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The *Developmental Disabilities Network Journal (DDNJ)* is a peer-reviewed, open-access journal published two times per year by the Institute for Research, Policy & Practice (IDRPP), Utah State University, Logan UT 84322-6800, USA. The journal is available online at http://digitalcommons.usu.edu/ddnj.

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Journal Subject Area: The DDNJ publishes 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.

Advertisements: The DDNJ accepts digital advertisements. For advertising rates and specifications, contact editor.ddnj@usu.edu. Articles appearing in the DDNJ are not currently included in

any research indices because there is not enough content for indexing purposes. The DDNJ will be indexed after the publication of Volume 1, Issue 2.

Cover Design: The DDNJ cover and logo were designed by Kelly Smith and Mary Ellen Heiner from the Institute for Research, Policy & Practice at Utah State University.

Acknowledgments

We are excited to finally publish this Spring edition of the Developmental Disabilities Network Journal. This particular issue is a catch-up issue with a wide variety of different articles that we have been wanting to publish for a long-time.

Although this was not a specific thematic issue, there is a clear theme of participatory methods and collaboration in the articles in this edition. It has been inspiring to see the range and scope of participatory methodologies that different programs are using to ensure that the voices and perspectives of people with disabilities and their families are front and center. Perhaps the most important work that we do as a DD Network is amplifying the voices of individuals and family members. It is

too easy within large bureaucracies to allow "the system" to dictate the direction of our programs, and it takes intentional focused effort to listen and learn from the communities that we serve. The articles in this issue provide many approaches to listening and learning, and we are excited to share them with you.

Our next issue of DDNJ is already in progress! It is a partnership between DDNJ and the AUCD Multicultural Council and will be focused on diversity, equity, and inclusion initiatives within the DD Network. We have already screened the abstracts that were submitted and have invited papers for this special issue. We are looking forward to sharing those with you this fall. Although the fall issue is already coming together, we are still seeking submissions for an open issue in Spring 2023. We would like to invite you and your colleagues to consider submitting work for that issue!

As with past issues of DDNJ, we are deeply indebted to the hard work of many people who have served as peer reviewers for this issue of the journal. We have had faculty, researchers, teachers, graduate students, family members, and self-advocates who have contributed to the reviews this time and we would like to thank each of you who have taken the time to provide your feedback to the journal staff and the authors. The strength of this journal is within the network of people who help provide these reviews and feedback, which strengthens the quality of the articles that we publish. Thank you!

If you would like to be a reviewer for DDNJ, we would love

to add you to our reviewer board. We are seeking individuals with broad expertise in disability research, policy analysis, participatory action research, diversity, equity, and inclusion. We are especially interested in recruiting individuals with developmental disabilities, siblings of individuals with disabilities, and/or parents of children with disabilities as reviewers. If you are interested in joining our review board, please send us a short email describing your areas of expertise and any past review experience. If you have a resume or CV, please attach that to the email. Please send emails to editor.ddnj@usu.edu. You can also call us at 801-797-0836 if you need assistance submitting this information.

Thank you so much for reading and supporting the work of DDNJ! We hope that you find value in this issue, and we are interested in your thoughts and feedback. If there are ways that we can make this publication more accessible or inclusive, we want to hear from you. Please send your comments and feedback to editor.ddnj@usu.edu.

Thank you so much.

Matthew T. Wappett, Ph.D.

DDNJ Editor-in-Chief

1.

Alan B. Cobo-Lewis

[Equitable Vaccine Access within an Age-Based Framework PDF File](#)

Abstract

Objectives:

When vaccine supply was limited, several states adopted age-based prioritization for COVID-19 vaccine eligibility because it is simple (especially when age is quantized by decade), and age is strongly associated with COVID-19 mortality. But this approach raises equity concerns based in law and ethics. This study proposes data-driven solutions for equitable policy within an age-based framework.

Methods:

Using the Centers for Disease Control and Prevention (CDC) and U.S. Census Bureau data, 538,627 U.S. COVID-19 deaths were analyzed by age and race-ethnicity through February 2021 and the risk ratios were compared to published data on risk ratios for other conditions.

Results:

COVID-19 mortality rose 2.56-fold per decade of life. Down syndrome, organ transplantation, and intellectual/developmental disability all have risk ratios higher than that.

Conclusions:

People with specific conditions associated with a risk ratio of 2.56 or 6.54 should become vaccine-eligible along with people 10 or 20 years older, respectively. Even as vaccines become more available, data collection and reporting through disability systems should be integrated with general public health systems, including vaccination databases, in order to assess COVID-19 mortality associated with intellectual or developmental disability per se and

to make it possible to track vaccine progress in this marginalized population. People from these groups should also be involved in decision making and advisory bodies.

Plain Language Summary

Older people are more likely than younger people to die from COVID-19. Some states have let older people get vaccines before younger people, even if the younger people had disabilities. These states gave 70-year-olds vaccine access, then 60-year-olds vaccine access, and so on. So how much does risk of COVID-19 death go up when people age 10 years? When you are 10 years older, your risk of dying from COVID-19 is 2.6 times higher. People with severe kidney disease and people with intellectual or developmental disabilities who live in group homes are also about 2.6 times as likely to die from COVID-19. People with Down syndrome, people with intellectual or developmental disabilities living in Intermediate Care Facilities (ICFs), and people with organ transplants are even more likely to die from COVID-19. If a state or country lets old people get vaccines early, then they should let people with organ transplants or severe kidney disease get vaccines with people 10 years older. They should let

people with intellectual or developmental disabilities in group homes or ICFs get vaccines with people 10 or 20 years older. They should let people with Down syndrome get vaccines with people who are much older. States and countries should also include disability when they report data on COVID-19. This should include vaccination data. They should not segregate data about disability. People from marginalized groups should be included in decision making, and decisions should change with new information.

When COVID-19 vaccines were in short supply in the U.S., several states moved to age-based prioritization for COVID-19 vaccine eligibility (modified to also prioritize teachers and childcare workers, who President Biden identified as a federal priority based on their role as essential workers for reopening schools rather than on increased COVID-19 risk *per se*). There was substantial variability in how states consider disability (Johns Hopkins Disability Health Research Center & Center for Dignity in Healthcare for People with Disabilities, 2021), but as of March 8, 2021, adults with high-risk conditions were not prioritized in 12 states (Harmon & Ivory, 2021). Age-based prioritization is simple, especially when states quantize age by decade, opening vaccines to people at least in their 70s, then adding people in their 60s, etc. States typically justified age-based prioritization by older people's large risks of serious

COVID-19 outcomes, including death, and by the need for simple, fast, and transparent systems (*Governor Lamont Announces Connecticut Will Continue Age-Based Approach To COVID-19 Vaccine Eligibility; Educators and Childcare Providers to Have Dedicated Clinics in March*, n.d.; Maine Department of Health and Human Services, 2021). But strictly age-based prioritization has come under assault as being unethical (Persad et al., 2020), and the U.S Department of Health and Human Services Office for Civil Rights (2017) has advised that, under the Affordable Care Act's nondiscrimination provisions, a state or other entity is "only permitted to consider age as one factor as part of its overall decision-making." Consequently, two complaints were filed with the Office for Civil Rights challenging Connecticut's age-based prioritization (Disability Rights Connecticut, 2021a, 2021b).

Vaccines remain in short supply in other countries, and shortages (of vaccines and other resources) may return in the U.S. in future public health crises. How do you reconcile any large age-associated effects with ethical and legal demands for equity in jurisdictions that prioritize on age? The answer is found in a proper quantification of the age-associated effects and a commitment to better data collection and reporting and inclusion in decision-making.

Methods

To quantify the association of age (as well as race and ethnicity) with COVID-19 mortality, publicly available data were downloaded from the U.S. Centers for Disease Control and Prevention (CDC) and the U.S. Census Bureau. In calculating COVID-19 mortality (COVID-19 deaths per capita), the CDC data provided numerators (number of COVID-19 deaths), and the census data provided denominators (population). Because the data were aggregated and de-identified, no IRB review was required. Data were analyzed for COVID-19 deaths through February 2021, when vaccines were in short supply, some states were prioritizing vaccine distribution based solely on age, and the Delta variant had not yet emerged.

Census data were from 2019 estimates (the most recent available at time of analysis in September 2021) of U.S. population (by age group for the first analysis, by age group and racial/ ethnic category for the second analysis). To analyze the overall increase of COVID-19 mortality by age, data were downloaded on number of COVID-19 deaths by age group from https://data.cdc.gov/resource/9bhg-hcku.json. (The data file includes number of total deaths, number of COVID-19 deaths, number of pneumonia deaths, number of influenza deaths, and number of deaths in more than one of these categories, by time [month, year, or cumulative across the dataset], age group, sex, and U.S. state [or U.S.-wide]. Only

COVID-19 deaths by month and age group were used.) To analyze associations involving race or ethnicity, additional data on COVID-19 deaths by age group and racial/ethnic group were downloaded from https://data.cdc.gov/resource/tpcp-uiv5.json. (That data file includes total number of deaths and number of COVID-19 deaths, by time [week, month, year, or cumulative across the whole dataset], racial/ethnic group [missing for < 1% of COVID-19 deaths], and HHS region [or U.S.-wide]. Only U.S.-wide COVID-19 deaths by month, age group, and racial/ethnic group were used.) Race and ethnicity groups were constructed to match those used in a previous study of racial and ethnic disparities (Bassett et al., 2020): Hispanic, Non-Hispanic American Indian and Alaska Native, Non-Hispanic Asian or Pacific Islander (including Native Hawaiian), and Non-Hispanic Black. The three racial categories were nominally for people reporting those races alone (but < 1% of COVID-19 deaths recorded more than one race).

All analyses were conducted in R 4.1.0 (R Core Team, 2021). COVID-19 mortality was calculated for 9 age categories, from under 5 years old to 85+ years old. To quantify how much COVID-19 mortality changed with increasing age, quasipoisson regression was used (a technique similar to linear regression, but specifically appropriate for count data—quasipoisson can be especially useful when there may be additional unmeasured effects on the outcome variable). COVID-19 deaths were regressed on age as well as

jointly on age and racial-ethnic category, in both cases with an offset term for the logarithm of population. (This method recognizes that the death count depends both on the mortality rate in a group and on what the overall population is in the group.) In the regressions, age was taken as the mean age in each age category, calculated from census estimates of U.S. population for each 1-year age span from 0 through 100 years old. (This was close to the middle age in each category. For example, mean age for the youngest group [under age 5] was 2.0 years, and mean age for the group of people in their 30s was 34.5 years. Mean age for the group of people age 85+ was 89.4 years.) In the regressions involving race and ethnicity, the general population was treated as the reference category. All results are reported with 95% confidence intervals.

For the main analysis, COVID-19 deaths through February 2021 were analyzed. In a subsequent "sensitivity analysis," data from March 2021 through September 11, 2021, were analyzed to evaluate whether conclusions remained broadly the same. To evaluate robustness to other methods of analysis, logistic regressions of the COVID-19 mortality rates and linear regressions of the log-transformed COVID-19 mortality rates were also conducted.

The full content of the R code is available from the author or download it from github. In order for the code to run for the first time, a census API key must be obtained from https://api.census.gov/data/key_signup.html as described in "Working with the Census Data API" and installed using the

census_api_key() function in the tidycensus R package
(Walker, 2020). For a low-bandwidth analysis such as this, no
API key is required from the CDC.

Results

Age

CDC data covered 538,627 U.S. COVID-19 deaths through
February 2021. Figure 1 plots COVID-19 mortality rate versus
age, pooling across the entire population (see also Table 1).
COVID-19 mortality during this period was lowest for 5-17
year olds, but otherwise increased consistently with increasing
age. Overall, COVID-19 mortality in the U.S. increased by a
factor of 2.56 (95% confidence interval [CI] 2.49, 2.62) per
decade of life (so risk of dying from COVID-19 through
February 2021, more than doubled for every 10-year increase
in age).
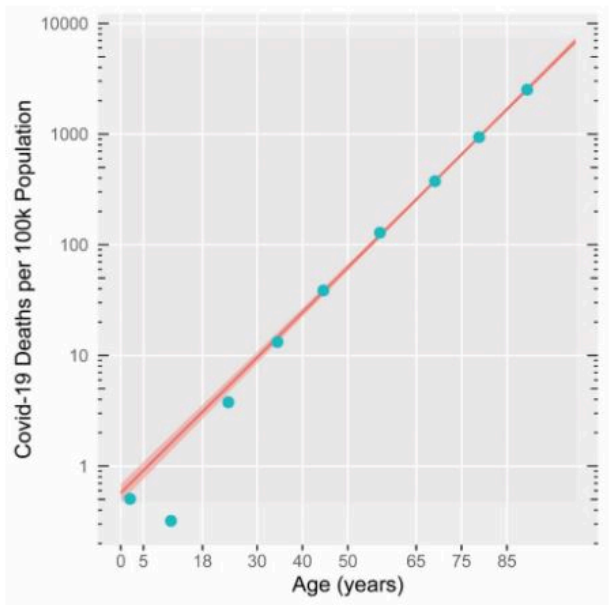
Figure 1 *US COVID-19 Mortality vs Age for U.S. Population Through February 2021*

Note. Numerators for mortality rates are from CDC, and denominators are from U.S. Census Bureau. Line and 95% confidence interval reflect quasipoisson regression relating COVID-19 mortality to age and indicates that mortality increases by a factor of 2.56 per decade of life [95% confidence interval (2.49, 2.62)]

Table 1 *Population, Number of COVID-19 Deaths, and COVID-19
Mortality per 100k Population by Race/Ethnicity and Age, for U.S.
COVID-19 Deaths Through February 2021*

Race/ ethnicity	Age group	Mean age (years)	Population	Number of Covid-19 deaths	Covid-19 mortality per 100k population
All Races and Ethnicities	0—4	2.0	19,576,683	99	0.51
	5—17	11.0	53,462,467	171	0.32
	18—29	23.7	53,728,222	2,033	3.78
	30—39	34.5	44,168,826	5,852	13.25
	40—49	44.6	40,319,374	15,596	38.68
	50—64	57.0	62,925,688	80,928	128.61
	65—74	69.1	31,483,433	118,200	375.44
	75—84	78.8	15,969,872	149,636	936.99
	85+	89.4	6,604,958	166,112	2,514.96
Non-Hispanic American Indian and Alaska Native	0—4	2.0	161,894	1	0.62
	5—17	11.0	454,056	3	0.66
	18—29	23.7	455,166	81	17.80
	30—39	34.5	334,201	269	80.49
	40—49	44.6	284,857	476	167.10
	50—64	57.0	443,316	1,673	377.38
	65—74	69.1	191,853	1,720	896.52
	75—84	78.8	82,649	1,328	1,696.80

Race/ethnicity	Age group	Mean age (years)	Population	Number of Covid-19 deaths	Covid-19 mortality per 100k population
	85+	89.4	26,916	739	2,745.58
Hispanic	0—4	2.0	5,094,211	37	0.73
	5—17	11.0	13,593,354	71	0.52
	18—29	23.7	11,797,900	850	7.20
	30—39	34.5	9,096,112	2,543	27.96
	40—49	44.6	7,962,287	6,911	86.80
	50—64	57.0	8,389,407	25,849	308.11
	65—74	69.1	2,822,119	25,204	893.09
	75—84	78.8	1,307,751	22,197	1,697.34
	85+	89.4	509,096	15,800	3,103.54

Race/ ethnicity	Age group	Mean age (years)	Population	Number of Covid-19 deaths	Covid-19 mortality per 100k population
Non-Hispanic Black	0—4	2.0	2,684,389	22	0.82
	5—17	11.0	7,322,768	41	0.56
	18—29	23.7	7,759,337	483	6.22
	30—39	34.5	5,810,545	1,367	23.53
	40—49	44.6	5,100,103	3,449	67.63
	50—64	57.0	7,491,213	17,674	235.93
	65—74	69.1	3,100,660	21,892	706.04
	75—84	78.8	1,366,933	20,060	1,467.52
	85+	89.4	511,540	15,215	2,974.35
Non-Hispanic Asian or Pacific Islander	0—4	2.0	999,341	4	0.40
	5—17	11.0	2,831,788	11	0.39
	18—29	23.7	3,400,086	87	2.56
	30—39	34.5	3,363,152	304	9.04
	40—49	44.6	2,934,483	680	23.17
	50—64	57.0	3,419,606	3,517	102.85
	65—74	69.1	1,531,140	5,183	338.51
	75—84	78.8	725,748	5,721	788.29
	85+	89.4	296,443	6,076	2,049.64

Race and Ethnicity

Figure 2 presents the data for each racial-ethnic category in a separate panel, while also repeating the data and fit for the overall population in every panel (see also Table 1). Adjusting for age, the difference in COVID-19 mortality between racial-ethnic category and the overall population was largest for Non-Hispanic American Indian and Alaska Native, with risk ratio 2.14 (95% CI 1.41, 3.25), then Hispanic, with risk ratio 1.92 (95% CI 1.71, 2.15), then Non-Hispanic Black, with risk ratio 1.59 (95% CI 1.41, 3.25). The difference in COVID-19 mortality was not significant between Non-Hispanic Asian or Pacific Islander and overall population, with risk ratio 0.82 (95% CI 0.65, 1.03).
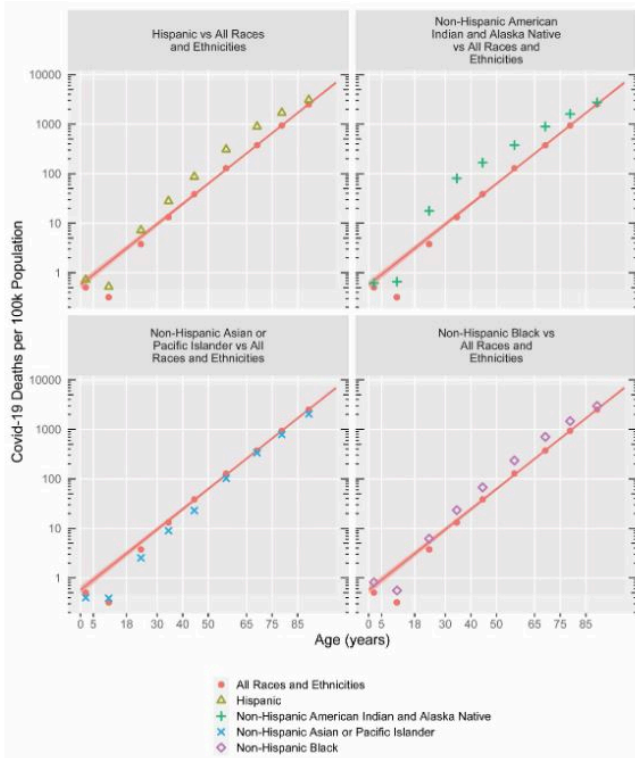
Figure 2 *U.S. COVID-19 Mortality vs Age, Through
February 2021, for the Entire U.S. Population and for Four
Racial-Ethnic Groups*
Note. Numerators for mortality rates are from CDC, and
denominators are from U.S. Census Bureau. Data and
quasipoisson fit (including 95% confidence interval) for entire
population are repeated in each panel, showing risk ratio for
mortality increasing 2.56 per decade of life, [95% confidence
interval (2.49, 2.62)].

COVID-19 mortality among racial and ethnic minorities also

appeared especially elevated from levels in overall population in early adulthood through midlife, especially for Non-Hispanic American Indian and Alaska Native people. Rather than pursuing curvilinear fits over a small number of age categories, for each racial-ethnic category, the raw COVID-19 mortalities in age group were compared directly to the corresponding values in the overall population (a "model-free approach" because it compares raw rates instead of fitting lines or curves to the data). The maximum risk ratio by age was similar to the regression-derived risk ratios for three racial-ethnic categories, but for the Non-Hispanic American Indian and Alaska Native, the risk ratio was as large as 6.08 (95% CI 5.38, 6.86) for people in their 30s, compared to a risk ratio of 2.14 (95% CI 1.41, 3.25) for that racial-ethnic group's regression-derived value.

Sensitivity Analyses

When analyzed via quasilogistic regression instead of quasipoisson regression, the results are essentially the same (odds ratio of 2.57 per decade of life in quasilogistic regression vs risk ratio of 2.56 per decade of life in quasipoisson regression, for example). When log mortality rate is analyzed via linear regression, the age effect increases somewhat, to a risk ratio of 2.84 per decade of life, because linear regression increases the slope of the best-fitting line in Figures 1 and 2 to better fit the COVID-19 mortality in people younger than 30;

whereas quasipoisson and quasilinear regression recognize the lower statistical reliability of those data points.

When analyzing the data from March 2021 into September 2021 (120,127 COVID-19 deaths) instead of data from the beginning of the pandemic through February 2021, the pattern of results remained similar. The association of age with mortality was somewhat weaker, with COVID-19 mortality increasing by a factor of 1.96 (95% CI 1.84, 2.09) per decade of life (versus 2.56 per decade of life through March 2021), and the racial/ethnic disparities were reduced for Non-Hispanic American Indian and Alaska Native (risk ratio 2.14 through February 2021 reduced to 1.44 from March 2021 forward) and for Hispanic (risk ratio reduced from 1.92 to 1.47). The patterns in the graphs looked otherwise very similar.

Discussion

Many potential risk factors elevate COVID-19 mortality by a factor less than the 2.56 risk ratio that people experience from a decade of life and might be excluded from prioritization with comparatively small effects on mortality equity (though a full consideration of equity would also consider effects beyond mortality). However, some conditions and demographic characteristics are associated with elevation in COVID-19 mortality that approaches or even exceeds that level—sometimes substantially. Ignoring those characteristics perpetuates health inequities.

Figure 3 displays risk ratios deriving from the present study's regressions, along with risk ratios from other studies for Down syndrome, intellectual or developmental disability, organ transplant, and kidney disease. A risk ratio greater than 1 (data points to the right of the vertical dashed line) indicates COVID-19 mortality higher than in the general population. A risk ratio less than 1 indicates COVID-19 mortality lower than in the general population. For example, a risk ratio of 3 indicates a tripling in COVID-19 mortality. [For one study (Gleason et al., 2021), an odds ratio is displayed instead, and for two studies (Clift et al., 2020; Williamson et al., 2020), hazard ratios are displayed instead, but COVID-19 mortality is low enough that all the ratios in Figure 3 can be treated similarly]. For people with Down syndrome, intellectual, or developmental disability, some ratios show mortality risk separately depending on a person's residence (intermediate care facility vs. group home vs. own home, family home, or shared living), as type of residence is a strong predictor of COVID-19 mortality.

Note. Error bars indicate 95% confidence intervals.
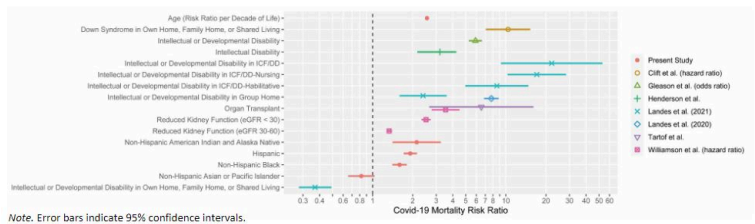
Figure 3 *COVID-19 Mortality Risk Ratios from the Present Study for Age and Racial-Ethnic Category (U.S. Data Through February 20221) and from Published Studies for*

Down syndrome, Intellectual or Developmental Disability,
Reduced Kidney Function, and Organ Transplant
Note. Error bars indicate 95% confidence intervals.

