intellectual disability				
Mild			49	45
Moderate			33	30.3
Severe			3	2.8
Unspecified			24	22
Have guardian				
Yes			35	32.1

Characteristic	*M*	*SD*	*N*	%
No			74	67.9
Residence type				
Independent home or apt.			9	8.3
Parent or relative's home			57	52.3
Host/sponsored home			8	7.3
Agency 1-2 residents			2	1.8
Agency 3-6 residents			29	26.6
Agency 7-12			4	3.7

Participants' age ranged from 18 years to 65 years. Slightly more than half of the sample were women, and most were either African American (46%) or White (44%). Two-thirds of participants did not have legal guardians. More than half lived at home with a parent or relative, and 30% lived in a group home.

Several administrative records on program participants contained incomplete information. As a result, 22% of the sample had an unspecified level of ID. Most participants had a "mild" ID label, an additional 30% had a "moderate" label. Only three participants were described as having "severe" ID.

LEAP Intervention

The LEAP intervention is four sessions that are approximately 1½ hours each. The curriculum focuses on teaching key concepts of healthy relationships, a widely accepted primary intervention for abuse prevention (Centers for Disease Control and Prevention [CDC], 2018; Foshee et al., 2004; Ward et al., 2013; Wolfe et al., 2009). It was developed by a team of adults with disabilities, family members, disability support providers, and professionals from health, domestic violence, child advocacy, and social services.

LEAP provides introductory information and supports taking action to identify and avoid potentially unhealthy relationships. Each session reinforces the concepts taught in the previous session and reiterates an empowering statement, "I am strong. My feelings are important. I deserve to feel safe. I deserve respect." Table 2 outlines each LEAP training session and the key concepts discussed during the sessions. The multimodal curriculum uses different teaching strategies outlined in Universal Design for Learning, such as visual, auditory, kinesthetic, and tactile, along with behaviorally based instructional approaches including prompting, rehearsal, reinforcement, and role-plays (CAST, 2015; Parsons et al., 2012; Rapp, 2014). The LEAP intervention also reinforces ideas and concepts through consistent repetition, which has been shown to increase comprehension for people with ID (Archer & Hughes, 2010).

Table 2
LEAP Session Summaries

Sessions	Summary of session content
Session 1: Relationship basics	• What it means to deserve something, the meaning of respect, internal and external strength • The meaning of trust and how it relates to the relationships each person has/encounters – using a map to show levels of relationships • The different relationships in the participant's world – very good friends, trusted family members, friends, paid staff, acquaintances, strangers, love interests, and those who people no longer wish to have in their lives • Exploration of the question: "Are all staff your friends?"

Sessions	Summary of session content
Session 2: Private versus public behaviors, consent, body parts	• Reinforcement of the key concepts from session one • Characteristics of healthy, unhealthy, or confusing relationships • Correct names for private body parts and why it is necessary to use them • Rules surrounding consent and the meaning behind "saying yes, saying no, or saying nothing" • Experiential activities to model the complexities of consent and practice different ways to deny consent.
Session 3: Identifying confusing or inappropriate relationships	• Reinforcement of the key concepts from sessions one and two • The meaning of healthy, unhealthy, or confusing touch • Activities that allow participants to practice distinguishing between the different types of relationships and touch through example scenarios • Rules for healthy touch are explained

Sessions	Summary of session content
Session 4: When and how to get help	• Reinforcement of the key concepts from the three previous sections • How to get help if someone is in an unhealthy or confusing relationship • How to get help if someone is in immediate danger of abuse • Who to contact in confusing and unhealthy situations

A LEAP Implementation Manual (How-To Guide for Trainers) complemented the curriculum and established trainer preparation and fidelity protocols. The guide provided scripts, specific instructions for delivering the training, suggestions for participant engagement, and described the main points to emphasize in each session. The LEAP manual supported fidelity of implementation across 15 sites and 12 trainers. A unique feature of the LEAP program is a training approach that includes two trainers, one person who has a disability and one who does not. The peer trainer modality is designed to promote positive role models regarding healthy relationships and abuse prevention and answer questions based on lived experience.

