



Developing Culturally Responsive Resources to Support Advocacy for People with Intellectual and Developmental Disabilities



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For more information, please contact:

Emily Murillo, MSW
pmolina@omni.org
(303) 839-9422 ext. 155

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Additional OMNI Contributors

Ivonne Parra, Paola Molina and Melissa Richmond

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Introduction

Students with disabilities are at a higher risk for school discipline than other students, with African American/Black and Latino(a) students with disabilities at an even higher risk. Although there is limited research focusing on the experiences of students of color with disabilities, a 2015 U.S. Commission on Civil Rights report showed that black students with disabilities are almost four times more likely to have multiple suspensions and are twice as likely to be expelled compared to white students with disabilities (Laird, 2019). These exclusionary practices take time away from the classroom which can lead to students with disabilities missing important instructional time, repeating a grade, and/or dropping out of school (Laird, 2019; Southern Disability Law Center, 2014). Harsh disciplinary policies such as zero-tolerance policies have been found to be ineffective and can increase the likelihood of misbehavior, poor achievement, and later criminal activity (Darling-Hammond, 2018; Laird, 2019). Additionally, adults with intellectual developmental disabilities (IDD) can also face obstacles in other settings through exclusion or restraint for misunderstood communication and behaviors (Suarez, 2017; United Nations, 2018)

The Colorado Developmental Disabilities Council (the Council) partnered with the OMNI Institute (OMNI) to identify currently available resources and tools recognized as promising or best practices for individuals with disabilities and their families, with a particular focus on resources and support for communities of color. This research consisted of a literature scan, as well as focus groups and key informant interviews with community members impacted by the issues. The aim of this work is to inform the Council's development of resources and advocacy trainings for families so that they will receive the knowledge and tools they need, in the format they request, to advocate for alternatives to expulsion, suspension, and other exclusionary practices for both youth and adults with IDD.

Methods

OMNI utilized multiple data sources and methods to identify potential resources, trainings, and supports for people with IDD and their families.

Literature and Information Scan: A literature scan was conducted to surface key research studies, resource websites, and IDD service or advocacy organization websites that identified existing resources for families and individuals with IDD. High-level information from the scan was organized and summarized by content areas, which included general information, statistics on disabilities, resources for educators, and resources for families and individuals with IDD.

Focus groups: Three focus groups were organized, with adequate attendance resulting for two of the offerings. Both focus groups were facilitated in Spanish, primarily with parents of youth with IDD. A total of 14 parents took part in these groups, as well as one youth with IDD who participated along with their parent. A child and family advocate who assisted with recruiting parents was also present in one of the focus groups, though served mainly in a listening and support role so that conversation remained focused on parents.

Key informant interviews: A group phone interview was conducted in Spanish with 8 additional parents of individuals with IDD who were not able to attend one of the focus groups. Additionally, OMNI participated in a group dialogue with CDDC and Dr. Rosemarie Allen, a key community

researcher, professor, leader and consultant who shared her extensive knowledge and perspectives from her work focused on school discipline inequities experienced by African American youth.

Demographics: Seventeen of the 22 focus group and interview participants completed demographic surveys (77%). The majority of participants identified as female (91%) and living in an urban part of the state (76%). Nearly half were between the ages of 30 and 39 (47%). With the exception of a key informant who identified as African American, all participants reported identifying as Latino. All participants also reported having at least one family member with an IDD.

Qualitative analysis: Focus groups were audio-recorded and transcribed, and key informant interviews were recorded through verbatim notetaking. Data were coded for thematic analysis and key themes were aggregated across focus groups and key informant interviews. Analysis was guided by the development of key themes and a standard coding structure. Analyses placed particular emphasis on issues raised by many participants, issues raised with particular intensity, and/or unique reflections or ideas for action steps.

Findings

Literature Scan

The literature reviewed was grouped into three categories, including: 1) General Information; 2) Training and Resources for Educators and Service Providers; and 3) Training and Resources for People with IDD and their Families. Literature found was recorded, organized, and provided to CDDC in a separate summary document. A brief summary of each key area is provided below.