People Living in Congregate Settings Have Higher COVID-19 Mortality

Intellectual or developmental disability is associated with about a 3-fold (Henderson et al., 2021) to 6-fold (Gleason et al., 2021) elevation in COVID-19 mortality overall (when living situation is not considered). But COVID-19 mortality rate differs substantially by type of residence. People with intellectual or developmental disabilities living in ICFs have COVID-19 mortalities elevated by 8.6-fold to 17.1-fold, depending on type of ICF (Landes et al., 2021b), and people with intellectual or developmental disabilities living in group homes have COVID-19 mortalities elevated by 2.4-fold to 7.8-fold (Landes et al., 2020, 2021b). Compare these elevated COVID-19 mortalities in congregate settings to those among people with intellectual or developmental disability living in their own home, family home, or shared living, where the risk ratio is 0.37 (COVID-19 mortality almost three times lower than in the general population). Clearly, congregate living situations are associated with high COVID-19 mortality.

Although some of the COVID-19 mortality risk associated with congregate settings may be attributable to an increased likelihood of people with more significant medical conditions

living in such settings, some of the risk is surely associated with the settings' congregate nature *per se*, as social distancing is less achievable in such settings.

People with Down Syndrome Have Higher COVID-19 Mortality

Down syndrome has been reported to be associated with a 10-fold elevation in COVID-19 mortality even among people living in their own home, family home, or shared living (Clift et al., 2020).

People with Organ Transplant Have Higher COVID-19 Mortality

Organ transplantation has been reported to be associated with an elevation in COVID-19 mortality of 3.5-fold (Williamson et al., 2020) to 6.5-fold (Tartof et al., 2020).

People with Substantial Kidney Disease Have Higher COVID-19 Mortality

Kidney disease has been reported to be associated with a fairly moderate elevation in COVID-19 mortality of 1.3-fold for moderately reduced kidney function [estimated glomerular filtration rate (eGFR) = 30 to 36 ml per min per 1.73 m^2] but a

more substantial elevation in COVID-19 mortality of 2.5-fold
for more substantially reduced kidney function (eGFR < 30)
(Williamson et al., 2020).

American Indian and Alaska Native People, Hispanic People, and Black People Have Higher COVID-19 Mortality

Elevations in COVID-19 mortality by race and ethnicity are
not as large in the present analysis as were found earlier in
the pandemic (Bassett et al., 2020), but they are still present,
though in most cases not as large as the elevation in
COVID-19 mortality associated with being 10 years older. In
particular, the point estimate is 2.1-fold for Non-Hispanic
Native American Indian and Alaska Natives, though the risk
ratio rose as high as 6.1-fold for 25-34-year-old Non-Hispanic
Native American Indian and Alaska Natives.

Limitations

This study considered only COVID-19 mortality, not other
substantial medical outcomes like diagnosis or hospitalization
nor other outcomes like social isolation or the impact of
COVID-19 on formal or informal supports to persons with
disabilities. In addition, the available data from the literature

did not distinguish among living in one's own home or own family's home versus living with another family (shared living).

The data are inherently correlational. (For example, there was a large association between congregate living and elevated COVID-19 mortality, but because there is no random assignment to congregate living, it is impossible to know the extent to which correlates of congregate living are drive that association.) The data also do not reveal the extent to which correlates of disability (such as income or wealth) may be associated with differences in COVID-19 mortality.

No attempt was made to examine geographic patterns or trends over time (other than beginning of pandemic through end of February 2021 vs. March 2021 into September 2021), nor was sex included in the analysis. The racial/ethnic analysis did not examine the intersectionality of race and ethnicity, as the CDC datasets did not break down data on COVID-19 deaths of Hispanic people by their race.

Conclusion

States that use a strictly age-based framework for prioritizing eligibility for vaccines typically justify that approach by noting the enormous risk ratio for COVID-19 mortality of the oldest groups versus young adults. For example, people at least 85 years old had a COVID-19 mortality of 2514.96 per 100k population through February 2021, versus 3.79 per 100k among 28-29 year olds—an enormous risk ratio of 664.65.

But mean age between these groups differs by 65.7 years (6.57 decades). States prioritizing by age typically quantized age by decade—for example, opening up vaccines to 70-year-olds, then 60-year-olds, etc., so the appropriate metric is the risk ratio *per decade*, which can be calculated as $664.65^{1/6.57} = 2.69$. By calibrating potential risk factors for COVID-19 mortality against the risk ratio per decade (2.56 per decade when fitting all the data via quasipoisson regression), we can identify characteristics that should be considered for vaccine access even within an age-based framework. This analysis—and the data that informs such analyses—lead to specific policy prescriptions:

Policy Prescription 1: Access to Vaccines

A 2.56-fold elevation in COVID-19 mortality is the same risk conveyed by being 10 years older, and a 6.54-fold elevation in COVID-19 mortality is the same risk conveyed by being 20 years older (because $2.56^2 = 6.54$). In order to begin to address equity, in any jurisdiction adopting an age-based framework for COVID-19 vaccine prioritization, people with conditions associated with a 2.59-fold elevation in COVID-19 mortality should become eligible for vaccines along with people 10 years older, and people with conditions associated with a 6.54-fold elevation in COVID-19 mortality should become eligible for vaccines along with people 20 years older. For example, a

30-year-old with severely reduced kidney function (eGFR < 30) should become vaccine-eligible at the same time as a 40-year-old from the general population, and a 50-year-old with severely reduced kidney function should become vaccine-eligible at the same time as a 60-year-old from the general population. People with organ transplants might also be reasonably prioritized by 10 years, though that policy recommendation might depend on how effective vaccines are for that population and whether booster shots for organ transplants might yield protection equivalent to someone from the general population without a booster shot. People with intellectual or developmental disabilities living in congregate settings should be prioritized by at least 10 or 20 years and should arguably receive *absolute* prioritization. People with Down syndrome—even when living in noncongregate settings such as their own home, their family's home, or shared living—should receive vaccines along with people 40 years older than them (or simply given absolute priority). Important for speeding vaccine delivery, identifying residents of congregate settings is easy, and they can also be reached easily. Also important for speeding vaccine delivery, Down syndrome is easy to identify.

It is unfortunate that, although Down syndrome and organ transplantation are both found on the CDC's list of medical conditions with sufficient evidence to conclude they put people at increased risk of severe illness from COVID-19 (CDC, 2021), states that implemented age-based prioritization

did not all prioritize these two groups with substantially increased risk of COVID-19 mortality. This decision was an inequitable threat to the health of these populations.

Policy Prescription 2: Access to Data

In the U.S., state developmental disabilities agencies, for the most part, have COVID-19 data about people with disabilities—at least for people receiving services from state institutions or home- and community-based services funded through Medicaid—because COVID-19 cases and deaths constitute "critical incidents" that must be reported to the agency. But the data collection systems for people with intellectual or developmental disabilities are largely segregated from the general public health data systems. Consequently, while COVID-19 dashboards, which are common throughout the U.S., track and report data by several risk factors (age and race among them), they rarely if ever report data on disability, even though states could link their public health and vaccine databases with databases supporting their developmental disabilities agencies or Medicaid agencies. This makes it impossible to assess the COVID-19 mortality associated with intellectual or developmental disability *per se*. Only recently has multistate data become available on COVID-19 deaths by disability and residential setting, and it remains incomplete and, at least in the extant literature, has only been used for calculating case-fatality rates (risk of dying given that a person

already has a COVID-19 diagnosis) rather than mortality rates (overall risk of dying from COVID-19; Landes et al., 2021a). This exclusion of disability data from public health data dashboards is shocking in light of longstanding Surgeon General recommendations to improve health-related surveillance for people with intellectual disabilities (U.S. Public Health Service, 2001). The segregation of disability data systems from broader public health data systems also makes it impossible for the public to track vaccine progress in this marginalized population—important considerations even after vaccine eligibility is broadened to the general adult population. This must change.

Policy Prescription 3: Inclusion in Decision-Making

In the future—during the current pandemic, in future public health crises, and even between crises—perceived convenience for policymakers and public health personnel on the ground should not be allowed to exacerbate the inequities that contribute to health disparities. Laws, rules, and policies should be written to recognize previous marginalization—and ongoing marginalization—and to prevent recurrence. Stakeholders from marginalized groups should be appointed to meaningful roles in decision making and advisory bodies in all jurisdictions, including at the state and federal level. And when data or analyses come to light challenging previously

adopted policies, jurisdictions should heed the data and re-examine the policies. "Nothing about us without us."

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2.

ASSESSING NEED AND ACCEPTABILITY OF A YOUTH MENTORING INTERVENTION FOR ADOLESCENTS WITH AUTISM BY ADULTS WITH AUTISM

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Gunty, K., Weiler, L., Keyzers, A., & Hudock, R. (2022). Assessing Need and Acceptability of a Youth Mentoring Intervention for Adolescents with Autism by Adults with Autism. *Developmental Disabilities Network Journal, 2(2)*, 15–25. https://digitalcommons.usu.edu/ddnj/vol2/iss2/3/

Assessing Need and Acceptability of a Youth Mentoring Intervention for Adolescents with Autism by Adults with Autism PDF File

Abstract

Background:

Adult mentors can positively influence development, yet youth with autism spectrum disorders (ASD) have too little access to adult mentors who can provide role modeling, guidance, and support. Furthermore, neurotypical adult mentors (i.e., adult mentors without ASD) may not understand the day-to-day realities that youth with ASD face and the social world they navigate. Therefore, it is possible that adults with ASD may be particularly well-suited as mentors for youth with ASD.

Method:

Six semi-structured focus groups of four to seven people each explored the need for a mentoring program to bridge the gap between the supports youth with ASD need and what they currently receive. These focus groups included key stakeholders: youth with ASD, adults with ASD, and parents of youth and adults with ASD.

Results:

Focus groups with key stakeholders demonstrate a significant need for the development of a one-to-one youth mentoring program delivered by adults with ASD.

Conclusion:

There are significant gaps between the supports (particularly social supports) that adolescents with ASD need and those that are available to them. All of the focus groups concluded that a mentoring program in which adults with ASD are mentors for youth with ASD seems to be an acceptable and much-needed support for adolescents with ASD. Such a program is not currently known to exist.

Plain Language Summary

Youth and young adults with autism face difficulties. They often feel like they do not have the friendships they want. They also often feel like they are not connected to their communities. Sometimes, adults can support youth informally through mentoring. There are few mentoring programs for youth with autism. Also, all the known programs like that use

mentors without autism. This study looks at whether people think it would be useful to develop more mentoring programs for youth with autism. It also looks at using young adults with autism as mentors for youth with autism.

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social skills and the presence of repetitive, restricted patterns of behavior (American Psychiatric Association [APA], 2013). Because of the different ways ASD can impact an individual's functioning and well-being, many individuals with ASD need and/or benefit from services and supports throughout their lives (Bower Russa et al., 2015). While there are many interventions available for young children with ASD (Howlin & Magiati, 2009), availability of supports wanes by adolescence (McStay et al., 2014). This paucity of services and supports continues during and through the transition to adulthood (Bower Russa et al., 2015).

Despite showing high levels of family coping, families of children with ASD also report high levels of uncertainty and stress during adolescence (Bower Russa et al., 2015; O'Brien, 2016). Indeed, youth with ASD are vulnerable to social, emotional, educational, and vocational difficulties during and around the transition from adolescence to adulthood (Roux et al., 2015). One of the core symptoms of ASD that can have a significant impact on an individual's well-being is difficulty

forming and maintaining relationships (APA, 2013). Adolescents with ASD are more likely than other youth to report that they never receive calls from friends or invitations to social activities and never see friends outside of school (Shattuck et al, 2011). Yet, many youth with ASD desire friendships and close relationships and report that friendships are important to their overall well-being (Danker et al., 2019).

Youth who lack quality social support from family and friends are vulnerable to mental health problems (Colarossi & Eccles, 2003; Klineberg et al., 2006) and at-risk of negative life trajectories. Adults with ASD tend to be under-engaged with their communities and often experience low self-efficacy regarding relationships, employment, and independent living (Henninger & Taylor, 2013; Roux et al., 2015). They are also more likely than the general population to experience suicidal ideation (Cassidy et al., 2019). At the same time, young adults with ASD want supportive help to overcome unwanted difficulties so that they can be full, contributing members of their communities (Sosnowy et al., 2017).

It is necessary to identify services that are accessible and satisfactory to young people with ASD because of the difficulties people with ASD face in adolescence and young adulthood. In the general population, relationships with caring, nonparental adults (i.e., mentors) are critical to healthy child and adolescent development (Rhodes & Lowe, 2008). Such relationships can positively influence many outcomes, including interpersonal relationships, academic achievement,

self-confidence, mental health, and problem behaviors (Raposa et al., 2019). Despite these important effects, mentoring interventions have rarely been investigated specifically for youth with ASD.

One pilot study examined a program that paired nine adolescents with ASD with neurotypical college- or graduate-student mentors and found evidence of adolescent participants with ASD feeling more socially connected (Curtin et al., 2016). Social connection, in turn, is associated with better mental health for this population (Gotham et al., 2015). Given the reciprocal nature of youth mentoring relationships, there is potential for a program to also benefit young adult mentors. Previous research found that mentoring can positively impact mentors' self-esteem and interpersonal and problem-solving skills (Weiler et al., 2013). It could be advantageous to explore a model in which young adults with ASD provide mentorship for adolescents with ASD. Such a mentoring program could have substantial positive effects for participants on both sides of the mentoring relationship.

Although youth and adults with ASD may have challenges building relationships, this unique model could bolster resilience for youth and adults. There is evidence that bringing people with ASD together in a group setting can relieve loneliness and ameliorate comorbid mental health difficulties such as anxiety and depression (Spain & Blainey, 2015). A mentoring program in which all participants have ASD could produce similar effects because of the shared experience of

living as a person with ASD in a world built around neurotypical individuals. In addition, having mentors who have faced the challenges mentees are currently facing could allow for more targeted and relevant support. Despite this potential, no known program has used adults with ASD as mentors for adolescents with ASD.

Given these preliminary results and associations, mentoring seems like an important and promising support for adolescents with ASD that could benefit from further investigation. The purpose of the current acceptability study was to assess how well the proposed mentoring intervention for adolescents with ASD was received by members of the target population and the extent to which they believed the new intervention might meet the needs of the target population. Following guidelines for assessing the acceptability of a new social and behavioral health intervention with qualitative methods (Ayala & Elder, 2011), our primary research questions were: (1) To what extent do youth with ASD, parents of youth and young adults with ASD, and adults with ASD perceive a need for a mentoring program for adolescents with ASD? (2) To what extent do youth with ASD, parents of youth and young adults with ASD, and adults with ASD perceive the proposed mentoring program as acceptable (i.e., Do the benefits outweigh the costs? Is the model satisfactory?)?

Method

Researchers obtained Institutional Review Board (IRB) approval from the associated university. Participants were informed of the study opportunity in collaboration with a local public high school, an ASD advocacy organization, and a local post-secondary program that supports adults with ASD in developing life skills. Participants included high school students with ASD, parents of high school students or young adults with ASD, and adults with ASD. Adolescents and their parents learned of the opportunity through email from special education teachers and school counselors. Parents also learned of the opportunity through the advocacy organization email announcements. Adults with ASD learned of the opportunity via email announcements from the post-secondary program and/or the advocacy group. Participants who expressed interest were referred to the study team. Inclusion criteria for each group was as follows: high school students with ASD between the ages of 14-21, parents of individuals with ASD, and adults with ASD. Participants also had to be able to commit to up to 2 hours of participation. Adolescent participants did not have an intellectual disability (IQ under 70), as determined by school personnel, and all participants spoke and understood English fluently. Informed assent and consent were obtained from research participants with accommodations made as needed (e.g., reading the consent aloud) in accordance with guidelines from the IRB.

In six semistructured focus groups of four to seven people each (total N = 33 participants; see Table 1 for demographics of focus group participants), researchers worked with participants to explore the need and acceptability of a mentoring program to bridge the gap between the support youth with ASD need and what they currently receive. The six groups consisted of three groups of youth and young adults with ASD and three groups of adults who were parents of youth with ASD or other adults with ASD. Focus groups were held within conference spaces at a local autism advocacy organization. The focus group format was semistructured and included a series of open-ended questions with follow-up probing questions. Sample focus group questions included the following.

Table 1
Demographics of Focus Group Participants

Focus Group	People with autism			Parents of people with autism		Comb
	Young adults	Adolescents	Adults	Young adults	Adolescents	Comm
N	6	4	6	6	7	6
Gender[a]						
Male	4	4	6	5	5	2
Female	2	0	0	1	2	3
Race[a]						
White	6	3	5	6	6	5
Asian	0	1	1	0	1	0
Age (years)	18-32	14-17	19-56	49-69	35-59	28-48[a]
Education[a]						
High school diploma	4	N/A	2	3	4	0
Some college	1	N/A	1			3
Graduate or professional degree	0	N/A	1	3	2	1

[a]Not all participants reported this demographic. Data
reported are for participants who provided information.

- Given our brief description and discussion of this potential mentorship program, what are some of the pros and cons of participating in such a program?
- Do you have concerns or worries about participating in a program liked this?
- What type of training would you find helpful before participating?
- Has your child had a relationship with a person who has provided them with ongoing guidance and advice (mentor)? If yes, please describe this relationship.
- Do you believe your child would benefit from having a relationship with a mentor who also has ASD? Why or why not?
- Do you believe you have/would have benefited from having a relationship with a mentor?
- What type of mentoring experiences do you feel would have been helpful to you as a child/teen?

Trained facilitators were encouraged to follow the discussion thread of the group so long as it fit within the scope of the study. Each focus group included two facilitators including one of the principal investigators and a graduate student researcher.

Focus groups were audio recorded and transcribed verbatim. Two graduate student researchers used thematic analysis to analyze the transcriptions (Braun & Clarke, 2006). Student coders were supervised by a principal investigator who

has extensive experience with qualitative research and thematic analysis. Each researcher analyzed the transcripts separately and identified content themes within and across the transcripts. Given the clear scope and purpose of the study, identified codes and subsequent themes were very similar between reviewers and consensus coding was used in finalizing the themes. The coding structure was reviewed by the principal investigators, including an expert in ASD (licensed psychologist in a specialty autism clinic, researcher evaluating autism interventions) and an expert in youth mentoring intervention models (researcher evaluating youth mentoring programs). The research team discussed the themes and their relative importance. Namely, researchers discussed which themes from the focus groups were most important and relevant when considering the development of a program in which adults with ASD mentor youth with ASD. Researchers then brought the themes to the community steering committee (composed of adults with ASD and parents of youth with ASD) for a final member check to ensure that the identified themes were comprehensive and complete. The final step was contextualizing the themes and writing an integrated storyline to show relationships among the themes.

Results

Three themes were identified in the focus groups: need for mentoring relationships, acceptability of a mentor with ASD

(benefits), and acceptability of a mentor with ASD (concerns). A summary of these themes is provided in Table 2 and described below.

Table 2
Identified Themes

Theme	Description
Need for mentoring relationships	• Current supports not adequate for meeting adolescents' needs • Decreasing availability of supports for adolescents • Need for belonging and social affiliation • Mentoring could fill the gap between needs and current access
Acceptability of a mentor with ASD: Benefits	• Common ground • Relatability • Allows people with ASD to learn from other people with ASD • Better able to understand youth's challenges • Vision of what is possible for the future • Normalizing youth's experiences • Youth could feel more comfortable and open • Benefit for the mentor – being able to contribute to community
Acceptability of a mentor with ASD: Potential Concerns	• Similar struggles • Adult readiness to be a mentor • Lost benefits of neurotypical mentor such as social modeling

Need for Mentoring Relationships

Overall, there was a perceived need for mentoring of youth with ASD. Parents of youth with ASD reflected on the support their children had received up until adolescence: therapy, social skills groups, personal care assistants (PCAs, people [usually young adults] hired to help someone with a disability with activities of daily living), and nannies or other support professionals. However, parents did not feel that these supports were adequate for meeting the adolescents' current needs for social and emotional support. One parent put it this way, "He has a PCA.but we still feel like we don't meet his needs." Another parent spoke to the decreasing availability of formal supports and recreational activities targeted towards youth with ASD as her son aged, saying, "As he got older and those options started closing in or wrapping up, it has been a little bit more difficult to find or give him the [social and relational] support he needs." A third parent agreed, stating that her adult son "never had a support group or anything like that, and I've always wished he could have. So, I think there is a need [for a mentor program] out there." Overall, the parents conveyed confidence that a mentoring program would help fill the gap between current supports and the needs of youth with ASD.

Coupled with increased need for social and emotional support during adolescence, participants (particularly adults with ASD and parents of individuals with ASD) worried

about youth with ASD finding belonging and social affiliation. One adult simply stated, "There's a lot of need out there.... Young adults [with ASD] struggle to maintain connection." One adult with ASD stated that they would have liked having a mentor to gain an "insider's perspective" on growing up with autism. One participant specifically expressed that high school had been very challenging for him and that there was a lack of support in high school. Of those who noted previous mentoring-like experiences, mentors were typically paid professionals (e.g., social workers, case workers, and mental health practitioners). An adult with ASD spoke about these difficulties, saying of the transition from elementary school to high school, "Heaven help you if you're different in any way." In addition, a youth with ASD noted the importance of having a non -parental adult to talk with, saying, "Sometimes it can be difficult to talk a lot with parents. But, yeah, I think it would be easier talking about [social difficulties] with a mentor."

Across all participants, the need for a mentoring program was clear. Each group of participants highlighted the difficulties of adolescence and the difficulty for youth with ASD. All participant groups indicated that a mentoring program could start to fill the gap between what youth with ASD need and the supports to which they have access.

Acceptability of a Mentor with ASD

Following a brief description of a new intervention model that

would include adults with ASD as mentors, participants were asked to discuss the acceptability of the model, including any potential benefits and challenges of such a program. All parents of youth with ASD agreed that they would want their child to participate in a program like the one presented. Participants were quick to share their enthusiasm for the idea of building a program with mentors with ASD despite a few potential challenges (noted below).

Benefits

Many participants reported that having a mentor with ASD would provide common ground between the mentor and mentee. They believed a mentor with ASD would be able to relate to a mentee with ASD and share their own experiences of growing up. One adult with ASD shared, "Having someone on the spectrum who is doing [the mentoring] is a whole different thing that is really valuable." Another adult with ASD stated the rationale for this very clearly:

> It's important for kids on the spectrum to be with adults on the spectrum. We come with our own set of challenges and knowing that, knowing what to expect, knowing where to go for help, knowing how to advocate for yourself.... In this, we have an opportunity with this generation of autistic kids to help them be a little more successful than maybe [we] were.

Furthermore, an adult with ASD noted a potential downside

of having a neurotypical mentor, stating, "There is so much stress on mainstreaming that the kids with ASD who can learn from each other are being spread out too far." This participant was speaking to a frequent recommendation for parents to place their child with ASD in settings with neurotypical peers (referred to as "mainstreaming") as often as possible, so the child learns socially acceptable behavior from peers. This encouragement to mainstream children was also reflected in parents' comments in focus groups, but this adult with ASD noted a possible loss that occurs when such recommendations are followed—children with ASD do not have the ability to learn from each other.

