

Accessing Services and Increasing Advocacy for Relative/Kin Caregivers Raising Native Children With Disabilities

Purpose: The National Indian Child Welfare Association (NICWA) created this resource as a supportive tool—grounded in respect, culture, advocacy, and relationship building—to help families, particularly relatives and kin who are raising Native children with disabilities. It provides guidance to help caregivers access services and advocate for the Native children they are raising.

If you are reading this toolkit, thank you for taking on the profound responsibility of raising a relative child with disabilities. Many Tribal Nations have beliefs about children/individuals with disabilities and see them as sacred.

Note: This resource uses “relative/kin caregiver” and “relative child” to refer to adults and children, respectively, who are connected to each other by kinship bonds, whether as extended family members or close friends. Throughout the toolkit, “child” and “children” refer to Native children being raised by a relative/kin caregiver. “Native” means American Indian and Alaska Native.

Description: Tribal Nations offer varying levels of support to their children and families—ranging from comprehensive services to more modest services supplemented by state, county, or private agency services; this resource is not exhaustive. The information and examples provided may vary based on geographic location, staff and resource capacity, eligibility requirements, and community-specific considerations.

Caregivers may not always know what services to request or what services their relative child might be eligible for, so this resource offers a place to begin. By collaborating with various service providers, relative/kin caregivers can effectively advocate for essential services and resources that promote positive outcomes for their relative children with disabilities.

How to use the toolkit: This toolkit begins by offering broad guidance on supporting children with disabilities, emphasizing the importance of culture as integral to care, strategies for working with service providers, and understanding service eligibility. It then moves into specific service areas that may be helpful for meeting your relative child’s needs—including child welfare, financial assistance, health, education, and more. **Each item in the table of contents below is linked, allowing you to jump directly to any section of the toolkit with a single click.**

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Getting Started: Tips for Raising Native Children With Disabilities

Supporting Native Children With Disabilities

- ▶ **Lead with understanding.** You and your relative child may both be navigating big changes. Give yourself permission to learn as you go.
- ▶ **Honor your family's story.** Your caregiving journey is shaped by history, relationships, and circumstances that outsiders may not see. Trust that you know your family best.
- ▶ **Celebrate the child's strengths.** Every child possesses distinct talents, interests, and ways of communicating. Focusing on these unique strengths and joys helps create a more supportive environment for growth.
- ▶ **Remember that a diagnosis is not the whole child.** It helps explain needs, but it does not define who they are or what they can become. Engaging children directly in service planning creates natural opportunities for them to voice their own needs—ensuring their personal preferences and goals guide their care.
- ▶ **Honor the child's pace.** Some children may not follow “typical” developmental timelines, but they grow and learn in their own way and in their own time. You can adjust, learn, and grow together.
- ▶ **Access community resources.** Building a strong network through schools, community programs, medical providers, or trusted family, friends, and community healers provides valuable support. Navigating these resources is a collaborative process that strengthens your care system.

- ▶ **Take care of yourself, too.** Caregiving is meaningful and demanding. Rest, connection, and small moments of joy can help you stay steady for the child.
- ▶ **Build your support system.** Lean on family, friends, other caregivers, mentors, school or workforce connections, community programs, and support groups. Navigating multiple systems can be exhausting, especially for families raising a child with disabilities. You don't have to do this alone.
- ▶ **Document everything.** Keep records, notes, reports, and paperwork organized. You may need the documentation later for services, benefits, legal, or school support.

Making Culture a Core Part of Caregiving

- ▶ **Culture is medicine.** Explore ways to adapt cultural practices for the child's needs.
- ▶ **Use storytelling to support learning and transitions.** Stories can help children, especially those with disabilities or sensory processing differences, prepare for what's coming next and feel more grounded throughout the day. Storytelling is also a powerful way to teach and pass on values.
- ▶ **Incorporate songs when helpful.** Music can make explanations easier to process and can soothe children who become overwhelmed by sensory input.
- ▶ **Seek guidance from elders and trusted community members.** They can offer cultural approaches for including children with disabilities in daily life, ceremonies, and community activities.
- ▶ **Use spiritual and cultural practices for comfort and healing.** Ceremonies, prayer, and traditional healing can provide emotional regulation, connection, and strength for both the child and the family.
- ▶ **Adapt tools to the child's individual needs.** Some children may need quieter spaces, visual support, or sensory-friendly adjustments. Children who use medical support devices—such as wheelchairs, feeding tubes, oxygen, or communication devices—may also need extra space, time, or modifications so they can participate comfortably and safely.

Sharing Key Information With Service Providers to Strengthen Support

- ▶ **Describe what helps your relative child thrive.** Tell service providers (school staff, physicians, therapists, child/respite care providers, etc.) what brings your

relative child joy, what motivates them, how they communicate, and what helps them feel safe. A simple, one-page summary of their favorite activities, stories, games, dislikes, and how to navigate specific behaviors can ensure care is designed around your relative child's identity. This can help service providers promote engagement and foster a sense of safety.

