


Timing of Referrals to a Down Syndrome Parent Group by Race

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Introduction: The Down Syndrome Association of Central Ohio (DSACO) is a nonprofit organization that supports families, promotes community involvement, and encourages lifetime opportunities for people with Down syndrome. **Methods:** At DSACO, ongoing efforts for quality improvement included: a Medical Advisory Committee in 2016, the creation of resources groups for Latino families in 2017, for Somali families from 2018 to 2019, and for African American families in fall 2018, presentations at birth hospitals, and close tracking of referrals from hospitals when an infant with Down syndrome is born. In addition, the timing of referrals, either “early” (on the day of birth or the first day after birth) or “late” (2 or more days after birth), were tracked and plotted in p charts. **Results:** From January 2017 to April 2021, DSACO received 167 referrals; of these, a median of 65% was received “early.” When analyzing all referrals to DSACO, no special cause was seen over the time studied. When evaluating the timing of referral to DSACO by race, referrals for 78% of White families were early (105/135 referrals). In comparison, referrals for 9% of minority families were early (3/32 referrals). **Conclusions:** The timing of DSACO referral differed by race. Outreach efforts did not change referral timing but led to a more diverse DSACO membership. Future study is needed to confirm if there is racial disparity in the timing of referrals to resources nationally and to understand the barriers in referring diverse families to Down syndrome nonprofit organizations. (*Pediatr Qual Saf* 2023;8:e632; doi: 10.1097/pq9.0000000000000632; Published online February 13, 2023.)

INTRODUCTION

Annually, 5,100 infants with Down syndrome, also known as trisomy 21, are born in the United States.^{1,2} Down syndrome occurs in all races and ethnicities; there may be differences in the prevalence of elective termination by U.S. region, race, ethnicity, and maternal age, but the actual differences in live birth prevalence are small.¹ Of the people with Down syndrome in the United States: 67% are non-Hispanic and White, 13% non-Hispanic and Black, 16% Hispanic, 3% Asian or Pacific Islander, and 1% American Indian or American Native.¹ Racial difference in prenatal screening

for Down syndrome exist; among 238 women, 35 years of age and older, presenting for care at 20 weeks to assess diagnostic test use, Latinas (33%) and African American women (33%) were less likely to undergo prenatal diagnosis than White (72%) and Asian women (75%).³ Underlying patient values and preferences, economic and insurance barriers impacted decision-making; African American and Latino women who were unemployed and uninsured were less likely to opt into prenatal testing.³ Latino and African American women reported barriers: transportation, time off from work, and child care.³

However, the 1996 survey may not reflect the current views and practices. A study of women of different racial-ethnic backgrounds found that all had some knowledge of Down syndrome, but misconceptions and beliefs varied among racial-ethnic groups.⁴ Many Hispanic and African American women reported they only saw or knew of White people with Down syndrome and requested culturally diverse educational material.⁴ African American and Hispanic women reported knowing features of Down’s syndrome but not any scientific information about it or that it was a genetic mutation compared with their White counterparts.⁴ White women reported that pregnancy with Down syndrome was more common in women 35 years and older, and women experience increased risk if family genetics play a role. In contrast, minority women reported that pregnancy with Down syndrome was due to environmental factors, drug use, and older age.⁴ One African American participant stated, “I have no idea what life with a child with Down



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Supplemental digital content is available for this article. Clickable URL citations appear in the text.

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To cite: Ansong E, Jones K, Santoro SL. Timing of Referrals to a Down Syndrome Parent Group by Race. *Pediatr Qual Saf* 2023;8:e623.

Received for publication July 13, 2022; Accepted January 5, 2023.

Published online February 13, 2023

DOI: 10.1097/pq9.0000000000000632

syndrome would be like; I wish I heard more stories about it from other African American families.”⁴

Many approaches to educate and address misinformation about Down syndrome exist, including standardized fact sheets,⁵ parent-friendly health information,⁶ evidence-based care,⁷ and policy statements from national professional organizations^{8–10} on best practices in delivering a diagnosis. Families report benefits from speaking to other parents of children with Down syndrome^{11,12} when receiving a prenatal or postnatal diagnosis. It is common practice for Down syndrome parent groups to offer “first call” programs that provide information and direct parent-to-parent connections.¹³

Building on previous quality improvement work,¹⁴ we aimed to study the referral patterns to a local Down syndrome parent support group. When assessing referrals to the Down Syndrome Association of Central Ohio (DSACO), the timeline after delivery dictates success. Based on healthcare guidelines, a postpartum stay would last 48–96 hours, depending on the delivery mode, absent complications.¹⁵ It is essential that families are referred within 48 hours to receive information before discharge and support through the initial diagnosis and after that. Specifically, this study aimed to evaluate the frequency of early and late referrals and trial solutions. We hypothesized that not all families were referred to DSACO within 48 hours and that a difference in referral timing between minority and White families could exist. Studying the referral process would identify opportunities for DSACO to connect, educate and support families sooner.

