An Analysis of Parents' Reports on Educational Services for Their Children with Albinism

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Structured abstract: *Introduction:* The purpose of this study was to gain information from parents in the United States about their children with albinism. The first article (in this issue) focused on the data from this study that addressed medical and low vision care. This article focuses on information and services related to the education of children with albinism. *Methods:* An online questionnaire was used to collect data for this study from parents of children with albinism. Representing 223 children with albinism from 40 states in the U.S., 192 parents completed surveys and had opportunities to submit additional information. *Results:* A snapshot of the data indicates that, as a whole, parents perceive their children to do well academically, but they experience social and emotional challenges; 98 children were receiving direct instruction from a teacher of students with visual impairments and 84 were receiving consultation services. Although parents were generally satisfied with their level of involvement in the development of their children's education plans, many could not provide key information about the assessments their children had received, their children's reading rates, or the services with which their children were being provided. *Discussion:* These data illuminate the fact that, despite the premise of the Individuals with Disabilities Education Act (IDEA, 2004) that parents be equal partners in the education of their children with special needs, these parents of children with albinism were not as informed about the assessments and services that their children were receiving as might be expected. Findings also suggest the possibility that students with albinism may not be receiving appropriate educational services to address the limitations imposed by their low vision. In particular, it appears that these students, most of whom will be non-drivers, are not receiving orientation and mobility services. In addition, there was evidence that over half of these children may not be receiving instruction in the use of low vision devices. *Implications for practitioners:* The data gathered in this study provide directions for educators who work with children who have albinism and their families, as well as for those who design and administer services for children with visual impairments. Based on these reports from parents, it appears that children with albinism are not being assessed in the areas key to understanding their functioning and, although as a group they are doing well academically, other needs related to the Expanded Core Curriculum (ECC) are not being addressed as frequently. Teachers of students with visual impairments may want to be more explicit when describing to parents the assessments on which their educational recommendations are being made. Further research is needed to determine if children with low vision are being provided with educational services based on educational assessments and needs or if other administrative factors are driving these services.

This article is the second of a nationwide study of the medical, low vision, and educational services that are provided to children with albinism. The authors' first article in this issue (Corn & Lusk, 2018) addressed the children's medical and low vision services; this article focuses on the information related to the education services the children were receiving at the time of the survey and their parents' understanding of them. The Individuals with Disabilities Education Act (IDEA, 2004) has provisions for payments for medical evaluations that are sought to improve functioning within special education, assistive technology assessments, the provision of devices, and instruction in the use of those devices. Data regarding these topics are presented in this article.

Children with oculocutaneous albinism generally have visual acuities between 20/100 and 20/400, and those with ocular albinism generally have visual acuities between 20/60 and 20/100; in addition, people with albinism experience photophobia, strabismus, and nystagmus (Schwartz, 2010; see also Corn & Lusk, 2018, for more details on these forms of albinism). These children are eligible for assessments to determine whether their disability has an effect on their learning and, if so, whether they are eligible for special education through IDEA (2004). From birth to age 3 years, IDEA requires that an Individualized Family Service Plan (IFSP) be written to describe the services to be provided to the family and the child; at 3 years of age an Individualized Education Program (IEP) is written to describe the child's educational needs, as determined through a multidisciplinary assessment, and the special education and related services that will be provided to meet those needs. If assessments determine that these children do not meet the criteria for eligibility for special education, they may be eligible to receive services and accommodations described in a 504 plan under the Rehabilitation Act of 1973, which prevents discriminatory practices in schools (U.S. Department of Education, Office for Civil Rights, 2010).

Those children who receive special education services and those who receive accommodations under 504 plans are entitled to a free and appropriate public education (Sartorius, 2017). With IFSPs, the term *appropriate* may mean instruction for the family by an infant specialist or a teacher of students with visual impairments. For those from 3 years of age until age 22 years, the teacher of students with visual impairments is typically the service provider of direct or consultative services to address needs related to the visual impairment. In addition, for all ages, children identified as having special needs under IDEA are eligible to receive related services to meet their educational needs, which include, but are not limited to, those services provided by orientation and mobility specialists, occupational therapists, and physical therapists.