- ▶ **Share what has worked—and what hasn't.** If certain services, approaches, or communication styles have been helpful, say so. If something caused stress or harm in the past, it's important for service providers to know that, too.
- ▶ **Be open about the support you need.** Raising a child with disabilities can be demanding. Service providers can support you best when they understand the full picture—they rely on your voice.
- ▶ **Talk through approaches that support safe and meaningful contact with parents.** When safe and appropriate, helping the child stay connected to their parents can strengthen their sense of identity and belonging. Keeping contact predictable, supported, and centered on the child's needs can help the parent-child relationship grow in healthy ways over time. Ask service providers about ways you can support parent-child relationships. This can include communicating the same needs mentioned above with the parents, so they can mirror supportive techniques within the home environment. Consistent communication regarding the child's preferences and motivators helps create a predictable, unified care system.

Understanding Eligibility for Services as a Relative/Kin Caregiver

- ▶ **Eligibility depends on the program, the child's Tribal affiliation, and where you live.** Some services are available only to Tribal members, including those who live off Tribal lands. Others are based on residence or serve Native people more broadly. Because requirements vary, ask each program what your relative child qualifies for.
- ▶ **On Reservation and Tribal lands, Tribes design and operate programs for children and families.** Available services vary by staffing and resources and may include social services, Tribal Temporary Assistance for Needy Families (TANF), food, housing, child care, health care, and other **supportive services**.
- ▶ Tribal governments and organizations can help members apply for **state and federal benefits** and navigate service systems.

- ▶ Native children and families may also qualify for **state or county resources**, whether they live on or off Tribal lands.
- ▶ If a Tribe does not operate a **developmental disabilities program**, it may help families connect with state, county, or community providers.
- ▶ **Urban Native organizations and centers** may offer health and other services. Some Tribes also operate offices in urban areas with large Tribal member populations.
- ▶ Families in rural areas or places with fewer Native-specific resources may need to explore flexible options. Ask the child's Tribe about virtual cultural resources, such as videos, books, art, music, storytelling, and interactive activities. Other caregivers, families, and local experts may also help you navigate available support.

Child Welfare

Indian Child Welfare Act

The Indian Child Welfare Act (ICWA) is a federal law that protects the rights of Native children, families, and Tribal Nations when a Native child is involved in a state child custody case. It helps keep Native children connected to their family, Tribal community, and culture, and ensures Tribes can exercise their right to be involved in decision-making that impacts their children and families.

Action Steps

- ▶ If you are raising a Native child who is involved in a state child welfare case (foster care, guardianship, termination of parental rights, or adoption), contact the Tribe's ICWA office or [ICWA-designated agent](#) right away. Ask about available Tribal services, disability supports, and how the Tribe can be involved in the case to support you, the child, and the whole family.
- ▶ For additional support, check out this resource on [How Relative Caregivers Can Advocate for Relative Native Children in State Child Welfare Agency Custody](#).

Guiding Questions

- ▶ As the child's relative/kin caregiver, how can I be involved in supporting their connections to family, culture, and community?

- ▶ What connections can you help us make—with programs, disability services, or ICWA-informed community partners—to strengthen our support network and help us access the services we are eligible for?
- ▶ Am I able to get respite care for the child I am raising?
- ▶ Are we able to get financial assistance to help support the child I am raising? How does financial assistance work? Do you need anything from me to help expedite the process?

Tribal Child Welfare

Tribal child welfare programs focus on keeping Native children connected to family, culture, and community while keeping children safe. Some offer prevention services to help families stay together and may be able to provide more culturally grounded support than non-Tribal systems. Many families may be unsure or afraid to reach out to Tribal or state child welfare agencies for support, but Tribal child welfare programs can be a valuable resource. Tribes may offer kinship navigator programs or related programs that help relatives understand available services, financial support, and how to navigate systems.

Action Step

Contact your relative child's Tribal child welfare or social services office to ask what support is available for you as a relative/kin caregiver, especially prevention services, kinship navigator programs, and help accessing resources to keep the child safely with family.

Guiding Questions

- ▶ What services are available for caregivers raising relative children, including programs focused on the needs of children with disabilities?
- ▶ Am I able to get respite care for the child I am raising?
- ▶ Are we able to get financial assistance to help support the child I am raising? How does financial assistance work? Do you need anything from me to help expedite the process?

Wraparound Services

Wraparound services help families create a coordinated plan of care that supports the child's emotional, cultural, educational, and disability-related needs. For children in foster care, relatives can request a family team meeting and ask for all service

providers—such as disability specialists, therapists, school staff, medical providers, community healers, and supportive extended family—to be included. Wraparound services are also available to children who are not involved in the child welfare system, and can be provided by local disability organizations, school resource centers, and community agencies. Coming prepared with what the child needs helps the team build the right plan.

States and Tribes are responsible for offering services that help prevent out-of-home placement and support children with disabilities. Guardian ad Litem (GAL) and Court Appointed Special Advocate (CASA) programs may also help ensure the child's needs are understood in court.