METHODS

Specific Aim

In this project, our overall aim was to: increase the percentage of families of newborns with Down syndrome that receive early referrals to the DSACO to 100% and sustain for 12 months. When we began this project in 2016, the baseline rate of early referrals was unknown, but from other work,¹⁴ we knew that the referral process was imperfect. Therefore, we created a Key Driver Diagram (Fig. 1) to guide our improvement.

Context

The DSACO is a nonprofit organization that supports families, promotes community involvement, and encourages lifetime opportunities for people with Down syndrome. DSACO serves 23 counties in central Ohio and receives membership in various ways, mainly through hospital referrals. In addition, a DSACO coordinator outreaches to local hospitals and parents to provide information.

While studying the referral process, in 2018, DSACO reviewed family-reported race and ethnicity data from membership forms. From this self-report data, DSACO identified that 95% of members were from White families. The race and ethnicity of DSACO members did not reflect the local demographics of Columbus, OH residents: 73%

were White, and 24% were African American, Latino, or Asian (U.S. Bureau of Census, 2017). To reach the minority community in Columbus, DSACO developed a strategy to improve representation within DSACO and to target referral placement for all families.

We tracked the race and ethnicity of the families referred. Race and ethnicity were obtained from either new membership application forms completed by parents or referral forms. On both forms, the prompt “Race”: was followed by the response options “White,” “African American,” “Hispanic,” “Somali,” “Asian,” “Middle Eastern,” “Indian,” “Vietnamese,” “Nepali,” “Armenian,” “more than 1 race in household,” “2 or more races,” “other,” or “prefer not to state.” In 2020, DSACO updated forms, and “Ethnicity”: became an open-response format. As we collected data for our quality improvement initiative related to the DSACO referral process, due to the small frequency of DSACO members (5%) of African American, Hispanic, Somali, Asian, Middle Eastern, Indian, Vietnamese, Nepali, Armenian, more than 1 race, 2 or more races from 2018 data, we described families of these races as “minority families” in the remainder of this article based on prevalence in the DSACO membership.

Interventions

At DSACO, after previous quality improvement work,¹⁴ Ongoing efforts for quality improvement included creating a Medical Advisory Committee (MAC) and resource groups.

First, in 2016, DSACO created a MAC—a team of healthcare professionals who DSACO could refer for questions and provide expertise, insight, and guidance in improving referral timing. Next, DSACO developed “Nurse Talks” and “Teaching Moments.” “Teaching Moments” consisted of a MAC member presentation to staff on how to best deliver a Down syndrome diagnosis, when to give resources and referrals, certain dialogue to use, and other essential tips. For example, DSACO and the MAC chair gave presentations to physicians in a primary care network, the obstetrician/maternal fetal medicine physicians at a large birth hospital, the obstetrician chief at a second birth hospital, a medical student maternal fetal medicine physician/neonatology interest group, and the Ohio Association of Women’s Health, Obstetric and Neonatal Nurses/American College of Gynecologists in 2017.

DSACO established a safe space for minority families by creating resource groups. These groups provided families a space to get to know one another, discuss their needs, and inform them about what DSACO offers. Resource groups included: a Latino resource group in 2017, a Somali resource group in 2018–2019, and African American group in the fall of 2018. To support and lead these resource groups, DSACO created outreach coordinator positions. DSACO hired 1) a Minority Outreach Coordinator in May 2017, 2) a Latino Outreach Coordinator and Spanish-speaking support liaison in May 2017, 3) a Somali Outreach Coordinator in June 2018, and 4) an African American Outreach Coordinator in July 2018 to increase family engagement. In addition,

