



North Dakota Part C Early Intervention recognizes service coordination as one of the building blocks of the system that supports infants and toddlers with delays and disabilities, as well as their families. Service coordination is defined as an active, ongoing process that assists and enables families to access services and assures their rights and procedural safeguards. The Individuals with Disabilities Education Improvement Act (IDEA) specifically references service coordination as a service all children and families have available to them without a cost if eligible for Part C Early Intervention.

Rooted in IDEA...



§1431. Findings and policy

(a) Findings

Congress finds that there is an urgent and substantial need—

- (1) to enhance the development of infants and toddlers with disabilities, to minimize their potential for developmental delay, and to recognize the significant brain development that occurs during a child's first 3 years of life;
- (2) to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age;
- (3) to maximize the potential for individuals with disabilities to live independently in society;
- (4) to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities; and
- (5) to enhance the capacity of State and local agencies and service providers to identify, evaluate, and meet the needs of all children, particularly minority, low-income, inner city, and rural children, and infants and toddlers in foster care.

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Across the country, including North Dakota, services and supports to infants and toddlers with delays and disabilities, as well as their families, are authorized by IDEA. In the 2004 reauthorization of the federal law, Congress found an “urgent and substantial need” to mitigate disability, enhance school readiness, and maximize brain development for our country’s children. In the language of the subsection entitled Part C of IDEA, Congress clearly stated their intent to also support families so that they can meet the needs of their infant and/or toddler with delays and/or disabilities. We often associate service coordination as the Part C service that can best address outcomes for families.



Learning about federal law and reading regulation should always be broken up by pictures of babies and families. That's what it's all about it!

Rooted in IDEA...



303.34 **Service coordination services** (case management).

(a) General.

(1) As used in this part, service coordination services mean services provided by a service coordinator to assist and enable an infant or toddler with a disability and the child's family to receive the services and **rights, including procedural safeguards**, required under this part.

(2) Each infant or toddler with a disability and the child's family **must** be provided with one service coordinator who is responsible for—

(i) Coordinating all services required under this part across agency lines; and

(ii) Serving as the single point of contact for carrying out the activities described in paragraphs (a)(3) and (b) of this section.

(3) Service coordination is an **active, ongoing** process that involves—

(i) Assisting parents of infants and toddlers with disabilities in gaining access to, and coordinating the provision of, the early intervention services required under this part; and

(ii) Coordinating the other services identified in the IFSP under §303.344(e) that are needed by, or are being provided to, the infant or toddler with a disability and that child's family.

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The language included on this slide is from the section of definitions in Part C. It is clear from this regulatory language that service coordination is not an optional service when a family decides to participate in services through a state's Part C system. The intent of the law should be noted in the words, "*active and ongoing*". These words create a sense of urgency and connectedness to the family and their needs for their child's growth and learning. Assisting and enabling the family to understand and act on their procedural safeguards is also clearly noted as a function of service coordination. We will go into these various functions a bit later in this presentation.

Service Coordination in North Dakota



- Is a dedicated model
- Is provided by state employees located at the Regional Human Service Centers
- Performed by Developmental Disabilities Program Management staff
- Every family in ND Part C Early Intervention has a Service Coordinator
- Paid for by a mix of state general funds and Medicaid funding

Every state has had the ability to design a Part C service delivery system that works for them, so the way service coordination is funded and delivered can look very different from state to state. North Dakota has what is called a “dedicated” model of service coordination. *Dedicated model of service coordination* means it is provided by a person that works for an agency that is totally separate from any other service provider. Our state’s Regional Human Service Center Developmental Disabilities (DD) Program Management units serve as the single point of entry and the provider of service coordination in ND.