Action Steps

- ▶ Ask your Tribal or state child welfare worker to schedule a wraparound or family team meeting and request that disability-related providers—such as medical specialists, school special education staff, behavioral health providers, cultural healers, and community advocates—be invited so the child's full needs are met.
- ▶ For more guidance, take a look at one of our tip sheets, [How Relative/Kin Caregivers Can Access Services and Advocate for Native Children in Their Care](#).

Guiding Questions

- ▶ How does this meeting fit into the overall case plan and timeline?
- ▶ How are parents, including incarcerated parents, accommodated?
- ▶ How are confidentiality and privacy protected during the meeting?
- ▶ Can you walk me through what services or supports you can put in place to address my relative child's specific disability-related needs, and what the next steps are to activate them?

Prenatal Substance Exposure

Leading health and research organizations estimate that roughly [15%](#) of infants born annually in the United States have been prenatally exposed to alcohol, illicit drugs, or both. Many parents involved with the child welfare system face [substance use](#) challenges, which means children placed with relative/kin caregivers may have a history of prenatal exposure. Prenatal substance exposure has long-lasting effects on children and often goes undiagnosed. Understanding this connection can help relative/kin

caregivers better identify the root of a child's unique behavioral and developmental needs.

Action Steps

- ▶ Generations United has created a series of tip sheets for [families impacted by opioids and other substance use](#).
- ▶ The Grandfamilies & Kinship Support Network and its partners at ZERO TO THREE published a resource on [Caring for a Child Affected by Fetal Alcohol Spectrum Disorder](#).
- ▶ Creating a Family offers a free, three-session online [Prenatal Substance Exposure Workshop for Foster, Adoptive, and Kinship Parents](#).

Guiding Questions

- ▶ What is the **developmental age** of the child I am raising? What can I reasonably expect for my relative child's developmental age?
- ▶ What are some suggestions for how I need to parent a child with prenatal substance exposure?
- ▶ What programs or services are available to support my relative child? Does the child's school system have programs in place?

Financial Assistance

Tribal Temporary Assistance for Needy Families Programs

Tribal Temporary Assistance for Needy Families (TANF) can help with financial support for children, **even when relative/kin caregivers have income**. Many Tribes run their own Tribal TANF programs, which can offer cash assistance, child care assistance, job training, and support overcoming barriers like housing and transportation. Tribal programs often include culturally grounded activities that strengthen Native families.

Action Steps

- ▶ Use this [map](#) to find state and Tribal TANF programs.
- ▶ Check your state's social services site or search directly for your relative child's Tribal social services department to ask about what benefits the child may qualify for and how to apply as a relative/kin caregiver.

- ▶ If you reside outside a specific Tribal TANF service area or the child's Tribe does not operate its own program, explore [Temporary Assistance for Needy Families: Help for Kin Caregivers](#).

Guiding Questions

- ▶ What are the eligibility requirements for my relative child, and what documentation do you need from me as a relative/kin caregiver to access Tribal TANF services?
- ▶ If eligible, what steps should I take to access and utilize the education, cultural, or family support services that Tribal TANF offers, and how do I stay connected to keep these supports readily available to the child?

Social Security Benefits

People with disabilities may qualify for monthly payments through Supplemental Security Income (SSI) if they meet income, resource, and medical criteria. The criteria include children under 18 if they have a medically determinable physical or mental impairment resulting in "marked and severe functional limitations" lasting at least 12 months or expected to result in death. There are also family benefits available if you are the spouse, ex-spouse, or child of someone receiving Social Security disability.

Action Steps

- ▶ Contact your local Social Security office to ask what documentation you will need or learn more online about the [SSI application process and applicant rights](#).
- ▶ It may also help to talk with the child's doctor, school, or a benefits advocate to gather medical and educational records that support the application.
- ▶ If the child is placed with you through the child welfare system, ask the child's caseworker whether an SSI application has already been started, who is responsible for applying, and how the benefit will be managed. In many cases, the caregiver, Tribe, or state may need to coordinate the application, and knowing this early helps ensure the child receives the support they are eligible for.
- ▶ Many Tribes also have offices to help Tribal citizens apply for SSI, such as social services and Tribal health clinics.
- ▶ You can start an SSI application online [here](#).

Below is a streamlined set of steps to guide you through the process.

1. **Check eligibility.** Begin by confirming that the child's disability meets SSI criteria and that the household's income and resources fall within program limits.
2. **Gather documents.** Collect medical records, school evaluations, therapy notes, and any paperwork showing that the child lives with you and you are a relative/kin caregiver.
3. **Start the application.** Call the Social Security Administration (SSA) to begin the SSI application process and, if possible, start the Child Disability Report online.
4. **Complete the disability report.** Describe how the child's condition affects daily functioning and list all doctors, therapists, and school contacts involved in their care.
5. **Respond to SSA requests.** Return forms promptly and make sure the child attends any exam scheduled by Social Security that could help determine eligibility.
6. **Review the decision.** Look over the approval or denial notice carefully and consider appealing, if the claim is denied, within 60 days of receiving the notice.