Key Driver Diagram

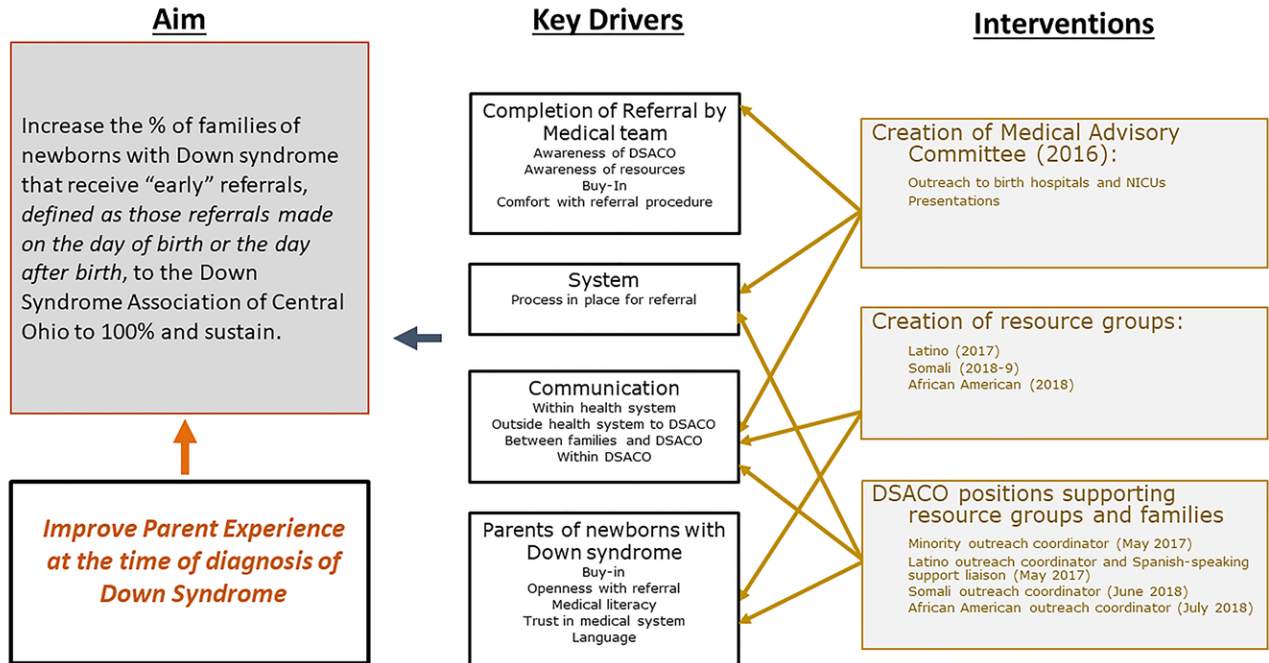


Fig. 1. Key Driver Diagram.

to expand outreach to racial minority communities in Central Ohio, the Minority Outreach Coordinator was tasked with outreach to centers that serve predominantly racially and ethnically diverse populations that may not be aware of DSACO. These minority centers included: small clinics, health centers, churches, and community events.

The medical outreach coordinator at DSACO tracked hospital referrals to DSACO after the birth of an infant with Down syndrome. Details included the time of referral, demographics, and birth hospital site, which were reported on the referral form.

Measures

In this project, the key metrics were:

- 1) Process Measure 1—Timing of referral to DSACO: typically, birth hospital staff place the DSACO referral, but a pediatrician, specialist, or other health care professional could refer. Paper referrals are faxed or emailed to DSACO. Referral forms collect demographic information, including age, hospital of birth, and prenatal or postnatal diagnosis. In this project, we categorized referrals as either “early” if made on the day of birth or the first day after birth or “late” if made 2 or more days after birth.
- 2) Outcome Measure 1—Percentage of “early” referrals: calculated as the fraction of “early” referrals out of the total in a period.
- 3) Outcome Measure 2—Percentage of “late” referrals: calculated as the fraction of “late” referrals out of the total in a period.

Using demographic information on the referral form regarding race, we plotted this Outcome Measures 1 and 2 by race group.

- 4) DSACO Member demographics.

Statistical Analysis

Outcomes were plotted in p charts by quarter or year based on the volume of referrals. Centerline shifts were determined using standard statistical process control chart rules.^{16,17} We used the American Society for Quality rules to detect special cause variation on charts.^{18,19} From special cause findings, we performed a chi-square analysis to compare the % of early referrals by race group.

RESULTS

From January 2017 to April 2021, DSACO received 167 referrals for infants with Down syndrome born in the Columbus area (See Table, Supplemental Digital Content 1, which displays the 167 referrals to the Down Syndrome Association of Central Ohio for infants with Down syndrome, N (%), <http://links.lww.com/PQ9/A449>). Of these referrals, 132 were for infants with Down syndrome in White families, and 35 were for infants with Down syndrome in minority families (See Table, Supplemental Digital Content 1, which displays the 167 referrals to the Down Syndrome Association of Central Ohio for infants with Down syndrome, N (%), <http://links.lww.com/PQ9/A449>). As described above, based on prevalence rates in Columbus, we categorize families by race and ethnicity as “White” families or “minority” families throughout this

article. Over the 18 quarters of the years studied, on average, DSACO received 9.3 referrals each quarter (range = 2–20; SD = 5.04).