A related service provider not specifically identified in IDEA, but of particular importance for children with albinism and others with low vision, is the clinical low vision specialist. This ophthalmologist or optometrist with a low vision specialty may be identified as a medical specialist under IDEA if an evaluation is intended to improve a child's functioning. Alternatively, these evaluations may be considered as specialized assistive technology assessments, since they pertain to devices that one would not expect a generalized assistive technology specialist in a school system to have in-depth knowledge about, or training to select the appropriate tool for a student with visual impairments.

There is anecdotal evidence that some children with albinism may not be receiving nondiscriminatory and appropriate services through their school systems. In one case, a parent wrote about her experiences with the New York City Public Schools, which denied her daughter the use of her optical devices during testing for a program for gifted children (Schank, 2015). Similarly, a parent of two children with albinism described the school district in which her children were enrolled as having not hired a teacher of students with visual impairments until after Thanksgiving (that is, after late November; most primary school years in the United States begin in late August or early September) and that the teacher only provided services on one occasion. There are also numerous anecdotes about bullying of children with albinism in schools. As Alexis Foster, age 17 years, wrote, "There were many days I sat at lunch tables alone, cried myself to sleep, and despised my reflection in the mirror. The pain I experienced was the result of the pain of bullying I endured" (Foster, 2015, p. 23). Although other students with visual impairments may encounter bullying or other discriminatory actions, a child with albinism may be considered to be at a greater risk for bullying because of their appearance, which is more often than not different from their peers and family members. This type of treatment has the potential to lead to social or emotional problems (Copeland, Wolke, Angold, & Costello, 2013).

To learn about the education of children with albinism across the United States, we chose to ask parents for information about the educational services their children received. There are several reasons why parents' knowledge and opinions are important in such a study. Among these reasons are that parents are their children's first and most important teachers and that parents are members of the IEP team for their children. As such, parents are involved in making decisions regarding when educational assessments may be given and when special education programs may be delivered to their children.

Review of the literature

Research about the education of children with albinism is rare. There are medical studies about genetics and a few studies related to prescriptions for optical devices. In education, research on children with visual impairments generally includes children with albinism within a larger sample. A 2018 search of back issues of the *Journal of Visual Impairment & Blindness*, the leading research journal in the field, found no data-based studies published between 1994 and 2017 that included "albinism" in the title. Therefore, professional guidance and education research that are relevant to children with low vision, inclusive of those with albinism, are included in this review of the literature.

IDEA (2004) includes several provisions that are relevant for children with albinism, including the requirements that: education be provided in the least restrictive environment; assistive technology assessments be conducted; instruction in the use of assistive devices be provided; access to the general education curriculum be assured; and needed classroom accommodations and related services be made available. IDEA also requires that the child be "assessed in all areas related to the suspected disability, including, if appropriate, health, vision, hearing, social and emotional status, general intelligence, academic performance, communicative status, and motor abilities," Section 300.304(c)(4). The inclusion of clinical vision evaluations may be considered among the related services in IDEA, since they are intended to assist a child's functioning within special education. Therefore, school districts can be responsible for the payment of these evaluations, when appropriate, Section 300.34(a). In addition, for all students with visual impairments who are served under IDEA, instruction in the use of braille as a learning medium must be discussed at each annual IEP meeting.

IDEA also requires an annual determination of whether braille instruction is appropriate for a child who is visually impaired. This determination is done "after an evaluation of the child's reading and writing skills," 20 U.S.C. 1414(d)(3)(B)(iii) and 34 CFR 300.346(a)(2)(iii). As such, a learning media assessment to determine whether braille, print, or a dual-media approach to literacy is needed in order to make this determination.

As a promising practice, and by law in Texas, teachers of students with visual impairments and orientation and mobility specialists teach to the Expanded Core Curriculum (ECC) for Students with Visual Impairments, a body of knowledge and skills covering nine disability-specific curricular areas that lead to independent functioning. These areas comprise: compensatory skills, self-determination, career education, orientation and mobility, use of technology, sensory efficiency skills, independent living skills, social interaction skills, and recreation and leisure skills (Sapp & Hatlen, 2010). Today, assessments and a determination of whether instruction in the curricular areas of the ECC is necessary may be considered promising practices (Allman & Lewis, 2014).

