DEPARTMENT OF HUMAN SERVICES

DHS Report

Early Intensive Developmental Behavioral Intervention Licensure Study Stakeholder Engagement Report

Disability Services Division

August 2024

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انتباه. إذا احتجت الى مساعدة مجانية في ترجمة هذه الوثيقة، اتصل بالرقم الموجود في المربع أعلاه. Arabic

মনোযোগ দিন। যদি আপনি বিনামূল্যে এই নথিটির ব্যাখ্যার জন্য সহায় চান তাহলে উপরোক্ত বাক্সে থাকা নম্বরটিতে কল করুন। Bengali

သတိပြုရန်။ ဤစာတမ်းကို ဘာသာပြန်ဆိုရန်အတွက် အခမဲ့အကူအညီ လိုအပ်ပါက, အထက်ဖော်ပြပါ အကွက်ရှိ နံပါတ်ကို ခေါ်ဆိုပါ။ Burmese

ការយកចិត្តទុកដាក់។ ប្រសិនបើអ្នកត្រូវការជំនួយឥតគិតថ្លៃក្នុងការបកស្រាយឯកសារនេះ សូម ហៅទូរសព្ទទៅលេខក្នុងប្រអប់ខាងលើ។ Cambodian

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Cantonese (Traditional Chinese)

wáŋ. héčiŋhaŋ niyé wačhíŋyAŋ wayúiyeska ki de wówapi sutá, ečíyA kiŋ wóiyawa ed ophíye waŋ. Dakota

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સાવધાન. જો તમને આ દસ્તાવેજને સમજવા માટે નિ:શુલ્ક મદદની જરૂર હોય, તો ઉપરના બૉક્સ પૈકીના નંબર પર કૉલ કરો. Gujarati

ध्यान दें। यदि आपको इस दस्तावेज़ की व्याख्या में निश्शुल्क सहायता की आवश्यकता है, तो ऊपर बॉक्स में दिए गए नंबर पर कॉल करें। Hindi

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Lus Ceeb Toom. Yog tias koj xav tau kev pab txhais lus dawb ntawm cov ntaub ntawv no, ces hu rau tus nab npawb xov tooj nyob hauv lub npov plaub fab saum toj no. Hmong

ဟ်သူၣ်ဟ်သး. နမ့ၢ်လိၣ်ဘၣ် တၢ်မၤစၢၤကလီလၢ ကကျိးထံလံာ်တီလံာ်မီတဖၣ်အဃိ, ကိးနီၣ်ဂံၢ်လၢ အအိၣ်ဖဲတၢ်လွံၢ်နၢၣ် လၢတၢ်ဖီခိၣ်အပူၤတက့ၢ်. Karen

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تکایه سەرنج بدە. ئەگەر بۆ وەرگێرانی ئەم بەڵگەنامەیە پێویستت بە یارمەتی بێبەرامبەرە، ئەوا پەیوەندی بەو ژمارەیەوە بکە کە لە بۆکسەکەی سەرەوەدایە. Kurdish Sorani

Baldarî. Ger ji bo wergerandina vê belgeyê hewcedariya we bi alîkariya belaş hebe, ji kerema xwe bi hejmara li qutiya jorîn re telefon bikin. Kurdish Kurmanji

Hoȟpíŋ. Tóháŋ waŋží thí wíyukčaŋpi kiŋ yuhá níyuŋspe héčha čhéya, lé tkíčhuŋ kiŋ k’é náŋpa opáwiŋyaŋ. Lakota

ເອົາໃຈໃສ່. ຖ້າທ່ານຕ້ອງການຄວາມຊ່ວຍເຫຼືອຟຣີໃນການຕີຄວາມເອກະສານນີ້, ໃຫ້ໂທຫາເບີທີ່ຢູ່ໃນປ່ອງຂ້າງເທິງ. Lao

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Mandarin (Simplified Chinese)

Pa̱lɛ rɔ piny: Mi gööri luäk lɔrä kɛ luɔ̱c kä mɛmɛ, yɔtni nämbär ɛmɔ tëë nhial guäth ɛmɛ. Nuer

Mah Biz’sin’dan.
Keesh’pin nan’deh’dam’mun chi’wee’chi’goo’yan chi’nis’too’ta’man oo’weh ooshii’be’kan.
Ishi’kidoon ah’kin’das’soon ka’ooshi’bee’kadehk ish’peh’mik ka’shi ka’ka’kak. Ojibwe

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Àkíyèsí. Tí o bá nílò ìrànlọ́wọ́ pẹ̀lú tí tú mọ̀ àkọ̀ọ́lẹ̀ yìí, pe nọ́mbà tó wà nínú àpótí tí wà ló kè. Yoruba

LB (7-24)

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Minnesota Statutes, Chapter 3.197, requires the disclosure of the cost to prepare this report. The estimated cost of preparing this report is $100,565.

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Contents

I. Executive summary

In early 2024, the Minnesota Department of Human Services (DHS) launched a project to consider approaches to licensure or certification for Early Intensive Developmental Behavioral Intervention (EIDBI) services. DHS contracted with the Courageous Change Collective to carry out an extensive stakeholder engagement process that would gather input from EIDBI providers as well as families and caregivers receiving EIDBI services.

We engaged a broad and diverse set of stakeholders from communities across Minnesota. These stakeholders fell into two primary groups:

- Providers of EIDBI services and professionals who work in connected fields.
- Families and caregivers of children receiving EIDBI services.

EIDBI providers want the state of Minnesota to provide clear standards and guidelines that can be adapted to their context, e.g., geography, cultural community or service setting, etc. Providers and professionals believe that successful implementation of a licensure process for EIDBI services will require the state to increase staffing capacity and infrastructure to respond effectively and efficiently to the needs of providers. Providers are struggling to coordinate with schools when serving school-age children. They want to see statewide guidance offered that incentivizes coordination and collaboration between EIDBI and schools. Finally, providers recommend expanding the types of activities that qualify as billable hours. If new licensure requirements are put in place without the expansion of what qualifies as billable activities, providers believe their capacity to serve children will be reduced and their ability to stay in business will be challenged.

Families and caregivers are very appreciative of EIDBI services. These services have helped them understand the needs of their children and made them feel less alone. Cultural providers have been important in connecting autistic children to their cultures. However, families and caregivers need more support. There are often long wait lists to obtain a psychological assessment and a shortage of providers. Families also need support navigating the system from getting insurance to cover services, accessing transportation, understanding their rights and coordinating services. In particular the coordination between EIDBI providers and schools is going poorly, often leaving parents having to bridge the gap and serve as coordinators. Caregivers are concerned about the safety of their children in schools. Families are concerned that a licensure process could create additional barriers to accessing the EIDBI services for their children.

II. Background

The Early Intensive Developmental Behavioral Intervention (EIDBI) benefit became law in 2013 (Minnesota Statutes section 256B.0949). For many services, DHS has established agency certification or licensure processes. Originally, DHS intended EIDBI to follow a similar process once the benefit was initially established; however, this did not occur for a variety of reasons. This has left EIBDI agencies neither licensed nor certified, leading to concerns about monitoring the quality, safety and integrity of services provided. These concerns were exacerbated by the pandemic when site visits, which help ensure program quality, were put on hold.

The goal of this study is to identify solutions to these concerns while balancing access, equity and safety. Without the authority to license or certify EIDBI agencies or individual providers, DHS has few tools to provide quality assurance, oversight and enforcement of children's and families' rights, health and safety standards or use of effective evidence-based treatment modalities. Currently, formal enforcement by DHS occurs through Provider Eligibility, Compliance and the Office of Inspector General (OIG). Provider enrollment can disenroll or suspend payments to providers. The Surveillance and Integrity Review Section (SIRS), through the OIG, can follow up on concerns around fraud, waste and abuse.

DHS recognizes how vital EIDBI services are for children and families. In order to ensure these services continue to be provided with quality, safety and integrity, DHS launched a project to consider approaches to licensure or certification. In early 2024, DHS contracted with the Courageous Change Collective to carry out an extensive stakeholder engagement process that would gather input from EIDBI providers as well as families and caregivers receiving EIDBI services.

About Courageous Change Collective

Courageous Change Collective (CCC) is a women-led team shaped by their experiences as immigrants, people of color, indigenous and LGBTQ women. CCC is united by their shared passion for growing communities of love and justice through transformative facilitation. The team members each began developing skills as change agents from an early age as their beloved communities struggled to overcome systemic oppression. CCC's commitment and accountability to communities keep them grounded in their lifelong work of building a world in which everyone can thrive.

CCC has more than five decades of professional experience working hand-in-hand with communities, non-profit organizations, government agencies and health and education systems. They are a team of practitioner-consultants, drawing on experiences embedding a racial equity lens within their past organizations and continuing to lead and participate in community engagement, leadership development and racial equity initiatives.

III. Methodology

In partnership with DHS, CCC embarked on a four-month process gathering community input as part of the EIDBI stakeholder engagement process with two main constituent groups: providers and professionals, and families and caregivers. The main objectives of the stakeholder engagement process were to:

- Identify what is working in EIDBI for recipients, families, EIDBI providers, other providers and other stakeholders.
- Identify what is not working within EIDBI for recipients, families, EIDBI providers, other providers and other stakeholders.
- Identify themes in the areas of input related to:
  - Health and safety
  - Staffing and personnel
  - Service quality
  - Coordination
  - Evidence-based best practice.
- Identify any concrete suggestions identified through the engagement process.

CCC developed various approaches and outreach materials to target providers and professionals across the health care and social services spectrum including in-home EIDBI service providers, center-based EIDBI service providers, Greater Minnesota providers, corporate and large providers (serving 100+ children annually), small providers (serving fewer than 100 children), providers certified in ABA modalities, providers who serve traditionally marginalized communities, lead agencies including tribal entities, managed care organizations and county and contracted case managers, health care professions such as pediatricians, advanced practice registered nurses and primary care physicians, and educators and other professionals such as speech and language pathologists and occupational therapists.

Provider and professional focus groups and online survey participation results

Using existing DHS listservs and mailing lists, over 100 providers received emails inviting their feedback in focus groups and online surveys. The breakdown of stakeholder participation follows:

- Providers and professionals virtual focus groups – We conducted six virtual focus groups, with 75 providers and professionals attending.
- Providers and professionals online survey – 114 respondents completed the survey.

Family and caregiver focus groups and online survey participation results

Using existing DHS listservs and mailing lists, over 15,000 families received emails inviting their feedback in focus groups and online surveys.

The breakdown of stakeholder participation follows:

- Families and caregivers focus groups – 35 participants representing families of people with autism and related conditions, including those from underrepresented communities, attended four focus groups.
- Families and caregivers online survey – 52 respondents completed the survey online.

Underrepresented and BIPOC stakeholder engagement outreach

Special consideration of stakeholders from Black, Indigenous, people of color (BIPOC) and other marginalized communities participating in this process involved extended outreach to ensure participants from these groups felt valued and heard. For example, in consultation with Somali, Latinx and Indigenous community leaders, we identified organizations, focus group venues, interpreters and trusted voices from the community. All BIPOC focus group participants received $50 Visa gift cards. Additionally:

- Partnerships with SPAN (Somali Parents Autism Network) and Maangaar (the Somali word for autistic) Global helped identify families and individuals from the Somali community who participated in focus groups. 17 Somali community members attended an in-person focus group and others completed the survey online.
- Outreach to Latinx families involved CLUES and La Red organizations, which serve families with children. Emails were sent to Fraser and other larger providers, who serve Latinx families through their center-based programs. Although these organizations were supportive, they were unable to provide much access to families with autistic children.
- A number of Native parents of children with autism were reached through CCC's community networks; however, none were receiving EIDBI services. Further efforts were made to contact local Native nonprofits, but we received no response. CCC connected with a Native American autism advocate who suggested offering gift cards. A couple of Native parents attended the focus groups and some filled out the survey.
- We enlisted members of the Early Intensive Developmental and Behavioral Intervention (EIDBI) Advisory Group to reach out to Latinx and Indigenous communities.

IV. Provider and professional focus groups

Key learnings

Provide clear and adaptive standards and guidelines

Providers want more clarity on DHS standards and expectations for EIDBI providers. Additionally, providers need a balance of autonomy and clear minimum standards, not overly stringent guidelines or one-size-fits-all approaches that create barriers for families.

DHS systems need updating

Current DHS systems (enrollment faxing, hiring approvals, billing, etc.) impede the implementation of EIDBI services. Before proceeding with a licensure or certification process, DHS should consider how it can increase its capacity while offering high-quality support to providers.

Billable and nonbillable work financially affects the quality of client care

Increasing requirements without expanding support will ultimately reduce the number of providers/services available.

Unmet autistic students' needs because of ineffectual collaboration between EIDBI and schools

Schools often block EIDBI providers' efforts to support students and collaborate with school staff. Students cannot participate fully in school because there is no bridge between EIDBI services and special education.

Require evidence-based EIDBI-approved modalities

Any statute should require evidence-based and goal-centered treatment modalities.

Alignment between EIDBI providers and DHS essential to meeting culturally grounded goals

Placing a greater emphasis on getting at the heart of each family's values is vital. Agencies reported receiving pushback against their attempts to make cultural accommodations. Wherever possible, DHS should work toward embracing flexibility in areas of cultural competence.