Timing of Referrals

A median of 65% of all DSACO referrals was early (Fig. 2); 35% of all DSACO referrals were late. The least early referrals occurred in quarter 4 of 2017 (25%). Data from quarter 2 of 2019 to quarter 2 of 2020 are presented in red as they meet the special cause rule 3—points above 1 sigma. These times did not directly coincide with our interventions but could be the result of ongoing efforts and the long-term, broad impacts of the MAC, such as developing networks and connections with the birth hospital or as the resource groups gained membership. No shifts were seen over the time studied when analyzing the aggregate data of all referrals.

When evaluating referral data by race, DSACO received more early referrals for White families than for minority families (105/135 referrals, and 3/32 referrals, respectively; X2 statistic = 52.97, $P < 0.001$). More of the referrals DSACO received for minority families were late compared with White families. To further evaluate this finding, annual early referrals by race were plotted (Fig. 3) with special cause detected between races; annual early referrals were then phased based on special cause signals (Fig. 4). On average, DSACO received early referrals for 78% of White families and 9% of minority

families (Fig. 4). The highest rate of early referrals for minority families occurred in 2021 when 2 of 5 families (40%) were referred early. In contrast, the lowest rate of early referrals for White families occurred in 2017, when 63% were referred early.

DSACO Member Demographics

In 2018, 95% of DSACO members were from White families, while 5% were from minority families.

After our intervention, as of 2022, the full DSACO membership remained mostly White families (78%), but the number of minority families in DSACO increased to 22% (261/1,211 members; Table 1) and more closely matched the demographics of Columbus, OH (U.S. Bureau of Census, 2017).

Using the 2022 membership demographics, we created a Pareto chart of the race and ethnicity of minority families. African American families represented the largest percentage of minority families by category (31%; Fig. 5).

DISCUSSION

Providing accurate information and counseling about Down syndrome is an important first step in caring for individuals with Down syndrome.^{5,7,20} Referrals to parent support groups are one approach to providing information, resources, and connecting families with others.²⁰ Building on previous outreach efforts to improve genetics