General Information

Information and data specifically on school discipline for students of color with IDD is limited. Much of the research reviewed included discussion about reforms needed to impact the disproportionate rates of suspension and expulsion for students with disabilities *and* students of color but little about the intersection of these two groups. Below, general findings for each of these groups of students is

highlighted, acknowledging that the substantial gaps in information on students of color with IDD limits understanding of the prevalence and impact of the issue in this community.

Disparities in school discipline. Nationally, students with disabilities are suspended at twice the rate of their peers without disabilities; students with disabilities are also more likely than other students to be suspended more than once in a school year (Southern Disability Law Center, 2014). There were nearly 1,800 reported suspensions, expulsions and/or exclusions/isolations of students with disabilities in Colorado in 2018 (Schimke, Colorado schools gave out nearly 1,800 suspensions to young students with disabilities last year, 2018).

There is substantial evidence regarding the existence and prevalence of disparities in school discipline for students of color. Nationwide, young black boys (kindergarten to 2nd grade) are suspended at a higher rate than other children (Schimke & Park, Chalkbeat, 2018). These trends are also consistent in Colorado:

- 6,000 pre-school through 2nd grade students in Colorado are suspended each year, affecting boys, children of color, and students with disabilities the most (Hernandez, 2019).
- Black boys make up about 2.3% of Colorado's kindergarten to 2nd grade students, yet about 10% of suspensions; these disparities exist in 14 out of the state's 20 largest school districts (Schimke & Park, Chalkbeat, 2018).
- Similarly, young Hispanic boys are disproportionately suspended in most school districts. Young Hispanic boys make up 17% of Colorado's kindergarten to 2nd grade students, yet about 29% of suspensions (Schimke & Park, Chalkbeat, 2018).

Impact of school discipline. The socioemotional and other impacts that school suspensions and/or expulsions have on students of color and students with disabilities is also well documented (Southern Disability Law Center, 2014; Faer, 2015; Pitlick, 2015; Hernandez, 2019). Examples include:

- Gaps in learning as a result of missing important instructional time
- Enrollments in different schools within a year, which can delay a student from moving on to the next grade level and damage a student's relationship with the classroom and school engagement.
- Schools that implement harsh discipline practices such as zero tolerance policies often experience negative outcomes and challenges such as:
 - higher rates of suspensions or expulsions,
 - lower school achievement, higher risk of academic failure, and higher drop-out rates
 - Decreased school attachment and engagement from students
 - Contributes to the school-to-prison pipeline, as students who are suspended or expelled have increased risk of juvenile justice system involvement
 - Disproportionate rates of school discipline for students of color and/or students with disability (Rosa, Keelan, & Krueger, 2015).

In Colorado, the percentage of students enrolled in special education has gradually increased in the last 10 years, from 9.5% in 2009 to 11.2% in 2018 (Special Education in Colorado, 2018). The percentage of students enrolled in special education in Metro Denver ranges from around 10.1-13.5%, with Douglas County having the lowest percentage (10.1%) and Sheridan 2 district reporting the highest at 13.5% (Special Education in Colorado, 2018). Data on the percentage of students with disabilities who are students of color were not available; however, the bodies of research on these

groups separately suggest that these students may be at an additional increased risk for disparities in punitive school disciplinary practices and the negative impacts that result from those practices.

Training and Resources for Educators

Alternatives to Suspension and Expulsion. Research regarding alternatives to school suspension, including evidence-based or promising practices aimed at reducing school discipline was also reviewed (Rosa, Keelan, & Krueger, 2015). Examples of the types of information reviewed are:

- Training and professional development opportunities for educators to learn about alternatives
- Individual student-focused alternatives such as mental health counseling, self-management plans, or adult mentors
- Implementation of the MTSS, a school-wide prevention-based framework, which aims to improve learning outcomes by incorporating evidence-based instruction, intervention, and practices to assess support. Prevention approaches include Positive Behavioral Interventions and Supports (PBIS) and Response to Intervention (RTI).
- Additional prevention strategies like restorative justice, social-emotional learning, building a positive school climate, and early classroom interventions.
- Collaborative efforts between schools and communities such as fostering the involvement of parents and families or community service opportunities. Other examples include community strategies to identify students who need support or interventions to prevent school-based incidents/violent behavior.