Focus parent feedback on satisfaction and engagement

Caregivers' knowledge of modalities is insufficient to rate service quality adequately. Providers are more concerned with caregivers feeling connected, heard and supported.

Recommendations

Provide clear and adaptive standards and guidelines

Providers want more clarity on DHS standards and expectations for EIDBI providers. Additionally, Providers need a balance of autonomy and clear minimum standards, not overly stringent guidelines or one-size-fits-all approaches that create barriers for families. Below is a summary of what providers would find most helpful:

- Flexible guidelines that allow providers to make adjustments to meet the needs and preferences of the communities they serve. Be aware that context and culture matter. DHS should create guidance on minimum standards and facilitate flexibility.
- Delineate between optional and required standards. Define minimum standards from those “optional” or “gold” standards.
- DHS should develop customizable templates that reflect different service settings and diverse cultural communities.
- Provide a clear list of policies and procedures that organizations are required to implement. DHS could generate a list of recommended tasks and rank them accordingly: Exceeds, Great to Have, Need to Have.
- DHS should clarify health and safety guidelines and standards. Currently, DHS has provided minimal specificity on needed health and safety policies. Providers have identified some of the following areas where guidance is necessary:
    - Emergency restraint
    - Medication administration
    - Food hygiene
    - Transportation safety.
- No one-size-fits-all-approach. Policies do not necessarily work effectively for all providers. The attainability of standards varies considerably based on the context of service delivery. DHS should strongly consider developing policies addressing the following:
    - Service setting, e.g., home-based and center-based.
    - Organizational size, e.g., large social service agencies and small private practices.
    - Geographic community, e.g., rural and urban.
- Update the EIDBI Policy Manual so it is less cumbersome, more straightforward and accessible, especially to marginalized communities unaccustomed to operating in U.S. bureaucracy. Current guidelines and expectations are often too general and difficult to find.
- Cultural differences should be considered in health and safety standards, treatment planning and other areas. Providers should exercise their judgment when cultural accommodations are warranted.
- Integrate other credentialing and clinical licensure processes with EIDBI standards.

Many larger agencies that offer EIDBI services alongside other services are accountable for credentialing or licensing requirements (Rule 3, Behavioral Health Center of Excellence). Providers who adhere to requirements for their clinical licensure find that following these guidelines also benefits the EIDBI services administered. Providers worry that new regulations and oversight will add stress and become onerous.

DHS should increase its capacity and the quality of provider support before implementing a licensure or certification process. Below is a summary of the challenges providers have experienced:

- Integrate and embrace modern technology to improve communication effectiveness. DHS' continued use of fax machines rather than email and digital applications has resulted in incomplete fax transmissions and delays in service approvals.
- Improve DHS staff responsiveness and shorten approval wait times, including time-sensitive items such as treatment plans and staff hire approvals. Providers often wait 30 days for a response, which creates serious barriers to service implementation.
- Increase staffing and the quality of support offered to providers, especially BIPOC providers. Providers feel the system works against them. BIPOC providers experience the added pressure of navigating cultural differences and inefficient processes and are penalized for minor mistakes. Other providers shared that the info desk staff gave inconsistent guidance, the staff reviewing treatment plans were not trained in modalities enabling them to understand those plans and DHS site visits were short and unthorough. Adequate DHS staff capacity to answer provider questions, disseminate qualified guidance on treatment plans and conduct robust site visits is necessary.

Staffing and personnel

Make current staffing variances permanent

- Variances create greater access for diverse providers and help address the staffing shortages. Specifically, the qualifications for Level 2 providers and the ability to use remote BCBAs from other states have a tangible impact.
- Address staffing shortages by generating pathways for providers to become L1 and L2. Providers are encountering L1, L2 and QSP shortages in the labor market. Meeting the requirements for Level 1 hours is difficult. When agencies hire Level 1 providers, retention is challenging. Additionally, EIDBI compensation doesn't always align with education and career experience. Incentivizing staff to pursue more education and increasing pay can advance the field.
- DHS should support providers in expediting staff credentialing. Extended staff onboarding delays services for families.
- Expand activities considered billable work to reduce agencies' financial burden and impact clients' quality of care.

- Providers update and audit files, make referrals and coordinate with other specialists but do not receive reimbursement.
- Client-specific team meetings and coordinated care conferences are valuable tools that should count toward billable hours even if parents can't attend.
- DHS needs to cover training costs. While variances enable providers to hire more staff, DHS should cover training costs associated with training new hires. Current reimbursement rates don't cover these costs. Funding training would support diverse and rural communities and boost parents' confidence that the care their children receive is of high quality.
- Avoid overregulation to prevent barriers to service from occurring. Struggling small organizations and rural providers will ultimately reduce the number of providers and services available in these vulnerable communities. Focus on the minimum standards to ensure safety and provide funding and support for any necessary increase in requirements. The types of DHS support providers suggested include:
    - Fund the costs required to launch an EIDBI center. Licensing will also need to include support for facility development. A grace period is advisable to allow enough time to meet license requirements.
    - Make resources available to assist BIPOC organizations with ongoing capacity-building training, hiring on-call nursing staff and grants to help with worker shortages. There are concerns about increasing requirements for BIPOC-owned businesses. Increasing support will demonstrate the commitment DHS has to cultural engagement and inclusion.
    - Provide additional support for small organizations. Unlike larger organizations that can implement health and safety standards, smaller organizations need support from DHS to learn about and access resources.

Make more training options available for EIDBI providers of all levels

Providers value training and continuing education, but the current reimbursement rates and the inability to bill training hours are significant barriers.

Providers would like:

- Mandatory CPR and first aid training.
- DHS to offer free training on a variety of topics, including:
    - Creating person-centered treatment plans.
    - Medication administration (serving clients with epilepsy).
    - Cultural responsiveness and competency.
    - Best practices for critical incident reporting.
- All clinical staff to receive baseline training to understand autism and best practices to serve autistic clients effectively.
- Continuing education requirements for all providers, aligned licensure when applicable and topics most beneficial and relevant to the particular needs and context of their agency.

Coordination

DHS EIDBI services and the Minnesota Department of Education collaborate to create a clear statewide directive supporting coordination and the presence of EIDBI providers in schools. Leadership by MDE in this area is critical. The expectation is for MDE to spearhead the dissemination of EIDBI partnering guidelines and support all school districts in this initiative. A statewide mandate is imperative and noted by providers for the following reasons:

- The lack of collaboration between EIDBI and schools undermines the ability to meet autistic students' needs. Students aren't receiving the necessary support to participate fully in school. Schools often create barriers for EIDBI providers that prevent them from supporting parents and collaborating with school staff. Schools advise families to homeschool their children, rather than address the school administration's poor systems that contribute to worsening student behavior.
- The link between EIDBI services and special education does not exist. There is no formal transition process when clients move from intensive EIDBI services to a school setting. School practices often fail, requiring students to return to their EIDBI programs.

Maximizing state funds depends on effective collaboration

Schools are underfunded and short-staffed. Although funding is available to place EIDBI providers in schools, schools will not allow it.

Evidence-based practices and modalities

- All modalities should be evidence-based.
- As part of any state statute, include requirements for evidence-based, goal-centered treatment modalities.
- However, providers have reservations about listing specific treatment modalities in the statute. Listing specific treatment modalities in the statute might limit the inclusion of new modalities or hinder adapting to evolving and emerging views on best practices. Finally, given the negative experiences some communities have had with ABA, there may be greater receptivity to general descriptions of modalities.

Cultural competence

- EIDBI providers and DHS must work together to meet and support the culturally focused goals of parents and clients. Demonstrating that DHS values what families want will go a long way toward building credibility and trust with them. Agencies reported they received pushback when trying to make cultural accommodations. DHS should aim for greater flexibility to support cultural competence.
- As part of DHS' licensure process, take intentional steps to engage a broad coalition to define standards with an expansive, inclusive cultural lens.

- By broadening participation in DHS' process, communities and providers of color will feel less that DHS is forcing another "punitive tool of white dominance" on them that doesn't reflect the community.

Service quality

Focus parent feedback on satisfaction and engagement. Caregivers do not have the insight or judgment about modalities to rate service quality effectively. Providers are more concerned with knowing if caregivers feel connected, heard and supported.

Summaries by topic

Below you will find summaries of all of the provider and professional focus groups conducted during the stakeholder engagement process. They are organized by topic and stakeholder group. The topics include:

- Health and safety
- Staffing and personnel
- Service quality
- Coordination with schools
- Evidence-based practices.

The stakeholder groups we engaged were providers from Greater Minnesota, BIPOC providers, providers from the Twin Cities Metro Area and providers and professionals participating in collaborative and advisory groups.

Health and safety

Greater Minnesota focus group responses

What’s working

- Providers embrace the flexibility of current health and safety guidelines, which they can adapt to meet the needs and preferences of the communities they serve. On the other hand, they reject stringent, one-size-fits-all approaches that create barriers for families and caregivers.
- Behavioral Health code of ethics safety standards are helpful for in-home services.
- Agencies working to implement sustainable systems value safety checklists and general safety practices.
- Some providers want to maintain EIDBI health policies across service settings at a general level. More uniformity of EIDBI health policies would help prevent confusion and allow providers to use discretion depending on the circumstance.

- Many providers use registered nurses to administer medications and provide training. They also found the following resources beneficial in abuse prevention:
    - Mandated reporter training.
    - 245D abuse prevention plans.
    - Clinical reviews of restriction procedures.
    - Having established guidelines for physical restraint in place.
    - Autism spectrum disorder (ASD) 10-hour training.
    - ITP safety plan requirements.

What’s not working

- Providers need greater clarity and accessibility to the EIDBI health and safety guidelines.
- Among providers, there is a high demand for straightforward resources such as a credentialing checklist for new sites or revalidation. Existing EIDBI policies and procedures are too general and difficult to find.
- “When we added our newest location, it had been a while since we had credentialed a site. There wasn’t anything very straightforward, like a checklist of what DHS is looking for. We were kind of flying blind.”
- Providers require more medical training and access to nursing services, along with support and flexibility to train staff effectively in safety practices. With safety care providers in short supply, increases in hiring and retention costs, an EIDBI staffing shortage and high turnover rates, time and flexibility to train staff can moderate uncontrollable factors.

Concrete suggestions

- Avoid one-size-fits-all EIDBI health policy approaches. Each setting has its safety concerns. Not all policies work effectively across all settings.
- DHS might consider producing training videos focused on best practices in administering medications.
- Require providers to produce proof of a medical administration plan that a registered nurse approves.
- Post an online list of suggested policies and procedures. For example, suggest an optional fire marshal building review and details for accessing this resource.
- Create a practical list of recommended credentialing tasks for providers. Rank each suggested item as Exceeding, Great to Have or What to Have.

BIPOC focus group responses

What’s working

- The state's current capacity-building program focusing on continued development is having an impact.

- Dual grant programs create ongoing development opportunities and support employers in creating jobs. Providers acknowledge the state's efforts to fill current gaps with programming in critical areas.

What's not working

- Greater awareness of cultural considerations and celebration of differences is lacking. Making an effort to demonstrate greater sensitivity and intention in conveying the acceptance and value of cultural differences and traditions can affect BIPOC families positively.
- Uniform expectations across organizations are not possible. Adopting EIDBI rules and policies and applying them equally is unrealistic. An organization's size and limited resources to meet EIDBI requirements can significantly influence its ability to implement policies.
- Additionally, language barriers introduce another layer of complexity to comprehending the rules when an interpreter is involved. Ensuring standards aren't barriers to small BIPOC organizations is vital.
- An unsupportive and ineffective system is a barrier for BIPOC providers. BIPOC providers feel the system works against them when they attempt to place BIPOC children in programs. For example, phone calls and questions go unanswered, denying program admittance for small mistakes and varying audit practices. Simply trying to read and understand what is in the manual is cumbersome and takes the joy out of the work.

Concrete suggestions

- Consider how cultural differences influence health and safety standards – expand standards for greater inclusivity. Providers want the ability to exercise judgment when making accommodation decisions and developing treatment plans based on cultural considerations.
- Offer resources to support BIPOC organizations in the areas of capacity-building, training, hiring on-call nurses and available grants to fund positions to address worker shortages. Many providers expressed concern that increasing requirements are becoming a barrier to BIPOC-owned businesses. Expanding support will demonstrate DHS' commitment to cultural engagement and inclusion.
- Make rules and expectations more manageable and less complicated. Accessible rules and expectations that everyone can understand, especially for immigrant populations, instill greater trust and efficiency.
- Apply health and safety policies consistently to all providers. For example, when auditing organizations, all organizations receive monthly warnings in advance to ensure policies are applied equally.
- Differentiate policies for center-based and home-based providers, detailing responsibilities for emergencies. To reduce frustration and confusion, in-home providers need clear emergency policies that communicate expectations to parents, e.g., the responsibility of parents for handling emergencies during EIDBI sessions.

Metro focus group responses

What’s working

- Use other credentialing processes to determine standards, e.g., Rule 3. Many larger agencies operate EIDBI services alongside other services. Because of this, agencies are accountable for other credentialing or licensing requirements. Providers find that following these guidelines benefits the EIDIBI services they provide.
- Observation of and collaboration among clinicians are crucial to preventing abuse. Regular communication and consultation between providers, reviewing session notes and observing sessions with teams are proactive and effective ways to monitor the potential for abuse.
- Requiring grievance policies as part of the accreditation process, filing incident reports and including safety plans in individual treatment plans (ITPs) identifying young people who are most vulnerable to abuse offer providers more complete and integrated documentation.
- Safety plans in ITPs are a good addition and can help identify young people who are particularly vulnerable to abuse.
- Providers learned from COVID that when kids are sick, they need to rest and stay home for all of our health and safety.