As part of their preparation, trainers are instructed by

violence prevention experts on how to respond when participants reported that they are or have been victims of abuse. In the development of the curriculum and the training of trainers, it was essential to consult with experts to ensure that appropriate actions were taken in the event of a participant's disclosure of an abusive experience.

Measures

LEAP measures were focused on two areas: (1) developing protocols and monitoring tools to assess trainer fidelity of implementation and (2) evaluating participant outcomes.

Implementation Fidelity

The trainer fidelity of implementation protocol adapted a four-step process developed by Fixsen et al. (2005), which included: (1) identifying the critical components of LEAP; (2) identifying implementation steps and processes that trainers must follow when presenting the curriculum to participants; (3) developing an observational protocol that reflects these instructional steps and processes; and (4) testing and refining the protocol to examine feasibility, usability, and reliability across observers. This process resulted in an implementation fidelity checklist for each LEAP training session completed by a third-party observer trained in LEAP protocols. The checklists included items on room arrangement, time

management, co-trainers' use of required facilitation strategies, participant engagement, required content for each session, and a review of the main points of each module. Over four sessions, there were a total of 208 items in the fidelity checklists.

Video Vignette-Based Pre-Post Measures

Video vignette pre-post measures were developed using a research-based process (see Dinora et al., 2020; Martinez et al., 2014; Oremus et al., 2016; Stacey et al., 2014) and included a hypothetical story for the participants to evaluate. Vignettes were scripted based on the curriculum's core components (see Table 3) and reviewed by disability professionals, violence prevention experts, and a stakeholder advisor group of people with intellectual and physical disabilities. These reviewers considered content validity and sensitivity to uncomfortable subject matter. Three reviewers independently ranked each vignette on level of complexity, so a minimum of two straightforward, moderate, and complex items was included in the final instruments (Dinora et al., 2020).

Table 3
LEAP Video Vignetttes

Vignette storyline	Core concepts (Pre-Post)	Vignette complexity rating
Supervisor yells at an employee.	Trust, respect, boundaries	Easy
Assistant asks permission to help a person with counting money.	Difference between staff and friends, trust, respect, ask permission	Easy
Van driver sexually assaults person.	Trust, unhealthy touch, ask permission, respect	Medium
Friend betrays trust	Trust, respect, boundaries	Medium
Person is denied transportation to physical therapy as punishment.	Trust, respect	Hard
Staff respectfully supports a person putting away dishes.	Difference between staff and friends, respect	Hard

A set of six video vignettes were administered to participants before the first LEAP session (pretest) and immediately after the last session (posttest) to evaluate the comprehension of concepts presented in the four intervention sessions. All vignettes were administered using an iPad, and questions associated with the vignettes were read aloud to participants. Research assistants transcribed the participant responses.

Each assessment measure followed a general structure that included dichotomous *scenario identification* questions (e.g., yes that is right/no that is wrong; yes, it is ok/no, it is not ok). Correct answers were coded as "1" and incorrect responses as "0," and when summed across the six items, yielded total scores ranging from 0-6. Identification questions were followed by open-response *explanation* questions asking participants to describe why they made their response choice. Four of the explanation items were followed by open-ended *resolution* questions asking participants, "What would you do next?" The six explanation items and four resolution items were independently evaluated by three reviewers and rated as 0 "incorrect," 1 for "partial credit," and 2 for "full credit." Each explanation and resolution item yielded a total of 6 possible points. Within each time point, items were summed to create a total score. "Why" explanation response totals ranged from 0-36, and resolution response totals ranged from 0-24. Independent reviewers used a predefined codebook to evaluate participant responses. Codes were developed based on the core components of the LEAP training.

LEAP Research Implementation Process

As highlighted above, this study included two data collection time points: a pretest before the first session and a posttest after the fourth final session. Personal characteristics and demographic information were collected from participating ID provider agencies. Finally, a third-party observer completed

a trainer implementation fidelity checklist to monitor fidelity to the trainer implementation guidelines during each training session.

Data Analysis

Rater Agreement

At each time point, participant responses to six explanation items and four resolution items were coded by three raters. Fleiss' Kappa was used to measure the strength of agreement among ratings submitted by the three different raters. Kappa ranges from -1 to 1, and larger scores above 0 indicate stronger agreement between raters. Generally, a Kappa score of .80 is considered a threshold for acceptable agreement (Landis & Koch, 1977).