Participants also noted that a mentor with ASD would better understand what the youth is experiencing, which could be particularly important for youth who may have difficulty articulating their experiences. One parent whose daughter attended a support group led by an adult with ASD shared,

> It was really valuable to have someone on the spectrum who was doing the mentoring because she was able to interpret and explain to the parents a lot of things we just didn't understand and never would have figured out.

Generally, participants believed connecting adults and youth both with ASD would allow the mentees (and their parents) to see what is possible for the youth. The mentors could become types of models of what the youth could attain later in life. One parent said of possible adult mentors with ASD, "They've

been there. They've done it, and it's possible." Another parent shared how this benefit could extend to the rest of the family, "Maybe if we understood better his true capabilities, then we could understand [what his options are]."

Another very common theme throughout the focus groups was that connecting with a mentor with ASD could also normalize the youth's experiences, which could decrease loneliness. For example, parents stated, "I don't think my daughter understood ASD until she was around other kids with autism." Another discussed the ways in which youth with ASD appreciate connecting with other people with ASD, stating, "They get excited because they find other people like themselves." Participants indicated that mentors with ASD could help youth find and understand their identities generally, and their autistic identities specifically, through the mutual understanding that would emerge in this type of relationship.

Another noted benefit to utilizing mentors with ASD was that youth might feel more comfortable and open. Youth with ASD often struggle with social skills, and this difficulty can cause social anxiety. Participants discussed how having mentors with ASD might lessen this social anxiety. One stated,

> I think just letting them...express themselves freely would be important for any kid on the spectrum because social abilities are probably one of the toughest things out there. For them to be able to communicate with someone else and know it's okay if something comes out that's not

appropriate…. Just to be able to express themselves would
be a big plus, with the freedom to be able to [make
mistakes].

Participants also spoke about how this type of mentoring
relationship could directly benefit the mentor. Adults with
ASD, in particular, focused on the fact that people with ASD
sincerely want to help others, but they do not always have an
opportunity to do so. One such participant shared, "When a
person with autism actually genuinely helps somebody in a
legitimate way, that's very meaningful to them." This potential
for such a program to benefit the mentor is an important
aspect that would be unique to a model that includes mentors
with ASD.

Concerns

Participants' concerns regarding mentors with ASD were two-
fold. First, participants suggested that the mentor and the
mentee might have similar struggles (e.g., co-occurring
disorders). For example, one adult with ASD shared, "If both
individuals have some anxiety issues…worst case scenario
would be they both start shutting down." In this case,
participants noted that with the right type of training and
support, mentors with ASD could successfully provide this
support despite such possible struggles. One participant stated
that adult mentors with ASD would need

…guidance continuously throughout the mentorship, just

kind of sitting in the background... and then if they get to
a place where they're stumped or something, they step in
and just nudge a little bit in the right direction.

Second, some of the parents of the young adults with ASD
were skeptical about whether their adult child would be ready
to be a mentor for a youth with ASD. Others felt that they
could see their child being a mentor under certain conditions
(i.e., with quality training). Some participants thought there
would be more benefits to having a neurotypical mentor. For
example, a few participants suggested that neurotypical
mentors may have an easier time modeling socially acceptable
behavior for the youth. One young adult with ASD stated, "It
could also be beneficial if they have [neurotypical] mentors to
help with things that people with autism could not."

Discussion

An intervention in which adolescents with ASD are matched
with adults with ASD in supportive mentoring relationships
could meet a current unmet need in formal support services
for young people with ASD. Adolescents with ASD, parents
of adolescents and young adults with ASD, and adults with
ASD agreed that adolescence is a particularly challenging
developmental stage when many youth experience social and
emotional difficulties. A mentoring program could intervene
to ameliorate some of these negative feelings and experiences.

When presented with a program model that included adults with ASD as mentors, participants thought it would lessen youth's feelings of being different and increase the empathy felt by the mentor. Participants discussed the many benefits that come when people with ASD can be together and learn from one another.

It was also noted that this type of mentoring program could increase individual and parental expectations for the youth's future. The mentors would become models for what is possible in the youth's lives over time. Individual and family expectations strongly influence outcomes for people with intellectual and developmental disabilities (including ASD, e.g., Carter et al., 2012), so the potential influence on expectations may be integral to the success of this type of mentoring program. Despite overwhelming support for a mentoring program for adolescents with ASD in which adults with ASD provide mentorship, there were some potential concerns (e.g., mentors and mentees sharing similar struggles rendering the relationship too difficult).

Though there were a variety of perspectives represented in the focus groups, participants were recruited through a few programs within one metro area where the proposed mentoring program was anticipated to run. It is possible that individuals not connected to these types of programs or who live in rural communities would have different perspectives on this topic. Furthermore, this is an assessment of need and acceptability in one community, so these results might not be

generalizable to other communities. This was also a conceptual exploration in which participants were asked to respond to an idea about a possible program; these same participants might feel differently when responding to the actual implementation of such a program.

As such, a vital next step in this area of research is to explore the development and implementation of the proposed intervention model that includes incorporating feedback from participants in this study. Researchers need to investigate whether such a program is feasible, practical, and likely to improve the well-being of mentors and mentees. Closely studying intervention implementation will help identify what types of structure, support, and training are required to enhance the success of a mentoring program in which both the mentor and mentee are diagnosed with ASD. This is a promising area of inquiry that may open new avenues through which youth with ASD are supported and through which young adults with ASD contribute to their communities in a way that only they can.

Conclusion

Participants in this study were clear that youth with ASD need social support from non-parental adults beyond what is currently available. All key stakeholders agreed that a mentoring program in which youth mentees with ASD are paired with adult mentors with ASD would be an acceptable

model for this. The participants reported that such a program would have potential to benefit both the mentor and the mentee. As this type of program is developed, it will be important to use quantitative and qualitative methods to better understand the potential impacts on participants and the types of supports that are needed to make the model a success.

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3.

EXPERIENTIAL LEARNING THROUGH PARTICIPATORY ACTION RESEARCH IN AN INTERDISCIPLINARY LEADERSHIP TRAINING PROGRAM

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Experiential Learning Through Participatory Action
Research in an Interdisciplinary Leadership Training Program
PDF File

Abstract

Background

Experience in multidisciplinary collaboration
among healthcare providers, leaders in public health,
and educators is essential to effectively address the
diverse needs of children with intellectual and
developmental disabilities (I/DD) and their families.

Purpose

We describe three participatory action research
(PAR) projects from an interdisciplinary training
program, which used experiential learning to
enhance leadership competencies and promote
inclusive services. Trainees report their leadership
growth as providers and advocates for children with
I/DD using experiential learning through PAR.

Approach

Trainees discuss their engagement with

organizations serving children with I/DD and ways that experiential learning supported leadership skill development, commitment to inclusive person- and family-centered practices, and contributions to disability advocacy and support programs.

Conclusion

PAR is a beneficial experiential learning approach to foster interdisciplinary collaboration through inclusive community engagement. Related training programs may adopt a similar approach to build leadership skills among professionals in health care, public health, and education, and promote optimal health outcomes for children with I/DD.

Plain Language Summary

In this article, we describe three research projects that used a method called experiential learning to improve leadership skills and program care for children with intellectual and developmental disabilities (I/DD) and their families. We find that when healthcare providers, public health leaders, and educators work together in this way, it can lead to positive health outcomes for children with I/DD.

Background

Children represent nearly one quarter of the U.S. population, and approximately one in six has an intellectual or developmental disability (I/DD) or developmental delays (Child and Adolescent Health Measurement Initiative, 2018; U.S. Department of Health and Human Services [HHS], 2015; Zablotsky et al., 2019). In accord with the joint position statement of the American Association on Intellectual and Developmental Disabilities (AAIDD) and the Arc, authors define I/DD as individuals with intellectual disabilities and/or developmental disabilities, which includes disabilities that may be intellectual, physical, or both (AAIDD, The Arc of the United States, 2016). Effective programming and evidence-informed advocacy are essential to promoting optimal health outcomes for children with I/DD who experience multiple challenges and persistent disparities in accessing quality healthcare and support services (Halfon et al., 2012). Community, state, and federal organizations exist to address the diverse needs of children with I/DD and their families, yet these organizations generally have specific foci and may not be designed to form the effective partnerships needed to optimally address needs (Margolis et al., 2013; McGrath et al., 2019). Training future care providers, public health leaders, and advocates could focus on essential interdisciplinary communication, negotiation, and conflict resolution skills, but seldom does (Clarke & Cilenti, 2018; Kavanagh et al.,

2015). Likewise, training that includes collaborating with community stakeholders and working on interdisciplinary teams within various healthcare and government systems could be beneficial but is seldom provided (Margolis et al., 2013).

This article offers perspectives for educators to understand the benefits of participatory action research (PAR) in an interdisciplinary context and presents ways that PAR could be included in training programs to encourage future leaders and providers to understand the needs and barriers of populations from within the group itself and work collaboratively towards supporting inclusive services and positive change. We describe three PAR projects from an interdisciplinary training program, Leadership Education in Neurodevelopmental and Related Disabilities (LEND), at Georgia State University, which used experiential learning to enhance leadership competencies and advance local disability advocacy and support programs. Participating LEND trainees report the influence and perceived impact of experiential learning through PAR on supporting their leadership growth.

Participatory Action Research as Experiential Learning Tool

In order to prepare future professionals for effective interdisciplinary work, it is important for training programs to allow students to be active partners in the learning process

through experiential learning. As a framework, experiential learning theory includes opportunities for experience and practice, reflection, conceptualization, and experimentation (Kolb, 1984). Experiential learning theory has been used as a framework within interdisciplinary training programs to support activities such as simulation-based learning (Poore et al., 2014; Stocker et al., 2014). However, there is limited examination of ways in which community-engaged research projects can be included in an experiential learning theory framework for an interdisciplinary training program, such as through PAR.

PAR is a continuous and integrative set of processes and principles designed to foster meaningful collaboration between researchers, community members, and organizations as they address contextually relevant problems and provide support and advocacy for change (Greenwood et al., 1993; Kidd & Kral, 2005; McTaggart, 1997). PAR has been employed in the healthcare, public health, and education fields to engage stakeholders as they assess health-related needs and develop feasible, culturally relevant, and effective responses (Akintobi et al., 2014; Rodgers et al., 2014). In PAR projects, contextual relevance is enhanced by soliciting and valuing the views and experiences of all participants, especially community members, throughout the inclusive PAR knowledge acquisition, translation, and dissemination processes (Dudgeon et al., 2017). Although PAR is fundamentally centered around research, education, and action, it differs

substantially from traditional research in the manner in which it facilitates action or change to address the identified needs, as continuous engagement and collaborative communication require additional expertise beyond traditional research skills (Dudgeon et al., 2017). Facilitating change requires future professionals to engage in both personal and professional self-reflection as they examine the interface of their chosen profession and community needs (Baum et al., 2006). This process is similar for researchers engaged in PAR. As such, PAR can be a way for future professionals to gain direct experience with community engagement, advocacy, and inclusive, person- and community-centered practice, while also allowing learners to reflect on their own experiences to foster professional growth.

In combination with the experiential learning theory framework, PAR can be employed as an experiential learning tool to develop leadership skills using the mechanisms of self-determination theory (SDT), which is a well-developed approach for the study of the relationships between intrinsic/extrinsic motivation and cognitive/social development (Niemiec & Ryan, 2009; Ryan & Deci, 2000). Essentially, SDT seeks to enhance intrinsic motivation by facilitating human interactions that meet the core psychological needs of competence, relatedness, and autonomy (Ryan & Deci, 2000). In SDT, people are at their most satisfied, productive, and intrinsically motivated when they engage in tasks that are challenging but achievable (competence), work with others

toward a valued goal (relatedness), and have the agency to make meaningful choices (autonomy). PAR projects can provide the means to both engage interdisciplinary leaders in such activities themselves and learn to lead others using the principles of SDT. Consequently, SDT builds upon individual competencies and expertise to support leadership growth (Truscott et al., 2012), which is similar to what McTaggart (1997) called the "self-reflective spiral," wherein PAR requires sequences of reflecting, planning, engaging, and observing leading to personal and organizational growth. As such, including PAR projects in healthcare, public health, and education leadership training programs can provide an evidence-based method to engage trainees in processes that support change by considering the needs, barriers, and contexts of children with I/DD and their families.

Participatory Action Research and Georgia LEND

To promote optimal health outcomes for children with I/DD and their families, the Maternal and Child Health Bureau funds programs that provide developing leaders with tools and training to strengthen infrastructure and effectively address systemic challenges of children and families (Clarke & Cilenti, 2018). LEND programs are one example. LEND is an interdisciplinary, graduate-level leadership training program designed to develop future leaders with the skills to improve

systems of care for children and adolescents with, or at risk for, neurodevelopmental and related disorders (Health Resources and Services Administration, n.d.). There are currently 52 LEND programs across the country, each using a unique approach to develop clinical competence and leadership skills in research, teaching/training, and policy/advocacy (Association of University Centers on Disabilities, 2011; Leff et al., 2014). LEND programs encompass faculty members and trainees from a range of health and disability-serving disciplines, and often include individuals who identify as having a disability and/or their family members.

Like most LEND programs, Georgia LEND (GaLEND) trainees participate in didactic and experiential coursework on neurodevelopmental disabilities, systems of care, and leadership. They also participate in a longitudinal, team-based PAR project. This PAR component was developed to provide trainees with hands-on experience in identified maternal and child health leadership competencies of communication, negotiation and conflict resolution, interdisciplinary/ interprofessional team building, and working in and promoting inclusive systems and communities (HHS, 2018). Following the highly collaborative nature of GaLEND and the PAR approach, 2016-2017 PAR project participants also included post-doctoral fellows from the Morehouse School of Medicine's Satcher Health Leadership Institute and public health students from Emory University's Rollins School of Public Health in addition to LEND trainees. Consistent with

experiential learning theory and SDT, the PAR component of GaLEND training provided opportunities for trainees to work collaboratively. Trainees worked within their competency range but also practiced skills that enhanced their capabilities. By forming interdisciplinary teams of professionals, self-advocates, and family advocates, GaLEND trainees were able to integrate more meaningfully into partnerships with each organization. This unique aspect was built into the GaLEND projects, which added value to trainees' experiential learning and enabled them to operationalize SDT more thoroughly throughout the PAR process. SDT's intrinsically motivated outcomes provide a critical platform for learning (Niemiec & Ryan, 2009). Accordingly, trainees predominantly focused on the educational outcomes of the process (i.e., maternal child health leadership competencies and PAR as a process for growth) alongside the research and action components of PAR.

GaLEND faculty aimed to create opportunities for trainees to contribute to broader PAR initiatives through time-limited participatory projects designed to be completed within the LEND training cycle. As such, trainees engaged in a streamlined PAR adaptation (as full PAR projects are often multi-year initiatives). Trainees exercised some autonomy in deciding which project to join and in using their unique interests and skills on the team project. Although the PAR projects were consistent with SDT, trainees were initially unaware of the intended theory of change. The core value

of the PAR process lies less in a theory of change, and more in the opportunities for real-time experience working with community partners, which ultimately required trainees to improve their skills in communication, negotiation and conflict resolution, interdisciplinary/ interprofessional team building, and working in systems and communities.

Approach

This paper illustrates the impact of selected PAR projects implemented by GaLEND trainees and describes trainees' perceptions of how participation on those projects promoted growth in specific maternal child health leadership competencies. Each case presentation describes the process of community engagement, highlights trainee experiences, and reflects on PAR as a process for promoting inclusion and integrating the vision of community organizations in the context of limited resources. Perceived trainee leadership growth will be discussed in light of experiential learning theory and SDT and provide preliminary information of perceived competencies for future investigations and future leaders.

Case Presentations

The three projects described below are representative, but not exhaustive, examples of GaLEND PAR projects. Each was implemented in collaboration with either a nonprofit

healthcare organization serving individuals with I/DD (Projects 1 and 2) or a state health department (Project 3). Each project resulted in improved skills in leadership, conflict and resolution, interdisciplinary team building, and communication among trainees, as well as positive outcomes for community members. Throughout each project, trainees were required to think critically about the needs of families, consider cultural responsiveness, and focus on the intentional and inclusive nature of family-professional partnerships required for successful implementation. These projects engaged in preliminary work with community partners and as such, did not include any research activities with human subjects and did not require an Institutional Review Board approval.

Project 1

Trainees collaborated with a healthcare organization that served the medical needs of individuals with I/DD and aimed to (1) evaluate the evidence for fitness and nutrition interventions to reduce obesity in adults with I/DD, and (2) implement and evaluate the impact of three pilot workshops developed by trainees and organizational staff. Project outcomes featured reproducible workshops that resulted in 100% attendance by agency patients and their caregivers. Post-workshop outcomes indicated that attendees increased knowledge and skills to make responsible health and wellness decisions and planned to continue making healthy decisions in

the future. Anecdotal reports from patients, staff, and patients' caregivers indicated that attendees were more aware of their food and beverage choices. The facilitation of the workshops encouraged internal coordination among the trainee group, as well as external collaboration with the healthcare organization. Implementing the workshops in an inclusive and culturally appropriate manner enabled the trainees to meaningfully engage the community members and offered opportunities to reflect on their experience between each workshop.

Project 2

Trainees collaborated with a healthcare organization to assess the broad network of services provided to individuals with I/DD transitioning from pediatric to adult care, and identify improvement areas in their direct healthcare provision. Over the course of the project, trainees communicated with the organization's leadership and stakeholders to (1) evaluate literature on the current state of practice for adults with I/DD, (2) participate in clinical observations, (3) develop and pilot a protocol for stakeholder focus groups, and (4) develop a client satisfaction survey. This work highlighted the importance of inclusive, person-centered care and identified challenges experienced by individuals with I/DD and families. Trainees observed evidence-based practices to support inclusive, person-centered health care delivery (e.g., fluid communication among providers, patients, and parents; transparent billing practices; and comprehensive care plans

established in real time), and identified needs to improve access to quality care for individuals with I/DD, include the patient in care planning, and enhance patient and family autonomy while administering care tailored to the patient's needs (i.e., supported decision making). The activities involved in this PAR project provided a comprehensive experience for trainees to practice and advance their communication and advocacy skills and reflect on their experiences at different points throughout the project timeline.

Project 3

Trainees worked directly with a state health department to conduct a needs assessment for the implementation of audiology telehealth services (i.e., tele-audiology) for children with hearing loss living in rural areas. To conduct their research, trainees (1) conducted a comprehensive literature review of implementation barriers and successful practices for telehealth and tele-audiology in rural areas; (2) interviewed stakeholders from an early childhood hearing screening program, statewide telehealth program, nonprofit rural emergency medical technician program, and newborn hearing screening services to gather information about program experiences, barriers and successes, current project status, previous evaluations, and lessons learned about implementing telehealth protocols; and (3) created educational materials and surveys for medical and public health facilities. Project outcomes included a presentation of telehealth best practices

to the state health department to inform next steps and connect with additional community stakeholders. Additionally, trainees created educational fliers describing the tele-audiology process to present to families, and created family and provider surveys to collect feedback on future tele-audiology services. In working collaboratively with the state health department, trainees were able to practice communication skills by directly interacting with community stakeholders and reflecting on community needs. The creation of materials also allowed trainees to participate in the process of survey creation and practice inclusive, person- and community-centered engagement.

Findings

After completion of the PAR projects, the authors invited GaLEND trainees to reflect on their experiential learning in both group discussions and an individual survey of their perceptions of the PAR project's impact on their leadership competencies. In combination with a greater overall understanding of inclusive, patient-centered approaches for individuals with I/DD, trainees reflected on the influence of their PAR project involvement on specific leadership competencies, including communication, negotiation and conflict resolution, and interdisciplinary team building (Maternal and Child Health Leadership Competencies, HHS, 2018). The leadership competencies commonly mentioned by

trainees as areas where they experienced personal and professional growth included skills in negotiation and conflict resolution, interdisciplinary team building, communication, and family-centered care. Respondents commented that although developing leadership competencies was not an explicit PAR project goal, the skills were required indirectly and supported by the GaLEND faculty through reflective discussions. Trainees also reported perceived growth and increased competence in areas of professionalism, cultural responsiveness, interdisciplinary team building, and working with communities and systems. Overall, trainees reported greater awareness and value of patient inclusion in all aspects of healthcare planning and inclusive decision-making as an outcome of participation in the PAR projects.

Discussion

Although the PAR projects presented many opportunities to learn, they also presented challenges. Implementation challenges arose in areas such as establishing and maintaining communication with multiple and varied stakeholders, differences in timeline expectations between community partner and trainees, and decision-making related to focus groups implementation. Meeting the challenges required trainees to develop problem-solving, negotiation and conflict resolution, and priority-setting skills as they resolved differences with stakeholders, which also attributed to PAR as

a positive experiential learning tool. GaLEND faculty mentors supported trainee skill-building via coaching and guidance on communication and negotiation, resulting in improved engagement with stakeholders and interdisciplinary collaboration among trainees.

Findings from the case studies presented herein complement and extend knowledge gained from previous studies on PAR efforts within healthcare, public health, and education leadership training programs. Vargas et al. (2012) indicated the value of community engagement processes that foster leadership skills for clinicians in training and advocacy skills for families. Recent evaluations of similar leadership training programming indicate that participants continue to demonstrate interdisciplinary leadership in settings serving communities that have been marginalized following their training (Kavanagh et al., 2015), and that LEND participants develop inclusive, family-centered care attitudes, skills, and principles (Keisling et al., 2017). Similarly, findings from the survey indicated that trainees reported growth in the areas of negotiation and conflict resolution, interdisciplinary team building, communication, and family-centered care—skills directly related to the core psychological needs described in SDT. PAR supported leadership growth in trainees by building skills, knowledge, and relatedness while working in interdisciplinary teams, as well as practicing autonomy in their work as leaders. The collaborative work environment provided a valuable opportunity for trainees to gain experience

implementing inclusive leadership practices, expanding advocacy skills, and highlighting the impact of the I/DD network in community-based settings.

Implications for Practice

Consistent with a growing consensus on the need for inclusive, family-centered systems to serve children with I/DD and their families, future professionals require knowledge and experience in leadership qualities that enhance such systems. PAR's guiding principles and collaborative nature offer a promising approach to teach professional skills and promote inclusion in professional and community-based settings. Trainees perceived that participation in PAR projects contributed to the overall effectiveness of the GaLEND experience. GaLEND faculty members facilitated that effectiveness by defining, discussing, and reflecting on individual and collective leadership development during the process. The PAR projects supported GaLEND program goals by ensuring their relevance to participant needs (i.e., patients and caregivers, organizational staff, community partners). Each PAR group had opportunities to build leadership competencies through the experiential process, including negation and conflict resolution skills, interdisciplinary team-building skills, communication skills, and family-centered care skills.

These results parallel evaluations of other LEND and

healthcare, public health, and education leadership programs with similar projects for trainees (Humphreys et al., 2015). Likewise, application of SDT in leadership training enhanced trainee opportunities for leadership growth specific to the needs of each individual via self-direction and self-reflection inherent in the PAR process. Self-assessment of growth in domains of leadership competency strengthened the reflective process. Collectively, the PAR experience will extend the reach of the LEND experience and trainee interactions with future communities of practice, public health systems, and policies.