There are several position papers that speak to the roles of teachers of students with visual impairments and orientation and mobility specialists in ensuring that students learn to use their optical, electronic, and other technology devices. For example, the Division on Visual Impairments and Deafblindness (DVIDB) of the Council for Exceptional Children (CEC) updated and adopted their position paper (Spungin, Ferrell, & Munson, 2016), which emphasizes the need for functional vision assessments and learning media assessments to be given to students. In addition, DVIDB has adopted a position paper in which the need for orientation and mobility assessments is described, and which supports the idea that instruction in the use of optical devices is one of the specialist's responsibilities (Cmar, Griffin-Shirley, Kelley, & Lawrence, 2015).

Because the community of individuals with albinism has felt that the educational needs of their children were not well represented within the professional literature, and because of the unique needs of these children in schools, the National Organization for Albinism and Hypopigmentation (NOAH) has published texts including the series *Raising a Child with Albinism* (NOAH, 2008, 2014); the journal, *Albinism InSight*; and the *NOAH SchoolKit* (Garza, Gorman, Cowan, Sewell, & Bachofer, 2016). NOAH's extensive website also provides parents and students with a vast amount of information and support for children, their parents, and adults with albinism.

Research questions for this part of the study described here included: What educational programs and services do parents report are available to their children with albinism? Do parents report that their children with albinism are receiving assessments related to their vision such as functional vision assessments and learning media assessments? and Do parents report that their children with albinism are being provided with instruction that aligns with the ECC, including instruction in the use of optical and electronic devices?

Methods

DESIGN

The first part of the study was developed to gather demographics of the families and of the children for whom parents provided information. Other sections of the questionnaire had to do with medical information and services, including clinical low vision evaluations (Corn & Lusk, 2018), education information and services, and parent perspectives on their children's educational services.

The authors developed the questionnaire based on issues raised within the online albinism community and in literature concerning children with low vision. An initial draft of the questionnaire was sent to NOAH for review by its Scientific Advisory Committee. Their comments were addressed within the questionnaire. The Institutional Review Board of the Cincinnati Children's Hospital Medical Center approved the study protocol, the instrument used for data collection, and the recruitment materials before the collection of any data.

The questionnaire was put on SurveyMonkey. In addition, print and braille copies of the questionnaire were available, as well as offers to help parents complete questionnaires by telephone. If a family had more than one child with albinism for whom they were completing the questionnaire, they were able to restart the questionnaire without a need to re-respond to information that would apply to two or more children, such as the area of the country in which they lived.

RECRUITMENT

Several professional and parent organizations assisted with the recruitment of subjects. At the biennial NOAH conference in July 2014, information was distributed describing the purpose of and the website for accessing the questionnaire. Among other organizations that assisted with recruitment, the National Association of Parents of Children with Visual Impairments and the CEC distributed flyers electronically and via periodicals.

PARTICIPANTS

A total of 192 families of children with albinism completed questionnaires and met the criteria for inclusion (that they lived in the U.S., that their children had not completed their secondary education, and that they completed a majority of the questions). Twenty-five of the 192 families provided information for two children, and two families completed the questionnaire for three children. Therefore, a total of 223 children were represented in the data. Only one family completed a paper copy of the questionnaire, and those responses were fed into the electronic data file. Responses came from 40 states, including 21.6% ($n = 41$) from the northeast, 25.8% ($n = 49$) from the midwest, 29% ($n = 55$) from the south, and 23.7% ($n = 45$) from western states.

Results

Demographic information included the children's grades in schools, their ethnicity, and their visual acuities.

Parents were asked to give their children's grade in school. Thirty-one of the children (14.3%) were in the birth to 2 years range; 32 children (32.8%) were preschoolers; 42 (19.4%) were in kindergarten to second grade; 31 (14.3%) were in third to fifth grade; 37 (17.1%) attended sixth to eighth grade; and 35 (16.1%) were in ninth to 12th grade. An additional 9 children were in ungraded or "other" graded programs (including home schooling).

Parents also reported that 131 (68.2%) of the children were White-Caucasian and that 26 (13.5%) were Asian and Pacific Islanders, 11 (5.7%) were African American, and 9 (4.5%) were Hispanic. The remainder were of mixed ethnicities, the parents did not know their children's ethnic background, or they chose not to state this information.