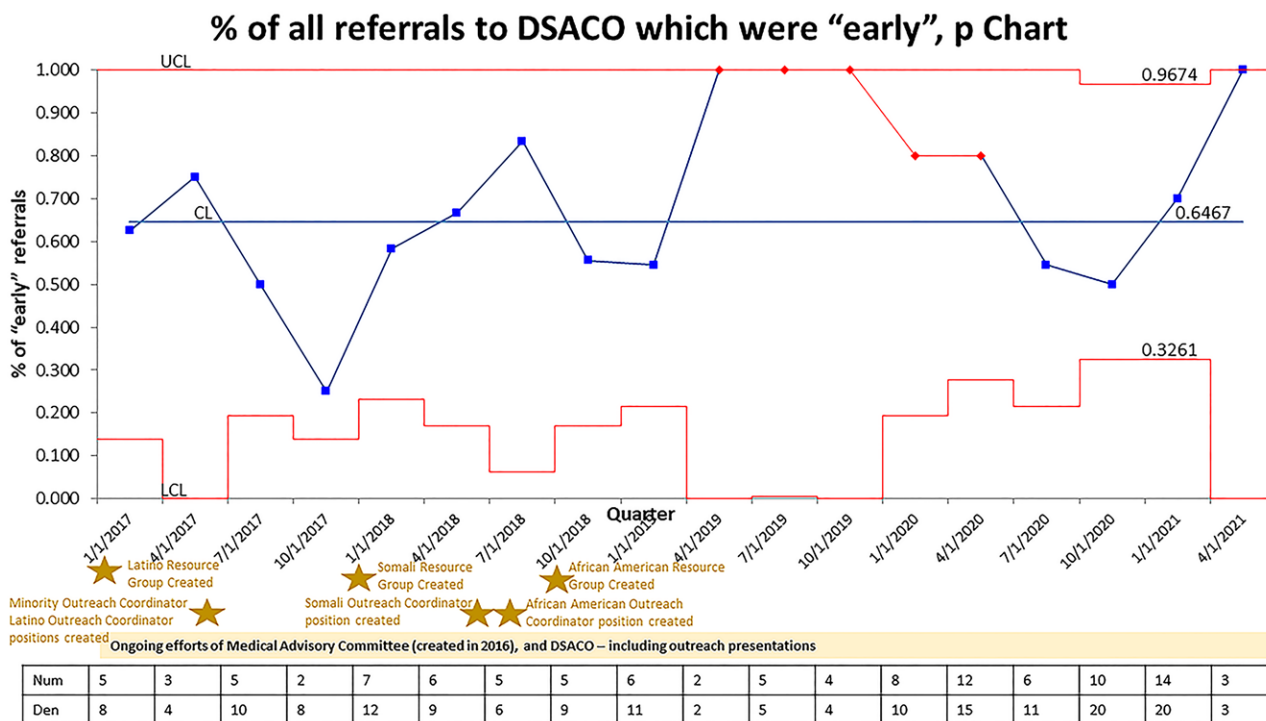


Fig. 2. Percentage of all referrals to the Down Syndrome Association of Central Ohio from January 2017 to April 2021, which were “early” defined as on the day of birth or the day after birth. Blue-gray lines indicate the process stage mean, which refers to the arithmetic mean for all points within that process stage; statistical rules indicate that there is 1 stable process stage. Red lines indicate the control limits (± 3 SDs based on the process mean and number for that month).

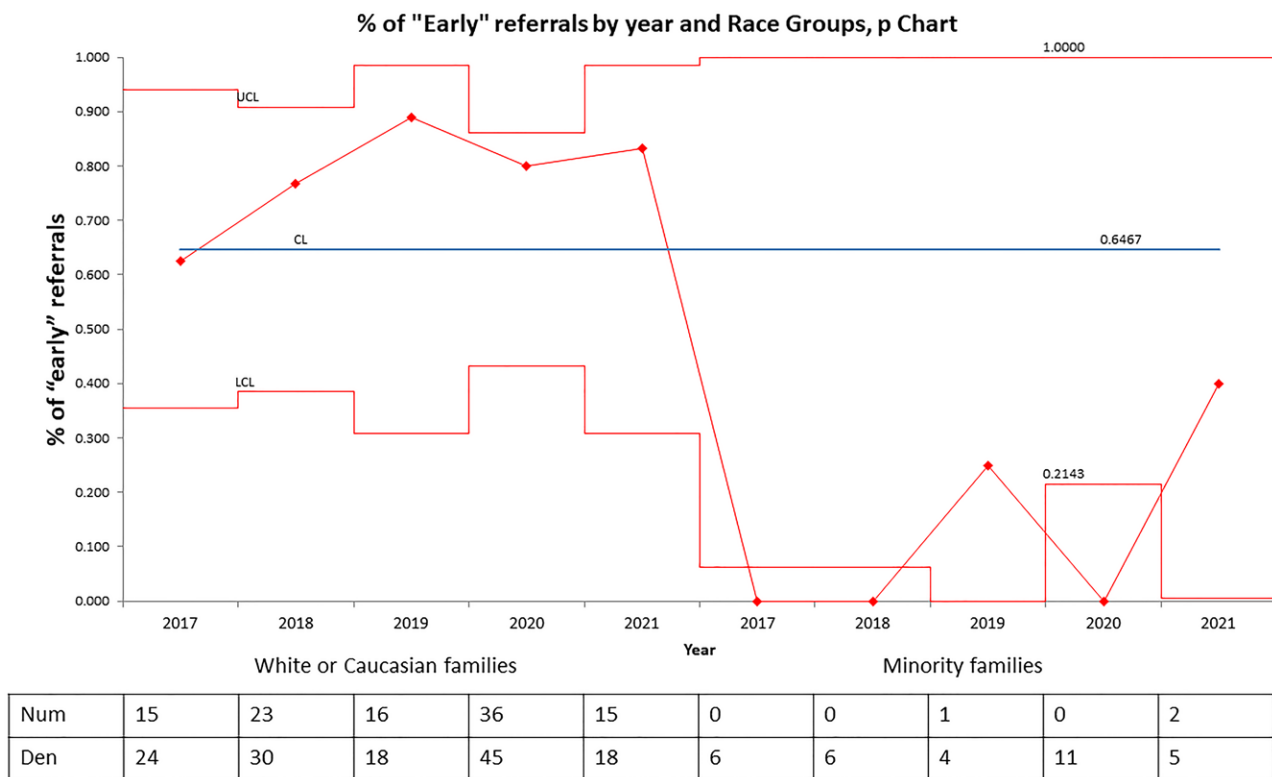


Fig. 3. By race, the percentage of “early” referrals to the Down Syndrome Association of Central Ohio from 2017 to 2021; “early” defined as on the day of birth or the day after birth. Blue-gray lines indicate the process stage mean, which refers to the arithmetic mean for all points within that process stage; statistical rules indicate that there are 2 stable process stages. Red lines indicate the control limits (± 3 SDs based on the process mean and number for that month).

department referrals after an infant with Down syndrome is born,¹⁴ we began this study to track the timing of referrals to DSACO, with attention to the demographic composition of DSACO members.