Non-Normal Distributions

To estimate the effects of the LEAP intervention, we analyzed change between pretest and posttest for scenario identification, explanation, and resolution items. Examination of data before analysis showed that the distribution of dependent variables had skewness and kurtosis that fell within acceptable ranges. However, Q-Q plots indicated that data might have had a non-normal distribution. Kolmogorov-Smirnov and Shapiro-Wilk tests were significant ($p < .05$) for identification, explanation, and resolution variables at pretest

and posttest, which further indicated that distributions significantly differed from distributions normal. Out of caution, nonparametric analyses were selected to show differences between pretest and posttest as well as between independent groups.

Testing Differences Between Pretest and Posttest

Wilcoxon Signed-Rank tests were used to examine differences in scores between pretest and posttest. The test was the nonparametric alternative to the paired-samples t test that ranks positive and negative score differences between time points. An approximation of the normal distribution is used to determine if systematic improvements were made during the intervention, and results were reported using the z statistic. Effect sizes were reported using r, which we interpret similarly to Cohen's d: 0.1 represents a small effect, 0.3 medium, and 0.5 or greater as a large effect (Cohen, 1988). Rather than using means and standard deviations, we reported dispersion using the median and interquartile range. It was expected that correct responses and strength of response explanations would increase significantly at each phase of the project.

Results

Identification scores were the sum of items correctly identified

as an abusive or exploitative scenario. Internal reliability for the six abuse identification items was poor at pretest (α = .15) and posttest (α = .45). The Wilcoxon signed-rank test showed that pretest and posttest identification scores (z = -1.69, p > .05) were not statistically different, although scores did improve marginally, medians and results of all Wilcoxon signed-rank tests can be found in Table 4. Overall, changes in response to the intervention were limited. However, results indicated that participants initially possessed moderate awareness of abusive or exploitative situations and that their identification skills can continue to improve, if even slightly, with additional preparation.

Table 4
Results of Wilcoxon Signed-Ranks Tests

Variable	N	Median			
		Pre	IQR	Post	IQR
Identification	95	4	4, 5	5	4, 6
Explanation	96	15.5	9, 24	21	14, 30
Resolution	107	12	5, 18	15	6,19

Note. IQR = Interquartile range.

LEAP participants followed vignette identification by explaining why a situation was or was not abusive/exploitative. Unlike identification items, which were either correct or incorrect, three reviewers rated the accuracy of participant

explanations. Fleiss' Kappa was .99 and .98 at pretest and posttest, respectively, indicating strong agreement between raters at all time points.

Explanation ratings were totaled and analyzed. Test results showed that posttest scores were greater than pretests ($z = -5.04$, $p < .001$), indicating that after the LEAP participants more accurately described why situations were abusive/exploitative. The effect of these results fell in the medium-to-large range.

After explaining their rationale for identifying situations as abusive/exploitative, participants were asked to state resolutions (i.e., actions) that could be taken to address problem situations actively. Again, three raters assessed responses and determined whether no credit, partial credit, or full credit should be given for each resolution offered by participants. Strong rater agreement was found for each time point, .97 and .98, respectively. Results of the Wilcoxon test indicated that participants got better at detailing resolutions to abusive/exploitative situations after the LEAP training compared to before the training ($z = -2.19$, $p < .01$). The effect was small to medium.

Last, the average trainer implementation fidelity score was 97% across 15 sites and 12 trainers.

Discussion

As abuse awareness, prevention, and intervention programs

for people with ID continue to be developed, there is a need for rigorous research that demonstrates measurable and meaningful outcomes for participants (R. B. Hughes et al., 2020; Mikton et al., 2014). This efficacy study responds to this need and addresses additional gaps in the abuse prevention literature. For example, LEAP staff intentionally recruited both men and women participants and people with more significant levels of ID participated with greater frequency than in prior studies.