The children had a range of visual acuities; 105 (55.8%, $n = 165$) met the United States criteria for legal blindness. Parents reported their perceptions of their children's range of photophobia. On a three-point scale, 80% of the children were reported to experience moderate to severe photophobia.

EDUCATIONAL INTERVENTIONS AND SERVICES

Several questions asked parents about the educational services their children were receiving due to their visual impairment. It is important to note that the numbers of children who were not receiving services differ throughout this section due to different numbers of parents who responded to individual questions.

Parents reported the age at which their children first began to receive educational interventions due to their visual impairment (see Table 1). These data were analyzed by visual acuity for 188 children (see Table 2). For 52.1% ($n = 98$) of the children whose visual acuities were between 20/120 and 20/400, the first intervention occurred at

Table 1
Age at first educational intervention due to visual impairment.

Age	Number	Percentage
Birth to 1	128	57.9
1 year	10	4.5
2 years	11	5.0
3 years	6	2.7
4 years	11	5.0
5 years	11	5.0
6 years	14	6.3
7 years	2	0.9
8 years	5	2.3
9 years	1	0.5
10 years	0	0
11 years	0	0
12 years	1	0.5
No specialized interventions	20	9.1
I don't know	1	0.5
Total	221	

1.72 years of age, and 6 with the same range of visual acuities were reported not to have had any educational interventions. First educational interventions for children whose visual acuities were in the 20/50 to 20/60 (*n* = 12) range occurred at an average age of 3.4 years; yet 3 in that range had not had educational interventions. Seven parents reported that their children with visual acuities better than 20/50 received a first intervention at 1.5 years of age.

Children who were currently receiving special educational services due to their visual impairment had IFSPs (*n* = 31) and IEPs (*n* = 134); 20 children were provided with services on 504 plans. Some parents did not know what type of service plan described the services their child was receiving (*n* = 5), an additional 18 parents indicated an "other" plan than those listed in the options, and no services were being received by 21 children.

When asked about the type of service delivery their children were receiving, parents provided 299 responses, since some children were reported as receiving more than one type of service delivery (for instance, direct service and consultation service). Children and families received early intervention services in the home (*n* = 42) or at centers (*n* = 13). School-age children were provided with instruction at center-based preschools (*n* = 8), in a resource room dedicated to children with visual impairments (*n* = 9), or in a resource room dedicated to children with special needs (*n* = 15). Most children were provided with consultation services (*n* = 55) or direct instruction from an itinerant teacher (*n* = 81). Some children were enrolled at a specialized school for children with visual impairments (that is, those who are blind or have low vision; *n* = 11). Other children were home schooled (*n* = 12), had "other"

Table 2
First intervention by visual acuity.

Visual acuity	Average age, first intervention	Percentage of children receiving no intervention
Better than 20/50 (*n* = 7)	1.5 years (*n* = 4)	42.9 (*n* = 3)
20/50 to 20/60 (*n* = 12)	3.4 years (*n* = 10)	16.7 (*n* = 2)
20/70 to 20/100 (*n* = 42)	1.21 years (*n* = 39)	7.1 (*n* = 3)
20/120 to 20/400 (*n* = 104)	1.72 years (*n* = 98)	5.8 (*n* = 6)
Worse than 20/400 (*n* = 1)	0 years (*n* = 1)	0 (*n* = 0)
Unknown or other (*n* = 22)	0.90 years (*n* = 20)	9.1 (*n* = 2)

services ($n = 16$), or received no services ($n = 38$).

Direct instruction ($n = 98$) or consultation ($n = 84$) was provided by a teacher of students with visual impairments, an orientation and mobility instructor ($n = 75$), another special education teacher ($n = 25$), or an early childhood interventionist ($n = 22$). Twelve children were receiving support from a paraeducator on a full-time ($n = 3$) or part-time ($n = 9$) basis. Additional responses included "other" interventions ($n = 19$), unsure of interventions provided ($n = 5$), and no interventions provided ($n = 43$).

A separate question asked parents of children who were not receiving services why they were not. Reasons included the parent not feeling the child needed intervention ($n = 13$), the parent feeling that services would be beneficial but that the school or teacher did not think the child needed services ($n = 10$), the parent saying that the child had not been evaluated for any services ($n = 5$), and other reasons ($n = 28$).