Guiding Questions

- ▶ What are the eligibility requirements for the child to receive SSI or other Social Security benefits, and what documentation do you need from me as a relative/kin caregiver to help with the application or review process?
- ▶ If my relative child is eligible, what steps should I take to help access, manage, or maintain their Social Security benefits, and how can I stay informed about required updates or reviews?
- ▶ I am a foster parent receiving foster care payments. Will these payments impact my relative child's SSI benefits?

Legal Assistance

Caregivers of children with disabilities often require legal assistance because their caregiving responsibilities depend on having formal decision-making authority.

- ▶ Relatives raising Native children without child welfare involvement frequently begin caregiving without legal paperwork but later need temporary guardianship

or custody to manage school enrollment, medical consent, and access to disability-related services or benefits.

- ▶ When children enter care through the child welfare system, relative/kin caregivers must understand their rights as placement options, the process of becoming a licensed or approved kinship home, how to obtain financial support, and how to engage in case planning and court proceedings to advocate for the child's needs.

In both pathways, the link is clear: **legal authority may be necessary to ensure caregivers can effectively advocate on behalf of a child with disabilities**, securing access to education, health care, and services.

As children with disabilities reach adulthood, specialized legal planning becomes essential to secure their future and protect their well-being. This could involve establishing adult guardianship or alternatives when they turn 18, alongside creating trusts and designating successor caregivers to ensure seamless care and financial security if the primary caregiver passes away.

Action Steps

Reach out to the child's caseworker, Tribal child welfare office, or a legal aid organization to learn what legal options and rights apply to your situation and what steps you may need to take to secure the authority to raise the child.

- ▶ If your relative child is involved in a state child welfare system, see our resource on [Legal Assistance for Native Kinship/Grandfamilies Involved with Child Welfare](#).
- ▶ In Tribal court proceedings, ask the Tribe's legal department for support. Sometimes legal aid programs will provide legal assistance in Tribal courts free of charge, and they may be able to practice in Tribal courts. You can also ask the court clerk for a list of attorneys barred to practice family law in Tribal court.

Guiding Question

Are there legal support services available that can help ensure my relative child has access to all the educational, medical, and benefit-related support they need?

Housing

Children with disabilities may require ramps or stair-free entry, wider doorways, grab bars or bathroom modifications, space for medical equipment, a bedroom on the main floor, sensory-friendly spaces, or other home modifications necessary for safety.

Housing stability is central to preventing disruptions to routines that children with disabilities often rely on—including schooling, therapies, medical care, and access to services. Caregivers often need support navigating housing vouchers, home modification grants, SSI-related housing supports, Medicaid waiver programs, and local disability housing resources.

Action Steps

- ▶ Contact your Tribal or local housing authority, urban Native organization, or a statewide resource line like 211 to find support.
- ▶ If the child is placed with you through the foster care system, the state or Tribe may also be able to provide support and guidance.

Guiding Questions

- ▶ What is the child eligible for in terms of housing or disability-related programs—like vouchers, home modification grants, SSI supports, or Medicaid waiver housing benefits—and what do you need from me to apply?
- ▶ What steps should I take to request disability-related accommodations or keep our housing support active as the child's needs change?

Transportation

Transportation support is often essential to ensuring that children with disabilities can attend school and medical appointments, and that caregivers can go to work, pick up groceries, attend group activities, and travel to visits or appointments. Some Tribes offer their own transit services or partner with public transit. Services may include a daily bus route, scheduled transportation to medical appointments, or scheduled transit to activities located in surrounding counties. Tribal members often ride free by showing a Tribal ID. Indian Health Service Community Health Representative programs can also provide transportation to ensure patients make their medical appointments—acting as a transport of last resort in many Tribal communities.

Action Steps

- ▶ Contact the Tribe's transit program or contact other programs—social services, health, elders, employment, education, culture—to ask for assistance identifying local transportation options.
- ▶ If a child welfare agency is involved, contact the child's caseworker for supportive services.

- ▶ Connect with local service agencies, or contact public transportation to learn more about eligibility, scheduling, and available ride programs.
- ▶ You can contact your relative child's school district directly to request specialized transportation services. Obtaining this service usually requires the child to have an Individualized Education Program (IEP)/504 plan (discussed more on [page 19](#), below) that documents the service as a necessary accommodation.
- ▶ You can also explore eligibility for Medicaid transportation and check the availability of school district supports, nonprofit ride services, or mileage reimbursement programs.

Guiding Question

What is the process for requesting accommodation or specialized transit to school, appointments, and activities?

Health

Indian Health Clinics

Indian Health Clinics—run by the Indian Health Service (IHS), Tribes, and urban Indian health programs—provide physical, mental, social, and spiritual health care to Native families. Many offer developmental screenings to help connect to specialists, care coordination, and culturally grounded support for children with disabilities. Clinics often host community events and partner with other programs to expand services for families.