What’s not working

- Providers want clear health and safety guidelines and standards from DHS.
- Require CPR and first aid training.
- DHS should provide reasonable and supportive medication administration guidelines for small and large providers. Medication administration is often outside the scope of EIDBI providers' practice. Yet, in some cases, administering medication to clients is necessary, especially in the instance of epilepsy and seizure protocols.
- Food hygiene guidelines should address basic food safety and food allergies. The capacity to clean center-based settings is a challenge and providers want basic guidelines for cleaning.
- Transportation safety guidelines are needed, especially for children with autism. Medical Transportation is a key to service access. However, sometimes transportation options are not safe.
- Outdated DHS systems are inaccessible to providers. Providers have experienced challenges because of DHS's outmoded communication (fax machines), resulting in service delays for children and families. MPSE systems are challenging to navigate and cause a drain on provider resources.
- Develop clear guidelines for the use of restraints and staff training. Not all staff are aware of current DHS policies, putting them at risk of having outdated information and training.

Concrete suggestions

- DHS should offer basic training focused on the acceptable handling of epilepsy and allergic reactions required for all providers.
- Standardize food hygiene. Although EIDBI services differ from those in schools, a regulated approach is welcome.
- Include facility development support in licensing. DHS should fund the activities required to launch EIDBI centers and give center-based providers a grace period to become operational before meeting license requirements.
- DHS should provide clear health and safety guidelines and standards.
- Require CPR and first aid training.
- DHS needs clarity about its requirements for medication administration.
- All staff should participate in training at the time of hire, plan to offer follow-up training and allow comprehensive multidisciplinary evaluation (CMDE) to identify problems and vulnerabilities.
- Develop a monitoring system to heighten awareness of potential abuse and track children's well-being.
- Differentiate health policies according to service setting and provider size and capacity.
- Develop in-home services policies to include expectations for a responsible adult to be present and guidelines that determine when or if sessions should continue if siblings or parents are ill.

Collaborative and advisory groups responses

What’s not working

- Providers need a balance of autonomy and clear minimum standards. DHS should provide guidance on minimum standards and offer optional gold standards for providers to work toward.
- Rural communities are unaware that EIDBI services exist. Silos prevent different referral sources, e.g., health care plans and school districts, from informing families of available EIDBI services.
- Referring clients to other providers, e.g., pharmacy and behavioral health, is challenging.
- Qualified supervising professionals (QSPs) are taking on large caseloads. For example, one licensed professional with a 60-patient caseload puts patients at risk.
- While larger organizations have more capacity to implement health and safety standards, smaller organizations need increased support from DHS and opportunities to learn about existing resources.
- Translating safety signage in different languages, e.g., first aid and washing, is an additional expense and effort for organizations.
- Currently, the level of specificity in DHS health and safety policies is minimal.

- Providers are forced to figure out standards because food and emergency restraints don't exist in some areas.
- The absence of food regulations means people must research national standards and determine how to apply them.
- There is confusion about applied behavioral analysis (ABA)-related services and EIDBI services that can’t be provided in educational settings.
- Providers described their experiences with site visits as short and incomplete.
- “When we opened up our new location, they gave us a list of what they are looking for, like bathrooms. They drove three hours to Marshall and it (the site visit) was 10 minutes. Asked a few questions about QSPs, numbers serviced. Surprised it was so short. Much concerned about our 60-year-olds having transcripts.”
- There is a lack of communication with providers around changes.

Concrete suggestions

- DHS should pay for translating safety signage, such as first aid and hand washing, into multiple languages, e.g., Somali and Karen.
- Caseload limits should be put in place.
- Site visits need to be more robust.
- Context and culture matter. DHS should create guidance on minimum standards and allow flexibility for providers to adapt them for their community.
- DHS should compile policies and procedures and customize templates for providers.
- DHS should encourage providers to create medication administration policies and allow for flexibility in implementation.
- Providers need autonomy and clear minimum standards. DHS should outline minimum standards and expectations and articulate what qualifies as optional or the gold standard.
- Develop an internal review process for providers to use to ensure compliance.
- Home-based providers want guidelines on the presence of firearms in the home.
- When possible, parents should administer medication.
- Offer optional and affordable health and safety training.
- Avoid overregulating to prevent service barriers. Focus on the minimum standards to ensure safety and allow providers to self-monitor.
- Continuously review and monitor modalities to ensure specific evidence-based practices occur.

Staffing and personnel

Greater Minnesota focus group responses

What’s working

- Providers appreciate the 2024 staffing updates, especially the variances that offer more movement and flexibility for staff. The updates have helped with the staff shortages many providers are experiencing.
- Regularly monitoring the successful implementation of individual treatment plans helps assess EIDBI providers' quality.
- EIDBI providers follow various clinician licensure certifications, e.g., licensed professional clinical counselor (LPCC), board certified behavior analyst (BCBA), aimed at keeping their work within their scope. Some feel that additional regulations and oversight will become stressful and taxing.
- Providers already follow various requirements for continuing education (BCBA, occupational therapy (OT), LPCC). Additional requirements aren't needed.
- “As social workers, it's already very laid out. I don’t want extra things to do on top of what I already have to do to maintain that license.”
- Agency satisfaction surveys, Google ratings and DHS satisfaction surveys are valuable tools in assisting parents with rating provider quality.

What’s not working

- Providers encounter L1, L2 and QSP shortages in the labor market. Create more pathways to become L1 and L2 providers. While updates on variances have helped some, exclusively focusing on the ABA health care experience produces continued barriers.
- Providers want stricter qualifications for health care experience, especially in group homes.
- Simply working with someone who has autism in a group setting is insufficient to meet the bar for training and experience.
- “I used to work at a center in Baxter. They had [staff] coming from group homes …. They may have been supporting someone with autism, but were not providing ABA. Most anyone can get a job at a group home. Even if they work there for four to six years, I don't think it's enough experience to qualify.”
- The longer it takes to onboard staff and meet training requirements, the longer families wait for services. Providers face shortages in the labor market and long patient waiting lists.

Concrete suggestions

- Implement registered behavior technician (RBT) certification in Minnesota to introduce certification pathways and help fill the staffing shortages.
- Create a parent resource with EIDBI providers and treatment options to meet their needs.

- Suggested continuing education topics:
    - Emotional intelligence and mindfulness.
    - Developing therapeutic rapport, especially with nonverbal people.
    - Behavior skills training (consisting of topics beneficial for Level 1 providers).
    - Allow people to choose topics that are most beneficial for the particular needs and context of their agency.

BIPOC focus group responses

What's not working

- Providers experience staffing and personnel challenges. The workforce shortage and inadequate reimbursement levels require supervisors to shoulder significant responsibilities without support.
- Efforts are lacking to address the provider shortage. Leveraging available licensed professionals across the state is not happening because EIDBI hasn't addressed the issue.
- Determining billable and non-billable work puts a considerable strain on agencies. Providers do not receive reimbursement for doing work, such as updating client files, auditing files, making referrals and coordinating with other specialists.
- Although efforts are under way to introduce a BCBA license, the process is lengthy.

Concrete suggestions

- Enhance the appeal of EIDBI positions so it is a more attractive job option. Given the high turnover rate and workforce shortages, the EIDBI field needs more people.

Metro focus group responses

What's working

- Variances to address staffing shortages. The qualifications for Level 2 providers and the ability to use remote BCBAs from other states are making a real impact.
- Minnesota's collaborative team approach to EIDBI is a strength. Clinicians with different training work together to offer robust services. This approach requires cross-training to ensure that everyone on the collaborative team understands autism.
- Continuing education is part of observation and direction. Embedding training in the workday means training happens in real time with real clients.
- Shifting RBT to Level 2 providers incentivizes providers to make more training available for staff. DHS's requirement that Level 2 providers take the initial training for Level 3s is a positive step.
- Interdisciplinary collaboration is another strength of Minnesota's system. Varied clinical training is helpful for oversight and thinking about services differently.

What's not working

- Providers continue to struggle with staffing shortages – especially of Level 1 providers. It is difficult to meet the requirements for Level 1 hours. And it is even more difficult for agencies hiring Level 1 providers to retain them.
- Inconsistency in required autism/EIDBI training diminishes the meaningfulness of provider levels. Providers trained in other mental health fields, e.g., LICSW or LMFT, do not use the same language or understand key concepts central to EIDBI services.
- The lack of role clarity between BCBAs and QSPs leads to confusion about boundaries and decision-making. Without sufficient guidance from DHS, providers perform roles differently from organization to organization. QSPs' involvement varies greatly. They are typically not at an organization daily and have less knowledge about autism. Even so, they are accountable for overseeing treatment plans and supervisory responsibilities, resulting in power dynamics.
- "There is a lack of understanding between the roles of the BCBA and QSP. The little bit of guidance doesn't make things black and white. [It gets] executed very differently in each agency."
- EIDBI providers need more training options at all levels. DHS could help by making providers aware of all training opportunities.
- Training requires time and funding. Providers with staffing shortages don't have the luxury of hiring and training new staff for weeks. Instead, they opt for observation and direction. Providers would offer more staff training opportunities if training were a billable expense. Many staff are licensed and must complete CEUs — these should count toward training requirements.
- Providers have different perspectives on RBT. Many providers think having the option for staff to become an RBT is a positive step. Other providers worry about the ongoing supervision requirements to maintain RBT licensure and the upfront training time to acquire RBT certification. Providers were concerned about their capacity if RBT were to become a requirement.
- QSPs taking on large caseloads can reduce the quality of oversight. Currently, guidance on caseloads falls to individual organizations.
- Not all providers understand documentation requirements. Additional documentation training and coaching would help large organizations ensure all documentation is happening, considering the involvement of more people working with each client.
- EIDBI compensation doesn't always align with education and career experience. To move the field forward, incentivize staff and increase their pay for additional education.
- Parents are uninformed about how to rate service quality and are unable to give meaningful feedback on family and caregiver engagement.

Concrete suggestions

- Be more explicit in guidance defining the division of work and differentiation between BCBAs and QSPs.
- Update the policy manual.
- Conduct an engagement survey to learn about team involvement and access to clinicians.
- Require QSPs without ABA training to give providers offering ABA services baseline training.
- Make staffing variances permanent. Not having the variance would be detrimental.
- Requiring all providers to become RBTs would present challenges to them; it would be best to maintain the current requirements.
- Create an option for completing RBT training that does not require meeting the same supervision standard but provides baseline knowledge.
- Providers should take different CEUs based on licensure.
- Basic training should include:
    - How to perform observation and direction.
    - Basic ABA (what is it, how to do it and the differences).
    - Make inter-observer agreement (IOA) a part of observation and direction.
- Include BCBA and QSP signatures on ITP. Delineate responsibilities with sections dedicated to ITP and signatures for advanced certification holders.
- Require caregiver training and counseling and include families in therapy.

Collaborative and advisory groups focus group responses

What's working

- Due to many variances, increased access for diverse providers has helped address staffing shortages.
- Variances allow for hiring flexibility and billing at higher rates. Permitting a middle tier in Minnesota, compared to other states, allows providers to bill at higher rates, hire undergrad and grad students and serve more clients.
- "Variances allow us to hire undergrad and grad students. Flexibility to hire and higher pay grade is awesome."
- Supporting parents broadly through parent and caregiver training.
- "Parent and caregiver training doesn't have to be tied to the ABA. It can be provided to family support, helping them access resources, going with the family in the community. They are just trying to learn about autism, not really about ABA. How do I navigate school systems? How do I talk to my child's teacher?"
- Training resources offered through EIDBI services such as 101 cultural competency.

What’s not working

- The staff credentialing process is frustrating. For example, requiring proof of a BA and MS in a related field, submitting transcripts and obtaining a professional license are cumbersome processes that delay service to families in need.
- "Frustrating process – a lot of staff are licensed mental health therapists. Fact that I am having to ask someone to go get transcripts who has worked for 20 years is absurd."
- “The challenge for us is that our staff have to drive 45 minutes to get to a location where the fingerprint can be done.”
- An outdated and inefficient communication system, including the "clunky" portal and faxing paperwork. The loss of paperwork and delayed responses for 30 days are common.
- “For tele-medicine, the credentials need to be updated. There are 10 ways you qualify but only a few are in the portal. Not all requirements are on there.”
- “Sometimes faxes get lost and you have to wait 30 days to find out something is missing.”
- QSPs operate outside the scope of experience and have little knowledge of autism or the evidence-based modalities used in EIDBI services.
- Worker shortages block parents from accessing the care and services needed for their children. Don’t artificially limit the workforce – explore ways to expand it.
- While variances enable providers to hire more staff, training new hires is a significant financial burden. Current reimbursement rates barely cover costs. Funding training would support diverse and rural communities. Equally important is parents fear their child does not receive high levels of care from staff who are not adequately trained.
- “Idea that there is no money for training and supervision is ridiculous. It takes a long time to get staff up to speed and the bottom line is that children suffer because people don’t know the modality.”
- “Adequately fund the training and supervision. Until you do that, you are looking to blame the agencies for a structural problem. It starts at the foundational level. We don’t have the money to just provide all this training up front.”
- Greater Minnesota faces the added barrier of transportation challenges.
- Different modalities have different certification pathways, making it difficult to differentiate between services.
- “There are modalities that have certification pathways and there are ones that don’t. Yet they are all in the same bucket – that’s getting challenging. As we have more EIDBI providers, we are experiencing families that have no idea that they already did a CMDE and a service agreement.”