PBIS and restorative justice, in particular, have been shown to lower the rate of disciplinary practices and to help improve behavior and repair connections among students, schools and the community (Laird, 2019). There are a variety of resources and trainings on these models specifically for educators, as schools commit to employing these alternatives. Professional development training for educators, including training on implicit bias have also shown to be effective at reducing discipline (Darling-Hammond, 2018). Although the review identified numerous potential resources, many do not provide sufficient levels of publicly available training/instruction on how to effectively implement the protocols. It is also unclear how widely they are used and implemented, what training protocols entail, or what resources are specific to students of color with disabilities.

Modifying Teaching Approaches and Providing Accommodations. There is also substantial general information accessible for educators who want to learn simple strategies for working with students with disabilities. Many of these strategies emphasize the importance of modifying teaching approaches and providing accommodations to support students with IDD (Effective Teaching Methods for People With Intellectual Disabilities, 2019). These tips or strategies are easily accessible online for educators seeking general guidance.

Culturally Responsive Instruction: There is research that educators who participate in professional development or training programs on cultural competency are more likely to better manage the classroom and create a positive classroom climate (Metropolitan Center for Urban Education, 2008). Cultural competency trainings can support educators learn about how their cultural biases and assumptions affect interpretations of student behavior or how to accommodate classroom instructions/teachings that embrace cultural differences (Metropolitan Center for Urban Education, 2008; Ryans & Krasnoff, 2016). Cultural competency trainings can also help educators develop culturally sensitive interpersonal skills to help reduce misinterpretations of student behavior

(Hanover Research, 2014). Examples of culturally competency strategies include working with the student's parent/caregiver to ensure language needs are being met during the development of an IEP as well as understanding a student's cultural traditions to provide a comforting link between the home and school (Glimps & Ford, 2006). The incorporation of culturally responsive strategies in the classroom not only improves student behavior, but also the family's relationship with the school (Fallah, Murawski, & Moradian, 2018).

Though there is research and information on the importance of culturally competency trainings for educators, there is little information on culturally responsive strategies for educators or teachers who instruct students of color with IDD. The review of available resources stemmed from academic journals; however, it did not identify accessible curriculums for educators that outline how to implement these responsive strategies or practices in the classroom. This may be related to the wide range of disabilities and/or needs a student can have, which may limit the research on culturally responsive strategies or practices for IDD.

School Policies. Finally, there is also information on policy changes that school districts can utilize to monitor suspensions and help administrators respond appropriately (Darling-Hammond, 2018; Rafa, 2019). Recommendations included:

- Eliminating zero-tolerance policies, particularly for lower-level offenses
- Establishing statewide systems to increase student access to supportive programs
- Training teachers on alternatives to suspensions and implicit bias
- Creating data systems to assess patterns of suspensions and/or expulsions in school with technical assistance to support data collection and reporting

Training and Resources for People with IDD and their Families

The literature scan also identified trainings and resources that are available to individuals with IDD and their families. This included:

- National or statewide advocacy organizations such as the American Association on Health and Disability, American Association on Intellectual and Developmental Disabilities, The Arc of Colorado, Ability Connection Colorado, Personal Assistance Services of Colorado, and other websites to obtain online resources or suggestions. Some of the online websites have community platforms used to connect people for support or get up-to-date information on disability-related issues.
- Information for parents and self-advocates about legal issues and general rights, educational rights, etc. (e.g., "know your rights," "what every parent should know"). This included information for parents to learn more about developing their child's IEP, IEP rights and 504 plans, action steps to take if their child is suspended, and other advocacy efforts.
- General information for parents of children with disabilities related to supporting their child with a disability. Information is not specific to IDD per se, but provides information on issues related to discrimination or communication at a high level (e.g., "10 ways to improve communication with your child").