EDUCATIONAL ASSESSMENTS RELATED TO VISUAL IMPAIRMENTS

Parents were asked which assessments related to their child's visual impairment had been conducted within the last three years, reporting for 218 children. Based on parents' reports, only 54.6% of the children had received a functional vision assessment, 47.7% of the children had received an orientation and mobility (O&M) assessment, and 21.6% of the children had received a learning media assessment. For 27.5% of the children, parents reported that they had not received any assessments or that they did not know if their children had received a functional vision assessment, a learning media assessment, or an O&M assessment.

Table 3
Assessments provided in ECC areas.

Area of ECC	Number
Compensatory skills	19
O&M	84
Assistive technology	45
Sensory efficiency	14
Independent living skills	17
Social skills	28
Recreation and leisure	13
Career education	15
Self-determination	10
No assessment given	82
I don't know	36

Parents reported for 208 children as to which assessments for each of the nine areas of the ECC had been conducted within the last three years. A total of 245 assessments had been given to these children, with the most prevalent being in O&M ($n = 84$, 40.4%), followed by assistive technology assessments of 45 students (21.6%); students' social skills were reported to have been assessed for 28 (13.5%) students. Responses for 82 (39.4%) of the children indicated that no area of the ECC had been assessed. See Table 3 for more information.

Children were reported to use various learning media, and parents frequently reported the use of more than one medium by their children. Large print was the most often used ($n = 117$), followed by standard print with optical devices ($n = 91$), and standard print without optical devices ($n = 79$). Braille was being used by 18 students. For those children receiving instruction in dual media (braille and print), parents were asked the reasons for this decision. A learning media assessment reportedly was conducted to support this decision for five children, and 10 parents had requested braille instruction.

Another question concerned all the methods by which children were receiving instruction in braille. Parents reported that 13 students were permitted to see the braille, while five were blindfolded for this instruction. Three students were shown the print while reading by touch; use of translucent barriers, opaque partitions between the child's eyes and the braille, and auditory access to the information being read in braille were also identified as being used during instruction.

Parents were asked if they were provided with information about their child's reading rate and their perceptions of their child's visual reading stamina. Responses were provided for 151 children. Parents knew the reading rates of only 13.9% ($n = 21$) of the children; 86.1% ($n = 130$) did not have this information. Reporting on 135 children, parents perceived visual or reading stamina to be a problem for 65.2% ($n = 88$) of children, and not a problem for 34.8% % ($n = 47$). Parents did not know if visual or reading stamina was a problem for 35.7% ($n = 75$).

OPTICAL AND ELECTRONIC DEVICES

Another set of questions asked parents who paid for their children's clinical low vision evaluations and for any prescribed optical and electronic devices, and who provided instruction in the use of these tools. One hundred and sixty-three options for payments were chosen as sources of funding for the evaluations, with parents able to choose more than one source. Parents were a source of funding for most of the evaluations (52.2%), followed by local school districts (21.8%), and low vision clinics (10%), an outside agency (8.1%), and other sources (10%). Fifteen parents did not know who paid for their children's clinical low vision evaluation, which may not be surprising since in some states low vision clinics are offered to eligible students through a state-supported grant or agency and parents may not have been told of the funding source.

Two hundred and twenty-four sources of optical device funding were chosen by parents of children using optical and non-optical devices such as slant boards and special lighting tools. Most of the devices used by the children in this study were also paid for by parents (55.9%), followed by payment by local school districts (15.6%), and outside agencies (5.8%); the remainder of the devices were paid for by "other" funders or a specialized school for children with visual impairments (4.9%); three parents reported they did not know who paid for their children's devices.

When parents were asked who paid for electronic devices such as portable and desktop video magnifiers, a different order of funders occurred, with 107 options chosen. School districts were most often chosen as a source of funding (43%), followed by parents (30.8%), outside agencies (13.1%), low vision clinics (3.7%), and a special school (0.9%). Seven parents did not know who paid for the electronic devices their children were using.

When asked who provided instruction in the use of optical devices, 188 sources of instruction were chosen. By far, teachers of students with visual impairments were most often mentioned (49.4%), followed by clinical low vision specialists (19.1%), and O&M specialists (15.4%).

Table 4
Percentages of parents who were satisfied with educational services.