Over 5 years, DSACO received 65% of its referrals early. The referral process worked: from the uptake and buy-in at the birth hospital to the successful placement of multiple referrals each quarter to the work of the team at DSACO in completing these referrals. Connecting with other families of children with Down syndrome is valuable; it is recommended by the American Academy of Pediatrics to “offer parent-to-parent contact and information about local and national support organizations because communication with experienced parents is often a very helpful resource for caregiver decision-making.”²⁰ Multiple studies demonstrate the benefit of connecting parents of infants with Down syndrome with local parent support groups²¹ and with other parents,^{22,23} including the need to offer parents’ contact information.¹² We demonstrate a nonprofit organization can collaborate with birth hospitals to provide resources and psychosocial support to families receiving a diagnosis of Down syndrome. Down syndrome nonprofit organizations have shown success, and national “First Call” models and diagnosis networks exist for Down syndrome; other conditions or genetic syndromes could apply this diagnosis network model.

Referral timing is crucial because referrals before discharge¹⁵ allow families connection, support, and information. Unfortunately, in this study, DSACO received many (35%) referrals “late,” after 48 hours, with the potential for mothers to be discharged without a DSACO referral. As mothers prefer learning about Down syndrome quickly, even when the diagnosis is not confirmed,²¹ parents would likely prefer the opportunity to connect with other parents as soon as possible. If families are discharged and not referred to DSACO, they may go days or weeks without information about Down syndrome and the important family connection that parents seek. Additionally, not connecting with DSACO early in life could risk relationships, resources, and long-term support.

We found differences in the percentage of women referred “early” or “late” by racial groups: White women were referred “late” to DSACO only 22% of the time on average, while 91% of referrals for minority women were “late” (Fig. 3). Our results align with studies showing differences by race in views of prenatal testing for DS,³ and knowledge, attitudes, and beliefs about Down syndrome.⁴ This racial disparity in the timing of referral warrants further research to understand the barriers to referral, the family’s views of referral to DSACO, and to understand how differences in the timing of referral could have impacts on future care, such as connections