Conclusion

Future health and human service professionals play a critical role in supporting the health and well-being of children with I/DD and their families. Collective efforts, as expressed in PAR, offer the best opportunities for individual providers and organizations to identify needs, perspectives, models of service delivery, and best practices that foster inclusion of individuals with I/DD within their communities. PAR offers applied research opportunities to develop trainee leadership competencies while also providing rich and meaningful experiences from inclusive, person- and family-centered approaches to care provision and research. The GaLEND case examples highlight the importance of mentored experiences with community organizations and the value of integrating individuals with I/DD and family advocates into the

interdisciplinary teams. PAR can serve as a model for similar LEND programs to develop future leaders who are able to work collaboratively and inclusively with individuals with I/DD and community stakeholders.

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4.

PERCEPTIONS OF COLLEGE STUDENTS WITH AUTISM SPECTRUM DISORDER ON THE TRANSITION TO REMOTE LEARNING DURING THE COVID-19 ON THE TRANSITION TO REMOTE LEARNING DURING THE COVID-19 PANDEMIC PANDEMIC

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Perceptions of College Students with Autism Spectrum Disorder on the Transition to Remote Learning During the COVID-19 on the Transition to Remote Learning During the COVID-19 Pandemic Pandemic PDF File

Abstract

COVID-19 caused a major shift in how college students, including those with disabilities, received their education during the Spring 2020 semester. The rapid shift to remote learning resulted in new challenges, but also some benefits for students. This study presents the results of open-ended responses of a cohort of 31 students with autism spectrum disorder (ASD) who were part of a larger study and enrolled in very competitive to highly competitive institutions (as rated by U.S. News and World Report) during the Spring 2020 semester regarding their experiences—both positive and negative—in shifting to remote learning. The students described advantages (including personal and academic benefits) with remote learning as well as disadvantages. These problematic areas included the structure and infrastructure of course delivery,

environmental factors, social factors, and personal factors. Specific examples of each are presented to help richly capture the experiences of these students during an unprecedented period in history.

Plain Language Summary

COVID-19 required most college students with autism spectrum disorder (ASD) to take their courses remotely during the last part of the Spring 2020 semester. This resulted in both benefits and challenges for students. Thirty-one college students with ASD described their experiences and what went well and what were challenges. Advantages included more convenient schedules. Challenges included taking courses online, learning at home, and less chances to talk to teachers and peers. We provide comments from the students that describe their experiences during this unique time.

Students with disabilities constituted 19.4% of all undergraduate students in American colleges and universities in the 2015-2016 academic year (National Center for Education Statistics, 2019) and those with autism spectrum disorder (ASD) are reported to be an increasing subcohort within this group (Dijkhuis et al., 2020; Hillier et al., 2018; Van Hees et al., 2015). The most recent available national data

related to students with ASD in college comes from two sources. The National Longitudinal Transition Study-2 (Sanford et al., 2011) reported that 46.6% of students who received special education services under the ASD category went on to some type of postsecondary institution, more often to a 2-year school (32.6%) than to a 4-year school (20.4%). The U.S. Department of Education (2017) reported similar numbers with 33% of students with ASD who graduated from high school attending a 2-year school and 20.9% attending a 4-year school in 2013.

The extant literature notes that college students with ASD are likely to face academic and nonacademic challenges in college that can more often lead to unsuccessful outcomes than for their peers (Bolourian et al., 2018; Cox et al., 2017; Dijkhuis et al., 2020). Reis et al. (2021) interviewed 40 college students with ASD. Participants reported that difficulties with mental health issues, time management and organization, and unclear instructional delivery by instructors were the major barriers to their academic success. They also noted that they responded more effectively to instructors who were passionate about their content area and were empathetic to student needs.

Given that this was the context prior to the switch to remote learning in March 2020 necessitated by the COVID-19 pandemic, it is important to consider how students with ASD were impacted by this shift. It was estimated that over 96% of postsecondary institutions in the U.S. transitioned to remote learning during the Spring 2020 semester because of the

pandemic (College Crisis Initiative @ Davidson College, 2021), and moreover, this was a rapid shift that took place within a few weeks (Madaus et al., 2021).

Several studies and nonpeer-reviewed articles have been published over the past year that explore the experiences of students with disabilities during this time period, but none have examined the perceptions of students with ASD specifically. The Association on Higher Education and Disability (AHEAD) from the U.S. surveyed their members (i.e., staff at disability service offices; Scott & Aquino, 2020) and found that their members perceived that online learning was more difficult for students with disabilities versus the general population of students during the Spring 2020 semester—immediately after the shift to remote learning. A follow-up investigation of this group reported that disability service professionals perceived that those students were having less difficulty during the Fall 2020 semester (Scott & Aquino, 2021).

The change in instructional delivery also brought changes in the types of accommodations needed and received by students with disabilities as well as in the environment in which students worked (Lalor & Banerjee, 2021; Madaus et al., 2021). Kunkes (2020) and Zhang et al. (2020) conducted surveys of college students with disabilities at specific institutions and both reported that students indicated that their needs for accommodations changed in the remote learning environment. Zhang et al. also found that students

with disabilities reported having high levels of distress and anxiety during the Spring 2020 semester. These findings were echoed in a sample of Irish college students with disabilities—the majority of whom disagreed with an item that said they were coping well with the shift to remote learning (AHEAD-Ireland, 2020).

Madaus et al. (2021) surveyed 334 college students with disabilities from across the U.S. Similar to the previously cited research, the students in this sample indicated that they required a shift in their accommodation needs. They reported feeling supported by their instructors and the staff they work with at the disability services offices. They also noted that family demands (i.e., working from home or caring for family members) negatively impacted their learning during the shift to remote instruction.

Given the increasing numbers of college students with ASD and their previously noted unique academic and nonacademic experiences, it is important to understand these perspectives during this unique historical moment. Thus, this study captured the perspectives of a sample of 31 (N = 31) college students with ASD, who were participating in another study about the experiences of college students with ASD, and who completed pen-ended written response related to their experiences in the Spring 2020 semester during the switch to remote instruction.

Methods

The current investigation expanded upon the research of Reis et al. (2021), who interviewed 40 academically talented college students with ASD. Institutional Review Board approval was received to conduct the investigation, and recruitment emails were sent to the accessibility services office at very competitive to highly competitive postsecondary institutions. Interested students needed to meet the inclusion criteria, which included (a) the student was in college or was a recent graduate; (b) had been diagnosed with ASD by a K-12 school, a clinical psychologist, or psychiatrist; (c) was receiving services from a college accessibility services office on the basis of ASD; and (d) had a history of being identified as a gifted or talented student in K-12 education or of participating in a gifted education program. Each student also agreed to participate in any follow-up questions that emerged. Participants provided informed consent and were provided with a $20 gift card after the interviews were completed.

As noted, 40 students with ASD who were enrolled in or were recent graduates of 4-year postsecondary institutions located in Western, Midwestern, and Northeastern states participated in either face-to-face or virtual interviews about their high school and college experiences. Each of the institutions was rated as a top college or university in the U.S. in the *U.S. News and World Report* (2021) *Best National University Rankings*, and eight were private schools and two

were public schools. A profile of the total sample of students interviewed in the parent study indicates that 22.5% were first-year students, 12.5% were sophomores, 20% were juniors, 15% were seniors, and 10% were graduate students. An additional 20% were in-between years in terms of academic credits earned at the time of the interviews. Each of these students were registered with their campus disability support office as a student with ASD.

As part of the parent study, a follow-up electronic questionnaire was sent to all 40 participants interviewed. Given that the time frame overlapped with the Spring 2020 semester, the following open-ended questions were added.

- During the Spring 2020 semester, what were your experiences with the transition to online learning?
- What benefits or advantages did online learning offer you?
- What barriers or disadvantages did online learning offer you?

Present Sample

Thirty-one students (of the 40 students contacted) responded to this questionnaire, which represents 78% of the students who participated in the parent study. Of these, most identified as male (58%), followed by those identifying as female (32%), and non-binary (10%). Twelve percent of the respondents

indicated having a disability in addition to ASD. The students ranged in terms of class standing, with 19% reporting as first-year students, 7% as sophomores, 16% as juniors, 19% as seniors, and 10% as graduate students. An additional 26% of the students were in-between one of these class standings credit-wise, and one student (3%) was a recent college graduate. Twenty-six out of the 31 students (87%) indicated majors in the following areas: STEM (e.g., civil engineering, software engineering, computer science, physics, psychology, pathobiology, atmospheric science); business (e.g., journalism, economics, business analytics, digital media and design, management information systems); or liberal arts (history, creative writing, dramatic writing). The remaining students did not indicate a declared major. As noted, 78% of the students who participated in the full-interview parent study responded to the follow-up survey and the demographics of this subsample were representative of the whole sample of 40 students. Thus, we consider this subsample to be acceptable as this was an exploratory study that sought to assess how a sample of college students with ASD responded to the transition during the rapid shift to online learning in the spring of 2020.

Data Analysis

Data analysis followed the guidelines suggested by Braun and Clarke (2006). The first two authors began the analysis by

independently doing a broad reading of each response and identifying common statements. As Braun and Clarke described, they "generated an initial list of ideas about what is in the data and what is interesting about them" (p. 88). They then collaborated to identify and define specific codes and subcodes over three rounds of review and discussion and a final set of codes and subcodes was established. The data from the respondents were then entered into Dedoose, a qualitative data analysis software program. The two authors independently coded each response using the determined codes and subcodes. Discrepancies were identified and the two authors met and resolved each. The third author conducted a reliability check with 25% of the excerpts. A Kappa of .65 was calculated, which is within accepted guidelines (Syed & Nelson, 2015). A frequency analysis of each code was conducted, and the codes were re-examined and, in some cases, collapsed into other codes if there was insufficient data to support them as a unique code. Two broad themes emerged: (1) benefits of remote learning, and (2) drawbacks to remote learning. Within each, subthemes were identified and described, as described below. A thematic map of the data is shown in Figure 1.
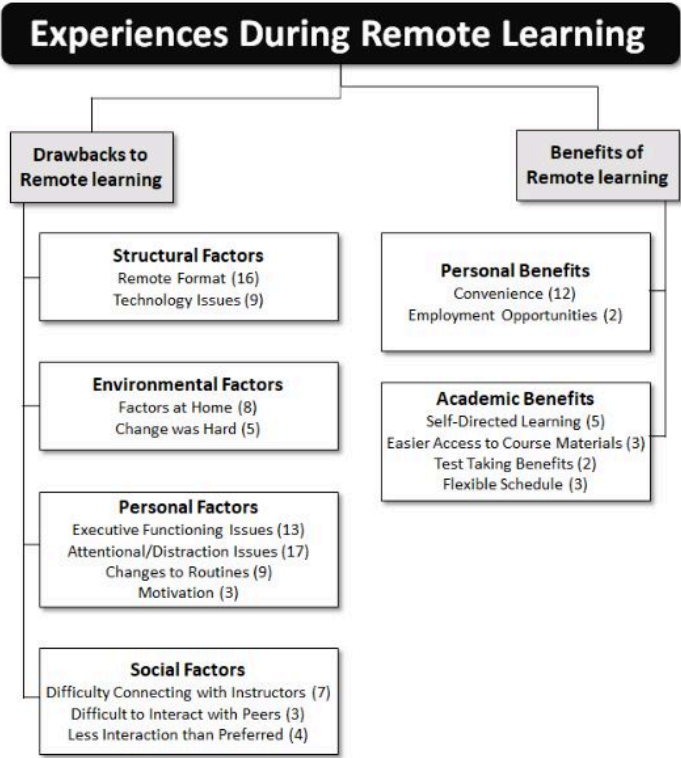
Figure 1 *Thematic Map of Experiences During Remote Learning*

Results

Benefits of Remote Learning

Student comments that described the benefits of remote learning clustered into two subthemes—personal benefits and academic benefits.

Personal Benefits

In terms of personal benefits, the most commonly mentioned advantage of remote learning was the convenience (n = 12). For example, students described being able to get ready for class quickly, with less preparation, and being able to better set their own schedule to study with the extra time. A male student wrote, "I had a lot more time to study because I wasn't walking back and forth, looking for food, looking for a place to study between classes, or trying to recover from anxiety." A female student wrote, "It was nice to not actually have to drive to campus and park and take the shuttle first thing in the morning." Another male student described that "I was having sleep problems during the semester, which made it hard to attend class but having it online made it much easier to participate in class."

Academic Benefits

The most common academic benefit to remote learning, cited by five students, was that remote learning allowed them to self-direct their learning and one student described that he was able to "target my studying to the time of day when I felt most alert." A male student from a 4-year postsecondary institution wrote, "I felt like I could do assignments more freely and in my own time. I didn't feel as pressured to do things at an incredibly fast pace." Another male student wrote, "I enjoyed

having the opportunity to devote time to individualized learning without fear of distraction."

Three students commented on the benefits afforded by having a more flexible schedule, with one male student stating, "I found it much easier on my schedule since due dates were much more flexible and I was able to do my schoolwork in accordance with my schedule." The same student wrote, "I took up a part-time job, and I found the online format was easy to work around with my part-time job."

Other benefits related to notetaking and testing. Being able to access recorded lectures to watch at any time and having access to online notes was noted by three of the students. One male student stated that "it was nice to be able to watch lessons without having to be there all the time and make my own schedule for completing work." Two students commented on benefits of taking exams remotely. As a female student wrote, "online exams were more comfortable for me than in-person exams."

Drawbacks to Remote Learning

The student responses also described drawbacks or disadvantages to remote learning. These clustered into four subthemes: (1) structural factors, (2) environmental factors, (3) student personal factors, and (4) social factors.

Structural Factors

Issues that we considered structural centered on such things as the format of remote courses, technology, and dealing with the transition from face-to-face instruction to remote learning. For example, 16 students specifically described how remote learning was more challenging and that the format interfered with their learning, especially when course structure and expectations changed. Some students mentioned specific content areas, such as art, acting, painting, music, dentistry, second language classes, and courses with group work that were more challenging remotely than face-to-face. A male student from a 4-year postsecondary institution wrote, "Some barriers I encountered were consistent changes in curriculum, which was difficult since I do have difficulty adjusting and adopting to sudden deviations from a routine." Another male student from the same 4-year postsecondary institution described,

> I certainly know that I have an incredibly difficult time learning online compared to in a classroom, particularly when a professor merely posts videos or PowerPoints (sic) or uses some other format that completely loses the interactive experience of learning.

One student explained that the rapid shift also impacted instructors, which in turn impacted students, stating:

> Most of the issues with the online learning were that the teachers were thrown into this as fast as the students were,

so they had to scramble to figure out how to teach online
just as we were scrambling to learn.

Nine students commented on issues with technology that negatively impacted their learning. These tended to center on internet connections, and as a male student described, "The biggest transition was that our new songs could no longer be performed live, as no two bandwiths (sic) on zoom are created equal." Students also commented on the impact of technology issues impacting social interactions. As summarized by a male student, "Internet issues often made online calls a bit difficult."

Environmental Factors

A number of students expressed that they experienced challenges leaving the campus environment and returning home (*n* = 8). Some noted that home is where they would normally relax and that it was harder to focus and do work there. One male student wrote, "I found I was having a hard time being as productive working at home as I was at school. It was easier to work faster versus at home." But other students described that the home environment itself created the challenge. This included having space to work, and also family situations that impacted learning. As one female respondent stated, "It was harder to get extra help if needed because of all the chaos going on (especially whilst also living in a turbulent household)." Another female student commented "It was

pretty awful for me, because my family is very large, and it was hard to focus on school."

Personal Factors

Perhaps the most commonly described drawbacks centered around the student specifically, and issues with attention and being distracted (n = 17). One student wrote, "I became too easily distracted in the familiar environment," while another stated, "It did also mean that I had less impulse control, as I could access the internet whenever I wanted during class hours." One female student wrote that "I kind of have a Tetris addiction, and I'd be tempted to play or surf the web instead of listen." A male student described:

> The biggest disadvantages was [sic] what I would call P.Q.S. "pandemic quarantine syndrome." I actually had significant time to watch Netflix and catch up with friends and especially old high school friends that I never had before. While this did not impede my work flow and output, it definitely [sic] productivity harder and also more draining.

Thirteen of the students described the impact of executive functioning skills (most commonly around time management) on their learning in remote environments. One student stated, "My time management was worse than it was with in-person classes, the long class times were monotonous." A male student from a 4-year postsecondary institution described that

"Online learning was harder in some ways because different classes had different deadlines and I had a hard time remembering when they all were."

Nine students described challenges dealing with changes to their routine. One student stated, "I hated having to live at home again instead of campus, as I had just gotten done acclimating to being on campus and then I had to transition again and live at home." Another wrote, "I was in the grove [sic] of things on campus. My routine was set in stone. I felt very independently driven. At home I had to readapt everything routine wise."

Social Factors

Students commented on the drawbacks of not being able to interact or communicate with their professors and peers. Seven students focused on not being able to obtain the live time support and answers to questions that are available in face-to-face learning. This included not receiving answers to emails and having professors with inconsistent office hours. One female student from a 4-year postsecondary institution summarized these concerns this way, "I also did not have professors readily available, as they now had to do more at home with their own families and children, which I understand entirely, but was frustrating as a student." Another female student stated, "The barriers I faced were emailing professors and not getting answers to questions about assignments in a helpful way. Sometimes, the professors only

respond to emails once per day, then the next thing you know, it's exam day." Another noted, "Office hours with instructors moved around frequently and the Zoom links would change from time to time, which led to some initial frustration. All in all, it was an interesting experience."

Social interactions with peers were also noted as a challenge by three students. One female student commented that online learning "did not allow me as much connectivity with my peers as I would have liked." The other two students commented on the impact of lack of connection on group projects. As one female student wrote, "Group assignments became harder because I actually had to contact other students who I didn't really know."

Discussion

To the authors' knowledge, the present study was one of the first to explore the experiences of college students with ASD specifically during the shift to remote instruction during the Spring 2020 semester. Studies of heterogenous samples of students with disabilities collected during the same period noted that students indicated that they needed different accommodations in online environments (Kunkes, 2020; Madaus et al., 2021; Zhang et al., 2020). The students in the present study did not comment on their accommodations specifically but many discussed how the environment (both the space in which they completed work and the remote

learning environment) impacted their learning. For example, many participants noted that working from where they lived was challenging as they found it difficult to relax. They also reported more distractions in this environment, a finding echoed in research conducted with heterogenous samples of college students with disabilities (Madaus et al., 2021).

The students who participated in this investigation were clear that there were some advantages to remote learning; namely the convenience of being able to work with a more flexible schedule and at a pace that was more self-directed. While this may be in part due to the way the prompt on the electronic questionnaire was worded, this finding echoes the results of Madaus et al. (2021) whose sample reported on the convenience of remote learning in terms of self-scheduling and pacing. Madaus et al. also found that students felt their instructors effectively communicated with them but did not feel as connected to their instructors or other students in the remote learning environment. The students in the present study also noted feeling less connected and experiencing social difficulties in the online environments. College students with ASD have been reported to have social challenges also in the traditional instructional paradigm. Hillier et al. (2018) stated that the students in their sample faced issues with loneliness and social isolation, and both Bolourian et al. (2018) and Van Hees et al. (2015) noted that college students with ASD described a need for social interactions—exhausting as they may be. Regardless of the challenges, the students in the

present study were clear that not being able to interact face-to-face with instructors and to socialize with their friends and peers was a detrimental experience.

Many students (n = 13) in the present study reported issues with executive functioning; specifically, most often regarding time management, changes to routines, and self-scheduling. This is perhaps not surprising given that literature about college students with ASD often describes difficulties in these areas during traditional instruction paradigms in college (Bolourian et al., 2018; Hillier et al., 2018; Van Hees et al., 2015). Therefore, early and frequent emphasis and practice in areas related to time management, setting realistic goals and work deadlines, and work completion should be a key part of secondary transition planning, and when possible, in postsecondary environments via freshmen seminar courses and other academic support initiatives. As colleges offer more remote learning options in the future, it will be important for administrators and instructors to be aware of and address the structural issues that students experienced in the Spring 2020 semester, namely having clear and stable course structure and expectations, with technologies that are consistent and accessible and that allow for timely interactivity among instructors and students.

Implications

Some of the common challenges faced by college students with

ASD in traditional learning settings were perhaps exacerbated by the rapid change to remote learning. Students who relied on routines to help manage academic demands found these thrown off and having to develop new ones in familiar settings. However, these familiar settings often led to other distractions. As students begin to transition back to face-to-face instruction, it will be useful for service providers and other college student affairs personnel to assist them in reidentifying and re-establishing routines and organizational plans that best help the students to readjust. It might also be useful to assist students to re-examine and re-establish social networks and activities that can help them connect with both their instructors and peers. The respondents also noted some advantages to remote learning as they also discussed the benefits of being able to structure their learning and at work at times that were convenient and more productive for them. These types of executive functioning skills can be taught to students and can be of long-term benefit.

Limitations

The switch to remote learning in the Spring 2020 semester was a rapid, complex, and dynamic experience. We recognize that individualized interviews would reveal richer and deeper insights than written responses to an open-ended query. As noted, the students described within this investigation participated in individual interviews about their secondary and

postsecondary experiences as part of a larger parent study. Those interviews began and were held prepandemic, or right as the pandemic was shifting learning into remote formats, so exploring students' perceptions about this topic was not a consideration when the full interviews were conducted. The students agreed to answer follow-up questions about their interview, and the timing of this part of data collection at the end of the Spring 2021 semester lent itself to an inquiry about this topic. We sought to capture and record an important point in history with a purposive sample of students with disabilities at minimal intrusion into their time.

We also recognize that a broad definition of academically talented students was used, in keeping with the rationale used by Reis et al. (2021). Moreover, we acknowledge that the *U.S. News and World Report* (2021) *Best National University Rankings* is only one way to capture the "competitiveness" of the institutions in which the students were enrolled. However, it does provide a commonly used framework by which institutions are ranked, including the competitiveness of their admissions process.

Summary

It is important to note that the present results capture the perceptions of college students with ASD regarding the Spring 2020 semester specifically. However, as noted by Madaus et al. (2021), such descriptions provide future researchers with

a "clear benchmark" for understanding student experiences during this unprecedented point in time. Future investigations should continue to explore student experiences with remote learning, especially as colleges transition to hybrid and eventually back to face-to-face instruction. Given the academic challenges faced by students with ASD, such knowledge is critical to enhancing their success in college.

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PARENTS' PERCEPTIONS OF THE COLLEGE EXPERIENCES OF TWICE-EXCEPTIONAL STUDENTS WITH AUTISM SPECTRUM DISORDER

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Parents' Perceptions of the College Experiences of Twice-

[Exceptional Students with Autism Spectrum Disorder PDF File](#)

Abstract

Students with Autism Spectrum Disorder (ASD) are accessing college in increasing numbers. Within this group, there is a cohort of academically talented students who can be considered twice-exceptional, or 2e-ASD. While research about college students with ASD is increasing, there is a relative dearth of literature about 2e-ASD college students and their secondary transition and college experiences. The current study presents the results of individual interviews that were conducted with 10 parents of 2e-ASD college students to explore their perceptions of their children's experiences, including what things went well and what were problematic areas. Parents described clear and early expectations that the student would attend college and that college provided the student with independence and the chance to be with people who shared similar interests. They described factors that were considered during the college search including the size of the campus and distance from home, and the importance of letting the student take increased responsibility, and if necessary, make and learn from

mistakes. The need to focus on executive functioning and social skills was also noted. Implications for families, secondary transition personnel, and vocational rehabilitation counselors are presented.