Action Step

Contact your local Tribal or [Indian Health clinic](#) to ask about developmental screenings, care coordination, and disability-related supports available for your relative child.

Guiding Questions

- ▶ What is the child eligible for in terms of IHS services or programs, and what documentation do you need from me as their relative/kin caregiver to help them access care?
- ▶ What steps should I take to request specialty care, referrals, or continued support through IHS (if the child has disability-related or ongoing medical needs)?

Medicaid and the Children's Health Insurance Program

Relatives raising Native children with disabilities may be responsible for helping a child access health care coverage. Many IHS and Tribal health clinics have staff or benefits

coordinators who can help you fill out Medicaid forms, gather documents, and understand what the child may qualify for. You can also apply directly through your state's online portal or by visiting your local Medicaid office.

Additionally, the Children's Health Insurance Program (CHIP) offers low-cost health coverage for children whose families earn too much to qualify for Medicaid. Every state runs a CHIP program connected to Medicaid. You can apply by calling 1-800-318-2596 (TTY: 1-855-889-4325), or you can [apply online](#).

In many states, children automatically qualify for Medicaid upon entering foster care, and the state assumes responsibility for ensuring their health care needs are met. Coverage typically begins when the child enters foster care and continues throughout their time in care, ensuring uninterrupted access to physical, mental, and behavioral health services.

Action Steps

- ▶ Contact your Tribal or IHS clinic and ask to speak with a benefits coordinator. Let them know that you are a relative/kin caregiver and need help applying for Medicaid or CHIP and understanding what services the child may qualify for.
- ▶ You can also explore [Medicaid and CHIP for American Indians and Alaska Natives](#) or check out this [booklet](#) that shares about other benefits, such as SSI payments for children with disabilities, employment support programs for young people with disabilities, and more.

Guiding Questions

- ▶ What Medicaid or CHIP services, including disability-related supports, are available to the child, and what do you need from me as their caregiver to get coverage started?
- ▶ What steps should I take to request referrals, specialized programs, or continued Medicaid/CHIP support to address the child's ongoing medical, behavioral, and disability-related needs?

Home Health Care Providers

For relatives raising Native children with disabilities, home-based support often comes from a mix of Tribal, federal, and state programs working together. These services help children remain safe at home, reduce caregiver stress, and ensure that care is culturally appropriate.

Many families receive support through:

- ▶ **Medicaid Home and Community-Based Services (HCBS) waivers** that provide in-home support workers, respite care, therapies, equipment, and other services that help children stay safely at home.
- ▶ **Tribal Home Visiting programs** that offer parenting support, help navigating disability services, and culturally rooted guidance for caregivers.
- ▶ **Kinship Navigator Programs** that connect relative/kin caregivers to benefits and services, such as financial assistance, case management, legal services, in-home support, and more.
- ▶ **Indian Health Service and Tribal health programs** that help coordinate care, connect families to specialists, and link caregivers with community health workers.
- ▶ **Community Health Aide Programs (CHAPs)** that have locally trained behavioral, community, and dental health providers that can help families access culturally appropriate services. Community Health Aides help bridge the gap between clinical care and rural communities by integrating their cultural knowledge with specialized training in primary, emergency, and preventative care.

These programs work together to strengthen family caregiving, improve access to disability services, and ensure children receive care that respects Tribal values and community strengths.

Action Step

Start by contacting your Tribal or local clinic and asking to speak with a case manager or community health worker. Let them know that you are a relative/kin caregiver and need help exploring waivers, home-based supports, and culturally specific services available for the child you are raising.

Guiding Questions

- ▶ What does the child qualify for in terms of in-home services, and what documentation do you need from me?
- ▶ Who is responsible for coordinating the child's ongoing care across programs like Medicaid, IHS, home visiting, and school-based services, and how can I be involved in supporting continuity of care?

Developmental Disabilities Programs

State developmental disabilities programs help children and adults with developmental disabilities access services that support daily living, independence, and community participation. These programs can connect families to case managers, in-home supports, therapies, and other services that help children grow and thrive.

Action Steps

Contact your state's intellectual and development disabilities (I/DD) agency and ask them how to start the intake process for the child you are raising. Tell them that you are a relative/kin caregiver needing access to disability services and support. To find your state's I/DD agency, visit <https://www.nasddds.org/state-agencies/>.

Guiding Questions

- ▶ How do I apply if I don't have legal custody of my relative child?
- ▶ What authority do I need to consent to evaluations, access records, and participate in service planning?
- ▶ How does your program coordinate disability services with Medicaid, school-based supports, and other state or Tribal systems, and what additional resources become available because the child is in relative care?

Mental and Behavioral Health Providers

Tribal mental and behavioral health programs support Native youth with disabilities through culturally rooted, holistic care. These programs blend traditional healing with modern therapies and often work through IHS, Tribal health departments, and Native-led nonprofits. Many offer wraparound support, youth-specific services, and community-based approaches that honor Tribal values.