Service or professional	Very satisfied	Satisfied	Neutral	Dissatisfied	Very dissatisfied
Teacher of students with visual impairments	37.3 ($n = 66$)	36.2 ($n = 64$)	14.7 ($n = 26$)	7.3 ($n = 13$)	4.5 ($n = 8$)
Orientation and mobility instructor	35.4 ($n = 40$)	43.4 ($n = 49$)	15.0 ($n = 17$)	4.4 ($n = 5$)	1.8 ($n = 2$)
General education teacher(s) in the past year	38.2 ($n = 81$)	42.0 ($n = 89$)	13.2 ($n = 28$)	4.3 ($n = 9$)	2.4 ($n = 5$)
Parent involvement in the development of service plans	35.1 ($n = 65$)	41.1 ($n = 76$)	11.4 ($n = 21$)	7.6 ($n = 14$)	4.9 ($n = 9$)

Others who parents reported provided instruction included assistive technology specialists (6.9%), certified low vision therapists (3.7%), occupational therapists (3.2%), and other ophthalmologists or optometrists (2.1%). These data should be considered in light of the fact that not all of the children using these devices were provided with related services from an O&M specialist or other professionals. Eighteen parents also noted that their children had not received instruction in the use of their optical devices.

LEVELS OF ACADEMIC AND SOCIAL SKILLS OF CHILDREN WITH ALBINISM

Parents were asked to compare their children's development with same-age typically sighted peers in order to provide responses regarding academic performance ($n = 199$) and social skills development ($n = 208$). Although 69 (33.2%) of the children were reported by their parents to be functioning below their same-age peers in social skills, 40 (19.2%) felt their children were functioning above their peers in this area. The pattern of children functioning below or above their peers in academic skills was reversed, with 42.2% ($n = 84$ of 199) of parents reporting their children were functioning above their peers academically and 18.6% ($n = 37$ of 199) indicating that their children were functioning below their peers in academic learning. The remainder of the children were reported to be functioning at similar academic and social levels as their same-age peers without disabilities.

PARENTS' SATISFACTION WITH EDUCATION SERVICES

Using a five-point scale, parents were asked the extent to which they were satisfied with their children's teachers of students with visual impairments, O&M specialists, and general education teachers. In addition, they were asked for their level of satisfaction of how they were able to participate in planning for their child's education. These data are compiled in Table 4.

With a score of 1 as very dissatisfied and 5 as very satisfied and 217 parents responding, average parent satisfaction with their child's teacher of students with visual impairments was 4.0; for O&M specialists and general education teachers the average rating was 4.1. However, these scores need to be considered in light of the fact that within each category there was a full range of responses from very dissatisfied to very satisfied.

As noted earlier, parents had the option of writing comments on the surveys. One issue for which there were several comments concerned how schools responded to children with albinism. One parent's statement described how her child was isolated from other children for a full school year because administrators believed albinism was contagious. Several parents expressed concerns about losing services when their children were succeeding academically even though the visual impairment impacted functioning in other areas; schools maintained that if they are doing well academically, their visual impairment did not impact their learning. Another parent spoke of services for special education being denied because her child didn't "look albino." The extent to which discrimination by school administrations in schools is prevalent is not known, but apparently it does occur with some students and families with albinism.

These data reported by parents are presented as an initial snapshot of the educational services provided to children with albinism. The following discussion highlights certain aspects of these data that the authors believe warrant further consideration and study.

Discussion

This study presented parents' reports regarding the education of their 223 children diagnosed with albinism. Respondents were from 40 U.S. states. Since there is no comparable study of children with similar clinical visual measures or of children without albinism, it is unknown the extent to which this study reflects how educational services can be described for all children with visual impairments in the United States. However, the data revealed interesting information about the perceptions of parents of the educational services provided to their children with albinism, and these discoveries should be considered in light of how they may be applicable to other groups of children with visual impairments.

Data presented both positive and negative aspects in the education of children with albinism. Among the positive outcomes identified through this study were that:

- Parents are generally pleased with the educational services their children are receiving from teachers of visually impaired students, O&M specialists, and general education teachers.
- Parents are generally pleased with their own involvement in their children's educational service plans.
- As a whole, parents feel their children are doing well academically.
- Although each child may not have had access to all placement options within the continuum of educational services, many placements were included, and were not limited to, general education classrooms with consultation or direct services of a teacher of visually impaired students, a resource room devoted to children with visual impairments, and specialized schools for children who are visually impaired.