Concrete suggestions

- Providers’ credentials should align with proposed services.
- Create access to multiple avenues for staff to get credentials including accepting different experiences.

- DHS should cover training costs.
- Require transparency with potential families about providers' specializations.
- Itemize training costs for different modalities so DHS can better understand providers' financial obligations.
- DHS needs to hire more staff to monitor EIDBI provider qualifications.
- Overall, clarification of continuing education requirements for EIDBI providers is needed.
- Create opportunities for parents to rate provider quality, such as a consumer feedback survey once or twice a year.
- Parents are only able to provide feedback addressing quality if they understand modality. For more relevant feedback, focus on feedback about parents’ experiences.
- Parents should receive training focused on their rights, e.g., how often they should meet with their EIDBI team.
- Rather than adding new requirements, document existing required CEUs for providers that focus exclusively on autism.
- Require a certain number of training hours annually consistent with other programs.
- Meet weekly for clinical review.
- Twice a year, create opportunities for parents to rate provider quality, such as a consumer feedback survey.
- Track family engagement, being mindful to respect families' diversity and needs. Some want more hands-on, while others have a lot going on.

Service quality

Greater Minnesota focus group responses

What’s working

- Monitoring quality of EIDBI services is dependent on the ITP.
- The licensing review process is a means to ensure person-centered care takes place.
- Regular safety training focused on behavior and crisis management resources is helpful.

What’s not working

- For some providers, the 245D is not the most effective protocol to use when working with children. Providers worry that licensure requirements will become too strict, creating more barriers for providers to work safely with children.
- "I'm most concerned about this area (emergency restraint protocol) mirroring 245D in full because of some of the downfalls we have seen with it… As we know, children don't learn and adapt the same way an adult does. I worry a little bit that we will go too far the other way that providers won't be able to serve children – 'I can't because licensure prevents me from doing that safely.' I want to serve the kids who are super challenging. I don't want those kids to just not get service."

- EIDBI services' involvement in case management and coordinated care is inadequate.
- Case management and coordinated care with EIDBI services is lacking.
- Providers want more accessible guidelines for restraint certification programs that don’t place a strain on smaller agencies.

Concrete suggestions

- To ensure that person-centered services are a priority, DHS should sponsor more training resources and refresher options.
- Require proof of policies and procedures clearly outlining organizations’ training protocols, incident reports and complaints while allowing organizations to decide what works best for them.

BIPOC focus group responses

What’s not working

- The emphasis on early intervention does not align with the lengthy process to obtain services. Parents don't necessarily recognize issues in their children — in addition to extensive diagnosis requirements to prepare children to receive services.

Metro focus group responses

What’s working

- DHS incident reports are working well.

What’s not working

- DHS staff lack the clarity and qualifications to review treatment plans. DHS needs staff trained in evidence-based modalities to provide substantive site visits and reviews of treatment plans. Additionally, Acentra forms need to align with DHS staff expectations.
- DHS responsiveness to providers lags. Time-sensitive items like treatment plans and approvals for staff hires require timely responses.
- Persistent progress and outcomes documentation present challenges. Autism is a wide spectrum and each child's goals are different. For this reason, those with clinical expertise in autism should review progress outcomes.
- Client-specific team meetings and coordinated care conferences are valuable tools that should be eligible for billable hours, even if parents can't attend.
- Greater flexibility by DHS is needed to support cultural competence.
- "Our agency is trying to do something culturally aware. The person signed the document by writing their first name. 'No, that doesn't count as a signature,' DHS says. 'Do it like us.' "

Concrete suggestions

- Appoint a neutral party above DHS to review complaints and mediate conflicts with DHS staff.
- More specific training covering what qualifies as a critical incident, the steps involved and where and how documentation is done.
- Identify criteria for quality control and compliance audit including the frequency of DHS audits and how to develop internal audit protocols. Determine if audit process information already exists.

Collaborative and advisory groups focus group responses

What's working

- The iPad program used for interpretation services is effective.

What's not working

- The clinical complaint procedure is not well-defined. Currently, multiple avenues for complaints are unclear and confusing.
- Adding requirements without additional support will reduce the availability of providers and services. More realistic reimbursement rates and procedures to fund training and supervision would enable providers to meet DHS standards and remain in business.
- "DHS needs to figure out where support for providers is lacking. How do we meet that need first. Then we can talk about having these types of standards. Otherwise, we are just going to go backward and there are going to be even fewer providers."
- "Unless there are additional supports provided for the agencies, you can add in all of the rules that you want to add in. But if agencies don't have the tools to meet the standards, the only thing that you are going to do is lose agencies and then there's going to be even (fewer) providers, even (fewer) services."
- DHS should engage a broad group to define standards for a more inclusive cultural lens and diverse perspectives.
- Without flexible crisis plans for high-needs clients, there is a risk of limiting access for those clients.
- EIDBI providers work to meet parents' and clients' expectations for culturally-informed services.
- Autistic children cannot attend religious or cultural schools like many of their peers. Treatment plan goals that enable children to engage in cultural activities are important.
- Licensure could become a punitive tool of white dominance. DHS must avoid unintentionally creating tools that work well for larger, white-led organizations but undermine providers of color.
- "DHS says that we are families first; that is our focus. I understand that you want us to accommodate. If I accommodate those things, then we don't meet DHS standards. There aren't enough cultural adaptations."

Concrete suggestions

- Consider a web-based complaint navigator that guides users through a series of questions.
- Provide families with accessible ways to give feedback to providers.
- Before approval, make sure parents' signatures are on treatment plans.
- Distinguish larger providers and health care systems from private practitioners and small providers.
- A unique characteristic of EIDBI is that its results are not apparent for two to three years. DHS should create medium-term outcomes — the state is the only entity that can accomplish such a large-scale initiative.

Coordination between EIDBI providers and schools

Greater Minnesota focus group responses

What's working

- Some providers in Greater Minnesota report good experiences coordinating with education services, especially with short-staffed schools.
- Providers have been successful at:
    - Providing training and staffing support to educational professionals (principals, SPED directors, paras and teachers) has been especially helpful in districts experiencing staffing shortages.
    - Attending care coordination meetings.
    - Obtaining the release of information from schools.
    - Using MOUs to establish successful collaboration guidelines.
- Parent education as a strategy is successfully empowering parents to advocate for EIDBI coordination with schools.

What's not working

- Schools often create barriers for EIDBI providers to support parents and collaborate with school staff.
- "[School barriers are] a huge problem for us. We're not allowed into schools. Only once or twice a year maybe for IEP meetings. Not even allowing us into the classroom to observe what's happening … Children end up coming back to you because they're not able to function."
- Students have difficulty transitioning from EIDBI programs into schools. Because school practices are unsuccessful, students must return to their EIDBI programs.
- Parents often struggle to choose between EIDBI services and school-based services for their early intervention needs. Many parents feel overwhelmed by ABA or choose school interventions without knowing about other available options.
- Although there is some improvement, a lack of understanding about EIDBI services in general and a fear of limited funding persists.

- “Providing ABA in the Midwest is typically misunderstood. Generally, I am finding in my own agency there is misunderstanding (about) what it looks like. Schools are always worried about who is funding it – want to be released of fear of funding.”

Concrete suggestions

- Mandate integrated collaboration of EIDBI and educational services (DHS and MDE).
- Consider the value of making region-specific DHS Q-and-A sessions available.

BIPOC focus group responses

What’s working

- Some providers report that mandatory care coordination meetings are helpful.

What’s not working

- Providers say they experience hostility or pushback during coordinating meetings when making recommendations they believe would benefit the child. Negative experiences leave BIPOC providers feeling there is no value in coordinated services.
- Parents aren’t required to and don’t tell providers about the scope of services their child receives.

Concrete suggestions

- DHS should visit programs and observe the actual services that the clients receive.
- Create a forum for BIPOC providers to safely report discrimination.

Metro area focus group responses

What’s working

- Recognition of EIDBI as a medical and not educational intervention

What's not working

- Transitioning to school—a bridge between special education and EIDBI services is nonexistent. There is no formal transition process for clients to move from intensive EIDBI services to a school setting. Despite EIDBI providers' efforts, schools are unwilling to collaborate.
- "In Minnesota, this is a downfall of our state. I've worked in several other states. School systems acknowledge that ABA exists and integrate it into classrooms. Minnesota is really far behind. There is no bridge between special education and EIDBI services."
- A barrier to meeting autistic students' needs stems from a lack of collaboration between EIDBI and schools. To successfully participate in school, autistic students must receive much-needed support. Without consistent support, student behaviors worsen. And families being advised to homeschool their children does not address the underlying issue.

- Providers see school administration as the reason collaboration fails. Teachers and advocates are often on board to work together, but administrative leaders appear to undermine such efforts.
- There is an inability to leverage collaboration as a cost-saving measure. Schools are short-staffed because of underfunding. Funding for EIDBI school providers to offer additional support is available, but schools will not allow it.

Concrete suggestions

- DHS EIDBI services and the Minnesota Department of Education must create a clear statewide directive to support coordination that allows providers to be in schools.

Collaborative and advisory group focus group responses

What's working

- DHS' guidance on hours clarifies for providers that EIDBI services are not an educational intervention.
- In a limited number of schools open to collaborating, it works well.
- Educating parents about their rights and connecting them to advocates.
- Parents need to know they can invite whomever they want to IEP meetings, etc.

What's not working

- School districts refuse to collaborate with EIDBI providers. Parents want collaboration between EIDBI and providers, especially because of the negative impact on BIPOC communities that experience racial disparities. The absence of partnering leads to unmet children's needs.
- "BIPOC moms were saying the resounding answer of what they need is coordination of services. There is such a gap."
- Schools do not understand EIDBI services or how to work with EIDBI providers. Schools don't understand that EIDBI is a necessary medical service. As a result, coordination is often very challenging.
- Parents must do extra work to grant access to their child's data in the schools.

Concrete suggestions

- MDE should provide all MN school districts with EIDBI partnering guidelines and support.

Evidence-based practices

Greater Minnesota focus group responses

What's working

- Flexibility in EIDBI services should continue and evolve with feedback from parents and providers.

- “EIDBI is still a new program. Anything can be adjusted and accommodated with feedback from parents and providers. … The program has been flexible and we should continue that as we grow.”
- Some providers appreciate the level of specificity for approved modalities.
- They allow for more flexibility and expansive, individualized services in different contexts, e.g., home and center services.
- Some believe EIDBI works the way it should a majority of the time.

What’s not working

- Providers need clarity on eligibility for EIDBI services for related conditions.
- More general descriptions of approved modalities could cause confusion. Providers want a specific list of approved modalities.

Concrete suggestions

- Consider licensing board-certified behavior analysts.

Metro focus group responses

What's not working

- All modalities should be evidence-based.
- The practice of non-evidence-based modalities is harmful.
- Providers want clarity on the different modalities. Many providers are aware of ABA. DHS could do a better job of disseminating information on all modalities to providers. This would support referrals and could lead providers to expand their offerings.

Concrete suggestions

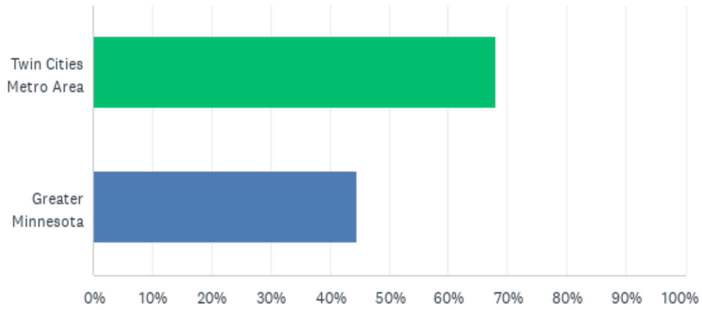
- Flexibility is key to meeting diverse client needs. DHS should list specific evidence-based modalities with generalized modality goals.
- There is a vast DHS manual with different protocols, but providers don’t always understand it. Alternative methods focused on building shared understanding could be more easily accessed by practitioners. Consider hosting more town hall meetings or open forums monthly where participants can ask questions.
- Broadly categorize modalities to include flexible descriptions. This would help remediate negative past experiences with ABA for some communities.
- Ensure services are person-centered by allowing a mix of modalities.
- “Our clients are all human. They don't fit in the box. Everybody's individual and we need to be able to have modalities and services that can be flexible and meet the needs of each individual client.”

Survey responses

Below you will find a summary of the findings from the online provider and professional survey conducted during the stakeholder engagement process.