Plain Language Summary

Some students with autism spectrum disorder (ASD) attend very competitive colleges. Unfortunately, there is very little published literature about their preparation and their experiences in college. We interviewed 10 parents of ASD college students who go to competitive colleges. The parents talked about things that went well and what things were difficult for their student. They had high expectations that their children would go to college. They also believed this gave their child independence and allowed them to be with people who shared similar interests. Many parents said that it was important to let their child make and learn from mistakes. They also talked about how important organization, time management, and social skills were in college. They described factors that they thought about during the college search. The information shared by these parents can help

families and teachers prepare high school students
with ASD for college.

Autism Spectrum Disorder (ASD) is a group of complex
neurodevelopmental disabilities that may lead to difficulties
with social and communication skills and restrictive, repetitive
patterns of behavior, interests, or activities (American
Psychiatric Association [APA], 2013). Individuals with ASD
may also have a number of strengths and unique skills such as
strong memory, consistency, creativity, dedication, focus, and
an eye for detail (Anderson et al., 2018; Nuske et al., 2019; Van
Hees et al., 2015). Some individuals with ASD have a range of
strengths and can be considered highly gifted individuals (Reis
et al., 2014). Highly gifted individuals with ASD are often
called twice-exceptional students with ASD (2e-ASD). Twice-
exceptional refers to:

> ...students who demonstrate the potential for high
> achievement or creative productivity in one or more
> domains such as math, science, technology, the social arts,
> the visual, spatial, or performing arts or other areas of
> human productivity AND who manifest one or more
> disabilities as defined by federal or state eligibility criteria.
> (Reis et al., 2014, p. 222)

Students who are 2e can be difficult to identify because high
abilities may overshadow the disability or the disability might
hide their high abilities (Reis et al., 2014). This can make it

difficult to determine exactly how many of these students are in K-12 settings and postsecondary education.

Postsecondary Education and Students with ASD

The rates of students with ASD who attend postsecondary education is substantially lower than the general population (Sanford et al., 2011), but their rate of attendance has been steadily increasing over the last decade (LeGary, 2017; Shmulsky et al., 2017). Students who have postsecondary education as a transition goal are more likely to attend postsecondary education (White et al., 2017). According to the National Longitudinal Transition Study 2012 (NLTS-2012), 75% of youth with ASD and 53% of parents of students with ASD expected that the student would attend postsecondary education (Lipscomb et al., 2017). The most recent data on college access of high school students with disabilities comes from the National Longitudinal Study-2. This indicated that approximately 47% of students with ASD were enrolled in postsecondary education within 6 years of exiting high school, but only 35% graduated or completed their programs (Sanford et al., 2011).

The parents of 2e-ASD students can play a critical role in the student's transition to college. They are officially members of the student's special education team, and therefore, are involved in secondary transition planning (Individuals with

Disabilities Education Improvement Act, 2004). Parents may also be involved in researching and helping to select the college that the student attends. This can include finding the right fit in relation to institutional location, size, and amount of support offered (Thierfield Brown et al., 2012).

Parental Roles in the Transition to College

Parents of students with and without disabilities experience a learning curve in regard to parenting when the child transitions to college (Morrison et al., 2009; Sosonowy et al., 2018). Parents of college students with ASD often act as the primary advocates and decision-makers for their young adult (hereafter referred to as child during their time in primary and secondary education; Morrison et al., 2009; Pena & Kocur, 2013; Van Hees et al., 2018). They may struggle to develop a balance between acting as a coach to their children with ASD, supporting their children in navigating the physical campus and campus services while still encouraging independence (Alverson et al., 2019; Pena & Kocur, 2013). Parents may feel that their children may not be ready to advocate for themselves or ask the right questions (Pena & Kocur, 2013). Crib et al. (2019) reported that parents perceived their child's lack of initiative, underlying difficulties with self-regulation, planning and organizing, and keeping track of time as having a negative impact on their transition. Needing to keep boundaries with

their child and finding a delicate balance of pushing them to do things and letting them be independent were also noted by families (Crib et al., 2019). Alverson et al. suggested that there needs to be "a balance between the individual's right to make decisions independently at age 18 and professionals collaborating with the family to ensure that ongoing supports are in place" (p. 62).

Parental Roles When Their Child Is in College

The roles of parents shift when the student enters college. At this point, only the student has a right to their education records under the Family Educational Rights and Privacy Act of 1974 (FERPA). Students may choose to sign a consent form allowing schools to share information and talk with their families, though this could result in a lack of opportunity to practice self-advocacy skills (Barnhill, 2016). Even with consent, parents may be told to limit their involvement so the student can learn to advocate for themselves (Pena & Kocur, 2013). Some parents may remain involved behind the scenes. For example, they may provide support with executive functioning skills, such as organization, as well as with financial and emotional support (Bolourian et al., 2018; Cai & Richdale, 2016).

Other perceived needs identified by parents include finding accommodating professors and identifying someone to serve

as an advocate and point person at the school (Morrison et al., 2009; Pena & Kocur, 2013). Support with study skills, organization, and socialization were also identified as important areas (Sosonowy et al., 2018). Some parents were unsure if their child understood what it would take to live independently and if they could keep up with tasks such as self-care, cooking, cleaning, and scheduling appointments (Sosonowy et al., 2018).

Study Purpose

The current literature base primarily focuses on the experiences of students with ASD in general, but not on 2e-ASD students. One literature review reported that there were no articles that focused on 2e-ASD students (Gelbar et al., 2014). Another recent analysis found the area of educational research on this topic to be lacking and emphasized the need for more research on 2e-ASD students in the field of education (Luor et al., 2021). There is also limited research on the perceptions of parents of 2e-ASD students (Gelbar et al., 2014; Luor et al., 2021; Nuske et al., 2019). Parents play a significant support role in the transition process and when the student is in college, so they offer invaluable perspectives that can assist in improving the experiences of future 2e-ASD college students. The purpose of this study was to add to the knowledge base on 2e-ASD postsecondary education students by capturing parents' perspectives and experiences as their children

transition to 4-year colleges. The study attempted to address first-person perspectives on parental involvement, their child's overall transition experience, and both challenges and difficulties faced in regard to academic and social experiences in college settings.

Methods

Ten parents of college students with ASD participated in individual interviews with the first author. Nine were parents of students with ASD who were enrolled in top national universities as rated by U.S. News and World Report (2021) and who participated in a study of 2e-ASD college students (Reis et al., in press). Each participant in that study was contacted and asked if they would be willing to have a parent be interviewed, and if so, to provide their parent's contact information. In total, 15 students provided this information, and nine of the parents agreed to participate. The 10th interview was conducted with a parent who learned about the study during a professional presentation and volunteered to participate. This participant's student was enrolled in a top regional university as rated by U.S. News and World Report and had been identified as gifted during his K-12 education.

Six of the participants were females and four were males. They all confirmed that their child had ASD; six described different ages of initial identification, including early childhood ($n = 1$), pre-adolescence ($n = 2$), late middle school

(n = 1), and high school (n = 2), while four did not specify an age. Each student discussed was identified as gifted while in K-12 education (n = 6) or took Advanced Placement courses (n = 3) or honors courses in high school (n = 1). Eight of the students identified with the pronouns he/him, one with she/her, and one with they/them. Four of the parents shared that their child experienced anxiety disorders; two that their child experienced depression; and one each mentioned a sensory processing disorder, oppositional defiance disorder, obsessive-compulsive disorder, mood disorder, and a learning disability. Four parents stated that their child did not experience any co-occurring disabilities. Five of the students discussed were graduates of public high schools, three were graduates of private schools that focus on neurodiverse learners, and two attended a combination of public and private schools.

A semistructured protocol was used for each interview. This was based on the protocol used by Reis et al. (in press) in order to ultimately facilitate comparisons of student and parent perceptions of the students' transition and college experiences. The protocols were sent to the participants prior to the interview to allow them to consider the questions being asked. All but one interview was conducted by phone and the other was conducted via videoconference at the parent's request. Each interview was recorded and lasted an average of 46 minutes. The recordings were transcribed and reviewed for accuracy.

Data Analysis

The first three authors analyzed interview transcripts using basic thematic analysis, which is "a method for identifying, analyzing, organizing, describing, and reporting themes found within a data set" (Braun & Clark, 2006, p. 79). The first step involved all three authors familiarizing themselves with the data by both listening to the interviews and reading the written transcripts. Throughout this process, each made notes along the way, documenting their initial reactions to data that may have been relevant to the research questions. Next, each author generated initial codes, or the smallest units of meaning in the transcripts, staying as close to the participants' words as possible. The authors then met to share their initial codes with each other, resolve any coding discrepancies, and note similarities and overlap among the codes. The last of these steps led to the identification of emerging themes. Themes were cross-referenced with the initial codes to ensure that they were inclusive of the codes within them (Braun & Clarke, 2012).

Trustworthiness Measures

The authors incorporated credibility measures into the analysis process to ensure the trustworthiness of the findings. Investigator triangulation, or the use of multiple investigators, was used to analyze the data. The authors also recorded audit

trails to make the analysis transparent. Rich and thick descriptions that relied on the participants' actual words were used as frequently as possible to provide evidence for the authors' interpretations (Merriam & Tisdell, 2016). Finally, the identified themes and corresponding codes were shared with the participants, who were asked to provide feedback on any that they disagreed with or if they felt the themes and codes did not reflect their perspectives and experiences. None of the parents provided such feedback.

Results

Expectations for College

Nine of the parents expressed early expectations that their children would attend postsecondary education. Five parents described how attending college was an expectation because of their child's intellectual capabilities, which aligned with college-level academic work. In addition, two parents mentioned how postsecondary academics involve research and deep exploration of specific topics, which fulfilled their child's need to study special interests. One parent said,

> There was no doubt that from a very early age, my child was happy learning, could contribute and would be enriched in every way with a college education, intellectually, discovery. My child's capacity for research is

so unmet. There was no, no doubt that they will, they will ultimately thrive and, and finish well at college.

Others indicated that special interests drove their child's determination to attend college. One parent explained that her child's interest and abilities in art dictated the school their child selected. This parent said, "it was bar none that she was going to go to college, and it was going to be an art college because this was a kid that everything came out in art form." Another parent commented that her son loved to learn and thrived in environments that met this need. She shared,

> He wants to be an engineer and he's very focused on that. It's a great field for him and he likes to learn new things, so he loves school. I don't know if he could be in a job where he's not constantly learning cause he loves to learn.

Two other parents indicated that because their children were not yet ready to enter the workforce or live completely independently, college was an appropriate next step of their children's transitions. A final parent stated that it was not important to her if her son went to college and that it was up to him to decide if he wanted to go.

College Search Process

Several considerations influenced the college search process for parents and their children, including identifying colleges that were close to home, that offered specific academic majors, and

that contained support services for students with disabilities. Identifying a school that contained their child's academic major of choice was a priority for six parents. One parent explained, "We looked mainly into something where he wanted to go for a major." Parents shared that the availability of academic majors was critical for their children for a number of reasons, including maintaining their intellectual interests and offering courses that could build on their children's prior knowledge or artistic talents.

Seven parents reported that selecting a school that was close to home was their biggest priority, so they could offer support to their children if needed. One parent shared,

> I also looked at schools that were about two hours' drive, two to three hours driving distance range. And that is because in case he had a meltdown, I wanted to, wanted him to be in an area where I could drive and you know, calm him down or, or, or help him get out of the meltdown.

Her child ended up attending college 1 hour and 30 minutes away from home, which the parent characterized as "a good distance." Other parents shared similar sentiments of wanting to be available if their children needed them or in case of emergencies. For the same reason, two parents described not supporting their children's interests in attending schools that were far away. One explained,

> I would only financially support somewhere that we could

drive to within 5, maybe 6 hours in case there was a major problem to go get him, because we had a big concern about his independent living skills.

The second major consideration driving the college search for these parents was the support services offered to students with disabilities. Parents wanted to ensure that colleges supported their children's academic and psychological needs, specifically by providing accommodations, mental health support, and academic counselors. One parent discussed how learning about available services at a college was a definitive moment for her as she helped her son select a college. She said,

> That was the absolute clincher that, and they had a department for, you know, kids that, you know, needed support...emotional stuff and whatever it was, you could see, you know, a psychologist. You could get kinda the executive functioning skills and just have somebody to help you get your homework and get on top of your schedule.

Parents were attracted to colleges that not only offered disability-specific services, but also included other professionals, such as faculty, who created a supportive environment. Offering to help students with general academic skill development, providing encouragement, and reminding students that additional supports were available were areas of importance that parents mentioned. Several parents commented on how these factors helped their children feel that college was an achievable goal for them. One said,

All of the other professors, the food staff, there's just so many people they've met this past year that could not have made my child feel like more success oriented. Like I'm going to do this. I'm going to apply myself. I'm going to love it. Like just excited and proud.

Another described that before enrolling, her son,

...had a couple of visits there and they were very welcoming and he had like a personal interview and they talked to him and I think that really made him feel comfortable, like it was approachable and that he could go there if he had any issues.

Three parents specifically mentioned that the level of support their child required would be more readily available at a small institution, which was another important factor in the college-decision process. One parent discussed not wanting her child to "get lost" in a big school and assumed he "wouldn't be able to get the attention" he needed. Another parent said, "We looked at very small schools where there'd be a lot more personal support." The last parent who shared this concern compared the supports offered by small colleges to the support networks that were available to her son in high school. She said,

A smaller school is better because...his classes are small and his teachers know him by now...people in the disability office know him by now...it's a community where you get to know each other. And when you're in a smaller college, it's a little bit closer to high school. It's not high school,

but you have a community and it's easier. It's not as overwhelming to navigate.

Only two parents emphasized the need for their child to lead the decision, and specifically noted that they tried not to treat their children like children, but young adults. One parent shared the importance of having her son actively involved in the decision-making process. She said,

> It's not treating them like a child, you know, they're, they're young adults and they're going to be adults. And part of that process is taking responsibility for where you go and what you do.

Five parents described that they, themselves, carried out much of the research involved in the college search and application processes, especially regarding how to register for and receive disability services. One parent explained the process of connecting with disability services, stating,

> It was all me. I had to connect and make all these relationships and connect and go behind the scenes like even to the point where two years before helping her figure it out and it was arduous.

Best College Experiences

Two themes emerged regarding parents' perspectives on their children's best college experiences, including enjoying independence and forming or solidifying relationships. Five

parents discussed how their children appreciated living and acting independently at college. One parent said, "He loved the experience. He loved being on the campus. He loved the freedom." Others shared how their children enjoyed independently making decisions, including how they spent money and practiced self-advocacy and responsibility. One parent noted,

> He does do what he needs to do: talk to the TA or the professor, or whatever about some issue, you know, some assignment or something, or for help on a test reviewing material and, and so on. So he was, he was able to do that."

Another parent stated, "He has to advocate for himself cause he's over 18 and I can't be there to like go to set up his appointments and talk to his teachers. He needs to do that and he's taken responsibility."

The second theme involved how students were able to meet and sometimes connect with others who shared their interests. Parents described their children meeting "like-minded" peers in classes and student organizations. One parent said,

> He had met a group of people who had joined clubs that he liked. So, he met people through there. And again, even though he wasn't in a huge group socially, and he didn't hang out with tons of people, there was a core bunch of people that he got along with.

Three parents discussed how their children were connected with student groups for students with disabilities. One said,

> They have a social group at that disability office...if you are
> having a bad week and you want it to end together, have to
> have a pizza group every week and he would go and he met
> some people that way. And it was just like, you go for pizza.
> Sometimes they would bring a dog and that you could pet.

Four parents shared how their children stayed in touch with friends from high school after they transitioned. One parent even noted that his child identified six peers from his high school who attended the same college and they continued to spend time together. He said of his son, "He went to school with like six of his friends. They all caught the bus, so he was comfortable with all his friends...they all went to the same school and the same classes."

Challenging College Experiences

All but one parent (9/10) indicated that executive functioning difficulties were an area of challenge for their children. The most commonly mentioned executive functioning challenge was time management. Students struggled to make schedules for themselves, plan time to study, or ensure they were planning time to care for their basic needs, such as eating meals. One parent discussed her son's difficulty with time management. She said that a challenge for him was,

> Figuring out time management. He has a very hard time
> with that, like the balance. He'll tell me, actually we talked
> yesterday, and he was doing, he told me eight hours of class

> or 12 hours of class. He doesn't have time to eat and I'm
> like, come on, you know? So we had to talk about that a
> little bit.

Other parents noted that their children struggle to follow up
with professors, know what schoolwork to prioritize, check
emails, and determine and use effective study and learning
strategies.

While the five previously mentioned students were able to
form new relationships at college, making friends was a
struggle for the other five students. Parents of these students
described that some of the biggest challenges involved
unstructured communication and social activities, especially
when the student had to initiate interaction. One parent
described, "He does not seek friendships if that makes sense.
If he is in a group and he starts talking to someone, they get
along, then that's fine, but he's not the one to go looking."

Another area of challenge reported by five parents included
the rigor of college-level work. Parents indicated that their
children were surprised, and sometimes disheartened, by the
increased academic demands, especially as academics came
easily to their children in high school. Students were
sometimes shocked by not earning A's, and also the required
level of work they had to complete. One parent said,

> The toughest part was academics because it came relatively
> easy to (name) in high school, but college is a different
> story. He didn't do as well as he thought he would in some

courses, especially the computer science classes, which have
been very difficult for him. So that's one challenging part.

Two parents added that their children were surprised when
work continued to become harder each semester. One parent
shared,

> Second year he got frustrated because it got harder…so he
> got a little discouraged because his grades wasn't what it
> was the first freshman year. And I told him every grade year
> you've to work harder.

A final area mentioned by four parents included dealing with
psychiatric issues. These parents described their children
experiencing depression, anxiety, substance use, or "feeling
upset." These individuals did not clarify if their children
sought or received treatment for these issues, although one
parent shared that she and her child did not seem to think
these services were available. This parent indicated,

> Most of the campus does not have enough mental health
> providers, like, I guess for student counseling. I guess it's
> the supply does not meet the demand. So, there were times
> when I'd say, "Well, can't you call dah dah dah, or can't
> you talk to dah"? And they made it sound like it was
> unavailable.

Supports Used in College

Nine out of 10 parents described that their children registered

for disability services, although one specified that his son chooses not to use the accommodations for which he is registered. The following accommodations were reported: extended time on exams (five students), approval to live in a single room (four), reduced distraction environment for exams (three), reduced course load (three), and note-takers (two). One parent explained why living in a single room was a beneficial accommodation:

> He's always had a single. We always figured just taking out the complication of a roommate would just make sense all along. He's been very happy to kind of be on his own. Well, he's very, he's neat. He's kind of fastidious in, as in, as keeping things the way he likes them. Yeah, he just enjoyed his freedom of kind of being able to go home sometimes and just unwind by himself.

Four parents reported that their children met with a disability services professional for help with course selection, accommodation provision, organization, and general support. One parent said, "She developed a system with someone where they would just do it over the internet when they couldn't do it in person to help her keep on track." Another parent described,

> The school has a good wellness and disability office that helped him write the letters he needed to write to all his professors so he could get the accommodations he needed. And they also have services where if he needed to go talk to someone cause he was upset or frustrated he could too.

One parent discussed the importance of his son's disability services advisor in his college experience, stating "He loves (disability services advisor name). When he has somebody, when he trusts somebody, and deal with somebody that's all he wants to deal with."

Parental Involvement

Five of the parents also addressed the need to allow their children to fail. Parents expressed the importance of "learning to fight (one's) own battle," and how "sometimes you have to fail to succeed." They also described the learning that comes from failing and picking oneself up to try again. One parent said, "It's okay if there's failure because one of the things in life, you've gotta level up to where you can fail and get up and pick up the pieces." Another parent shared that she supports her son but pushes him to self-advocate "as much as he can."

Three parents were frustrated with their inability to set up services for their children or have campus representatives to check in with on their children's progress. One parent described how when her daughter was reluctant to sign up for disability services, she tried to take the lead, but disability services wanted to work directly with the student. She said,

> I told her I was going to go walk in there or she was going to go do it herself and so we had to have a meeting my husband and I with the head of the disability office who

didn't wanna hear from us because its college and you
know and it's how it has to be.

All three parents also indicated that they desired a way to
"check in" on their children when they were unable to contact
them. One parent shared,

> As I recall with moving into a dorm and I couldn't hear
> from her and I was scared something happened...I couldn't
> get a hold of the RA, so I got a hold of the one that runs the
> whole dormitory situation. And she got a note from her.
> She wasn't happy with me, but I just wanted to make sure
> she was safe.

Another parent portrayed a similar situation. He contacted
campus police, who performed a wellness check. He said,

> An officer went over there who was very, very nice about it.
> And eventually, they got his RA and they managed to talk
> to him, and he got out and went down to the cafeteria for
> some food and it was mostly okay after that.

Discussion

Ten parents of 2e college students with ASD shared their
perceptions of their children's transitions to postsecondary
education and their college education. They reflected on the
positive and challenging experiences their children had
throughout their collegiate career thus far. They also discussed
the challenges they faced as they adjusted to their new role

as a parent of a college student. Half of the parents discussed understanding the need to make decisions and to be independent, even if it meant letting their child make mistakes. Despite allowing students to figure things out independently, a few parents were disappointed that they could not be involved with their children's education and work with disability services. This appeared to be a learning curve for several parents in this study.

Some takeaways align with previous research on college students who are 2e and college students with disabilities. Nine out of the 10 parents had expectations that their child would attend postsecondary education. These findings align with current research on students with disabilities, which state that parent expectations are positively associated with a student's likelihood of attending postsecondary education (Chiang et al., 2012; Doren et al., 2012).

The parents discussed the factors that came into play when choosing a college to attend. These included the availability of majors of interest, distance from home, and support available for students. Six out of the 10 parents in this study highlighted the importance of the availability of a major in the student's area of interest. This is similar to findings by LaFave et al. (2018) who reported that a "desired program of study" was ranked as the second most important factor when choosing a college by 74% of high school students. The importance of major availability in an area of interest may be increased because of specialized interests in the ASD population.

Distance of the college from home was discussed by seven parents in the study who preferred that the student be closer to home. In comparison, "being close to home" was only ranked as very important by 26% of high school students when discussing the choice of a college (LaFave et al., 2018). The additional support needs of the 2e-ASD population may explain the greater emphasis on the college distance from home when choosing where to attend.

Social relationships were noted by half of the parents interviewed to be a struggle for their children, which has been previously discussed in the literature on ASD. College students with ASD face challenges with social skills such as maintaining friendships. However, students with a higher sense of belonging have reported greater associated student satisfaction (Dymond et al., 2017; Fleming et al., 2017). Moreover, postsecondary education institutions need to focus on practices that can foster social skills and social relationships for students with disabilities, specifically 2e-ASD students.

Implications for Providers and Parents

The insights of these parents of 2e-ASD students raise implications for parents and for the professionals who support students in the transition process.