Relative/kin caregivers can access help through Tribal social services, behavioral health departments, IHS or Tribal clinics, and traditional healers. Kinship navigator programs—when available—can guide caregivers to Tribal and state resources. If the child is in state custody, the caseworker may help connect you to services that match the child's needs and case plan.

Action Steps

- ▶ Contact your Tribal behavioral health department or local IHS/Tribal clinic and ask to speak with a behavioral health provider or case manager. Let them know

that you are a relative/kin caregiver seeking mental health or behavioral health support for the child you are raising.

- ▶ There are also national resources, like We R Native, that provide youth-focused wellness information, such as [Self-Advocacy Tips for Youth with Disabilities](#) and [youth support resources](#), that may be helpful.
- ▶ Relative/kin caregivers can speak with the above providers about local caregiver support groups, respite resources, cultural supports, self-care materials, and other community programs that promote caregiver well-being.

Guiding Questions

- ▶ Can you help me understand how your clinic or department coordinates care for a child with a disability when the caregiver is not the legal parent, including how consent, confidentiality, and decision making are handled?
- ▶ How does the Tribe or local clinic determine eligibility and priority for behavioral health services for a child in relative care, and what additional support—cultural, clinical, or case management—can be activated because of their placement and disability status?

IHS Funded Urban Indian Organizations

Urban Indian Organizations (UIOs) are Native-led nonprofits that provide culturally based primary care, traditional healing, behavioral health services, and community support for urban Native populations. UIOs are in 22 states across 11 IHS service areas and offer a trusted place for families to access programs that honor culture and community.

Action Steps

Find the UIO closest to you using the [UIOs Facilities Map](#) and contact them to ask about medical, behavioral health, or family support services available for the child you are raising.

Guiding Questions

- ▶ What services can this UIO provide for my relative child—such as medical care, behavioral health care, care coordination, or referrals—and what information do you need from me to get them enrolled?

- ▶ How will this UIO coordinate the child's ongoing medical, behavioral, and specialty care across IHS, Medicaid, Tribal health, and local providers, and what specific actions should I take to prevent any gaps in their care?

Education

Tribal and State Head Start and Early Head Start Programs

Head Start helps young children from families with low incomes prepare to succeed in school through local Head Start programs and Early Head Start programs. Head Start delivers services to children and families in core areas of early learning, health, and family well-being while engaging parents/caregivers as partners every step of the way. Head Start may be able to provide services even if the child is not school-aged (three or four years old). Head Start can help access specialists in your area.

Action Steps

- ▶ Contact your relative child's school district to identify Head Start and Early Learning programs within your district.
- ▶ You can also contact a local [Head Start Center](#) or reach out to your relative child's Tribal education department to see if they have a Head Start program.
- ▶ Check out a Head Start resource on [children with disabilities](#).

Guiding Questions

- ▶ What services or supports are available to my relative child, and how do we start the enrollment or referral process?
- ▶ What services and support can Head Start provide to help with my relative child's developmental and educational needs?

Individualized Education Programs and 504 Plans

Individualized Education Programs (IEPs) and 504 plans are required by federal law to help ensure that children with disabilities receive the services and accommodation they need at school. For relative/kin caregivers, these plans can create stability by clearly outlining what the school must provide to support the child's learning and behavioral needs. Relative/kin caregivers should be active participants in the development of IEPs and should be involved in making changes as needed. You can learn more about [IEPs and 504 plans](#), what they provide, and the rights you have as a caregiver.

Action Steps

Request a meeting with the school to review current support offered to your relative child and ask whether an evaluation for an IEP or 504 plan is needed and how you can participate in the process.

- ▶ Invite a trusted friend, family member, or advocate with you to school meetings for support.
- ▶ Write down your questions and concerns ahead of time to help you prepare for meetings.
- ▶ Bring prior evaluations, counseling notes, and doctors' notes to meetings.
- ▶ Keep a file with copies of the IEP and notes for future reference, as these documents will also play a role in applying for disability and Social Security benefits.
- ▶ Share copies of the IEP with everyone involved to ensure consistent and timely support for your relative child.

Guiding Questions

- ▶ As the child's relative/kin caregiver, what information would be most helpful for me to share so the team can design the right plan?
- ▶ What steps do I need to take to support the child in accessing the supports and services outlined in the IEP/504 plan?
- ▶ How will the school keep me informed about the child's progress and any concerns, given my role as a relative/kin caregiver?
- ▶ Is there anything that I can do at home to help support the child's education and development?

Tribal Education Departments

Some Tribes have **Tribal Education Departments (TEDs)** that support the educational success of Tribal children and youth. TED staff often work closely with local schools—whether Tribally run, Bureau of Indian Education (BIE)-operated, or public schools near the Reservation. Because of these relationships, they understand what support exists for Native students, including those with disabilities, and can help caregivers navigate school systems, programs, and available services.