Among the concerns raised by the findings of this study are included: the delay between diagnosis and the age at which educational services are first provided to families and their children; the suggestion that social and behavioral disorders may be more common among children with albinism than they are in the general population; the need by families for more accurate information about the provisions of IDEA and Section 504 of the Rehabilitation Act of 1973 to which their children with albinism might be entitled; and the limited information about the need for, and provision of, educational services to students with albinism. These concerns naturally led to recommendations for action by educators and researchers interested in this population, which are detailed below.

RECOMMENDATIONS

Provide additional information about educational interventions for infants and children with albinism to physicians who diagnose albinism

At the time of diagnosis, parents need information regarding what infant services are available. In this study, the first interventions for children with albinism occurred most frequently for children with visual acuities ranging from 20/70 through 20/200 between 1 and 2 years of age. Since children with oculocutaneous albinism may be diagnosed at the time of birth, this identified gap of time in referrals for special education is beyond the 30-day referral period set as a goal within the *National Agenda for the Education of Children and Youths with Visual Impairments, Including Those with Multiple Disabilities* (Huebner, Merk-Adam, Stryker, & Wolffe, 2004). An effort to provide information about the availability and benefits of early interventions for children with albinism to all ophthalmologists, pediatricians, and obstetricians who are able to diagnose albinism at birth would be valuable for the parents of these children.

For children with visual acuities in the range of 20/50 to 20/60, however, interventions began on average when the child was nearly 3-1/2 years of age. This visual acuity range is more typical of children with ocular albinism, which could explain why these children may not have received diagnoses and interventions as early as those with oculocutaneous albinism. Still, pediatricians and ophthalmologists should be made aware that some of these youngsters will be eligible for special education and related services or Section 504 plan supports, and they should be encouraged to refer parents to schools for more information. A targeted nationwide campaign to get this information to pediatricians and pediatric ophthalmologists may be necessary.

Provide information to parents with regard to the provisions of IDEA and Section 504, especially as they relate to O&M services and low vision services

O&M services were being provided to 75 children with albinism. Although some may not benefit from these services, it was surprising that only 84 were reported to have received O&M assessments. This number seems lower than expected, given the need for addressing the use of distance vision and the effects of photophobia with these children. As noted in the companion article by Corn and Lusk (2018), only 48% of the children using optical devices had received input from a clinical low vision evaluation. It is clear, then, that not all children have had low vision evaluations, which has potential implications. For instance, visual acuities measured in the offices of general ophthalmologists or optometrists may have been taken in a darkened room, and it is possible that these visual acuities were recorded without regard to the effect of photophobia on the children's functioning. These recorded acuities could mislead educators who are considering whether to refer a child for an O&M assessment. At this time, only Texas requires an O&M assessment for all children receiving education services due to visual impairment, so it would not be unusual for a teacher of children with visual impairments or another educator to be responsible for making such a referral for children living in other states. Until such time that all states require a full O&M assessment by a trained professional, it would be of value if there were a standard tool used by teachers of children with visual impairments to screen a child with albinism for O&M services.

The findings of this study also demonstrate that parents may not be receiving information related to which low vision services are available, and that costly devices may be paid for by schools as a part of special education funding. Both clinical low vision evaluations and the provision of optical and electronic devices should be covered under IDEA's provisions for medical evaluations and assistive devices, Section 300.304(c)(4).

Students provided with services under Section 504 plans are eligible to receive related services if they are needed to access the environment (U.S. Department of Education, 2010). As such, orientation and mobility assessments and services and low vision services may be provided to students on 504 plans, although payment for such services would not come from IDEA funds.

The comments of parents who had difficulties with their children's schools understanding the educational effects of albinism provides a reminder of the importance of NOAH's attempts to address such concerns. The work of NOAH in this area, however, may be insufficient. Early interventionists, teachers of children with visual impairments, and program administrators may need to increase their efforts to meaningfully inform parents of their rights under these laws and the potential benefits of appropriate services and accommodations to the success of their children.