The LEAP theory of change was premised on the idea that gains in knowledge would lead to changes in behavior or action. Consistent with social cognitive theory, LEAP developers hypothesized that, through the role-playing, repetition, and reinforcement that was built into the intervention, people with ID would acquire skills and perform new behaviors. These behaviors would then influence participants' actions. The expectation was that if people with ID participated in instruction and role-playing about the differences between healthy and unhealthy relationships, how unhealthy relationships can lead to being targeted for abuse, and what to do if, in an unhealthy relationship, they would have the tools to protect themselves. As demonstrated in both the pre and posttest scores, this theory of change was confirmed in the research findings. After the intervention, people with ID improved their ability to report and contrast healthy and unhealthy relationships and better understood what to do if in an unhealthy relationship.

An important finding from the LEAP study (see Hickson et al., 2015 and R. B. Hughes et al., 2020) is that through the intervention, participants were better able to describe differences between healthy and unhealthy relationships as well as state appropriate actions to take if experiencing abuse. Immediately following the intervention, participants could use language presented in training to describe unhealthy and healthy scenarios more accurately and report what to do next if in a compromising situation. These are critical skills for addressing potential abusive situations.

There are several specific ways in which the LEAP research expanded the current ID abuse prevention literature. As recommended in best practice, rigorous implementation fidelity protocols were put into effect to ensure adherence and competence in carrying out the LEAP intervention across sites and trainers (Breitenstein et al., 2010). LEAP trainer implementation fidelity was very high. While some studies included elements of implementation fidelity as part of their research with mixed results (Hickson et al., 2015), others did not describe how they evaluated fidelity in their research design (R. B. Hughes et al., 2020). Understanding the effectiveness of any intervention is contingent on the accurate description, measurement, and implementation of the intervention (Bellg et al., 2004).

Limitations

Although efficacy results for the LEAP intervention were promising, there are several noted limitations in this research. First, although the level of ID provided some descriptive information on program participants and was used to examine differences in LEAP outcomes, the level of support need is considered central to classification, service delivery, and understanding disability (Arnold et al., 2014). In further research, we will seek to collect data on adaptive behaviors and the level of support need for participants.

When testing the intervention, we did not include a control group. A randomized study with a control group would help to improve our ability to minimize bias and use the most rigorous tools to assess cause-effect relationships between LEAP and participant outcomes (Hariton & Locascio, 2018). Additionally, measurement was a significant challenge for this study. Because many research participants did not read and did not feel comfortable with traditional paper-and-pencil "testing," the measurement tool was adapted to a more accessible, visually based format. While we conducted extensive pilot testing, this type of measurement is relatively novel. Further testing is needed to establish the reliability of our vignette tools.

Data were non-normally distributed for all measures at all time points, which required the use of nonparametric analyses; however, parametric measures may have provided better

insight into differences in the rate of change for those with different levels of ID. Our analyses used different tests to examine the same outcome variables increasing the likelihood of alpha inflation.

The identification items, which had poor internal reliability at pretest and posttest, were developed to measure a unidimensional abuse identification construct. The LEAP curriculum and video vignettes used for assessment explored diverse facets of abuse and exploitation, and poor internal reliability may indicate that items represent more than one underlying abuse and exploitation identification construct. We will continue to refine identification items and test the validity of these items and scales so that we can better discriminate differences in how people identify scenarios based on a variety of personal or contextual information.

Implications

People with ID are often targeted for abuse, neglect, and exploitation. The field must continue to research and systematically evaluate abuse prevention interventions to address this risk. The LEAP intervention was developed to provide people with ID with an understanding of the differences between healthy and unhealthy relationships and skills to protect themselves. Because outcomes from the training proved very promising, the scale-up of research-based

interventions like LEAP appears to be a concrete step forward to confront these challenges to the safety of people with ID.

Progress is being made in building evidence-based strategies; however, we must also continue to refine our measurement tools and processes to meet the needs of people with ID—a heterogeneous and complex population. Finally, for training interventions, in particular, program developers should also consider incorporating measures of implementation fidelity as part of their evaluation strategy. This will improve confidence in attributing participant outcomes to the intervention. Professionals in the field must continue to work in partnership with people with disabilities, families, providers, and other stakeholders to support a culture of prevention. This will help to ensure that skills and tools presented to people with ID in training interventions can be reinforced throughout their everyday life.

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