Action Step

Contact your relative child's Tribe and ask for the Tribal Education Department. Let them know that you are a caregiver of a Native child with a disability. They can help you connect with school staff, access educational support, and find resources for your relative child and family.

Guiding Question

How can your department assist us in navigating school systems—like special education, attendance, and cultural inclusion—and what steps should I take as the relative/kin caregiver?

State Indian Education Specialists and Foster Care Specialists

Many states have a **State Indian Education Specialist or Director** who works to support Native students' academic success. These specialists understand Tribal history, culture, language, and education systems, and they stay connected with schools, Tribal Education Departments, and programs that serve Native families. For caregivers of Native children with disabilities, they can be a powerful resource—they often know what supports exist statewide and how to help families access them. Some states also have foster care education specialists who can assist kids in care.

When children are living with relative/kin caregivers without legal ties or child welfare involvement, they may qualify for support under McKinney-Vento. Every school district has a McKinney-Vento Liaison who can coordinate services, including school enrollment, transportation, and meals, while also helping families access community-based programs and apply for benefits like TANF and health care coverage.

Action Steps

- ▶ Reach out to your state's Indian Education Specialist and let them know that you are a caregiver of a Native child with a disability. They can help you identify available services, connect you with school or Tribal resources, and guide you toward culturally relevant support. You can [find your state contact online](#).
- ▶ Reach out to your local [McKinney-Vento Liaison](#) to ask if your relative child qualifies for services under that law, and explore if your community has an education or health care consent law.

Guiding Questions

As a state Indian education specialist, state foster care education specialist, or McKinney-Vento liaison:

- ▶ What is your role in supporting the child's educational and disability-related needs?
- ▶ How will you collaborate with other programs to help our family?
- ▶ How can I be involved?

Bureau of Indian Education

Bureau of Indian Education (BIE) and Tribally operated schools provide culturally grounded education for Native children, including those with disabilities. These schools often have special education staff and the **Family and Child Education (FACE)** program, which supports children ages zero to eight and their caregivers through home-based services, early childhood education, and family engagement rooted in Tribal culture. These programs can be a direct pathway to academic support, early learning resources, and culturally connected services for your relative child.

Action Steps

- ▶ Contact your local BIE school's FACE program coordinator/administrator, or the child's teacher/parent liaison, and let them know that you are a caregiver seeking support. They can explain eligibility, enrollment, and available services, and help connect you with culturally relevant resources for your relative child and family.
- ▶ If you aren't sure about BIE schools near you, first reach out to your relative child's Tribal social services office or explore this [BIE School Directory](#).

Guiding Questions

- ▶ How will the FACE program work with the child's existing early intervention or special education services, and how can I be involved?
- ▶ What support can FACE offer to help me learn strategies to meet the child's developmental and educational needs, and how will you tailor the strategies to our family?

Indian Education Programs

Indian Education Programs use federal formula grant funds to support Native students' cultural identity, language, and academic success. Program directors know exactly

which students in each school identify as Native, making them valuable partners for connecting families, especially those raising Native youth with disabilities—to services and supports that align with their needs. Many districts and Educational Service Units run these programs, offering tutoring, cultural activities, and sometimes financial assistance.

Action Steps

- ▶ Reach out to your school district’s Indian Education Program director and let them know that you are a caregiver of a Native child with a disability. They can help you:
 - Connect with culturally relevant resources.
 - Access tutoring or academic help.
 - Learn about local Native organizations and services.
 - Navigate school resources with someone who understands Native students’ needs.
- ▶ If you don’t know your local Indian Education Program contact, call your district’s education office or call your state Department of Education and ask for the list of Local Education Agencies with Title VI programs.

Guiding Questions

- ▶ What documentation do you need from me to confirm the child’s eligibility for Indian Education services, what’s my role as a caregiver, and can you help in gathering any necessary information or filling out forms?
- ▶ How will Title VI services align with the child’s IEP or 504 plan, and who will coordinate these supports?

Other Tribal, State, and National Programs and Resources

Cultural and Community Events

To support your relative child’s connections to culture and community, you can speak with the child’s Tribe about cultural and ceremonial events, such as gatherings centered around sharing meals, singing, dancing, prayer, and other community-specific ceremonies. For example, powwows and other community celebrations are vibrant,

intertribal celebrations of life, culture, and community resilience, not just performances. Children with disabilities should be able to participate in ceremonial events and community celebrations when possible. Accommodations such as quieter spaces, earmuffs or sound-cancelling headphones, and flexible participation can help ensure that children with disabilities feel included. These events are also a great way for relative/kin caregivers to connect with other parents, guardians, and caregivers who may already be familiar with resources and connections in your community.

Action Steps

No website has a complete listing of all scheduled Tribal events nationwide, but you can contact your relative child's Tribe directly, check Tribal social media sites, or visit <http://www.powwows.com/>. You can also ask about any available accommodations or if there are other events or activities in your relative child's Tribal community that best align with their needs—such as sensory-friendly activities.