Provide supports for the social and emotional development of children with albinism

In the first article that described findings related to this study (Corn & Lusk, 2018), parents were asked to indicate if their children had disabilities in addition to those resulting from albinism; 9.1% indicated that their children had behavioral or emotional disabilities. As noted in these results, parents reported that 33.2% of their children were functioning socially below same-age peers. Although our purpose was not intended to measure the extent to which children with albinism are experiencing or have been diagnosed with disabilities, these two findings raise concerns about the stresses and difficulties experienced by these children. Teachers should be alerted to the possibility that students with albinism may need additional supports to deal with these stressors and, when signs of emotional distress are apparent, should work with other members of the IEP team, including the parents, to identify individual or school-based strategies to assist students to realize emotional stability and social success. Individual instruction in social interaction and recreation and leisure skills may be appropriate, as these areas are components of the ECC.

Conduct research on educational practices with students with albinism

Functional vision assessments, learning media assessments, and O&M screenings are essential assessments to understand how children with low vision use their vision and to determine whether their vision impacts their learning. Still, the parents of children with albinism who participated in this study reported low percentages of children who had received these assessments, with 29% indicating that their children had not been given any of these assessments. Similarly, the curricular areas of the ECC need to be assessed in order to determine the effect of the visual impairment on all areas of functioning. Here, too, parents reported low percentages of children who had received ECC evaluations, and 82 children reportedly had not received assessments in any of the ECC areas.

Data from this study raise the question of the extent to which children with low vision in general, or these children with albinism in particular, are receiving a high-quality battery of assessments to learn about their use of vision and what methods may improve their visual functioning in special education. Further study is needed to determine if children with albinism are being assessed appropriately.

Further study is also needed to determine the extent to which assessment data for children with albinism are used by IEP teams to make decisions regarding services or placement, and the extent to which administrative concerns play a role in such decisions. Providing assessments for eligibility and for the development of IEPs is among the roles and functions of teachers of students with visual impairments. They are also responsible for making appropriate referrals for related services, including, but not limited to, referral for O&M assessments.

Another topic of interest concerns how determinations are made regarding braille instruction. Of the parents who reported that their children were receiving braille instruction, few indicated that their children had been given learning media assessments, and most of the instruction was provided because of parents' requests. The extent to which learning media assessments are used and whether they are considered useful in making learning media decisions may be explored. Further, there were several methods used in the provision of braille instruction. An explanation of which methods are most effective for learning braille and how teachers determine which methods to use can benefit children with albinism for whom dual-media instruction is the chosen learning media approach.

A related topic is the lack of information parents have with regard to their children's literacy skills. For example, only 14% of parents knew their children's reading rate. Since reading rate is an important component of literacy skills, it should be provided as part of a learning media assessment. This issue may be related to the findings that learning media assessments do not appear to be routine for the children of the parents who responded in this study. Clearly, more comprehensive research that examines the assessments that are being conducted on children with albinism and how assessment results are used is necessary to better understand the extent of this phenomenon.

Conclusion

There were several limitations to the study, among which were that the authors used a convenience sample of parents who primarily were members of an organization of and in support of people with albinism, and therefore participants may or may not have been representative of the population of parents whose children have albinism. In addition, information was gathered about children in an indirect manner through a questionnaire, and all data were reported by parents and not confirmed through observations or reviews. There may have been language barriers, both due to study materials only being offered in English and due to the use of professional language. The authors attempted to provide descriptions and definitions for terms that might have been unfamiliar to parents.

Although these limitations occur in similar types of studies, the researchers believe there were also definite advantages to conducting the study in the manner chosen. The size of the sample and receipt of information directly from parents of children allowed for their voices, experiences, and perspectives to be included in the literature in a way that has not been captured previously.

This study was the first to describe parents' perceptions of the educational services provided to children with albinism in the United States. The data reveal a range of services provided and showed that parents were generally satisfied with them, but they raise questions about whether children with albinism are receiving the free and appropriate public education envisioned in IDEA. From the time the Education for All Handicapped Children Act (PL 94-142) was passed in 1975, parents have been considered a part of the educational team for their children. It is incumbent upon schools to not only conduct comprehensive assessments of children, but to include parents in planning for their children's education and give parents the information and tools to make decisions for their children based on assessed needs.

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