In terms of resources specifically for individuals of color with IDD, the review did not identify online resources such as teaching tools, family and individual training opportunities and self-advocacy with this specific focus on people of color with IDD and their families. Similar to what was found for parent, educator and school resources, there is general guidance or information available for

individuals with IDD and their families (e.g., high level tips on how to be a self-advocate). However, there are limited resources on applying self-advocacy efforts in different settings like in school or work or understanding behavior as communication.

Stakeholder Input

In addition to the literature review, OMNI conducted focus groups and key informant interviews to gather in depth perspectives on challenges and resource needs for individuals with IDD and their families. Three main themes emerged from discussions, which included:



Support and Connection

Overall, there was a strong desire and eagerness among focus group and interview participants to share their experiences and narratives. OMNI facilitators guided dialogue to explore concrete supports, resources, and trainings needed by participants. Participant discussion, however, typically returned to the sharing of stories, challenges and reflections on personal experiences. Participants shared in this way to lend voice to the issues they were describing, but also to seek support, connection and information from others with common experiences. At the end of one focus group, participants discussed attending an additional group - not as active participants, but to see what other information they might learn and to connect with others. Focus group participants and key informants also shared that informal peer support groups can serve as an outlet for chronic stress, and a trusted sounding board when challenges and advocacy needs arise. Participants clearly drew strength from these shared experiences and talking through what worked for them in their own advocacy efforts.

"I also think that forums like this [focus group]...are good because we can learn from each other, from other people's experiences. And, it also helps to know that we are not alone."

- Focus Group Participant

Common Challenges

Although some focus group participants and key informants shared some of their prior positive experiences with specific educators or psychiatrists, discussion mainly centered on the unfair treatment, discrimination and challenging experiences that participants confronted with schools or other service providers.

Lack of or challenging communication with educators/providers. More than any other area, communication challenges with educators and providers were raised. Communication issues included the following:

- Difficulty being able to advocate "in the moment" when parents are faced by a group of educators or service providers. Many parents who were highly knowledgeable about their rights explained that it is still incredibly challenging to face a team of professionals and ask them to change practice, particularly for individuals who speak English as a second language.
- Navigating bureaucratic processes and restrictions such as how to request a meeting with educators in between formal IEP meetings, how to exchange updated information ongoing, etc.
- Delayed communication from schools about critical issues or events (e.g., student disappearing from school and parents not being notified immediately)
- Challenges with linguistically and culturally responsive communication, such as:
 - Adequate, accurate, and professional interpretation/translation services. One parent shared that her child's school had relied on an administrative assistant to translate and that she understood enough English to understand the translator was downplaying her concerns to the other school staff.
 - Being able to speak to someone in a person's first language to resolve small issues or miscommunications. One parent shared that she was forced to change schools because she was unable to communicate the confusion about an issue with her bus stopping at the incorrect bus stop.

"There was a person who told me 'you are your daughter's advocate.' So, since that moment I said to myself that I'm the only advocate (for my daughter), I need to learn so I can be her voice. So I can defend her until she can defend herself."

- Focus Group Participant

"When I'm called for a meeting, I always request an interpreter, but not from the school. I want someone professional, discreet, who would tell what needs to be said. I had experiences where the interpreter (from the school) didn't communicate everything that he/she is told out of fear because of the teachers, principal, etc."

- Focus Group Participant

Lack of general information. Another commonly raised issue is that individuals with disabilities and families often "learn as they go", and that information either isn't available or is not centralized in an accessible, user-friendly way. **"It's very difficult to find information"** was a common experience and a general need for informative advocacy resources in all formats was emphasized. Key areas included

general rights, communication and advocacy strategies, IEP process information, approaches to discipline, protocols and expectations, and strategies to promote more communication and reduce discipline.