Guiding Questions

- ▶ How can your program support my relative child's participation in ceremony, community events, and gatherings, such as powwows, canoe journey, or stomp dance, that honor their cultural strengths—like dance, song, language, and extended family—while also meeting their disability-related needs?
- ▶ For non-Native caregivers
 - How can I support my relative child's cultural identity? What things should I be aware of as a non-Native caregiver when attending cultural events?
 - Who is the best person to ask about cultural protocols or expectations before the event?
 - Is this event open to everyone, or is any part limited to Tribal citizens, invited families, or specific participants?
 - Are there protocols for where we sit, when we enter or leave, and how we participate?
 - Are photographs, videos, or social media posts allowed?
 - Are there songs, prayers, ceremonies, regalia, medicines, or sacred items that should not be photographed, touched, or discussed outside the event?
 - How should I explain the event to the child beforehand in a respectful and age-appropriate way?

Urban Native Centers

Urban Native organizations and centers across the nation offer a range of community-based services for youth and families, including support with housing, educational assistance, peer support, communication about community events, and more. These organizations and centers often provide systemic support, helping Native families overcome barriers to accessing need-specific services and creating activities that are inclusive for children with disabilities and their families.

Action Steps

- ▶ If your relative child is involved in the state child welfare system and you reside in an urban area, ask the assigned state caseworker or the Tribal representative (sometimes known as the ICWA or Tribal child welfare worker for the child's Tribe) for support identifying local organizations or centers near you that serve Native children, youth, and families.
- ▶ If your relative child is not involved in the child welfare system, you can reach out to the child's Tribe directly for support, dial 211, or find the [GrandFacts fact sheet](#) for your state or Tribe to learn more about available services in your area.

Guiding Questions

- ▶ How can your program build on our family's strengths—such as our traditions, language, and caregiving practices—while supporting the child's disability-related needs?
- ▶ What opportunities are available from your center to help us connect with other support networks—such as cultural programs, caregiver circles, or disability-focused groups?

Programs for Elders

Many programs specifically support Tribal elders and aging caregivers raising grandchildren or other young relatives, offering services such as benefits navigation and help accessing health, nutrition, and educational resources. Typically, programs for elders begin around age 55, but eligibility can vary depending on how a Tribal community defines an elder. These programs recognize the unique role of elders as caregivers—seeking to strengthen both the caregiver and the child through community and culturally based services.

Action Step

Contact your Tribe's Title VI Native American Aging Program or local Area Agency on Aging (see the [Eldercare Locator](#)) and let them know that you are an elder raising a child. They may help you get connected with caregiver support services and culturally relevant resources that fit your family's needs.

Guiding Questions

- ▶ How can your program help build on our strengths as a family—such as routines, cultural traditions, and problem-solving skills—to support the child's disability-related needs?
- ▶ What opportunities does your program offer to help us strengthen and expand our support systems, such as peer groups, community partners, or other caregivers?

Home Visiting and Maternal and Child Health Programs

Tribal home visiting and maternal and child health programs provide culturally based, family-centered support for caregivers raising children, including children with disabilities. These programs may offer regular home visits, parenting guidance, child development activities, and developmental screenings. They help caregivers set family goals while connecting to health and community resources. Tribal Maternal, Infant, and Early Childhood Home Visiting program models (e.g., Family Spirit), public health nursing, and IHS partnerships collectively support healthy pregnancies, early childhood development, and family wellness. Some programs may provide virtual services or partner with urban Native organizations to support families who live off Tribal lands.

Action Steps

- ▶ Contact your relative child's Tribe and ask for the home visiting, maternal and child health, or early childhood program. Let them know that you are raising a child with disabilities and ask about available services, intake processes, and remote or off-Reservation options (if needed).
- ▶ You can also contact your local IHS or Tribal clinic and ask to speak with a public health nurse or program coordinator about home-based and developmental support programs.

Guiding Questions

- ▶ What are the steps necessary to enroll in this program, and can you help me complete any required forms, referrals, or eligibility verification as a relative/kin caregiver?
- ▶ What disability-specific supports or adaptations does your program offer—such as modified developmental screenings, alternative communication methods, or coordination with the child’s therapy providers?

In Closing

Thank you for your dedication to raising your relative child. Please note that this toolkit is not all-inclusive; service availability varies widely by Tribe, Alaska Native village, state, and county. Additionally, many relative/kin caregivers are raising children that are not involved in the child welfare system, which can alter access to certain programs. To bridge these gaps, we encourage you to research specialized resources and deepen your understanding of your relative child’s disability. By securing the targeted supports that match your family’s unique situation, you can best promote long-term growth and development.

The Grandfamilies & Kinship Support Network: A National Technical Assistance Center (Network) helps government agencies and nonprofits in states, Tribes, and territories work across jurisdictional and systemic boundaries to improve supports and services for families in which grandparents, other relatives, or close family friends are raising children whose parents are unable to do so. For more information, please visit www.GKSNetwork.org.

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