Characteristics of survey respondents

Q2 Where do you provide EIDBI Services? Select all that apply:

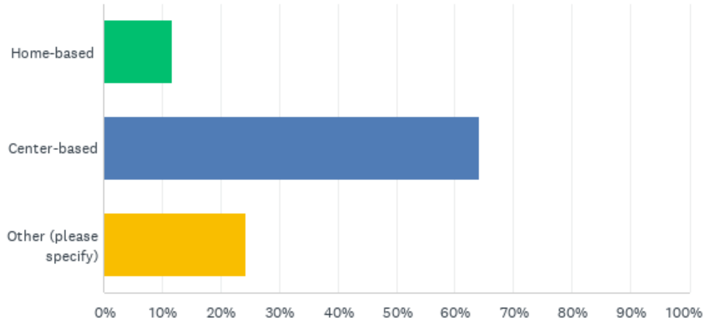


When respondents were asked where they provide EIDBI services, they responded:

- Twin Cities metro area: 67.96% (70)
- Greater Minnesota: 44.66% (46).

Out of the total number of respondents, 103 answered this question and 11 skipped it. This shows that a majority of the providers who responded to the survey are based in the Twin Cities metro area, with a significant number also serving Greater Minnesota.

Q3 What type of facility do you provide EIDBI services in?

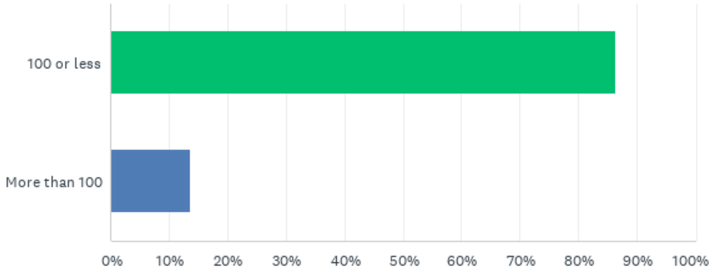


Respondents were asked about the type of facility where they provide EIDBI services, they answered:

- Home-based: 11.65% of respondents (12).
- Center-based: 64.08% of respondents (66).
- Other: 24.27% of respondents (25) chose this response. The majority of those respondents indicated that they provide EIDBI services in both home and center-based settings, one respondent said they provided services via local public health and one through telehealth options.

Overall, most survey respondents provide services in center-based facilities, with a smaller proportion offering services in home settings or other types of facilities. There were 103 responses to this question, with 11 respondents skipping it.

Q4 How many people do you currently provide EIDBI services to?

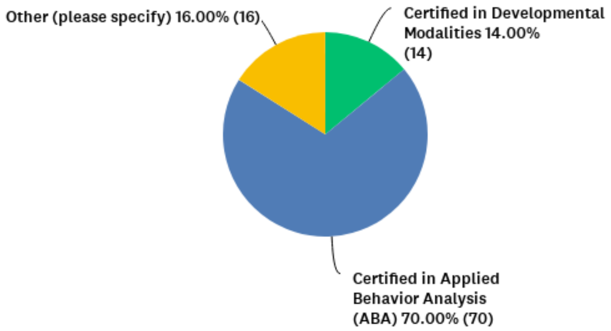


When asked about the clients currently receiving EIDBI services, respondents answered as follows:

- 100 or fewer: 86.27% (88)
- More than 100: 13.73% (14).

In total, 102 respondents answered this question, while 12 skipped it. This indicates that the majority of respondents work with a smaller number of clients, with a smaller proportion handling larger caseloads.

Q5 What certifications do you have?

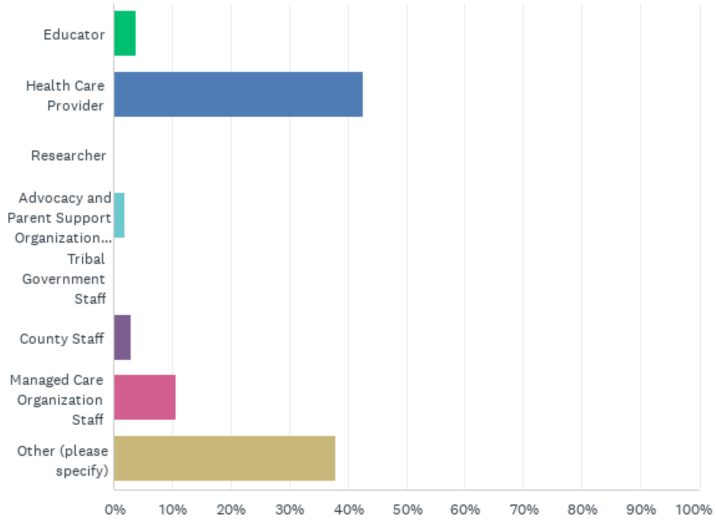


Certifications held by survey respondents are as follows:

- Certified in developmental modalities: 14% (14).
- Certified in AB): 70% (70).
- Other: 16% (16) have certifications not specified in the given categories. Those listed included LPSS, LICSW and public health nurse.

Out of a total of 100 respondents, 14 skipped this question. This data shows that the majority of respondents are certified in ABA, with a smaller but significant portion holding certifications in developmental modalities and other mental health licenses.

Q6 What is your professional role?



The data from the survey question about the professional roles of those who are not directly providing EIDBI services is as follows:

- Educator: 3.88% (4)
- Health care provider: 42.72% (44)
- Researcher: 0% (0)
- Advocacy and parent support organization staff: 1.94% (2)
- Tribal government staff: 0% (0)
- County staff: 2.91% (3)
- Managed care organization staff: 10.68% (11).
- Other: 37.86% (39) selected "Other" and provided unspecified roles. The majority of those who responded Other either play administrative or leadership roles in an EIDBI service organization or serve as a QSP.

How well are participant rights protected in EIDBI services?

Overall, more than 50 percent of providers (n=114) said the rights of participants are protected.

What changes, if any, should be made to better support participants' rights?

- Providers want participant rights, individual treatment plans and comprehensive multidisciplinary evaluation documents translated into languages other than English. They also suggested providers and families should regularly revisit current participant rights documents.
- "There should be a statement of rights that are reviewed at intake and follow through to staff training and woven into organizational standards and client programming. Incorporating areas in the ITP (where) the rights are visible may be beneficial. While families sign the document annually, they may not remember them as well as if they were on a document that is reviewed with the family more frequently."
- Mandate additional training in autism and treatment modalities for qualified supervising professionals and DHS staff.
- Providers see a need for more direction from DHS with clear rules and policies and inspections or audits. Respondents consider audits especially valuable in the first three years of service.
- The inability to access EIDBI services compromises clients' rights. Improve access by:
  - Making enrollment and intake processes easier.
  - Having better response times from DHS.
  - Making it easier for families to find providers.
  - Continuing to work to address workforce shortages.
- Current positive support rules prohibiting restraint prevent providers from working with certain clients thus denying those participants the right to EIDBI treatment. Respondents seek alternative approaches to restraint prohibition.

How well is coordination happening within EIDBI services (including coordination with educational services)?

Almost 40 percent of providers (n=114) found coordination between EIDBI and educational services "very good" or "good." A little more than a third of respondents found them "acceptable." In contrast, more than 30 percent find coordination "poor" or "very poor."

Is it well understood that EIDBI is a medical service and not educational?

Overall, almost half of providers (n=114), said that it is "very well" or "mostly" understood that EIDBI is a medical service.

Are guidelines needed to ensure that other providers can participate in planning when requested by parents?

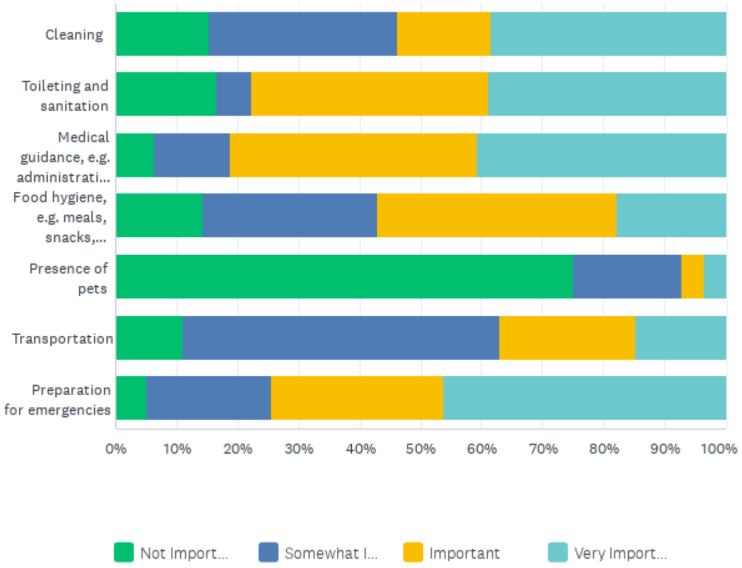
- Clear, supportive coordination guidelines outlining the relationship between EIDBI services and schools should include parent and student/client rights and clarify expectations for collaboration between schools and EIDBI providers.
- "Guidelines on MDE's end need to be put in place. EIDBI providers have all of the policies to ensure they are able to participate in school planning and school is able to participate in EIDBI planning. The barriers come from the school side of things, both with EIDBI participating in school planning and school teams participating in EIDBI planning."
- Providers say guidelines can support effective collaboration and care coordination among providers, provided they address communication, consent procedures, roles and responsibilities, conflict resolution processes, documentation requirements and confidentiality.
- "Guidelines aim to promote effective communication, collaboration and coordination of care among providers, ultimately benefiting the child and family by ensuring that interventions are well-coordinated and tailored to their needs."
- Conduct orientation for families and caregivers that covers the right to request other providers' participation, consent and confidentiality.

How should DHS ensure that providers are preventing abuse?

- Require all providers to participate in annual training and professional development focusing on abuse, mandated reporting, alternative restrictive methods and crisis intervention.
- Establish regulatory standards regarding abuse prevention, including credentials, caseload limits, supervision requirements and protocols for identifying, reporting and addressing instances of abuse.
- Require greater oversight of centers and staff (role of supervisors, observation of staff, drop-in site inspections).
- Implement a DHS recertification process, which consists of assessing sites, observation and document review regularly.

- Hire licensed providers who successfully pass background checks and reflect the families served to investigate abuse complaints. Be sure to incorporate caregivers' feedback and communication.

Q13 Should health and safety standards for EIDBI services include requirements around:



The majority of providers who responded to the survey, nearly 50 percent (n=114), say health and safety standards requirements to address emergency preparation are "very important," followed by medical guidance, toileting and sanitation at almost 40 percent. Less than a quarter of providers noted transportation and food hygiene as areas where providers see the need for health and safety requirements. Concerns for health and safety requirements around pet presence are much less critical (4 percent).

Respondents' perspectives on the importance of various health and safety standards for EIDBI services can be summarized as follows:

- Cleaning:
    - Not important: 4
    - Somewhat important: 8
    - Important: 4
    - Very important: 10
    - Total responses: 26
    - Weighted average: 4.33

- Toileting and sanitation:
    - Not important: 3
    - Somewhat important: 1
    - Important: 7
    - Very important: 7
    - Total responses: 18
    - Weighted average: 4.56
- Medical guidance (e.g., administration of medication):
    - Not important: 2
    - Somewhat important: 4
    - Important: 13
    - Very important: 13
    - Total responses: 32
    - Weighted average: 4.13
- Food hygiene (e.g., meals, snacks, preparation, etc.):
    - Not important: 4
    - Somewhat important: 8
    - Important: 11
    - Very important: 5
    - Total responses: 28
    - Weighted average: 4.10
- Presence of pets:
    - Not important: 21
    - Somewhat important: 5
    - Important: 1
    - Very important: 1
    - Total responses: 28
    - Weighted average: 4.33
- Transportation:
    - Not important: 3
    - Somewhat important: 14
    - Important: 6
    - Very important: 4
    - Total responses: 27
    - Weighted average: 4.56

- Preparation for emergencies:
    - Not important: 2
    - Somewhat important: 8
    - Important: 11
    - Very important: 18
    - Total responses: 39
    - Weighted average: 4.10

V. Family and caregiver focus groups

Key learnings

What’s working

- Individualized, intensive EIDBI services support children's skills development and appropriate behaviors fundamental to school, family and community participation.
- Services give parents respite, help them understand how their child's brain works and empower them with different parenting techniques and the confidence to advocate.
- Culturally specific providers and services have positively affected the community, enabling autistic children to learn about and participate in their culture.
- Family and caregiver training and counseling sessions offer practical skills based on the needs of families.
- Collaboration between service providers has culminated in personalized treatment plans and coordinated care.

What’s not working

- Not enough providers and psychologists leads to long wait lists for services and erodes relationship building.
- Parents want greater consistency in providers and outcomes and more support in helping their children develop social skills to engage with their families.
- Caregivers struggle to apply for EIDBI services and understand coverage.
- Rigid strategies, approaches and learning opportunities scheduled during the day don't work. More flexibility is needed.
- Bolster parent training. Not all parents understand their rights, how to access the services available or how to advocate for their and their child's needs.
- Many parents have experienced a lack of collaboration between schools and EIDBI providers, which means parents, by default, become the de facto coordinator.
- Parents worry school environments are unsafe and the services are inadequate for autistic children (schools only provide therapy for a few hours monthly, teachers don't have time to read IEPs and intensive EIDBI services to support children's social skills development).
- The ability to provide services that meet the unique needs of children is the most crucial factor in families' consideration of EIDBI service providers.
- There are concerns about the licensing process and the possibility of interrupting the quality of services.

Recommendations

The recommendations below represent the themes that emerged across all family and caregiver stakeholder groups.