Experiences of children not having their educational needs met. Parents expressed frequent challenges with seeking assessments, establishing IEPs, and/or revisions to IEPs, and working with schools to set appropriate goals for their children to promote growth and learning. One participant shared that she could not get a requested intervention until a social worker voiced that it was a violation of rights and offered to intervene on her behalf.

Inappropriate labeling. As mentioned above, educators or service providers may use inappropriate labels or alarming language to describe behaviors, reflecting biases about students of color and/or students with disabilities. Many examples were provided by participants to illustrate this issue, including a teacher describing a basketball game commonly played by youth in their own neighborhood as violent, or another school staff labeling a child with louder speech as aggressive.

Personal, family and financial impacts. Finally, chronic stress was highlighted consistently, as families face constant challenges navigating inequitable systems, and seeking out needed interventions and

“I’ve suffered in school, too. They unfairly suspended my son. I was in school every day. I had to leave work; I’m a single parent. I just cried. One day even a police officer threatened me ‘if you don’t come to get your crazy child...’ He told me those words. He said that he would send me to jail, that he would call social services for not taking care of my son.”

- Focus Group Participant

“(I told them) my son needs help. I need you to do an IEP evaluation for him. They didn’t do it until my son started breaking rules, hitting stuff, and all that. That’s when the school started to suspend him, and suspend him, and suspend him. I said to myself “this can’t keep going on”. I went to psychologists and other places to get help. The school didn’t help. Then, I found the psychologist who’s helping me. I found an advocate, and that’s when I got help. That’s when they told me ‘they can’t keep suspending your son because he has a disability.’ Then the school did the correct IEP and stated he had a disability. That’s when I got a little help for him. The school is not willing to help, because they say no... they say ‘public schools can’t, they don’t have enough money to meet the costs for their students’. I don’t know if that’s something that only applies to Hispanics or African Americans. But honestly, as a Hispanic, I’ve suffered because they say they don’t have the money to help with those things.”

- Focus Group Participant

advocacy. Many reflected on how taxing it can be to personal and family mental health to face a system that is repeatedly not meeting their needs. Many reported needing to leave work on a regular basis to address issues at school and make key meetings or appointments. Further, many stressed that school personnel often call in parents to deescalate a student or pick them up from school, rather than implementing simple new strategies or approaches that are known to work for parents. Families can experience additional economic strain from lost work due to issues the school could potentially address by learning to better work with their child.

Participants also shared about the fear of their child being inappropriately disciplined or other consequences from not responding quickly every time they are called by the school.

Desire for Systems Change

Another common response to questions about needed resources was to highlight the broader necessity for systems change. More specifically, participants surfaced a need to address educator training. Though the focus on resources for parents was appreciated, many participants noted that burden is often placed on parents to learn how to operate within a broken system. Instead, they emphasized the importance of training educators to better serve students, particularly related to understanding individuals with IDD and how other cultural identities may interface with disability for students of color. Commonly mentioned educator knowledge gaps included appropriately responding to behavioral issues, communication strategies and understanding needs of individuals with various disabilities.

"We want teachers to be trained so they are aware of our children's needs. We want them to understand that children with special needs behave different and act different. The system wants these children to adapt to them and not the other way around. How do we get there?"

- Focus Group Participant

"The teachers lack tolerance to deal with children with special needs...I think that the school has to be informed on how to deal with the child, like they do with children with autism or any other diagnosis...They sometimes think...the child is naughty, that he likes to be mischievous, and such. So, the only thing they do is to punish him, they don't give him a break...they don't know that when you punish him you are escalating his aggressiveness.

- Focus Group Participant

In addition to teacher training, Dr. Rosemarie Allen emphasized the importance of addressing the high suspension rates for African American youth (particularly boys) as young as those in early childhood education programs. Critical needs include requiring quality data collection, sharing data with the community and policymakers to highlight the issues, monitoring and contributing to policy change that regulates disciplinary practices in early childhood programs and schools, and ensuring that the education workforce is well-trained and equipped to implement policy changes and alternative disciplinary approaches.