Awareness of Support Services in College

The Office of Disability Services is often the primary resource accessed by students with disabilities to receive support. Parents in this study discussed services available as being key in choosing an appropriate college for their child as well as being the driving force in researching disability services on campus. Transition professionals should take the time to discuss disability service options prior to the student conducting their college search process. It can be useful for students to be aware of the services as well as the process required to access appropriate services. Information provided to parents should include the shift in legal responsibility. This includes the differences in services under the IDEA and Section 504 at the high school level and Section 504 and the Americans with Disabilities Act at the college level. Parents should be notified about the impact of FERPA, as they will no longer have access to their children's information at the postsecondary level. Parents should also be provided ways to support their child without attempting to contact the Disability Service Office and allow their child to do so independently. These suggestions may help with the reluctance of students to utilize services and support parents of students with disabilities as they transition into their new roles.

Supporting Students in College

Parents discussed specific challenges that their 2e-ASD children faced in postsecondary education. Almost all of the parents (9/10) mentioned executive functioning as an area of concern. Half (5/10) of parents mentioned challenges with social skills, and four mentioned mental health struggles. These findings align with current research on challenges for students with ASD in college. Executive functioning skills and social skills are noted areas of challenge for students with ASD (Dymond et al., 2017). Students with ASD may also experience co-existing conditions such as anxiety, depression, and social isolation in higher education settings (Fabri et al., 2020; Gelbar et al., 2014). These factors should be considered during the secondary transition process. Planning and services should focus on the development of executive functioning and social skills. In addition, mental health needs should be carefully considered. This includes what types of campus mental health supports are available at the schools that the student is interested. Consideration of factors like distance from home should be thought about if the student works with a private therapist and plans to continue. If the student will need to be connected to a new therapist closer to the college, consideration should be given to finding a trusted therapist and how the student will get to appointments. If the student needs medicine and will be away from home, thought should

be given to how the student can independently manage taking correct dosages and getting refills.

Limitations

As with many other qualitative research studies, this study contained a small sample size. A small sample size limits the generalizability of the results from the study. Participants may also have provided socially desirable responses, which potentially could influence the information that was shared with the researchers. There was also potential for researcher bias, which may have impacted the interpretation of the study results. The researchers who analyzed the data attempted to minimize potential biases by individually coding the data prior to comparing results to determine themes as well as by conducting an audit trail.

Conclusion

The perceptions of parents of 2e-ASD college students in this study provide important insight and implications for other parents, secondary teachers and related services school personnel, and vocational rehabilitation counselors. The importance of early expectations that the student can attend college, and of executive functioning and social skills, are pieces that can be incorporated into secondary transition plans. Families can be supported through an inclusive college search

process that involves parents, students, and counselors. This process can also focus on increasing awareness of support services available at college and providing specific support to this population based on their areas of need.

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6.

COLLABORATION BETWEEN SECONDARY SPECIAL EDUCATION TEACHERS AND COMMUNITY REHABILITATION SERVICE PROVIDERS: A FOCUS GROUP ANALYSIS

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Collaboration Between Secondary Special Education
Teachers and Community Rehabilitation Service Providers: A
Focus Group Analysis PDF File

Abstract

Collaboration by professionals across agencies has
been identified as a research-based practice
associated with successful post-school outcomes for
students with disabilities. Successful post-school
outcomes include community employment,
postsecondary education (such as involvement in 2-
or 4-year college programs), and independent living
for young adults with disabilities. Vocational
rehabilitation counselors, special educators, and
community rehabilitation providers (CRPs) must
collaborate to increase the probability of successful
outcomes, particularly given the advent of Pre-
Employment Transition Services (Pre-ETS). Five
core areas of Pre-ETS include: (a) job exploration
counseling, (b) work-based learning experiences, (c)
counseling, (d) workplace readiness training to
develop social skills and independent living, and (e)
instruction in self-advocacy. The purpose of this
study was to gather qualitative data on the current

status and future directions of relationships between high school special education teachers and CRPs regarding transition service delivery. In this study, focus groups were used to gather information specific to interagency collaboration. Three primary themes were generated: (a) barriers to effective interagency collaboration, (b) collaboration needs, and (c) recommendations to improve collaboration. Barrier included (a) lack of communication, (b) community issues, (c) school issues, and (d) student and family factors. Both special education teachers and CRP professionals offered information regarding needs and recommendations to improve collaboration. Specific recommendations were identified to improve collaboration, such as improving the intake and discovery process by interviewing the special education teacher prior to the Individualized Education Program (IEP) meeting and creating a roles and responsibility chart including methods for communication and follow up, among others.

Plain Language Summary

Students with disabilities have more success when educators work together. Working together is called collaboration. When educators collaborate, students

with disabilities are more likely to get jobs. Students are also more likely to continue with education after high school and live on their own in communities. Legislation states that teachers and other professionals should collaborate. There is a recent law called for "pre-employment transition services," or PRE-ETS. This law is a part of the Workforce Innovation Opportunity Act. This law requires that students with disabilities explore possible jobs with a counselor. The law also states that students should learn job skills at community employment sites. PRE-ETS requires educators collaborate as they work with students with disabilities. The purpose of this study was to gather information about collaboration from educators. The educators were special education teachers and other professionals who help students with disabilities get jobs (called Community Rehabilitation Professionals, or CRPs). We held "focus groups," which means teachers and CRPs met online with an interviewer. We asked questions about how much teachers and CRPs collaborated. The teachers and CRPs told us there were problems that limited collaboration. Teachers and CRPs made several recommendations to improve collaboration. We describe problems preventing collaboration in this article. Also, we

describe the recommendations made by teachers and CRPs.

Successful post-school outcomes for young adults with disabilities in the U.S. continue to lag far behind outcomes of their peers without a disability (Erickson et al., 2019; Newman et al., 2011). Youth with disabilities are less likely to enroll in postsecondary education than their peers without disabilities (Snyder et al., 2016), and those who do attend postsecondary education are less likely to graduate (Fleming et al., 2017). The Office for Disability Employment Policy (ODEP) found that only 43.9% of youth with disabilities aged 20-24 were employed compared to an employment rate of 74.4% of their counterparts without disabilities (ODEP, 2019). Because of poor post-school outcomes facing young adults with disabilities who no longer receive special education services, teams representing educational systems and service-delivery programs must collaborate to increase the likelihood of success.

Interagency collaboration in the transition process has been identified as a research-based practice associated with successful post-school outcomes (Povenmire-Kirk et al., 2015; Rowe et al., 2021, Test et al., 2009). Friend and Cook (2013) defined collaboration in educational settings as "a style of direct interaction between at least two co-equal parties voluntarily engaged in shared decision-making as they work toward a common goal" (p. 4).

Collaboration in the transition process for youth with disabilities has received attention in federal legislation (Brinck et al., 2021). As described in the Individuals with Disabilities Education Act (IDEA), schools must invite agencies to a student's Individualized Education Program (IEP) meeting (IDEA, 2004) if transition services will be provided. When these circumstances exist, IDEA clearly indicates that collaboration with outside agencies is required for transition planning. With the advent of the Workforce Innovation and Opportunity Act (WIOA; U.S. Department of Labor, 2014), Vocational Rehabilitation (VR) professionals may collaborate with secondary special education professionals to ensure secondary students with disabilities ages 14-21 years are provided with pre-employment transition services (Pre-ETS). Five core areas of Pre-ETS include: (a) job exploration counseling, (b) work-based learning experiences, (c) counseling on opportunities for enrollment in comprehensive transition or postsecondary educational programs at institutions of higher education, (d) workplace readiness training to develop social skills and independent living, and (e) instruction in self-advocacy (34 CFR §361.60).

With WIOA, state VR agencies are required to set aside 15% of their federal funds to provide Pre-ETS services to qualifying students. Qualifying students must be aged 14-21, enrolled in an education program (secondary or postsecondary), and have a disability under IDEA or Section 504 of the Rehabilitation Act (Carlson, 2021). Pre-ETS services are to be delivered by

VR counselors or providers with which they contract. Research indicates that VR counselors report being inadequately trained to provide Pre-ETS (Awsumb et al., 2020; Neubert et al., 2018). Neubert et al. found that VR counselors rated the importance of performing pre-ETS services higher than they reported their preparation to actually enact such services. The participation of VR counselors on interagency transition teams is identified as a necessary component for successful transition outcomes for students with disabilities (Luecking et al., 2018; Poppen et al., 2017). Unfortunately, because of the large caseload size and limited time, VR counselors often utilize the services of community rehabilitation programs (CRPs) to provide employment-related services to clients (Ipsen et al., 2019; Schultz, 2008).

CRPs are an important source of employment supports for individuals with disabilities and it is estimated there are approximately 12,000 CRPs in the U.S. (Domin & Butterworth, 2012; 2013). CRPs vary widely in size, the population they serve, and the services they provide. Increasingly, VR agencies contract with CRPs to provide Pre-ETS services to students with disabilities (Awsumb et al., 2020). With the implementation of WIOA (U.S. Department of Labor, 2014), CRPs may play an integral role of the planning and implementation processes because they are direct service providers much like special education teachers. According to a survey of 164 Pre-ETS providers, participants expressed confidence in their knowledge of WIOA but desired

additional training in each of the five Pre-ETS areas (Awsumb et al., 2020). Although Pre-ETS makes valuable pre-employment training opportunities available to youth and young adults with disabilities, it redefines the roles of VR, special education, and CRPs in service delivery. In many cases, VR may best play the role of service vendor. In turn, CRPs may become primary service providers but only if they collaborate with special education teachers who know the students' characteristics and histories. Pre-ETS may dramatically expand availability of services to youth and young adults with disabilities but makes imperative a collaborative approach to service delivery.

Despite legislation calling for interagency collaboration, researchers described barriers for professionals from different agencies in effectively working together to assist transition-age students with disabilities (Oertle et al., 2017; Riesen et al., 2014; Taylor et al., 2016; Trach, 2012). For example, in a national survey of 318 special education teachers of transition-age students and 78 VR counselors with transition caseloads, Taylor et al. asked respondents to rate the importance and feasibility of 14 collaboration practices related to transition. Practices rated highest in importance and lowest in feasibility (i.e., barriers) by both teachers and VR counselors were (a) the need for teacher training in transition, and (b) lack of coordinated referral and planning across agencies. Taylor et al. commented that transition teachers and VR counselors were not optimistic about whether collaboration efforts can be

improved. Similar results were reported by Oertle et al. in a survey of statewide transition supervisors (35 special education supervisors and 37 VR counselor supervisors) who rated collaboration activities as important but rated frequency and preparedness for the same activities as consistently lower.

Povenmire-Kirk et al. (2015) implemented and evaluated a model transition collaboration program called Communicating Interagency Relationships and Collaborative Linkage for Exceptional Students (CIRCLES) as one method to increase interagency collaboration during transition planning. In this type of collaboration model, community providers, school providers, and the IEP team members had set meetings and progress reporting procedures. The researchers studied 48 high schools in two different states and conducted focus groups with the district staff who used this collaborative model. Researchers generated themes from the focus groups to determine barriers and challenges as well as successes in implementing the program. They identified five barriers and challenges: (a) lack of awareness among agency and school staff, (b) inadequate preparation of the students and families for meetings, (c) providers not receiving student information prior to meetings, (d) issues with follow-up after meetings, and (e) practical issues (p. 63). Povenmire-Kirk et al. also identified four areas of success in implementing CIRCLES: (a) increased collaboration between agencies and school staff, (b) improved communication about services, (c) empowerment of students

and families to conduct meetings, and (d) assistance towards allowing students to change lives (p. 62).

Although researchers have identified a model program resulting in effective interagency collaboration, barriers remain at the practitioner level in many programs. While existing research explores the collaborative experiences of secondary special educators and VR counselors (Oertle et al., 2017; Taylor et al., 2016), there are limited numbers of studies on perspectives of CRPs. Yet, with Pre-ETS legislation requiring service provision to youth and young adults with disabilities, the importance of effective collaboration between secondary special education teachers and CRPs is heightened. Focus groups with special education teachers and CRPs may reveal ways to collaborate and thus create awareness and share information. Knowledge generated from the focus groups' current understanding of CRPs and Pre-ETS services may lead to the creation of training materials to educate both teachers and CRP professionals.

Purpose Statement and Research Questions

The purpose of this study was to gather qualitative data on the current status and future directions of relationships between high school special education teachers and CRPs regarding transition service delivery. Using focus groups, the researchers sought to address the following three research questions.

1. What will participants of each agency report as their current knowledge and understanding of services available for their students/clients, as measured by themes from focus group transcriptions?
2. What barriers will focus groups members identify that limit collaborative relationships between special education teachers and CRPs?
3. What activities will focus group members recommend to strengthen the relationship between special education teachers and CRPs?

Method

Focus Group Methods

Focus groups represent a research tool used to capture the views and experiences of participating individuals in an informal, conversational manner. According to Kitzinger (1995), focus groups are one form of group interview that capitalizes on communication and interaction among research participants. Focus groups explicitly use group interaction to explore people's knowledge, attitudes, and experiences. Using a focus group produces thematic data based on social interaction and nonindependence of responses as participants make their own connections from conversations with other participants (Levers, 2006).

Focus group research exploring aspects of service provision

in rehabilitation have been utilized as a way to improve collaboration and experiences of consumers (Packer et al., 1994). In the current study, focus groups were considered a method for gathering information specific to interagency collaboration of professionals working with transition-aged students with disabilities.

Participants and Setting

In one Western state, funds had been allocated from the State Office of Rehabilitation to develop a limited number of contracts between CRPs and school districts to provide Pre-ETS. This particular state was chosen for the research project because contractual relationships between school districts and CRPs had already been developed. At the time of the study, there were three CRPs in the state with Pre-ETS contracts in place with five school districts. Schools were able to connect with any of the state-approved Pre-ETS providers with oversight from the State Office of Rehabilitation, thus allowing for schools and CRPs to work directly with each other. For this reason, researchers viewed the working relationships between schools and CRPs ideal for focus group analysis.

Prior to starting the study, researchers submitted a proposal to the institutional review board (IRB) describing participant recruitment and safeguards, confidentiality and privacy, focus

group methods, and management of data. The study conformed to recognized human subjects research standards.

Once IRB approval was obtained, researchers contacted special education teachers and CRPs requesting participation. Five secondary special education teachers and five CRP professionals agreed to participate. They were divided into three focus groups for this research project. The inclusion criteria for participants were (a) licensed secondary special education teachers within a specified school district, or (b) CRP professionals with current Pre-ETS contracts in place with a school district. Focus groups were created by pairing the CRPs with the teachers from districts currently contracted to provide Pre-ETS services.

To initiate recruitment, the first author emailed the school district transition coordinators identified in the Pre-ETS contracts, who in turn, forwarded the study information to secondary special education teachers who were involved in the transition process. Additionally, the first author contacted staff of the CRPs named in the Pre-ETS contracts to participate in the study. Once participants emailed the first author agreeing to participate, they were emailed a polling tool used to schedule online focus groups. They also received a survey with questions asking about demographic information.

Demographics

Table 1 displays demographic information collected from 10

focus group participants. Three teacher participants had severe disability endorsements and two had mild/moderate disability endorsements. The five teacher participants had between 3-25 years of experience. Four of the five teachers reported being "somewhat familiar" with Pre-ETS and one teacher reported being "familiar." Three of five teachers were male and two were female. Because of previously established permissions from parents/legal guardians, all teacher participants were allowed direct communication with outside agencies to report on student progress towards IEP goals and four of five responded that they could initiate services with outside agencies and invite agencies to IEP meetings. The five CRP professionals had between three and 20 years of experience working with transition-age students. Four of five CRP participants reported being "very familiar" with Pre-ETS and one CRP participant reported being "familiar." All CRP participants were female. CRP participants stated that, in their role, they were allowed to communicate directly with their students' special education teachers. All participants identified their ethnic background as White and primary language as English.

Table 1 *Demographics of Teacher and CRP Participants*

Source	Sex	Years on the job	Role	Familiarity with Pre-ETS
Focus Group 1				
Teacher 1	Male	6	Teacher	Somewhat Familiar
Teacher 2 Male	Male	6	Teacher	Somewhat Familiar
CRP 1	Female	9	Administrator	Very Familiar
CRP 2	Female	6	Direct Service Provider	Somewhat Familiar
Focus Group 2				
Teacher 3	Male	3	Teacher	Somewhat Familiar
CRP 3	Female	6	Administrator	Very Familiar
Focus Group 2				
Teacher 4	Female	25	Teacher	Somewhat Familiar
Teacher 5	Female	15	Transition Specialist	Familiar
CRP 4	Female	20	Direct Service Provider	Very Familiar
CPR 5	Female	3	Direct Service Provider	Very Familiar

Procedures

Each focus group was scheduled for 60-90 minutes. The first author began with introductions and an explanation of the purpose of the research then briefly discussed focus group methods. Each focus group took place using an online video platform. The researchers opted to hold virtual focus groups to remove geographic and logistical barriers for the meeting. Each participant used a computer to attend and had the opportunity to turn on/off their computer's video camera and use their microphone to respond to focus group questions.

In each focus group session, the first author asked five semistructured questions to elicit participant responses related to knowledge and understanding of transition processes and outcomes, barriers, and collaboration recommendations. The questions were as follows.

1. Teachers – What is your experience working directly with CRPs who are providing services to your students? CRPs – What is your experience working directly with your student's special education teachers?
2. What would you like to know about (the other)? Go ahead and ask them.
3. What stressors or barriers do you have to deal with in your profession that you would like teachers/CRPs to know about so that they better understand you and your role?

4. How would closer collaboration benefit a student's transition services?

5. I will now give you 10 min to work together to generate the top three things you would recommend as a group to strengthen the relationship between CRPs and special education teachers. (10 min passage) What are your three recommendations?

After each question, the first author asked related "probe" questions that were raised as a result of conversations sparked by original question prompts. The discussion on each question continued until it appeared the topic was exhausted. Following each focus group, the first author summarized the key points of the discussion and asked the participants to confirm that their ideas were accurately captured.

Following data analysis, researchers sent a follow-up member-checking email to all focus group participants allowing them to see the overview of the findings and provide the researchers with feedback regarding the accuracy of the final coding and themes. The member-checking process adds credibility to the study as it checks the researcher's accuracy of understanding the participant's discussion and context (Creswell & Miller, 2000).

Data Analysis

Focus group sessions were recorded, with participant

permission, using the recording system embedded in the online video platform. The focus group discussions were transcribed verbatim into a spreadsheet allowing researchers to analyze transcripts to identify themes in the data. The thematic analysis utilized for this study followed the six-step process outlined by Braun and Clarke (2006) in which researchers: (a) familiarized themselves with the data, (b) independently generated initial codes, (c) independently sought out and identified themes, (d) reviewed themes and cross checked them with other researchers, (e) refined themes and created a definition and name for each theme, and (f) created the final report. Requiring each researcher to individually review, code, and thematically organize the data helped to control for interpretative validity problems (Altheide & Johnson, 1994).

Initially, three researchers reviewed the focus group transcripts independently and identified codes and themes individually. Next, the research team worked collaboratively to compare identified codes as well as to describe and define themes. When themes were identified and agreed upon, the researchers worked collaboratively to identify subthemes.

Finally, participants were sent an email for member checking that provided the final analysis and themes for their confirmation or feedback. This step allowed for assessing the internal validity of the data collection process by the researchers (Merriam & Tisdell, 2016). The timing of member checking overlapped with the worldwide COVID pandemic

in Spring 2020 when schools and places of employment were closed. This may explain the limited responses (i.e., only 4 of 10 participants responded to the member-check email—three teachers and one CRP). All four respondents confirmed themes identified by the researchers and offered no additions or changes.

Results

Three primary themes were generated from the multiple rounds of data review and thematic analysis: (a) *barriers to effective interagency collaboration*, (b) *collaboration needs*, and (c) *recommendations to improve interagency collaboration*. These themes are described below with additional findings that support the three overarching thematic claims. To remain true to the essence of the participant's conversations and descriptions, each section contains participant quotes to retain the "voice" of focus group participants.

Barriers to Effective Interagency Collaboration

Members in all three focus groups indicated there were numerous barriers to effectively working with participants from the other agency/organization. Nested within the barriers theme, four subthemes were identified: (a)

communication difficulties, (b) *community barriers*, (c) *school barriers*, and (d) *student and family barriers*.

Communication Difficulties

The concept of communication difficulties as a barrier to collaboration was embedded in each of the three focus group discussions. Both teachers and CRP participants felt that they would benefit from training focusing on increased effective communication. As transition professionals, teachers and CRP participants often had full schedules and demands from multiple stakeholders, which limited communication opportunities. This was explained by one teacher:

> We are all busy and sometimes things sort of slip through, and you don't know what the other person is doing or what their intent is or they don't know what my intent is or what my plan is with somebody.

One teacher described frustration with unclear communication:

> I know we had a couple of misfires when working with (specific CRP), a couple of things that didn't go as planned and probably, had I had a little more information, we could have avoided.

As a barrier, communication was discussed in context of various stakeholders, some of which will be discussed in greater

detail in the following subthemes related to other collaboration barriers.

Community Barriers

Focus group participants explained multiple community barriers that negatively affected their ability to be involved in effective collaborative relationships. Teachers reported not understanding when they were supposed to refer students for transition services, as well as confusion around the mission and services of both CRPs and State Vocational Rehabilitation office. One teacher described this community barrier as:

> I think there is still confusion about CRPs, VR, about who is funding it, whose supporting this area, and whose role and responsibility is it really, because you know we as teachers do what we can, but then also we start doing things that we realize this is actually the CRP role, so I guess, the question would be described in a nutshell: "what is your role and connection with VR and the schools?"

Within community barriers, participants described difficulty finding new employers in the community who were willing to take students for job exploration activities. Additionally, participants from both CRPs and schools described confusion that employers faced in understanding career exploration activities. For example, one teacher stated:

> I think the hardest thing is that those community partners, even though we have tried to explain it to them as simply

as possible, still don't grasp the whole concept of it. It's not
us coming in and doing their work, it's them letting us use
their environment to teach skills.

Beyond finding employers, participants working for CRPs also
described the struggle in finding employers that align with
student's vocational interest areas. Due to difficulty in finding
employers who would allow career exploration at their
location, CRPs may not be able to accurately access a student's
vocational abilities. A CRP participant described this scenario,
"I have one student that goes to a site every week and he is
completely disengaged every time he is there because he is not
interested and it has no bearing on his interests at all…"
Teacher and CRP participants both noted that beyond the
barriers they experience in the community, they also face
difficulty with certain school systems and administrations.

School Barriers

Participants noted difficulties with school policy "red tape," as
well as some school administrators who did not "buy in" to
the transition process. Additionally, teachers stated they were
often unsure how Pre-ETS worked and what CRPs can
provide. One teacher explained that when she was able to
locate employers to accept her transition students for career
exploration activities, she faced backlash from her
administration:

I have found that locating community placements makes

> my administration nervous and there is all this red tape and it's hard to get through the barriers of administrators that think of all the reasons why it wouldn't work, instead of all the reasons why it could work.

Beyond difficulties with school policy and administration, teachers reported additional barriers to collaboration with CRPs because the school district is a nonprofit enterprise. One teacher explained this:

> I'm frustrated because...(school district has a policy) about not promoting anything that is for profit so it's really hard to know and a lot of people will come in from such and such company and I'll have no idea what that company is. I would love it if we could get rid of this ridiculous- so I could know what the pros and cons of each of them are, but it seems like this is very hush hush. We can't really find out about that here because it's for profit.