Training and counseling

- Family and caregiver training and counseling could include more open sessions for siblings, community events and at-home training and coaching while dismissing less strict or rigid strategies.
- Allocate more resources to parent education and training to support parents' understanding of their child's developmental needs.
- Require all parents to attend family and caregiver training and counseling.
- Ensure parents have information about available options they can access to better advocate for their children.

EIDBI and schools coordination

- Schools and providers should coordinate services more. Collaboration should be the standard.
- Schools need additional education on EIDBI services.
- Schools should provide more early intervention beyond a few hours a month.

Other

- Improve accessibility to services by increasing awareness about the availability of programs, reducing the wait time to receive services, creating more centers and increasing the number of providers.
- Make free transportation available to parents for their children and identify drivers who specialize in transporting children with special needs.
- Sponsor support groups for parents and caregivers, focusing on culturally specific support groups for BIPOC parents.

Summaries by topic

Below you will find summaries of all of the family and caregiver focus groups conducted during the stakeholder engagement process. They are organized by topic and stakeholder group. The topics include:

- EIDBI services: what families and caregivers appreciate
- EIDBI services: what families and caregivers want to improve
- Experience with EIDBI training and support
- Experience with coordination between EIDBI providers and schools
- Involvement in treatment planning

- Most important factors for selecting EIDBI providers
- Perspectives on licensing.

We conducted four focus groups with the following communities: BIPOC communities, Somali community, families and caregivers from all communities and families and caregivers who were participants in collaborative and advisory groups.

EIDBI services: what families and caregivers appreciate

Somali focus group responses

- Efforts to help children develop appropriate behaviors for participation in school, family and community life. Parents reported that EIDBI services promote social skills for children to make friends, develop verbal skills and advocate for themselves in school. Providers assist families in navigating behaviors that put children at risk while addressing behaviors that cause barriers to engagement in family and community life.
- "My son used to grab any stranger and they called the police on my son. The therapist has talked to the police, so they now know what is going on. The police are no longer noting it as a disturbance; they come and ask how they can help."
- EIDBI services provide respite for parents who care for high-needs children with autism.
- Culturally-specific providers who offer support and education that enable autistic children from marginalized communities to participate in their culture.
- "I first started with the white people for five years. They helped him a lot, but we don't have the same culture. For the last two years, my son has been going to Somali center. Because we now have a Somali provider, my son knows our tradition, our culture, our food."
- Somali families are grateful for providers who can work with their children using culturally specific approaches and best practices. DHS should train these providers and help them close gaps where they exist.

BIPOC focus group responses

- Individualized and intensive support services with a clear purpose.
- Regular family skills sessions, including giving parents progress updates and home visits to support them with skills training.
- Providing beneficial services that meet the child's needs (occupational therapy, speech therapy and behavioral interventions).
- Coordinated care meetings.

General focus group responses

- Providers expediting approval and confirming coverage of EIDBI services.
- “They were confident that we would be approved, which made us have confidence that we wouldn’t be receiving huge bills. Felt they did a great job of just taking care of things behind the scenes like billing, supporting us, making sure things were covered in the right way and doing things right.”
- Successful collaboration with providers to personalize treatment plans
- The ARC advocacy group and parental peers assisting in the completion of a confusing EIDBI application process.
- EIDBI providers who are patient and enjoy working with children with special needs.
- Providers ensuring the safety of children in caring environments.
- “They care about my kids…My kids are safe, cared for, getting the treatment they deserve to get the progress they need. I don’t expect more than that. Sadly, it's not always out there.”

Collaborative and advisory groups focus group responses

- EIDBI services providing structure and essential communication skills for children. EIDBI services help parents understand how their child's brain works, offer parenting techniques, identify resources and empower advocacy.
- "Catapulted us into knowing the possibilities that my son could have to be successful as a teen and adult."

EIDBI services: what families want to improve

Somali focus group responses

- Parents want increased attention on children's social skills that support family engagement.
- Parents want results. In some cases, progress is not necessarily obvious to parents and they may not have confidence that EIDBI services benefit their children. As a result, they discontinue service because they don’t believe their child is benefitting. Also, there are concerns about a lack of consistency in speech and occupational therapy (OT) services.
- Parents want a broader range of modalities.
- “State has chosen a very narrow view of what is included. More different modalities should be incorporated beyond ABA.”
- Parents want more services. Some parents can't find providers willing to provide services to their children. Many parents of adolescent children with high needs who use in-home services would prefer center-based services, but none are available.
- "Centers are designed for little kiddos. They get kicked out after age 8. This is a disservice. Seems like they are being pushed out before they get to adulthood."

- DHS needs to address worker shortages. Families experience the impact of staff turnover on EIDBI services. They have also faced barriers because of a lack of psychologists to do evaluations and not being able to receive care from doctors who understand autism.

BIPOC focus group responses

- "[A] high turnover rate really impacts our children. Casualties are our children. DHS need to look at why are they leaving these jobs in droves? What is frustrating them to leave?"
- "With inflation, DHS needs to take into account the retention of staff – is the reimbursement rate fair? Not enough Somali ABA-trained providers. Forced to pay a lot more for white providers."
- BIPOC caregivers want to improve long wait times for medical diagnosis – private therapy centers do not accept Medical Assistance.
- “While we waited for Frasier, I took the opportunity to apply for MA. I also tried to get private therapy, but they wouldn’t accept MA. I don’t understand why private therapy centers wouldn’t accept MA.”
- BIPOC caregivers want schools to provide more therapy than a few hours a month.
- BIPOC caregivers want more consistent staff. High staff turnover makes relationship-building hard for the child.

General focus group responses

- There are limited options in rural Minnesota, where parents need an increase in providers with extended hours. Few options mean parents struggle with limited services over the summer or accessing services during the workday. These limited options are especially difficult for working parents.
- Aging out of EIDBI services in rural communities at age 7 is an issue.
- Applying for EIDBI services is confusing and frustrating. Caregivers struggle to find and access the needed resources to navigate the process.
- “My husband is a lawyer and I did a ton of research for my father because he was disabled and we still had a hard time getting ahold of the right people to just ask them if we were going about things the right way, like with the long paperwork, or if we were answering it from the right perspective. We were really confused and frustrated.”
- There is difficulty understanding what EIDBI services are covered. Caregivers with MA and private insurance receive mixed messages, causing uncertainty about treatment coverage. They fear responsibility for exorbitant medical bills.

Collaborative and advisory groups focus group responses

- Many parents voiced their dissatisfaction with the collaboration and coordination between EIDBI services and schools. Parents reported that providers didn't train school staff to support their children as much as they would have liked, especially high-needs children.
- "The home district we were in (was) not interested in doing anything with EIDBI. We had to open enroll out of our own district. I felt the ABA staff didn't do as much training for public school staff as much as I thought. Planned too small a transition just one week or two and then went down to one while my kid was still trying to adjust to the new school. Transition could have been better."
- "We as parents have to figure it out on our own. It was only (from) private services we were able to get services. We were told in the school district they were only able to provide 30 minutes while our IEP was three hours a week. Seems like you're begging for the schools to do the process. Need more staff or programming for just kids' needs and their development. We are making so much effort in private to get services, but they don't communicate with each other. Schools say, 'We are not allowing ABA services in the schools.' There's no collaboration."
- There aren’t enough providers and wait lists are long. Parents worry about their children moving from full-time to part-time EIDBI services and would prefer that their children stay in EIDBI services for an extended period.
- Ethnic communities lack awareness of EIDBI services. Parents who don't receive referrals for services are unaware services exist or how they might benefit their children.

Concrete solutions

- Improve accessibility to services by increasing awareness of program availability, reducing service wait times, creating more centers and increasing the number of providers.
- Schools should provide more early intervention.
- Offer support groups for parents and caregivers, especially culturally specific support groups for parents/youth of color.
- Allocate more resources, such as parent education and training, to help parents understand their child’s developmental needs.

Experience with EIDBI training and support

Somali focus group responses

- EDIBI family training and support services are not accessed by a majority of the Somali families we talked with. Parents suggested an increased focus on these educational services, including the idea of an initial orientation where parents learn about their rights and responsibilities, the goal of EIDBI services and how they can evaluate the effectiveness of those services in meeting their needs.

- “When parents know what we need, we can advocate. Centers give you family supports. But when parents don’t know their rights, they don’t know what they lose.”
- Families want trainings that include siblings or anyone who lives in the household with a child with autism.
- It is not necessary for agencies providing care to also facilitate training, which culturally specific groups such as SPAN or Maangar could offer.
- Session goals are responsive and reflective of our needs (in-home visits, meetings over Zoom, practicing skills in the community and securing interpreters).
- “They are very responsive. My priority is safety, getting my daughter to stay with her guardian while out shopping. They even went with me to Target every other week to teach my daughter to stay with me while at Target.”

General focus group responses

Support consists of:

- Allowing caregivers to drop in and observe their child’s treatment.
- Mandatory weekly appointments with caregivers that include an hour of training.
- Trainings including other family members.
- Most training opportunities occur at an agency or center during the work day, which can be difficult for working parents. Families embraced training in parks where facilitators demonstrated strategies to help reduce behavior issues.
- “Going through a private organization, we can actually be there and they give us more tools on how to best support her. We really feel like they’re really trying to make our whole family feel included in the process and how to best support her.”
- Some caregivers feel that the providers' strategies and approaches are too strict and rigid.

Collaborative and advisory groups focus group responses

- The skills parents have developed empower them to confidently address issues with their children.
- The support families receive helps families avoid escalations when changes are implemented.

Concrete suggestions

- Collaboration should be the standard
- Offer more at-home training options.
- Expand training opportunities and resources to involve family members. Increase family support groups and community events. Caregivers want more opportunities to get support from other parents, bond with their children and build community with other autistic families.
- Offer more in-home training options.

- Provide more training opportunities and resources for family members' participation, such as siblings and grandparents.
- Offer more family support groups and community events. Caregivers want to connect with other parents, bond with their children and build community with other autistic families.
- More quality caregiver support groups.
- Work to improve communication between families and providers.
- Teach children adaptive skills to adapt to various environments and situations.
- Require parent training to enable parents to understand their rights and advocate for their children.

Experience with coordination between EIDBI providers and schools

Somali focus group responses

- Parents sense their child is supported and providers meet their child's needs. However, schools are often unwilling to collaborate with EIDBI services. EIDBI providers advocate for parents, which may extend to schools where they are unwelcome.
- "My kid was struggling with self-advocacy. Center wanted to help but they said, 'No, you cannot come to school.'"
- Parents want wrap-around care that integrates school and EIDBI services. Although parents receive referrals for services, profound silos and separation between EIDBI services and school transition programs do not effectively support children's adjustment to school settings. Navigating barriers between DHS and schools at a lower level is impractical. Parents need straightforward ways to access services for their children.
- "Evaluation clearly shows there is a need for services, but EIDBI is so separate. Feel like they are cutting up the child into pieces. Education over there. ABA over there."
- Parents have witnessed autistic children being at risk in school settings. Parents say students have left school or hidden for hours without school staff's knowledge.

General focus group responses

- The Help Me Grow program has given some caregivers a good experience with education coordination and has shown interest in and taken the initiative to work with applied behavior analysts.
- Open enrollment can help caregivers access larger schools that are more willing to collaborate with EIDBI services.

BIPOC focus group responses

- Parents are often responsible for coordinating services.
- "Right now, I have to be the one to coordinate these services. I just met with the school and the provider last week. I am making sure the goals of the IEP and learning goals are aligned. I wish they would coordinate more and not leave it for me to do."
- Covering the cost of private transportation during the school year would help reduce the stress associated with long wait times for some children.
- "Transportation is provided by MA and she doesn't qualify for private transportation. She has to wait for the school bus, but she doesn't like to wait for the school bus – her wait time is three (minutes) but she can't wait. She will just run off. She doesn't care for her safety. When she goes outside, she gets very stimulated and she is getting taller and stronger. I just don't have the stamina to run after her. Wait time is a challenge. Sometimes it takes the bus like 10 minutes to get here or 5 minutes and she can't wait that long. She just went off. I got stressed out. During the school year, I will try to wait with her, but if it doesn't work out, I'll be driving her to school. It would be nice if DHS provides transportation for us."
- Although the proximity of personal care attendants is not as close as BIPOC families want, they reported feeling less isolated when PCAs are available.

General focus group responses

- Many schools are unwilling to collaborate with EIDBI providers.
- "Our EIDBI providers know my children best. They've known them since they were 3. Please listen to them. They are supposed to come into the schools to help with a transition period, but schools don't want their support even though they don't have their own qualified staff. EIDBI providers can best support the kids AND the staff, train the staff that will be with them in a public school setting so they don't have to move onto a level 4 and can keep moving into a less restrictive environment."
- Caregivers worry that schools can't provide all the services their children need, which leads some to consider homeschooling**.**
- "We are afraid school won't be a super safe place for her. We are working on IEPs and these things are long. Not sure teachers will have time to read it."
- Rural communities receive limited school funding, especially for special education services.

Collaborative and advisory groups focus group responses

- Several parents reported service providers are not collaborating, reinforcing existing silos.
- "This is not just EIDBI and school issue. [There is] no collaboration, even among service providers. Everything is really siloed."

Concrete solutions

- DHS covers the costs of alternative transportation for families.
- Schools and providers bear more of the responsibility for coordinating service.
- In general, make information about education options available (e.g., suspend Minnesota Comprehensive Assessments (MCAs) testing if it is not beneficial to students).
- Begin intervention early.
- Establish collaboration as the standard for service providers, EIDBI and schools.
- Educate providers, parents and schools about all aspects of EIDBI services.