Key Considerations and Limitations of Findings

The sample: Participants consisted primarily of Latino parents of youth with IDD who lived in urban areas around Denver. Parents were also joined by family members in some cases (e.g., grandparents) who also shared their experiences. There was one child and family advocate who participated, though feedback was minimal to enable focus on parent participants. As mentioned in 'Methods', input was also provided by a researcher and consultant who offered input on resources needed for the African American community.

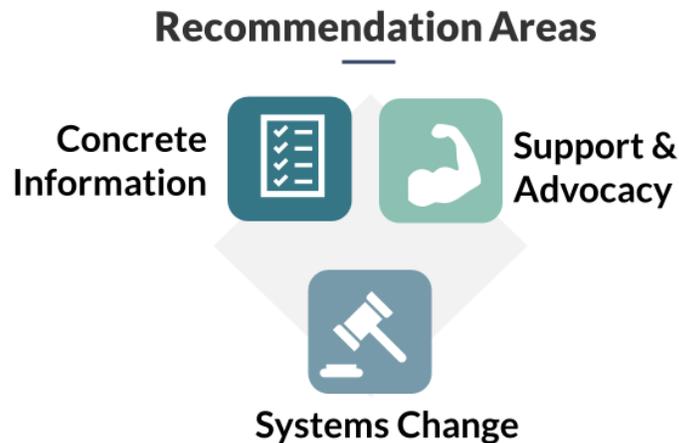
Recruitment: Despite outreach efforts (explained further below), input from self-advocates and adults with IDD was not obtained at this time. Considerable recruitment challenges limited the sample composition and raises considerations for future efforts. The main outreach and recruitment method utilized was to reach out to local networks – both the Council's and OMNI's. This included organizations as well as community and parent groups and IDD advocates. Ultimately, participation consisted primarily of Spanish-speaking families who were active in Advocacy Denver, El Grupo Vida, & Amigos de Mexico. Organizational advocates who connected OMNI with families also provided some input. Despite reaching out extensively to CDDC's contacts as well as OMNI's and asking parent groups and advocacy organizations to share information with their networks, participation in focus groups was lower than expected.

OMNI conducts a broad range of community focus groups and dialogue sessions and is typically successful in outreach and recruitment efforts. However, it can be challenging for community-based organizations to stretch already limited time and capacity to support additional efforts - particularly when these efforts are outside of paid staff time. To support inclusion of a wide range of voices from the IDD community, future efforts may include hiring consultants to support outreach or reimbursement to organizations that serve as formal connector/liaison. Project timelines should also be carefully considered, allowing adequate time for outreach and avoiding key periods such as school summer vacations, etc.

Generalizability: Finally, as with other qualitative methods, the findings presented in this report are rich in description and embedded in context but are not generalizable to all parents with youth who have IDD, or to self-advocates with IDD who may have offered additional perspectives on needed resources. The findings presented in this report should be read and interpreted as the perspectives of those who provided input at a specific point in time.

Recommendations

The following recommendations are grounded in findings from the literature and publicly available information, along with input from community members to understand key issues, needs and preferences. Some recommendations were specifically provided and emphasized by Dr. Rosemarie Allen and are noted accordingly. As CDDC moves forward in the development of resources and training for community members with IDD and their families, the following areas can serve as core components for those efforts.



Each recommendation area is detailed below, followed by a brief discussion of potential formats for resources and cultural responsiveness considerations.