Student and Family Barriers

Both teacher and CRP participants described difficulties in processes that were outside the community and school setting. Teacher and CRP participants reported that, in some cases, students seemed to lack motivation to participate in career exploration programming. In other cases, they reported students were overwhelmed with academic requirements needed to graduate from high school. One of the special education teachers described this barrier:

> ...our students are very focused on earning credit and

graduating and their grades can be affected when you want
to try and take them out of school to do the kind of things
that we want to do which are transition activities...they
don't want to participate in the transition activity because
they don't want to not get credit and not graduate.

Finally, participants noted ongoing confusion with parents
about how and when they should seek out transition services
for their high school student. One teacher explained her
difficulty describing Pre-ETS to parents,

I've had many parents say to me 'I don't know what to do'
and you give them these names (of CRPs), but I haven't
really known how to hook them up either.

Additionally, transportation to and from CRP activities was
noted as a barrier to effective service provision to transition
students. One teacher explained difficulties for transition
students to engage in after-school Pre-ETS with CRPs,

A lot of our students don't have resources. A lot don't have
drivers' licenses, they don't have money for buses, they
don't live near bus lines, and they don't have families who
will take them.

Collaboration Needs

The second primary theme identified was collaboration needs.
Within this theme, two subthemes were identified: (a) *sharing
of information*, and (b) *sharing of resources*. Although

collaboration among professionals assisting students with disabilities in their transition out of secondary education is expected, the sharing process can be an unclear and difficult reality.

Sharing of Information

A common frustration impeding collaborative relationships was duplication of work by both special education teachers and CRPs. CRP participants agreed with comments that special education teachers spend an enormous amount of time with transition-aged students and see them across multiple environments, making teachers a vital source of valuable student information. With both CRPs and special education teachers working with large numbers of students at various parts of the transition process, maintaining and sharing student information as well as resources was reportedly overwhelming. One teacher explained how she created an Excel file to both gather and share student information,

> You have to have an effective method to organize all the information you share. In my case, I co-teach and we have 24 students in our program...we work with all 12 job coaches as well. So, we have all these people to manage and it is hard for us to remember who is (the student's) DSPD coordinator or VR coordinator, so I have an Excel form that tracks things like when their IEP is, when their re-evaluation is, when they exit the school system and what other services providers do they have.

The teacher went on to explain how having this information contained in one place also assisted the team with writing the student's IEP.

Sharing of Resources

Another CRP participant commented on how increased collaboration can lighten the workload by sharing responsibilities:

> We work with some teachers where they are doing a great job at providing some of those Pre-ETS services. But maybe they don't have time to do all of them, so we collaborate and we let them do their thing with the ones you do have time for and do really well. And we can help with the others that you don't have time for, such as taking individuals out into the community into companies to explore or taking them on college tours which you really don't have time to do.

Additionally, CRPs noted that teachers have "so much on their plates" and understood they need to both act as a resource for teachers as well as a mediator to access existing employers (Taylor et al., 2016). A CRP worker explained,

> If we access resources for one student, we can share that with teachers so that the next time they can then be sharing that if they see a trend or that as a specific need.

Recommendations to Improve

Interagency Collaboration

The third primary theme identified by researchers was recommendations to improve interagency collaboration. Within this theme, three subthemes were identified, (a) increased communication, (b) improved forms, and (c) increased awareness of CRPs.

Increased Communication

As noted in the barriers section, communication was described as the most significant barrier to effective collaboration. Inversely, communication was noted most frequently as a targeted way to increase effective collaboration between special educators and CRP staff. Specific ways to improve communication included CRP staff contacting the special education teacher when they first began working with a new student, even if services to that student were initiated through VR or parent referral. While the intake processes may vary across CRPs, participants suggested that an interview with the special education teacher should be included as part of the initial intake and discovery process.

Participants reported that both parties should make efforts to communicate, but the weight of the communication efforts should be with CRPs, as they were perceived to have more flexibility in their daily schedules. While CRP participants reported they were being invited to IEP meetings more regularly, they would ideally prefer more frequent and regular

updates on student progress rather than only at annual IEP meetings. Beyond verbal communication, a teacher described a way to improve communication and build relationships,

> ...one thing that really strengthens any relationship is a willingness to have compassion and empathy for the other people on the team. I think that is a really essential skill that we often overlook.

Improved Documentation and Data Collection

As a way to increase efficiency and reduce redundancy, participants from schools and CRPs advocated for updated documentation processes. For example, a special education teacher described feeling frustrated when a CRP professional would start working with a student and conduct their own data collection procedures. Often teachers reported feeling the CRP assessments were incomplete as they were only from one time period in one location, whereas teachers worked with the students across time and multiple environments; therefore, giving them a larger picture of students' needs and abilities. One teacher noted that her school had been using grant funds to improve documentation among transition professionals.

> I love the form that we've been using, because it breaks it down...what [a student's] school day looks like, what their needs and interest are, the key support people in their life, and all these things so that it really can be a collaborative effort, a smooth transition so that we are all contributing

together during these transition years so that when they leave everyone is on the same page, because they have the same page.

Increased Awareness of CRPs

Although there has been an increase in Pre-ETS available in recent years, focus groups reported there are still many teachers, schools, and districts who do not fully understand Pre-ETS and CRP roles and services. Multiple participants desired better delineation of roles and responsibilities across community agencies involved in the transition process. One CRP participant noted,

> So, where we have been most successful is when schools say, "here's this person, this is this person's roles and responsibilities they will follow up."

A recommendation made by participants across focus groups was advocating for the creation of a formal roles-and-responsibility chart, including methods for communication and follow-up activities. Additionally, special education teachers recommended better understanding of how funding and eligibility works for Pre-ETS.

To improve teacher knowledge of CRPs, teachers requested more information and more visibility from Pre-ETS programs. One suggestion from a teacher was,

> I think being in the school and having students able to vouch for the providers is a good thing so I do think

recommendations for teachers and peers can help students
get engaged.

Additionally, teachers suggested they could be part of a
solution by exposing other teachers and high schools to the
CRPs they work with and to help support other teachers in
building collaboration with Pre-ETS providers.

Discussion

This study conducted three focus groups with special
education teachers and CRP professionals to identify their
current understanding of transition services, barriers to
collaboration across agencies, and recommended activities to
strengthen relationships. Researchers identified themes
regarding barriers in (a) communication, (b) community, (c)
school, and (d) student and family factors. Both special
education teachers and CRP participants offered information
regarding needs and recommendations to improve interagency
collaboration.

The barriers identified within the present study were similar
to the findings of existing literature specific to interagency
collaboration (Oertle et al., 2017; Plotner et al., 2020; Riesen
et al., 2014; Taylor et al., 2016). Similarities in findings were
noted despite different disciplines represented by participants,
including special education and VR state-level supervisors
(Oertle et al., 2017) and special education teachers and VR

counselors (Riesen et al., 2014; Taylor et al., 2016). Across these studies, communication between transition professionals was noted as a barrier to successful interagency collaboration when it did not occur, and a reason for effective interagency collaboration when it did. For example, Plotner et al. (2020) noted that higher levels of communication in the transition process led to increased levels of collaboration. Common barriers (or activities considered important but infrequently accessed or infeasible) included ineffective coordination and referral problems, lack of administrative "buy in," and failure to share information and resources. Common recommendations across studies included creating channels for communication and understanding of agency roles and responsibilities (Oertle et al., 2017; Plotner et al., 2020; Riesen et al., 2014; Taylor et al., 2016). The importance of joint training across disciplines was punctuated by findings of the Taylor et al., Riesen et al., and Oertle et al. studies. The commonality of findings across multiple studies, including this one, should lead researchers and practitioners to implement and evaluate models of interdisciplinary collaboration.

The findings of the current study yield specific recommendations from special education teachers and CRP professionals to improve collaboration. Specific recommendations on the day-to-day collaboration activities targeted Pre-ETS (e.g., CRPs contacting special education teachers when they first began working with a new student,

sharing student assessment data, using Excel spreadsheets on internet sites so that all collaborators could coordinate services, creating a roles and responsibility chart including methods for communication and follow up).

Although legislation (IDEA and WIOA) call for interagency collaboration related to transition and include provisions for personnel preparation, no legislation has targeted personnel training across disciplines. Legislation, in general, does not call for personnel training across disciplines because it must address only professionals within a given discipline. Therefore, it is left for professionals holding interagency agreements within states or regions to address the need for collaboration and training through interagency conferences, webinars, or other means. These events could involve professional development hosted by the school district or state agencies offering training to transition teams representing different disciplines.

Concerns about lack of administrative support were described in this study and were identified as a school barrier. Clearly, school administrators have wide-ranging responsibilities and priorities that can, at times, be discordant. As it relates to transition from school to adulthood, administrators must balance a student's college and career readiness with requirements for high school graduation. For students with disabilities like all high school students, administrators are often more concerned with meeting the requirements for graduation than planning for college and

career readiness. School-based transition efforts and CRP involvement to increase one's success in future environments may be, at least in today's school administrations, less of an immediate priority. Educators, VR, and CRPs must send strong messages to administrators regarding dismal post-school outcomes of students with disabilities as well as success stories illustrating the effects of interagency collaboration for specific young adults with disabilities. More specifically, administrators need step-by-step instructions in how to integrate highly rigorous academic standards with Pre-ETS and community-based career exploration.

Limitations and Implications for Research

There are at least three limitations to consider in this study. First, focus groups involved very small numbers of participants, which may have limited the amount of information obtained. We chose focus group methodology to gather thematic data to address research questions, but qualitative research, by its nature, is not intended to be generalizable. Second, on a related note, the focus groups were limited to specific school districts and CRPs who already had contractual agreements in place. If teachers and CRPs in other locations do not yet have agreements in place, the themes derived from the focus group questions could have been very different. New, yet undocumented barriers may be experienced

as the practice grows more widespread and mature. Third, this research focused exclusively on collaboration between special education teachers and CRP professionals. No attempt was made to gather thematic data from other service providers such as VR counselors or career technical educators. Larger, more robust groups of professionals representing other disciplines may have yielded new or different themes.

Research is needed to better understand systemic, logistic, and interpersonal barriers to effective collaboration. Once barriers are better defined, practitioners in the field may go about the task of unraveling them and developing ways to facilitate collaboration that is more effective. Researchers may use the themes identified in the focus groups to conduct further studies exploring effective ways to implement programs encouraging CRP, VR, career technical education, and special education teacher collaboration in schools.

Implications for Practice

The overarching barrier-related themes identified in this study have implications for administrators in state education agencies, school districts, and CRPs. With the advent of Pre-ETS, students with disabilities may finally have an opportunity to prepare for their adult roles while still in school. Pre-ETS has opened doors to community environments and teaching of functional skills. Yet now, the barriers to successful post-school outcomes clearly call on

administrators and policy makers to step up. Teachers and
CRPs can collaborate to improve transition outcomes for
students with disabilities, but their efforts may be thwarted
because of administration concerns related to credits needed
to graduate from high school, transportation, schedules, and
paperwork. Administrative buy in must occur starting with
the state agency overseeing Pre-ETS. Key administrators must
understand the opportunities at their fingertips and the
consequences of ignoring them. Consistent with focus group
recommendations, action plans must be developed to establish
agreements, define roles and responsibilities, and deliver joint
training to both special educators and CRPs.

A comprehensive training plan for interagency
collaboration is needed, starting with state-level administrators
followed by school-level and service provider training to fully
take advantage of Pre-ETS. All groups may be trained in ways
to take advantage of interdisciplinary networks to improve
collaboration. Training opportunities could be presented in
state, district, or school-level conferences focusing on ways to
break down barriers and develop interdisciplinary teams. In
any event, training should be provided jointly among special
educators and CRPs, at minimum, and potentially to other
service providers to improve collaboration throughout the
transition process.

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FAMILY PERSPECTIVES ON DEVELOPMENTAL MONITORING: A QUALITATIVE STUDY

Sarah Behrens; Evan Dean; and Marisol Torres

Family Perspectives on Developmental Monitoring: A Qualitative Study PDF File

Abstract

Developmental monitoring, an ongoing process to identify children at risk for developmental delays, is an essential component to the identification of a developmental disability in young children. In

collaboration with families, medical professionals are expected to monitor the development of a child; however, current research focuses on screening with less attention on developmental monitoring and the role of the family. Here, we show the experiences of families with medical professionals specific to developmental monitoring and how families obtain and develop knowledge on child development. We analyze qualitative data from a sample of family caregivers using semistructured interviews. With a thematic approach, we identified three themes: (1) developmental monitoring with physicians is not common, (2) families use diverse supports to learn about child development, and (3) contextual factors (e.g., maternal health, work demands, demographic components) influence and shape the child development experience within a family unit. These findings indicate variability in developmental monitoring practices in addition to unique needs of children and families.

Plain Language Summary

Accurately identifying a developmental disability is important to ensure young children and families get needed supports. Developmental monitoring is a process where medical professionals work with

families to identify children at risk for developmental delays. While family members have important information about their child, many times they are left out of the process. This study sought to better understand family experiences with developmental monitoring. We interviewed family caregivers of children ages birth to 5. We found three themes. The first theme is physicians often do not use developmental monitoring. The second theme is families use many ways to learn about child development—this includes community-based programs. The third theme is that contextual factors influence family experiences. There is a need to include families in developmental monitoring. Also, it is important to consider the individual factors and needs of a child and family.

Monitoring young children's development is both critical to early identification of a developmental delay and/or disorder and overall well-being of children and their families (Raspa et al., 2015). Developmental monitoring (DM) is an ongoing process where healthcare professionals' partner with parents and caregivers to learn about and record a child's developmental progress (Duby et al., 2006). DM generally involves a pediatrician or other medical professional working with families to document and track development through parent and other caregiver reports, observations, and

screenings (Lipkin & Macias, 2020). While DM is endorsed by the American Academy of Pediatrics (AAP), only about a third of children receive DM (Hirai et al., 2018) and only a small percentage of children are identified early enough to receive early intervention services (Boulet et al., 2009; Boyle et al., 2011; Rosenberg et al., 2008). Yet, research suggests that when family concerns are considered as part of the diagnostic process, professionals make more accurate diagnoses (Gaspar De Alba & Bodfish, 2011; Ozonoff et al., 2010; Young et al., 2003; Zwaigenbaum et al., 2009). This research suggests an opportunity for professionals to partner with families through DM to enhance the diagnostic process (Chödrön et al., 2020).

Developmental Monitoring

While developmental monitoring is generally led by medical professionals, active involvement from families is critical. Yet, research suggests family involvement is often undervalued (Barger et al., 2018). Insight from families informs medical professionals regarding nuances of behavior in multiple contexts, which is needed for accurately identifying developmental delays early. Evidence has shown that when families are given the opportunity to discuss their child's development and concerns, professionals make decisions and referrals that benefit the child and family's overall well-being (Glascoe, 2000). To improve DM practices, a better

understanding of a families' knowledge and perspectives on child development is needed.

The AAP recommends that DM, alongside the complementary practice of developmental screening, be a part of every well-child preventive care visit and addressed at routinely scheduled appointments. While developmental screening consists of the administration of a brief standardized tool to track child development and help identify children at risk of a developmental delay (Duby et al., 2006), DM is a broad practice that can take many forms (Lipkin & Macias, 2020). There are six components generally considered to be important to the DM process: (1) eliciting and attending to the parents' concerns about their child's development; (2) documenting and maintaining shared information; (3) reporting accurate observations of the child; (4) identifying strengths, risks, and protective factors of the child and family; (5) maintaining an accurate record of the developmental monitoring process; and (6) sharing findings with other professionals and community-based programs with whom the child and family are involved (Lipkin & Macias, 2020). This process allows for tracking of growth and development as well as the opportunity for families to speak with medical professionals about potential parental observations and concerns. Medical professionals can then educate families on effective ways to promote and encourage child physical, mental, and social health and well-being based on family observations (Lipkin & Macias, 2020).

Developmental screening has proven to be an effective practice in identifying children at risk for developmental delays (Council on Children with Disabilities et al., 2006; Earls & Shackelford Hay, 2006; Hix-Small et al., 2007; King et al., 2010; Sand et al., 2005). However, one study suggests DM and developmental screening completed individually is insufficient in the identification of delays. In analyzing families' responses to receiving developmental screening and/or monitoring for their children aged 10 months to 3 years, researchers found that children and families who reported receiving both developmental screening and monitoring were more likely to receive early intervention services compared to children and families who received developmental screening alone, DM alone, or neither (Barger et al., 2018). Findings such as these justify the need for further research in DM to meet the current and future needs of families and children who may have a developmental delay and/or disorder.

Importance of Partnering With Families in Developmental Monitoring

With accurate knowledge of child development, families can accurately communicate observations with medical professionals to support the DM and diagnostic process (Daniel et al., 2009). Today's families seek out information on child development and developmental milestones through a variety of sources including digital media (e.g., social media),

social support systems (e.g., family, friends), print materials (e.g., books, magazines), and providers of programs that serve children and families (Carter, 2007; National Academies of Sciences, Engineering, & Medicine et al., 2016; Zero to Three, 2016). These resources can vary in terms of scientific and medical evidence accuracy, representing an opportunity for medical professionals to educate families on the science of development in family-friendly language. Knowledge on child development is important for families to be active contributors to DM.

Family participation in DM is important, and recent research suggests that family insight can lead to earlier and more accurate diagnoses (Zwaigenbaum et al., 2015). The importance of family observation can be seen clearly in the diagnosis of autism spectrum disorder (ASD), which is a condition that is generally first noticed through differences in interactions (e.g., behavior, language development) rather than physical or genetic symptoms (e.g., Cerebral Palsy or Down syndrome; American Psychiatric Association, 2013). For example, studies have shown that family concerns for their child with ASD may predict a diagnosis (Gaspar De Alba & Bodfish, 2011; Ozonoff et al., 2010; Young et al., 2003; Zwaigenbaum et al., 2009). Additionally, the concerns of families with children with ASD may differentiate children with other developmental disabilities (Little et al., 2017) highlighting the importance of DM in early detection of childhood developmental disorders. A family's input during

the DM process is critical as they offer a well-rounded perspective of their child, therefore helping to identify risk of a developmental delay. The family perspective matters in identifying children at risk of a developmental delay, and with child development knowledge, family's input is critical to the DM process.

Study Purpose

While family observation is critical to accurate diagnosis, our review of the literature did not find any research that explores family knowledge and perspectives on development and DM. Given the importance of the family perspective in the DM process, research is needed to understand family knowledge and perspectives on healthy child development to improve the early identification practices of DM among early childhood providers. The knowledge and perspectives families have about child development can either support or inhibit a child's developmental trajectory. Additionally, when families are an equal partner in DM, their perspective can enhance the diagnostic process (Lipkin & Macias, 2020); therefore, we need to better understand family experiences with the DM process. To better understand DM through the lens of a family, we aim to answer the following research questions:

1. What are the experiences of families with medical professionals specific to DM?

2. How do families obtain and develop knowledge on child development?

Methods

Research Design Overview

To address our research questions, we used a phenomenological design that focuses on commonalities among a particular group and aims to describe a specific phenomenon (Creswell, 2013; Patton, 2002). We gathered data using 1-hour semistructured interviews. Next, we systematically analyzed our findings using thematic analysis, a common form of analysis within qualitative research that facilitates identification and interpretation of themes within data (Braun & Clarke, 2006). Through our analysis, themes emerged that provide insight into family's experiences with their own child's development and DM.

Study Team

The research team consisted of the lead author, the co-author, and students from health professions. The lead author developed and revised the interview guide with assistance from the co-author, performed all the interviews with the families, and reviewed all transcripts with the other team members. As a master's-level social worker and doctoral student, the lead

author worked many years in the field with families and children birth to 21 years of age providing support services, education, and behavioral strategies specific to ASD. These experiences led to the realization, supported by literature, that the foundational years of a young child's life are vital to their future health and well-being. The co-author served as an expert in qualitative research methodology and supervised the project from inception. Health professions students coded transcripts after receiving training from the lead author on codes identified and defined by the lead authors. Additionally, the students completed coursework in child development but had no training in DM.

Study Participants

We used a convenience sample (Miles & Huberman, 1994), consisting of English-speaking family caregivers with at least one child under 5 years of age. Ten individuals from two Midwest states participated and each identified themselves as a mother. Across all participants, there were a total of 20 children with a mean age of 4.39 years. The participants and lead author had no relationship prior to the interview.

Participants were given the option to complete the semistructured interview in person at their home or at a university-setting clinic. Interviews for the final five participants occurred in March of 2020, which coincided with the COVID-19 pandemic. Because of public safety measures

to prevent the spread of COVID-19 put in place by the lead author's university, face-to-face contact for research was suspended; thus, we added an option to conduct interviews remotely (via Zoom or phone). A total of 10 interviews were completed. Five interviews were completed at participant's homes, three were over the phone, and two via Zoom.

Participant Recruitment

We recruited families through a research registry affiliated with a university research center lab. A recruitment flyer with study information was sent via email to potential participants who had consented to be notified of research studies ($n = 1{,}591$). In addition, the flyer was posted to the university research center lab's associated social media account. Interested participants responded to researchers via email or phone. A total of 126 families responded to the recruitment flyer. Each one was contacted by the lead author with more details of the study and specific interview dates. Families who were still interested and were available on a preselected interview date were either scheduled or placed on a "wait list."

Participants did not receive incentives or compensation for their participation. In protection of the participants, the study was approved by the Institutional Review Board (IRB) at the University of Kansas Medical Center. Participants read and signed the approved consent form before beginning the interview. As part of the consenting process, the lead

researcher informed participants about the goals and procedures of the study, along with the lead author's interests in family's experiences with child development.

As part of the study design, the researchers continued recruiting and interviewing participants until saturation was met (Sandelowski, 2008). Saturation of data was evident within six interviews (Guest et al., 2006). A total of 15 participants were scheduled for an interview; however, five participants cancelled because of COVID-19 and increased demands of caring for their family. The final four scheduled interviews were conducted to ensure saturation.

Data Collection

We conducted one-time, semistructured interviews in English. A previously tested interview guide with probes explored family's experiences and perceptions of child development. The guide was developed by the lead author and researchers with expertise in qualitative research with families. The interview guide began with family demographic information and an overview of pregnancy and birth experiences. Participants were asked open-ended questions focused on three main categories related to child development: (1) family knowledge; (2) family perceptions; and (3) family practices (see Table 1). Interview lengths varied from 15 to 116 minutes, with an average interview time of 52 minutes. Field notes were taken both during and after the interviews and provided

additional context. The interviews, transcribed by an online service, were reviewed by the lead author for accuracy with the original audio recordings.

Table 1
Interview Guide

Category	Question
Family knowledge of child development	1. What does child development mean to you as a parent? 2. Do you feel like you have a good understanding of child developmental milestones? Explain. 3. Whom do you turn to when you have questions about your child's development and/or developmental milestones? 4. How frequently (daily, weekly, monthly) do you monitor or track your child's development? 5. If there was one resource on child development you wish you had, what would it be?
Family methods for obtaining child development information	6. Do you feel it is easy to find trustworthy information on child development? Explain. 7. What is your preferred method for receiving child development information? 8. Have you ever felt overloaded with information? If so, in what way (e.g., handouts, in-person, books,)? 9. At any point from pregnancy to now, have you felt any outside pressures regarding your child's development? Have these influenced your parenting?

Category	Question
Family experiences with developmental monitoring	10. Do you know of or has anyone told you about resources or tools about your child's development? Explain. 11. What child development information has your child's physician given you? 12. What are three child development tools/resources you would recommend to a new parent?