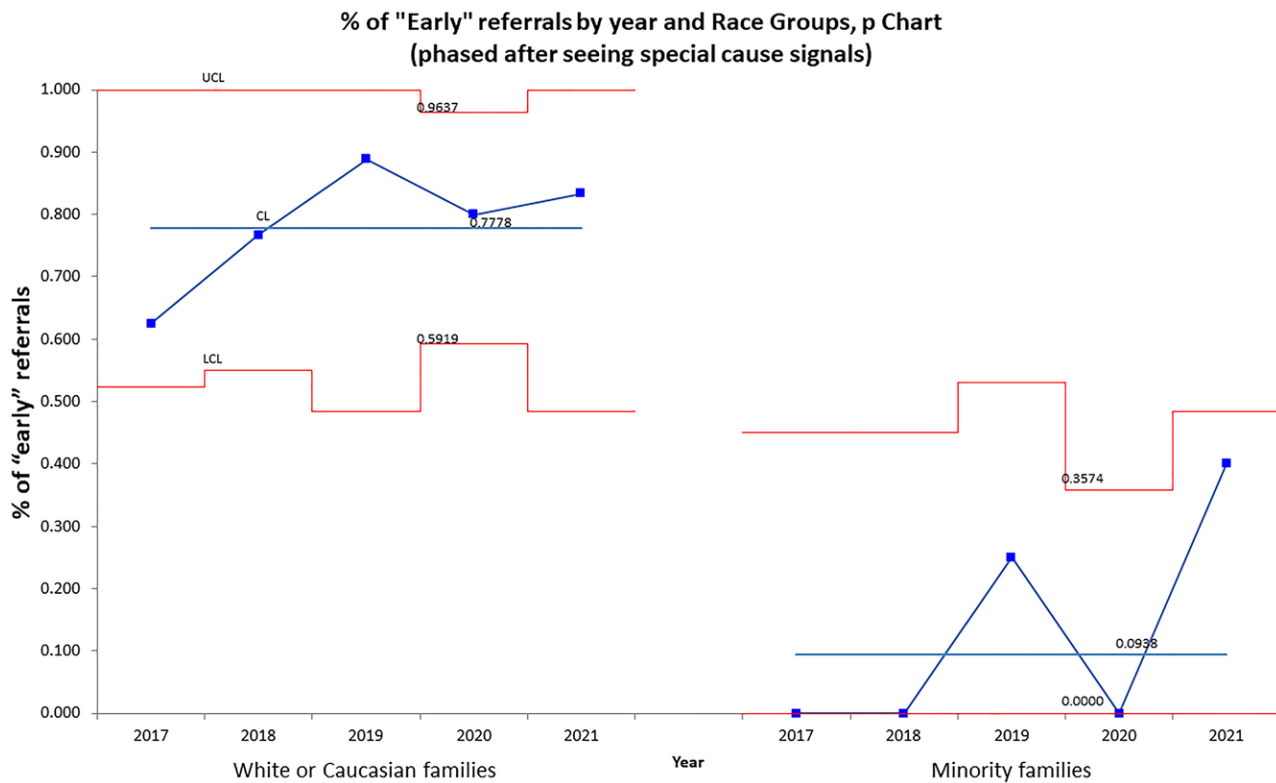


Fig. 4. By race, the percentage of “early” referrals to the Down Syndrome Association of Central Ohio from 2017 to 2021; “early” defined as on the day of birth or the day after birth. Blue-gray lines indicate the process stage mean, which refers to the arithmetic mean for all points within that process stage. Phased chart shows 2 stable process stages separated by race. Red lines indicate the control limits (± 3 SDs based on the process mean and number for that month).

Table 1. Demographic Traits of the 1,211 Members of the Down Syndrome Association of Central Ohio in 2022

Demographic Trait	N (%)
Race or ethnicity of parent(s)	
White	950 (78)
African American	80 (7)
Hispanic	44 (4)
2 or more races	37 (3)
Other	20 (2)
Somali	8 (<1)
Asian	6 (<1)
Middle Eastern	4 (<1)
Indian	4 (<1)
Vietnamese	2 (<1)
Nepali	1 (<1)
Armenian	1 (<1)
More than 1 race in household	16 (1)
Prefer not to state*	3 (<1)
Missing*	35 (3)
Primary language spoken, other than/in addition to English	31 (3)
Spanish	22 (2)
French	3 (<1)
Nepali	2 (<1)
Somali	1 (<1)
Other	3 (<1)

*If parent demographics unavailable, in these families, the child’s race or ethnicity was reported and known to be one of the minority categories.

referrals but no data on families who were never referred or declined. A healthcare professional could complete referral forms, but that information is not verified with parents. The basis of our analyses came from aggregate values based on “early” and “late” diagnoses. We did not have raw values to summarize the range of timing of referral; a referral received years later and a referral placed at 2 days of age would be “late” but with different implications. We did not have further details to review data to study the cause of late referrals. For example, 1) the day of the week could impact the timing of DSACO referral—infants born during the weekend might be less likely to be referred or 2) the time of day of birth could impact the timing of DSACO referral—infants born overnight might be less likely to be referred. Future studies could evaluate proposed factors impacting referrals (the parents’ views, the day of birth, and the time of birth), the value of earlier referral to parent resource groups, the impact of referral time on parent experience at diagnosis, long-term engagement with DSACO, or ongoing DSACO membership.

At DSACO, the focus on referrals, the use of parent resource groups, and the creation of outreach coordinator positions led to increased representation of minority families from 5% to 22%. As a result, the 2022 DSACO membership better reflects the local population. Still, work should continue to ensure that this continues

with resources or connections with the Down syndrome community of parents and advocates.

Our review at 1 Down syndrome parent resource group is limited. For example, we have data on DSACO