Concrete Information

Resources are currently fragmented, difficult to navigate and are not user-friendly, centralized or easy to access. The following areas of concrete information should be prioritized for the development of resources at this time:

- Communication strategies and information about behavior as communication, as well as ideas for how self-advocates and parents can share personalized information about these issues with providers and educators
- General rights around discipline and accommodations for students with disabilities
- IEP processes such as the staff involved in an IEP, what an IEP should contain, how often it should be reviewed, modified, etc.
- School disciplinary processes such as what parents should expect from the school, parental involvement, and the consequences that are employed for specific behaviors
- Approaches that are being implemented in schools to reduce disproportionate disciplinary practices (e.g., what strategies look like in practice, what parents can expect from their schools and teachers, etc.).
- Key resource lists that share how community members can access critical advocacy and support-related information such as:
 - Process for finding an advocate/advocacy support
 - Training opportunities
 - Interpretation and translation services

- Peer, Self-advocate and parent-to-parent support groups
- Assessment and screening services

Support and Advocacy

Chronic stress that families experience from systems inequities and navigation challenges results in a need and desire for resources that involve peer support and empowerment components. CDDC could support the development of peer-to-peer self-advocate, parent and family member support groups that promote:

- Interpersonal connection and relationship-building
- Co-sharing of experiences and learnings among peers
- Communication and advocacy “practice”, confidence-building, role playing and peer-to-peer coaching and mentorship
- Information-sharing across members

Additionally, Dr. Rosemarie Allen surfaced several needs that could potentially be addressed through the development of a parent advocacy firm. This group of trained parents would provide community-based, peer-led support, including:

- Peer support, guidance and information about rights
- Assistance writing letters
- In-person advocate support at key meetings (e.g., IEP meetings)

Systems Change

Though resources for self-advocates, parents and family members are needed, CDDC should also consider ways to support larger systems change efforts. Participants in this assessment emphasized the following:

- Training for educators, including early childhood educators and care providers. Dr. Rosemarie Allen recommended requiring the collection and reporting of relevant discipline data to understand disparities and training needs ongoing (e.g., by geographic area or school) and target training resources accordingly. Core training areas may include:
 - Types of disabilities (e.g., visible, invisible, physical, developmental, etc.)
 - Common behaviors for students with different types of disabilities
 - Mis-labeled behaviors that students with certain disabilities may use as communication strategies or to signal distress
 - Effective de-escalation and communication strategies
 - Resources for screening and assessment
 - Cultural responsiveness and inequity issues
 - Impacts of discipline on youth development (e.g., familial mental health and economic stress, juvenile justice involvement, school-to-prison pipeline effects, etc.)
- Policy-change efforts related to regulations for school discipline practices and implementation of positive alternatives (e.g., increasing these regulations for early childhood programs)
- Monitoring potential policy threats that could deepen inequities

Cultural Responsiveness and Resource Formats

Although focus group participants were largely parents of Latino Youth with disabilities, Dr. Rosemarie Allen also provided expertise and recommendations centered on resource formats and cultural responsiveness considerations for African American families.

- First, training and resources for self-advocates, parents, families and/or educators should all acknowledge and provide adequate space for learning about and discussing issues of inequity (e.g., race/ethnicity, language, immigration status, etc.). Examples include:
 - Impacts of school discipline and chronic systemic issues that present ongoing barriers for people of color with disabilities
 - Examples of culturally responsive practices and standards that should be expected from providers and educators
 - Intersections of race, disability and other cultural identities
- Partnerships should be established with trusted and well-connected community-based organizations and leaders to lead resource development, spearhead outreach efforts and facilitate groups, trainings or other forums
- Specific ideas for resource formats and outreach provided by Dr. Rosemarie Allen include:
 - Advertising trainings and resources at culturally appropriate spaces such as churches, barbershops or highly utilized community spaces
 - Social media and peer-to-peer community connections
 - Apps that allow for more regular connection and interface
 - Resource book or guide specific to the IEP process

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Appendix A: Focus Group Guide