Analysis

We used a phenomenological approach to explore the lived experiences and understand the perspectives of families of young children with respect to DM and child development (Marshall & Rossman, 2016; Patton, 2002). Consistent with a phenomenological approach, thematic analysis was used to identify, analyze, and report patterns or themes within the interview data (Braun & Clarke, 2006).

Analysis of transcripts included a rigorous coding process and interrater reliability to ensure the saturation of the data. The lead author read and independently coded each transcript as the process occurred. For identifying codes, the lead author and health professions students independently reviewed two transcripts at a time, generating codes from the text as concepts became apparent. The initial codes were further defined and categorized through group discussion. Using the finalized

codes and definitions, the lead author and one health professions student (i.e., the coding student) then re-read and coded each transcript for reliability purposes (described subsequently). Through further analysis of the category codes, patterns or themes summarizing the main ideas and experiences of the participants emerged (Creswell, 2013; Patton, 2002).

Interrater reliability was completed between the lead author and the coding student. A random sample of 11 interview snippets from each participant (representing 20% of total interview snippets) were separately coded by the lead author and coding student. Before coding the reliability sample, a threshold of 80% agreement was established for reliability. The two then met to compare their coding, classifying each interview quote as either agreement or disagreement. The percentage of agreement was then calculated as the total number of agreements divided by the total number of quotes. This resulted in an interrater reliability of 89%.

Results

Participant Characteristics

Ten English-speaking caregivers were interviewed (Table 2). Participants were mothers aged 25 to 41 years (M = 35; SD = 40.4). Nine family members reported gender as female and one as binary, non-gender. The participants identified as White

(80%), Black or African American (10%), and more than one race (10%), with the primary ethnicity being non-Hispanic (90%). Seven of the participants were married, one was separated, one was in a domestic partnership, and one was unmarried/single. All family members and their partners were employed with education levels ranging from no degree to some college without completion of a degree to professional with a degree. Two participants reported receiving Women, Infants, and Children (WIC) food supplements (Table 2).

Table 2
Participant Characteristics

Participant	Characteristic
1	Participant 1 was a married, White, female with two children, ages two and one. She had a master's degree and was employed as a high school family and consumer sciences Family and Consumer Sciences (FACS) teacher. Participant 1's children attended a daycare program and visited a pediatrician for well-child visits. Participant 1 had visited with the pediatrician about one of the child's physical and language development; however, the pediatrician did not voice any concerns. Participant 1 confirmed no child in the family had a developmental delay or a diagnosed disability.
2	Participant 2 was a married, White, female with two children, ages 5 and 2. She had a bachelor's degree and was employed as an event coordinator. Her children attended 8 hours of preschool along with 40 hours of in-home care provided by their grandparents. The children visited a family physician for well-child visits. There had not been a concern regarding the children's development from Participant 2 or the family physician. Participant 2 confirmed no child in the family had a developmental delay or diagnosed disability.

Participant	Characteristic
3	Participant 3 was a married, White, female with two children ages 7 and 3. She had a bachelor's degree and was a stay-at-home mother. Her child did not attend preschool but did receives services (e.g., occupational and speech-language therapy) as deemed necessary. The children visited a pediatrician for their well-child visits. Participant 3 reported the pediatrician had not voiced concern about the children's development. However, Participant 3 did express concern for one of her children's speech, fine motor, and feeding development. Participant 3 confirmed the oldest of her children having a delay with fine motor and social skills and the youngest of her children being diagnosed with anxiety and sensory processing disorder.
4	Participant 4 was a married, bi-racial, female who had a 3-year-old child. She had a master's degree and was employed as a financial planner/wealth manager. Her child did not attend daycare, preschool, or receive therapeutic services. Her child was followed by a pediatrician who had not voiced a concern related to the child's development. However, Participant 4 had inquired about development. Participant 4 confirmed no child within the family having a developmental delay or diagnosed disability.

Participant	Characteristic
5	Participant 5 was a married, White, female with two children. One child was 2 and another under the age of 1. Participant 5 had a bachelor's degree and was employed as a respiratory therapist. Her children attended daycare part-time. Neither of her children received therapeutic services. The children visited a pediatrician for well-child checkups. There had not been a concern regarding the child's development from Participant 5 or the pediatrician. Participant 5 confirmed that no children in the family had a developmental delay or diagnosed disability.
6	Participant 6 was a married, White, female with a 3-year-old child. She had a master's degree and was employed as a parent educator. Her child attended daycare, which included 6 hours of in-home care and preschool for 6 hours. For well-child visits, the child visited a family physician who had not voiced a concern related to development. However, Participant 6 had requested information related to ankle pronation as she claimed her child was a late walker. Participant 6 confirmed that no child within the family had a developmental delay or diagnosed disability.
7	Participant 7 was a married, White, female who had three children ages 10, 4, and 3. She had a master's degree and was employed as a teacher. Her children did not attend preschool or receive therapeutic services. Her children visited a pediatrician and Participant 7 voiced concern about a child's development; however, no child in the family had a developmental delay or diagnosed disability.

Participant	Characteristic
8	Participant 8 identified as non-binary and White. They had twins aged 4 years and was currently separated from the children's father. Participant 8 had a doctorate degree and was employed as a psychologist. The children attended daycare for 50 hours a week and did not receive therapeutic services. The children were followed by a pediatrician who voiced concerns related to their child's speech, occupational therapy concerns, and sensory issues. Participant 8 reported that the pediatrician had not voiced a concern related to development but confirmed that one of the children had a developmental delay or a diagnosed disability related to speech and fine motor skills.
9	Participant 9 was a White, Hispanic or Latina, married female. She was in a domestic relationship and had five children ages ranging from 3 to mid-20s. She had an associate degree and was employed as a nurse. Her children did not attend childcare, preschool, or receive therapeutic services. They did see a pediatrician for well-child visits, and the pediatrician had not expressed concern about development. Participant 9 confirmed none of the children had a delay or a diagnosed disability.

Participant	Characteristic
10	Participant 10 was an African American, single, female, who had two children under the age of 3. She completed some college courses and was employed as a customer service representative. Her children did not attend daycare, preschool, or receive therapeutic services. Her children were followed by a pediatrician who had not voiced concern about their development. Participant 10 stated when choosing a pediatrician, she asked a lot of questions and had to find a good fit for her family because of her decision to not vaccinate. Participant 10 also confirmed that none of her children had a delay or a diagnosed disability.

The number of children in the home ranged from one to five with an average age of 4 years. English was the primary language spoken at home with two families indicating the occasional use of sign language and Spanish. Two participants reported that they had one child (a total of two in the study) with a developmental delay.

Themes

After initial coding using a thematic analysis approach, four categories (i.e., child development knowledge and perspective, obtainment of knowledge, DM, circumstantial experiences) were identified and defined. The four categories were then combined into three themes: (1) experiences with DM, (2) child development knowledge (encompassing codes child development knowledge and perspective and obtainment of

knowledge) and (3) family contextual factors (encompassing code circumstantial experiences). DM included the family's experiences learning about child development from a physician. Three participating families actively engaged in DM (Lipkin & Macias, 2020) with their medical provider, while the other seven participated in informal monitoring (e.g., brief conversation, checklist of milestones). Child development knowledge and experiences was defined as a family's diverse insight on child development from informational sources (e.g., courses, websites, family members and friends, medical professionals), lived experiences (e.g., previous children, work in the field), and attitudes before and after having a child (e.g., parenting practices, personal experiences). Contextual factors emerged as a theme related to risk and protective factors that can impact child development though not always covered in the DM process. For this study, contextual factors were defined as the personal, environmental, and circumstantial factors that influence and shape the child development experiences within a family unit. The authentic experiences of the participants provided information important to child development and the needs to support young children and their families (Table 3).

Table 3
Themes

Theme	Definition	Example quote for each category
Experiences with developmental monitoring	The experiences for learning about child development from a physician.	Participant 7: "They [pediatrician] just hand out a sheet on where they [children] are [developmentally], what's typical milestones every time. And then we talk about it a little bit and she asks them questions. Participant 2: "I might ask him [physician] at our checkups and appointments that we go to, but I would say I rely more on my peers [for child development information]."

Theme	Definition	Example quote for each category
Knowledge and experiences with child development	A family's diverse insight on child development from knowledge gained, lived experiences, and attitudes and beliefs before and after having a child.	Participant 6: "Professionally, I've had much experience, but then when you become parents, it is a game changer." Participant 8: "One of the things that makes it [child development] challenging with twins is they are two people. And so, treating them as two people, sometimes it's hard. Is this one advanced in this area? And is this one where they should be? And is this one a little bit behind in those different types of things. Even though I try not to compare them, sometimes it's hard just to have a gauge of what is expected."

Theme	Definition	Example quote for each category
Contextual influences on child development	The personal environmental and circumstantial factors that influence and shape the child development experience within a family unit.	Participant 4: "I did have postpartum [depression]. I would describe it more as anxiety than like depression. I'm just very anxious about anything that had to do with him." Participant 7: "We live in a poverty area and because I've been a stay-at-home mom, we have a very low income right now. So, their (children) ability to get those things [extracurricular activities], we can't. Coming from middle class and then being in lower class, there's definitely a huge switch" Participant 8: "I do gender open parenting with the kids. I do not assign gender until they are old enough to articulate it for themselves. We did not label them as boys or girls, and we used "they/them" pronouns for them until they were old enough to tell us. We had very frequent conversations about sex and gender and body parts and lots of books."

Experiences with Developmental Monitoring

Participants demonstrated diverse perspectives regarding their

understanding of child development. In terms of experiences with DM, only three participants relied on their children's primary care doctor (e.g., family physician, pediatrician) as a support and resource for child development. Of those families, they felt they had a positive relationship with their provider, were comfortable sharing child development information with their provider, and received information about child development through routine screenings and in-office handouts or pamphlets. Seven families, however, stated the primary care physician monitored development as expected (e.g., screening, handout or pamphlet with milestones, brief conversation) and expressed that they had lower expectations of their physician's role in child development monitoring—knowing physicians could only do so much. Participant 10, who primarily obtained child development information from professional experience, family, and books, noted,

> They [doctors] have so many patients that they see. They're just going based off notes they have made previously. So that's why you cannot rely too much on what the doctor says about development. They have the broad knowledge of what the child's supposed to be doing at this age versus we see them in front of our face every single day and what step they're at or what they're doing and how they're doing it.

The individuals who participated in the interviews also shared that they monitor their child's development using photos and

videos, indicating the importance of family narrative to the DM process. Photos and videos were organized in a variety of ways including photo books and online services (e.g., Google Photos, Shutterfly, Facebook). Participant 8 shared,

> When I take them [children] in for developmental screenings and they ask when they started talking, I can scroll back through my photos and find out because I posted most of them or I sent messages to my family through Facebook and Instagram.

Knowledge and Experiences With Child Development

Rather than during medical visits, participants stated that they gleaned much of their child development education from their schooling, their own professional careers, social support, and a variety of other resources, including online sources and books. Eight participants had close relationships with family (e.g., grandparents, siblings, aunts, uncles, cousins) and friends, including neighbors, who were valued sources of child development information. When describing knowledge gained from other family members, Participant 4, who moved closer to her family after having children noted, "It's one of the reasons we moved out here. My parents live probably 10 minutes away and my three younger brothers go to college nearby." Two participants shared their closest friends happened to be physicians (e.g., pediatrician, obstetrician-

gynecologist) whom they could consult with on child development and family-related health.

Community-based organizations were highly utilized and valued as sources of child development knowledge. *Parents as Teachers* was the most common program of which the families spoke highly of and recommended to other families. For example, Participant 3 shared, "*Parents as Teachers* helped a lot because they [the educators] would say what was normal and above normal." Participant 3, a stay-at-home mother, also found value in a support system. She said,

> I definitely recommend a moms group of some kind. I prefer when I can be with other moms [learning] because it's so crucial for my children and their brain development.

For those involved with childcare, in-home childcare, or preschool, participants mentioned the programs as systems they are involved in but not necessarily as a resource for child development. Participant 7, whose children attended a childcare program observed,

> When they [children] were in the younger classrooms, they [teachers] would send home screening information and pamphlets, but not as much as the kids have gotten older.

When asked about attitudes and what child development means, Participant 5, who received most of her child development information from the pediatrician and friends responded broadly that, "Child development is the process

of growing up and how they figure out the world." Several were more concrete, describing child development as the promotion of skills specific to physical, mental, emotional, social, and cognitive development. Across all the participants, it was clear that each family played a significant role in laying the foundation for their child's development. Participant 8, whose children were 4 years old, shared her insight on being a parent.

> As a parent I think it's incredibly important to realize what they are capable of and then how to support them. I take a scaffolding perspective. So, helping provide the framework and then as they [children] become more capable of doing things, taking away some of that support. I'm still there, but as they can become more of a master in things, my support walking them through the steps becomes less and less. I'm there for emotional support.

Contextual Influences on Child Development

We did not ask specific questions about how family contextual factors affected the way families supported their child or children's development; however, this theme emerged from participant responses. Recommended by the AAP (Lipkin & Macias, 2020) as a component of DM, the identification of family strengths, risks, and protective factors, all contextual factors, can impact the well-being of the family and the development of a child. Contextual factors that influenced

the extent to which families supported development included: (1) maternal health, (2) work demands, and (3) demographic components. Across the participants, many shared experiences related to maternal health that impacted their support for child development. Some participants shared detailed events of the birth of their children. Seven families in our study faced unforeseen circumstances during pregnancy. For example, Participant 5 described a traumatic post-delivery event as "I almost died. I hemorrhaged and lost a lot of blood. It was very scary." This event led to Participant 5 realizing the value of taking care of herself through work and time to herself, which made her more present when at home to care for her family and support her children's development. Two participants shared their experiences in the Neonatal Intensive Care Unit (NICU), which provided a source of encouragement and confidence to support her child's health and development. Participant 1 shared,

> You're like a vessel at that point [in the NICU] and you do what they [nurses and doctors] tell you to do. But it was a great experience, and the people were wonderful.

Several shared unplanned health complications (e.g., gestational diabetes, high-risk) and experiences with post-partum depression (PPD) during the postnatal period or 4th trimester, which challenged their ability to care for their child. Despite the challenges, participants shared that the support they received from partners, family, friends, and healthcare

professionals was critical for them to take care of themselves and prepare to care for their child. Participant 9, a stay-at-home mother, shared

> My parents live about five houses down from us and my mom is basically here, like almost every day. And I have an aunt that is three houses down and a cousin that lives the same distance pretty much across the street from my aunt.

In general, the experiences at birth and shortly after, and the support the families received, impacted the families in a way that built resilience and confidence to care for themselves and their children, physically and developmentally.

Another contextual factor that impacted the way families supported child development was the degree to which participants and their partners worked outside of the home. Working parents expressed balancing the demands of work, caring for their children, and ensuring a safe and nurturing home environment was critical to promoting child development. Flexible and supportive employers were important and something families valued in their current jobs, along with the assurance that their children's development was supported while working. Several relied on family members to help support children while working. For example, Participant 2, who worked as an event coordinator, expressed,

> My mom is retired and is a big part of the kids' lives. She takes the kids to the library, other activities, and teaches them a lot.

Other individual factors in the families' lives (e.g., marital status, gender, socioeconomic status) also played a role in how families promoted child development. Participants reported that these individual factors posed a stress in their life. Participant 8, who was going through a divorce with her spouse, spoke to the challenges of different parenting styles on the impact of her children's development as, "He does not have realistic expectations about what they're [children] capable of and would act very angerly and not talk to them in way that was appropriate." This participant, who was a clinical psychologist, was confident that her professional knowledge on child development enabled them to support their children through the transition. Participant 7 spoke to the current change in her family's socioeconomic status due to her spouse's change in employment status and the resulting financial hardships as examples of changes that impacted her capacity and resources to care for her children. The financial hardships included moving to a new neighborhood, enrolling children in new schools, reduced access to healthcare providers, and access to fewer extracurricular activities. Like Participant 8, Participant 7 voiced concern about the impact of reduced finances on her children's development but was taking initiative as a professional educator to ensure positive experiences to promote her children's development. She shared,

> The church has an amazing child program. It is phenomenal. The program is designed by preschool

teachers, middle school teachers and is made for every age level. The activities are developmentally appropriate, and they send home information for parents to do with their kids that are developmentally appropriate.

A final participant shared their openness to gender diversity and identified personally as nonbinary. Their spouse is transgender, and they were raising their children with no identified gender allowing them to identify according to their preference. While they spoke to the judgment received from the healthcare system, they were confident in educating others and supporting their children's development with nonspecific gender norms embedded within their family structure.

Discussion

In this paper, we presented an exploration of the perceptions and experiences of families with young children regarding child development and DM. Key themes identified in our study included experiences with DM, knowledge and experiences with child development, and contextual influences on child development. This research provides valuable insight into parent perspectives on DM and child development, which can inform early identification efforts to fully include families in the DM process.

Experiences With Developmental

Monitoring

Our study found that few family members participated in DM activities with their physician during well child visits. Guidance by the AAP on DM state the physicians' role is to collaborate with families to better understand children, both physically and developmentally (Lipkin & Macias, 2020); however, family-physician DM involvement was not as expected by families. A study highlighting what families want from well-child visits conducted focus groups with families and their experiences and found that families needed increased information and resources on development and behavior (Radecki et al., 2009). This study's findings illustrate the importance of family and physician relationships and the key role families have in DM.

It is possible that physicians are engaging families in the DM process. However, if this is the case, physicians may need to clearly communicate both the steps in the early identification process and how they are engaging families in the process to ensure families recognize their involvement in the process. Previous literature suggests that physicians are not consistently using DM (Barger et al., 2018). Our research is consistent with this finding and suggests that more work is needed to educate (1) physicians on how to engage families in the DM process, and (2) families on how to partner with physicians on the DM process (Choo et al., 2019). The family needs to be a contributing partner in the child development discussion to

share developmental descriptions and concerns (Glascoe & Dworkin, 1995; Trivette et al., 2010).

Families use of personal photos and videos emerged as a novel example of how families monitor child development. The moments captured by the family became a tool to monitor their child's development. Research has suggested that the family's confidence and empowerment for the care of their children increases with the convenience and accessibility of information (Madge & O'Connor, 2006). This finding places more emphasis on the need for the families and medical professionals to collaborate in the DM process.

Knowledge and Experiences With Child Development

While our findings indicated limited use of DM, the families relied on technology, supportive relationships, and community-based programs for information and support in the promotion of child development. Technology is a vital means for connecting families to resources, information, and support on child development. A variety of digital tools exist including web-based platforms, discussion forums, social media, and mobile applications. Families used technology to gather ideas for promoting specific child developmental milestones. For example, one family used online resources and a mobile application to learn new strategies to assist their child in walking. Previous studies have found that close to half of

families surveyed use the internet and technology to obtain child development information (Hall & Bierman, 2015; Lerner et al., 2012; Walker et al., 2012). While families voiced an appreciation for information on child development from a variety of sources, families shared the need for quality resources (Yankelvich, 2000).

Families in our study highlighted the importance of supportive relationships within their day-to-day lives. Participants shared the value of reliable friends and neighbors with similar-aged children as well as family members to support them. These relationships served as a source for information regarding child development that supports the DM process. For example, more than one family member reported having a close friend who was in the field of child development. Relational supports can lead to families providing a caring and healthy environment for their children (Zero to Three, 2016). Additionally, supported families have the capacity to support their children (Swanson et al., 2011).

Through collaborative efforts, community-based programs can serve as a provider in the DM process. Our findings indicated a strong appreciation for community-based programs (e.g., early intervention services, early childhood mental health consultation, public library services, public housing and/or job assistance programs). Families shared positive experiences that included the trusting relationships with providers and knowledge gained through resources and personal interactions. Research has indicated that when

programs are well implemented, they can enhance (1) emotional well-being of families, (2) broaden social networks, and (3) facilitate child development (Cochran, 1990; Kagan et al., 1987). Additionally, the AAP's newest component to DM (sharing and obtaining opinions and findings with other professionals) encourages physicians to collaborate with community-based providers for ongoing monitoring of child development to support early identification efforts (Lipkin & Macias, 2020).

Contextual Influences on Child Development

The importance of identifying strengths, risks, and protective factors of the child and family, a recommended AAP component of DM (Lipkin & Macias, 2020), is crucial for the health and well-being of a child. The contextual influences on child development theme emerged from the data. While we were not specifically studying this phenomenon, such results indicate the importance of contextual influences in child development and DM. Our study found a variety of contextual factors that influenced family experiences with supporting their child's development, including: (1) maternal health, (2) work demands, and (3) demographic components. These factors do not stand alone but are rather interconnected to form an ever-changing experience for the family (Trivette et al., 2010). The effects of circumstantial, day-to-day experiences

can accumulate over time for families. For example, one participant described her experience with a change in socioeconomic status as a stressor for her family and reduced opportunities for play for her children. This finding echoed previous research showing that a reduction in socioeconomic status can lead to poor health behaviors (Pampel et al., 2010). Similarly, four participants shared their experiences with PPD as a new parent. The mental health challenge presented as anxiety and a new sense of worry for their child. While the participants found support through family, friends, partners, and therapists, many parents find themselves alone and may have decreased parent-child interaction (Ramchandani et al., 2005). Over time, these examples can lead to personal distress that impact family relationships and the promotion of development with a young child. Compounded stress can impact the parent-child relationship and weaken the child's bodily system and brain architecture for health, well-being, and development (National Scientific Council on the Developing Child, 2005/2014).

Implications for Developmental Monitoring

Findings from the in-depth interviews reveal that participation in DM practices varied across families. These findings indicate an inconsistency among the awareness and utilization of DM along with the diverse and individualized needs among families

with young children. The diversity of the experiences shared by participants provide insight to relevant factors that can impact a family dynamic and need to be considered as part of the DM process. Medical professionals and early childhood providers can make more informed early identification decisions by educating families and including families in the DM process. It is valuable to understand the perceptions and experiences of families of young children in addition to the importance of appropriate and individualized supports for children and families. The DM process needs to be holistic in its approach and consider all components of child development including the physical, mental, and emotional needs of the individual child and family.

Strengths and Limitations

Our findings yield important insights that researchers and health care professionals can use to improve child development practices. The participants' diversity in socioeconomic status and sexual orientation provided insights to the research questions and future samples. However, this study has several limitations. First, interviews were conducted in two Midwest states. It is possible that qualitative findings from other areas would have resulted in different insights and experiences. Second, all participants identified as mothers. Inclusion of other family members (e.g., fathers, grandparents) to make findings more generalizable is needed. Finally, many

participants were Caucasian. A heterogenous sample would provide more knowledge to better understand the individual perspectives of the DM process and identify a holistic approach that meets the needs of families today.

Conclusion

The purpose of this study was to obtain an understanding of families' knowledge regarding DM—an early identification practice. The results suggest there is a gap between families and their support systems and physicians in the DM process. Additionally, the emergence of circumstantial experiences provided context to the individual families and their role in promoting child development. DM is a collaborative process that is recommended in unison with families, physicians, and community providers. It is an opportunity to better understand the child from a holistic perspective and to work together to provide positive developmental outcomes for children. This study demonstrates the need for a comprehensive approach to DM with children and their families. Further research on systems and interventions specific to DM is needed.

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