Parental involvement in treatment planning

BIPOC focus group responses

- Parents want providers to inquire about goals for their children's treatment plans, feedback, suggestions for strategies and access to resources.
- Parents want to review progress at regular meetings with the treatment team.

General focus group responses

- Parents appreciated involvement strategies and approaches, including:
    - Daily information about their children's day.
    - An app or online portal with digitized notes on the child's treatment plan and progress.
    - Six-month check-ins.
    - Reviewing bi-weekly data.
    - Opportunities for conversations with providers.
- Vague reports don’t help parents understand how their child is progressing. Detailed information is essential to parents’ involvement and understanding of their child’s care.

Collaborative and advisory groups focus group responses

- Parents want to be involved and have an understanding of what is happening. They also want treatment plans that address issues and support progress. Providers do a good job of making sure we understand and see progress in real-time. However, they could do a better job of explaining things so that everyone can understand. Parents don’t hear anything from schools and are not involved in the treatment plans.

Most important factors for selecting EIDBI providers

Somali focus group responses

- Center-based care where children can socialize and learn from their peers.
- Somali providers who speak their language and understand their culture.
- Nearby locations, so transportation is not a barrier.

BIPOC focus group responses

- BIPOC stakeholders said location, years of experience serving individuals with autism and related disorders, licensed/certified providers, service hours, center-based services and cultural background are all important qualities they look for when seeking EIDBI providers.
- Flexibility is also a priority, along with compassion, following up and genuinely wanting to help are essential qualities BIPOC families look for in EIDBI providers.
- Several commented the most important factor is intensive and comprehensive services that meet the needs of the child.
- "For me it doesn't matter if the provider doesn't speak my language, what matters is what the child I'm caring for stands to gain."
- "I also need a whole year of service, so that when she is not in school, she can still be in therapy."

General focus group responses

- Recommendations from reliable sources (e.g., medical professionals, peers)
- Providers who are adequately staffed and offer continuous services (e.g., board certified behavior analyst or registered behavior therapist).

Collaborative and advisory groups focus group responses

- The willingness of the provider to collaborate and communicate with parents on their child's progress, especially for parents of non-verbal children.
- Culturally responsive providers who are curious about what is important to parents.
- One size does not fit all. Meeting the unique needs and situations of the child reduces parental stress.
- Ratings, referrals and shared values are important to parents. However, long waiting lists and providers who do not accept private insurance mean it comes down to families choosing providers willing and available to provide services that meet their circumstances.

Family and caregiver perspectives on licensing

Numerous families and caregivers raised concerns regarding licensing. While high quality and safe monitoring for kids and some level of uniformity for providers is good, they shared the following concerns and questions:

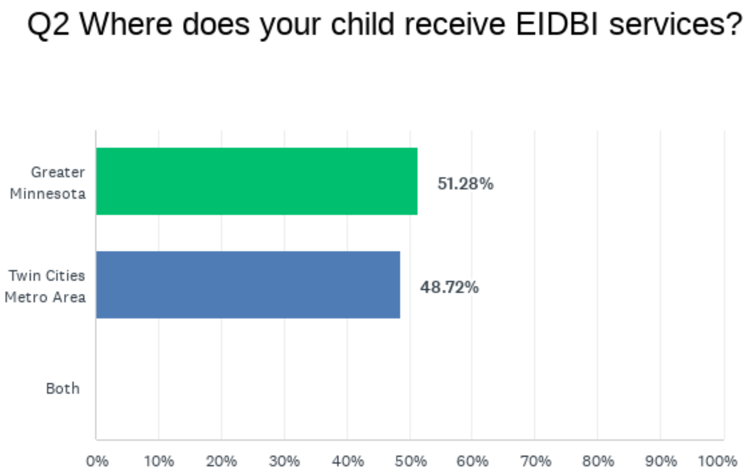
- Licensing can take a long time.
- Need to be really collaborative between providers, centers and DHS. Can providers be involved in what the licensing process looks like? Can providers have a way to inform future changes in regulations?
- When would inspectors come around to evaluate services?
- Inconsistent expectations from licensing office.

- People making the rules have zero experience as providers.
- This process interrupting quality services being provided.
- Paperwork becomes a barrier to providers.
- Will this come with accreditation or hours for staff training?

Survey responses

Below you will find a summary of the findings from the online family and caregiver survey conducted during the stakeholder engagement process.

Characteristics of survey respondents

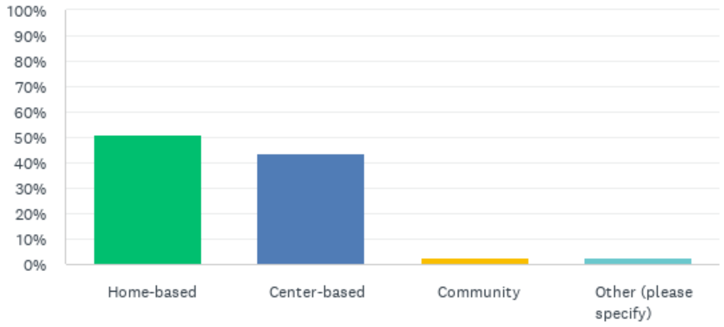


When respondents were asked where their children receive EIDBI services, they responded as follows:

- Greater Minnesota: 51.28% of respondents (20 out of 39).
- Twin Cities Metro Area: 48.72% of respondents (19 out of 39).

The total number of respondents who answered this question was 39, while 13 people skipped it. In summary, EIDBI services are relatively evenly distributed between Greater Minnesota and the Twin Cities metro area among the respondents.

Q3 What service setting does your child receive EIDBI services in?

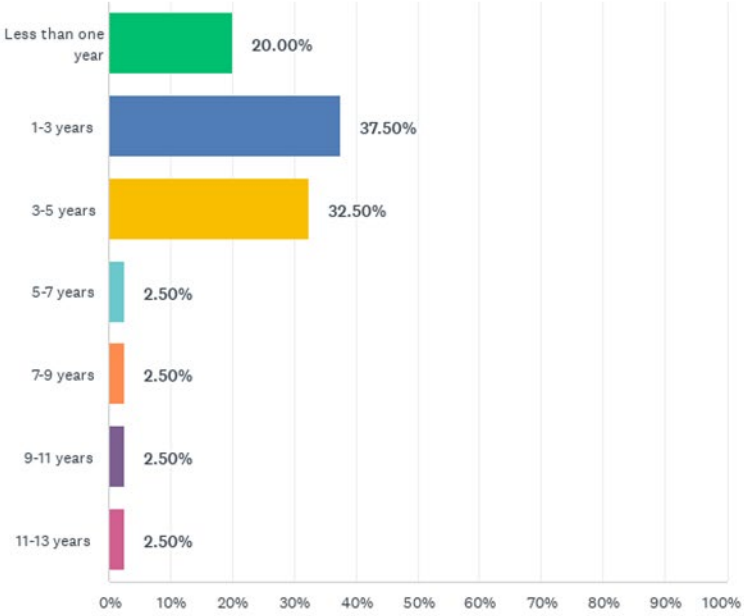


When respondents were asked what kind of service setting their children receive EIDBI services, they responded as follows:

- Home-based: 51.28% of respondents (20 out of 39).
- Center-based: 43.59% of respondents (17 out of 39).
- Community: 2.56% of respondents (1 out of 39).
- Other: 2.56% of respondents (1 out of 39) reported a different service setting not specified in the options.

The total number of respondents who answered this question was 39 respondents, while 13 respondents skipped the question. In summary, most children receive EIDBI services either at home or at a center, with very few receiving services in community settings or other unspecified locations.

Q4 How long has your child been receiving EIDBI services?

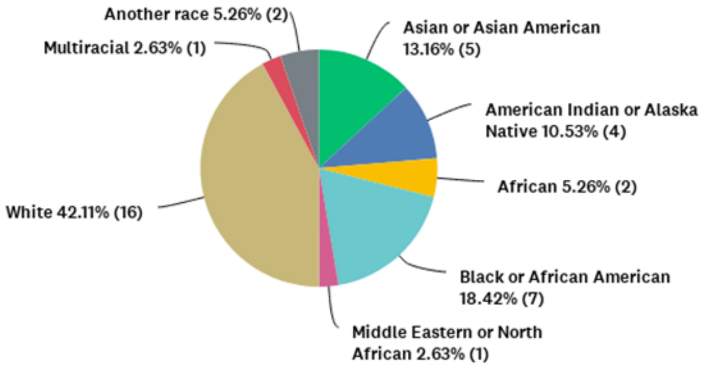


When respondents were asked how long children have been receiving EIDBI services, they responded as follows:

- Less than one year: 20% of respondents (8 out of 40).
- 1-3 years: 37.50% of respondents (15 out of 40).
- 3-5 years: 32.50% of respondents (13 out of 40).
- 5-7 years: 2.50% of respondents (1 out of 40).
- 7-9 years: 2.50% of respondents (1 out of 40).
- 9-11 years: 2.50% of respondents (1 out of 40).
- 11-13 years: 2.50% of respondents (1 out of 40).
- 13-15 years: 0% of respondents (0 out of 40).
- More than 15 years: 0% of respondents (0 out of 40).

The total number of respondents who answered this question was 40, while 12 respondents skipped the question. In summary, most children have been receiving EIDBI services for between 1 and 5 years, with a significant drop-off in the number of children receiving services for longer durations.

Q6 What is the ethnic identity of your child who is receiving EIDBI services?



When respondents were asked for the ethnic identity of the children receiving EIDBI services, they responded as follows:

- Asian or Asian American: 13.16% of respondents (5 out of 38).
- American Indian or Alaska Native: 10.53% of respondents (4 out of 38).
- African: 5.26% of respondents (2 out of 38).
- Black or African American: 18.42% of respondents (7 out of 38).
- Middle Eastern or North African: 2.63% of respondents (1 out of 38).
- White: 42.11% of respondents (16 out of 38).
- Multiracial: 2.63% of respondents (1 out of 38).
- Another race: 5.26% of respondents (2 out of 38) said that they were another race not listed.

The total number of people who answered this question was 38 respondents, while 14 skipped the question. In summary, the majority of respondents whose children receive EIDBI services are identified as White, followed by Black or African American and Asian or Asian American. Ethnicities such as Hispanic or Latino and Native Hawaiian or other Pacific Islander were not represented in the responses.

Survey responses

What have you appreciated most about the EIDBI service your child has received?

- Communication, behavioral and social and emotional.
- Person-centered care, targeted goals and individualized support.
- Skilled and caring staff who create safe and supportive spaces for autistic children.
- Significant improvement in their children.
- Improvement in the quality of life for autistic children and their families.
- Home-based services.
- Parent support and training.

- Providers who effectively coordinate with education services.
- Year-round support.

What would improve the experience you/your child have had receiving EIDBI services?

- Easier and faster access to services (more locations in rural areas, reduced waiting list, easier qualification).
- More experienced and trained providers.
- An increase in the age limit of who can access services.
- Updated technology and equipment.
- Improved collaboration between providers and schools.
- Better services. More specifically, clients want to receive the services intended for them, regular progress reports and communication from providers and scheduling consistency.
- Empowered families.

How well are participant rights protected in EIDBI services?

- More than 70 percent of caregivers (n=52) said that participants’ rights in EIDBI services are protected "very" to "extremely" well.
- What changes, if any, should be made to better support participants’ rights?
- Educating caregivers about their rights to manage treatment and ensure they know their child's treatment goals.
- Improving the consent practices with non-verbal children.
- Developing a comprehensive EIDBI guide that outlines services and their purpose.
- Improving providers' communication with the family and requiring them to involve families in the treatment plan.
- Improving accessibility, such as making ASL interpreters available to support the participation of the deaf and non-verbal.
- Not requiring caregivers to produce personal information.
- More intensive sessions.
- Making technology and pricing changes.

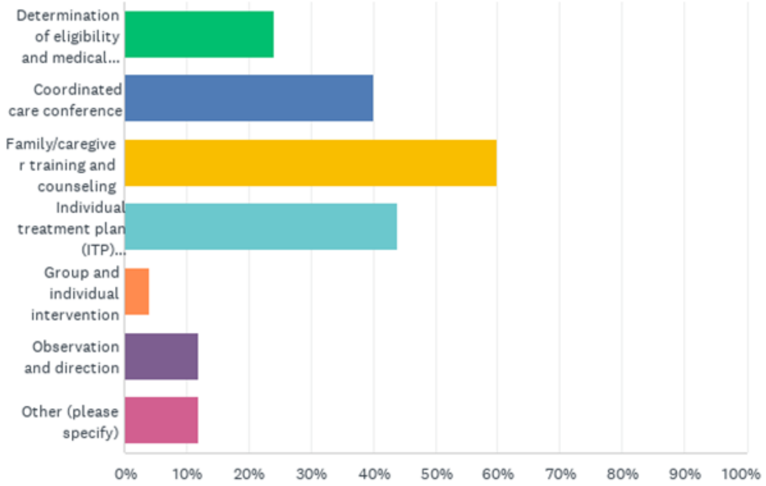
Describe your experience with EIDBI services and educational supports working together

- Homeschooling allows families to receive therapies for more than a few hours daily.
- Schools and EIDBI providers are disconnected and alignment between them is difficult.
- School staff are not prepared to support and integrate children with autism into a typical classroom.
- Schools are highly resistant to outside providers.
- It’s the parents’ responsibility to bridge schools and EIDBI providers.
- Families need a larger team of providers.
- Resistant schools need to change.