Purpose

- 1) Introductions (include that we are contracted by CDDC - Colorado Developmental Disabilities Council)
- 2) The purpose of this discussion is to gather your opinions and feedback about resources and training that families and individuals with IDD need to best advocate for themselves and their family members, especially related to behavioral needs and discipline in school settings. We know that disparities exist in school discipline – that is, students with disabilities are more likely to be disciplined (e.g., suspended or expelled) than students without disabilities. Students of color with disabilities are even more likely to be disciplined. Today we really want to understand what individuals and families need to be prepared to deal with these challenges.
- 3) Our role is to ask the questions we have for the group and to encourage everyone to participate. We won't be doing much talking but may ask you to explain more about your thoughts or to give an example to make sure we understand. Also, it's my job to see that everyone has a chance to voice their opinions, as well as to keep us moving along so that we have time to discuss all of the questions.
- 4) There are no right or wrong answers. Each person's experiences and opinions are valid, and we want to hear a wide range of perspectives.

Now I'd like to go over the consent information.

- 5) Review consent and then ask participant if everyone agrees to record the discussion.

Project Overview and Summary of Lit Scan

Our first step in this work was to find out what other work is being done to prepare families for challenges with understanding behavior and school discipline. We scanned state and national organizations that work with people and families with disabilities to see what training and resources already exist. We just want to share a little bit about what we found to start our conversation today.

- A lot of available information the existence and prevalence of disparities in school discipline – both for students with disabilities and for African-American/Black and Latino students
- Substantial training and resources for teachers and educators in various interventions to reduce suspension and expulsion and address related disparities. Heavy research on alternatives to school suspensions. These alternatives/strategies are shown to be effective at supporting students with disabilities.
- Some information for parents and self-advocates about legal issues and general rights (e.g., “know your rights”)
- Lots of general information for parents of children with disabilities regarding educational rights and supporting their child with a disability. This information is not specific to IDD but a rather

range of disabilities. Most of this does relate to discrimination or communication but is very high level (e.g., “10 ways to improve communication with your child”).

- Little information on culturally responsive strategies for educators that instruct students with IDD.

Potential Probes

- “Please tell me (more) about that...”
- “Could you explain what you mean by...”
- “Can you tell me something else about...”
- “Can you tell me more about that experience...”

Current Access to Information (content, sources and format)

1. What type of information have you used (or know of) to help advocate for yourself or your student when needed?
 - a. Where are some of the places that you currently get information? Where and whom do you turn to if you have questions? Why do you turn to them?
 - b. What has been easy about getting information?
 - c. What has been difficult or challenging?
 - d. *If participants don't mention all below, probe.*
 - i. Knowing rights about school discipline/understanding legal issues
 - ii. Advocating when you/your student is disciplined
 - iii. Strategies schools are implementing or should be implementing to better understand behavior and reduce discipline
 1. Do you know what the school is doing? What their programs or practices are to understand student behavior and reduce discipline? If not, what do you think that is? (e.g., schools are too busy, don't communicate, are not implementing anything, unsure, etc.)
 - iv. Strategies for you, your student, your family to implement at home to better understand behavior and communication?
2. Have the resources and information you found meet your language or cultural needs?
 - a. What are some examples of how resources have or have not met your needs?
3. What other strategies or tools do you use, even if it is something you have thought of or developed yourself? (Probes: support groups in social media (e.g. Facebook, websites), hospital hot lines, advocacy orgs, friends and family, etc.)

Needed Resources and Training (both content and format)

4. What additional information do you need that isn't available to you right now? Revisit the above areas in # 1d: and ask what is most needed in each area.
 - a. To prepare for possible challenges? (e.g., understanding the law, school responsibilities, student rights, etc.)
 - b. To deal with challenges that have occurred (including advocating navigating the system)
 - c. To learn strategies for communication?

5. What are some ways that would work for you to get this information? For example, trainings, online or written information shared by schools, through other parents, etc.
 - a. What is your most preferred (top) way to get this information?
 - b. What makes this way so valuable?
 - c. Are there other preferred ways of getting information?

Summary Questions (If time allows)

6. Of all the things we discussed today, what did you feel was the most important and why?

7. Is there anything you would like to mention, something you feel is important to note that we didn't address today?