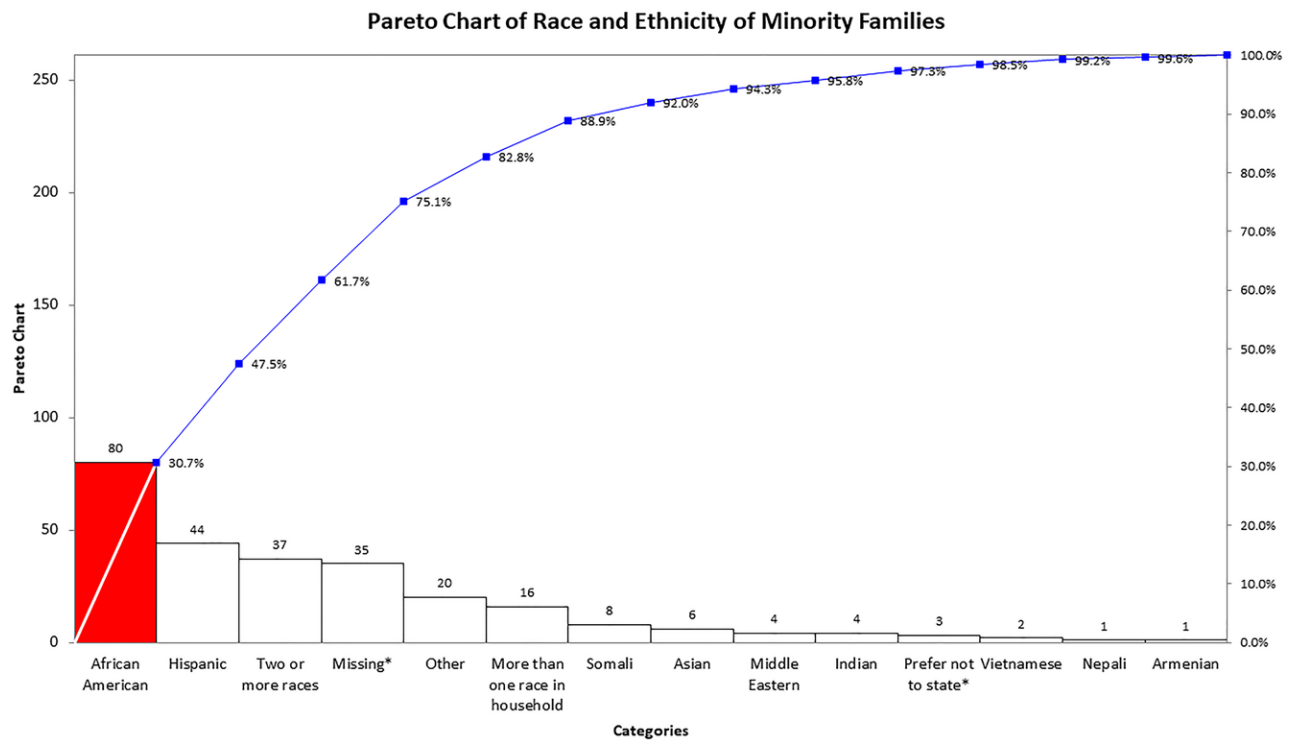


Fig. 5. Pareto chart of race and ethnicity of minority families in DSACO membership.

and that DSACO is accessible and serving all families of individuals with Down syndrome. Our data show that African American families are the largest category of race and ethnicity within minority families (Fig. 5); focusing outreach to African American families could be the most impactful. Future studies could also assess the demographic membership of other nonprofit organizations for Down syndrome, evaluate how well groups reflect their local population, and elicit feedback from members, such as focus groups or interviews, to assess membership benefits and the impact of DSACO referral timing.

Taken together, lower rates of early referrals in minority families but increased membership suggest that minority families become DSACO members but later. We wish to highlight how discrepant the referral timing between ethnicities was in our results: most (78%) White families were referred early, while few (9%) minority families were referred early. Rather, most (91%) minority families were referred late. We emphasize the need for future work locally to continue to improve rates of DSACO referral for all, ensuring that minority families receive equitable care. You cannot treat a problem until you identify it, and this is a clear example of nonequitable care that is important to name. Awareness of this disparity is the first step to addressing this and working to ensure that families of all races receive equitable care at the time of diagnosis. We found differences in the timing of referral by race at 1 parent group for Down syndrome. We propose future studies include a national survey of parents or multiple

parent groups throughout the country to replicate this result. Additional national research and efforts on racial disparities in referrals at diagnosis would be beneficial.

CONCLUSIONS

In this single-site study of referral timing to a nonprofit organization for Down syndrome, we found that many families (35%) were not referred within the first 48 hours after an infant with Down syndrome is born; timing of DSACO referral differed by race with minority families referred later than White families. Outreach efforts did not change referral timing but led to a more diverse DSACO membership.

ACKNOWLEDGMENTS

The authors thank Kim Baich for her ongoing work on medical outreach at Down Syndrome Association of Central Ohio. In addition, the authors acknowledge the mentorship of Ricky Allen, PhD, at George Washington University, for his guidance in this work. The authors also appreciate the help of Murugu Manickam, MD, for his guidance in this research and ongoing efforts in academic education on this topic.

DISCLOSURE

The authors have no financial interest to declare in relation to the content of this article.

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