How well did receiving EIDBI services via telehealth work for you/your child?

More than 72 percent of respondents (n=52) said receiving EIDBI services via telehealth is "good" or "acceptable."

Q19 Which of the following EIDBI services would you/your child like to be able to receive via telehealth?



When respondents were asked for the type of EIDBI services they would like to receive via telehealth, they responded as follows:

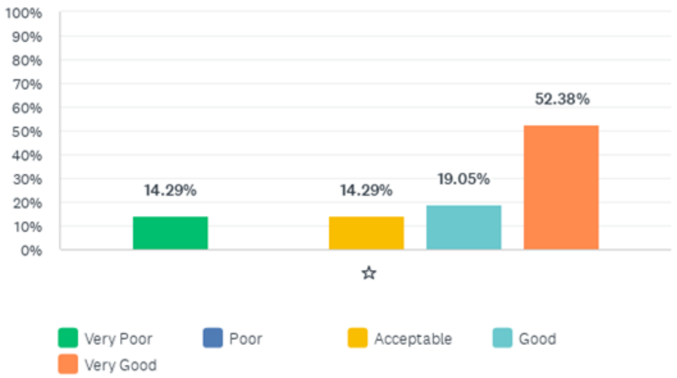
- Determination of eligibility and medical need for EIDBI services (comprehensive multidisciplinary evaluation): 24% of respondents (6 out of 25).
- Coordinated care conference: 40% of respondents (10 out of 25).
- Family/caregiver training and counseling: 60% of respondents (15 out of 25).
- Individual treatment plan (ITP) development and progress monitoring: 44% of respondents (11 out of 25).
- Group and individual intervention: 4% of respondents (1 out of 25).
- Observation and direction: 12% of respondents (3 out of 25).
- Other (please specify): 12% of respondents (3 out of 25) listed other services not specified which they would like to see offered via telehealth.

The total number of people who answered this question was 25 respondents, while 27 skipped the question. The highest interest in telehealth services is for family/caregiver training and counseling, followed by Individual treatment plan development and progress monitoring. Coordinated care conferences also have notable interest. There is less interest in telehealth for group and individual interventions, as well as observation and direction.

Describe your experience including additional providers in treatment planning

- EIDBI and medical providers were willing to work with others.
- Increased expertise.
- Demand for the inclusion of additional providers.
- Collaboration lacking between providers and schools.

Q20 Does the training and counseling you have received as a family through your EIDBI provider meet your needs and preferences?

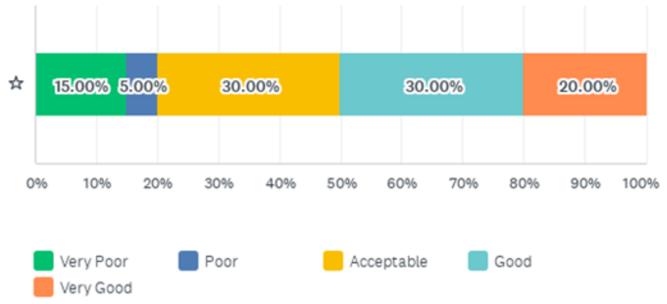


When respondents were asked whether the training and counseling received as a family through EIDBI providers met their needs and preferences, they responded as follows:

- Very poor: 3 respondents (14.29%).
- Poor: 0 respondents (0%).
- Acceptable: 3 respondents (14.29%).
- Good: 4 respondents (19.05%).
- Very good: 11 respondents (52.38%).
- Not applicable: 2 respondents selected "Not applicable," indicating that this question did not apply to their situation.

The total number of people who answered this question was 21, while 31 skipped the question. The overall sentiment about the training and counseling provided through EIDBI is quite positive, with a weighted average rating of 3.95, which is close to "very good." The majority of respondents rated the training and counseling positively, with over half rating it as "very good." Only a small fraction found the training and counseling to be "very poor" or "acceptable," suggesting a general satisfaction with the services.

Q15 How well have EIDBI service providers and educational staff worked together to support your child?

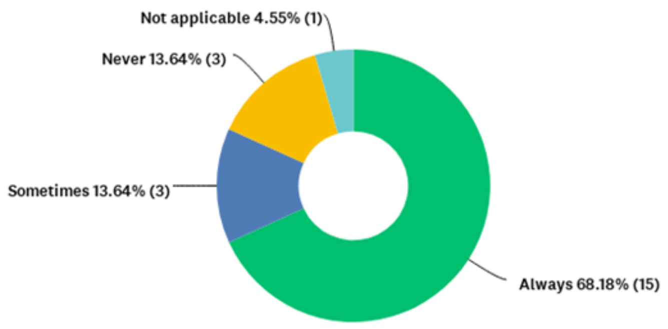


When respondents were asked how well EIDBI service providers and educational staff have worked together to support a child, they responded as follows:

- Very poor: 3 respondents (15%).
- Poor: 1 respondent (5%).
- Acceptable: 6 respondents (30%).
- Good: 6 respondents (30%).
- Very good: 4 respondents (20%).

The total number of people who answered this question was 20 respondents, while 32 skipped the question. The responses indicate a range of opinions about the collaboration between EIDBI service providers and educational staff. The average rating of 3.35 suggests that, on average, respondents view the collaboration as somewhat above "acceptable," leaning toward "good." However, there is notable variability in the responses, with some respondents rating the collaboration as "very poor" and others as "very good."

Q22 As a parent/caregiver, have you been able to participate in or observe EIDBI services provided to your child upon request?



When respondents were asked if they have participated or observed EIDBI services provided to their child, they responded as follows:

- Always: 68.18% of respondents (15 out of 22).
- Sometimes: 13.64% of respondents (3 out of 22).
- Never: 13.64% of respondents (3 out of 22).
- Not applicable: 4.55% of respondents (1 out of 22).

The total number of people who answered this question was 22 respondents, while 30 skipped the question. The majority of parents and caregivers (68.18%) have consistently been able to participate in or observe EIDBI services when they requested to do so. However, there is a small portion of respondents who have either been unable to do so at all or only sometimes. This suggests that while participation and observation are generally accessible, there is some variability in the extent to which parents and caregivers can be involved.

How would you as a parent like to be involved in reviewing the progress your child is making on their treatment plan?

- Regular progress updates where caregivers can learn about effective treatments.
- Regular interactions with staff (weekly meetings, regular phone calls, ad hoc meetings as needed).
- Opportunities to observe sessions in person or via video recording, which are helpful for caregivers of nonverbal children.

How should parents participate in rating provider quality?

- Providing opportunities for parents to give anonymous feedback (state survey, provider ranking or ratings).
- An annual review with supervisors is sufficient.

Could any changes be made to improve the health and safety of the environment in which you/your child receive EIDBI services?

- Ensuring providers have experience working with EIDBI children.
- Delivering services in a space that is secure, safe and spacious.

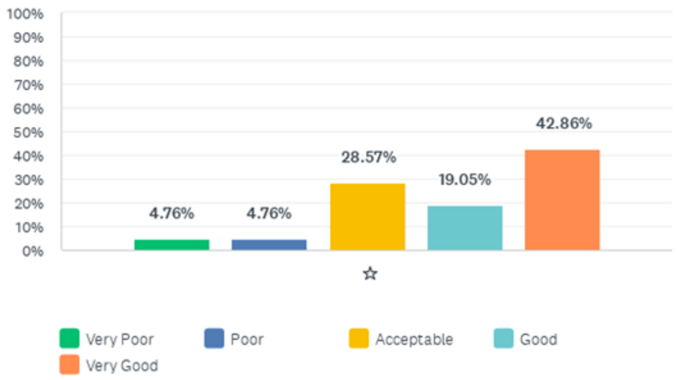
How person-centered are EIDBI services currently?

- Ninety-two percent of caregivers said that person-centered EIDBI services are currently "very good" or "good."

What changes would make EIDBI services more person-centered?

- Overall, caregivers said EIDBI services are person-centered. However, some parents felt a person-centered approach didn’t produce progress and caused various challenges.
- Caregivers suggest more emphasis on meeting children’s needs, such as building skills, personal preferences and progress, rather than making the child appear “typical.”

Q26 How culturally and linguistically competent* are EIDBI services currently?*Culturally and linguistically competent means “the person’s and family’s spoken language and culture, values, goals, and preferences must be reflected throughout the covered services. [Providers] must determine how to adapt the evaluation, treatment recommendations, and individual treatment plan to the person’s and family’s culture, values, and language preferences.”

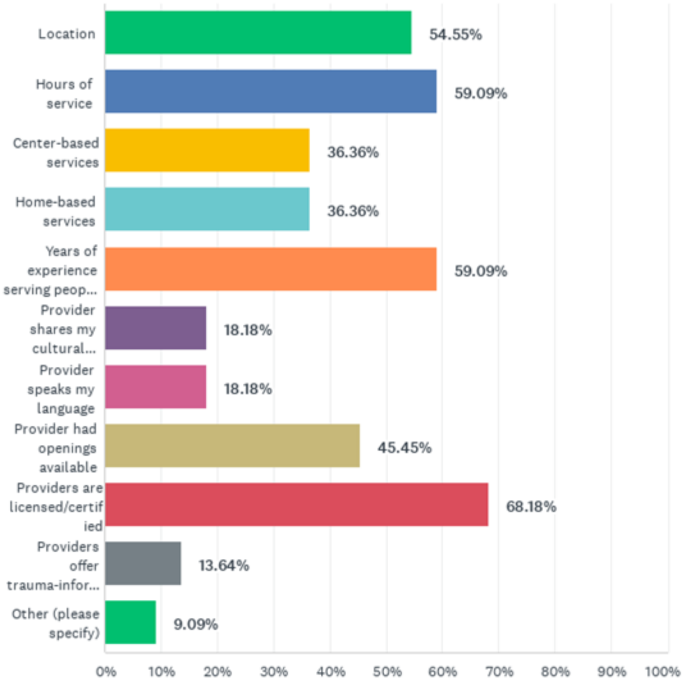


When respondents were asked about the cultural and linguistic competence of EIDBI services, they responded as follows:

- Very poor: 1 respondent.
- Poor: 1 respondent.
- Acceptable: 6 respondents.
- Good: 4 respondents.
- Very good: 9 respondents.

The total number of people who answered this question was 21, while 31 skipped the question. The majority of respondents rated the cultural and linguistic competence of EIDBI services as "very good" or "acceptable." Fewer respondents rated the competence as "good" or in the lower categories of "very poor" and "poor." The weighted average of 3.9 indicates a generally positive assessment of cultural and linguistic competence, leaning slightly towards "good" on the scale. The data suggests that while there is a recognition of good performance in cultural and linguistic competence, there is still room for improvement in fully meeting the cultural and language needs of families served by EIDBI services.

Q29 When you were looking for an EIDBI service provider, what factors were most important to you?



When respondents were asked about the factors that were most important to them when choosing an EIDBI service provider, they responded as follows:

- Location: 54.55% (12 respondents).
- Hours of service: 59.09% (13 respondents).
- Center-based services: 36.36% (8 respondents).
- Home-based services: 36.36% (8 respondents).
- Years of experience serving people with autism and related conditions: 59.09% (13 respondents).
- Provider shares my cultural background: 18.18% (4 respondents).
- Provider speaks my language: 18.18% (4 respondents).
- Provider had openings available: 45.45% (10 respondents).
- Providers are licensed/certified: 68.18% (15 respondents).
- Providers offer trauma-informed care: 13.64% (3 respondents).
- Other: 9.09% (2 respondents) mentioned other unspecified factors.

The total number of people who answered this question was 22 respondents, while 30 skipped the question. The factors most commonly identified as important were being licensed or certified (68.18%), hours of service (59.09%) and experience serving people with autism and related conditions

(59.09%). Factors such as offering trauma-informed care (13.64%) and sharing a cultural background or language (18.18%) were considered less critical. The data shows that while practical considerations like licensing, service hours and experience are key factors in choosing an EIDBI service provider, aspects related to cultural and language alignment are less emphasized.

What have you appreciated the most about the people who have provided EIDBI services to you/your child?

- Compassion and empathy.
- Person-centered staff who take time to understand families' needs, concerns and cultural beliefs essential to personalized care.
- Genuine interest in working with autistic kids and their families.
- Dedication and going the extra mile to be helpful.
- Transparency, openness and flexibility.
- Family and caregivers training and counseling.
- Creating safe environments.
- Location convenience.
- Proving services year-round.

VI. Appendix

Glossary

- ABA – Applied behavioral analysis
- ADA – Autism developmental assessment
- ASD – Autism spectrum disorder
- BCBA – Board-certified behavior analyst
- CBT – Cognitive behavioral therapy
- CMDE – Comprehensive multidisciplinary evaluation
- COE – Code of ethics
- DBT – Dialectical behavior therapy
- IOA – Interobserver agreement
- ITP – Individual treatment plan
- LPCC – Licensed professional clinical counselor
- MCA – Minnesota Comprehensive Assessments
- OT – Occupational therapy
- PCA – Personal care attendant
- QSP – Qualified supervising professionals
- RBT – Registered behavior technician.