Since service coordination is not an optional service under the law, every family participating in the ND Part C Early Intervention system will have a *Service Coordinator* from their regional human service center. More often than not, the family will associate that person as their DD Program Manager versus a *Service Coordinator*. In learning about their rights under Part C, it is important to have a discussion with the family that the two are the same. Presently, the funding for service coordination is a cost that is covered by funding dedicated to the regional human service centers. This cost is not billed out to the federal Part C discretionary grant that the state receives from the federal Office of Special Education Programs. For purposes of consistency, we will use the term *Service Coordinators* throughout the rest of this presentation instead of the

term they are employed under which is DD Program Managers.

More about Service Coordination in ND



- A family cannot be assessed a fee for service coordination.
- According to Part C, a family's Individual Family Service Plan (IFSP) could reflect service coordination as the only service they are receiving.
- Any infant and toddler under 3 who asks for assistance, no matter where they live, should be initially considered as a referral to the ND Part C Early Intervention system.
- The frequency and intensity of service coordination will be determined by the IFSP not agency policy.

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Part C is clear that families cannot be charged for service coordination, evaluation and development of the Individual Family Service Plan, known from here out as an IFSP. While families are presented with paperwork from the Regional Human Service Centers around participation costs, their Service Coordinators explain that there will be no costs for these services. This is a great opportunity to tie this conversation to the requirement in the federal law that access to service coordination, assessment/evaluation and IFSP development are a child and family's right.

Participation in Part C is voluntary on the part of the family; however Service Coordinators who receive a referral of an infant and/or toddler under 3 should start by informing the family of their right to service coordination, assessment/evaluation, and IFSP development under the law and how that would be helpful to their family. This should occur even if the family is deciding not to use any of the other Part C services as provided by our Infant Development providers.

Use of the

Intellectual Disability/Developmental Disability Medicaid Waiver...

- Service coordinators in ND also manage access to the state ID/DD Medicaid Waiver
- ID/DD Medicaid Waiver pays for "other" Part C services primarily provided through licensed Infant Development providers across the state for those families that choose to apply for Medicaid for their child.
- Families choosing only service coordination as a service on their IFSP's will not be screened to the ID/DD Medicaid Waiver and will not have an option to have a family income and asset disregard to receive Medicaid for their child.

North Dakota has a unique approach to funding the other Part C services beyond service coordination. North Dakota includes the service delivery system, which we refer to as Infant Development, under the state's Intellectual Disabilities/Developmental Disability Medicaid Waiver (IID/DD). The entry and service plan development for the waiver is managed by DD Program Management across North Dakota. This makes for a challenging job for our Service Coordinators because they have to pay attention to both the requirements of Part C of IDEA as well as the requirements under Medicaid as set forth by the federal Centers for Medicare and Medicaid. It is critical for our Service Coordinators to remember that if they are addressing the needs of an infant and toddler who is eligible for ND Part C Early Intervention, they have to assure that the Part C requirements are met, but they also have to understand and relay to the family what their decisions may mean to other benefits that they could access, such as having Medicaid for their child. A decision to only access service coordination will mean that a child will not be screened to the IID/DD waiver and therefore will not be able to have access to a family income and asset disregard for Medicaid.

Service Coordination...Supporting Families

- Linked to the practices of care coordination, family-centered services, and case management
- Key to the spirit of partnership
- Critical to coordinating services



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Service coordination is linked to the practices of care coordination, family-centered services, and case management. These are all terms associated with the social service delivery systems to children with special health care needs over the years. Case management was the original term used when the law was first legislated as Part H of IDEA reauthorization in 1986. However, the term fell out of favor as it was not considered child or family friendly to refer to children and families as cases to be managed. In 1997, as part of the reauthorization, the term was replaced with “service coordination.” This term and its associated functions continue today as an integral component of early intervention services. While the actual functions have evolved over the years the basic premise remains, which is to assist and partner with families to ensure they receive supports and services in a coordinated manner. [SEP]

The development of the family and provider relationship starts with the initial referral and continues through transition from the program. Service Coordinators must be knowledgeable about the guiding principles, program policies, and implementation procedures for each step in the early intervention process, as well as evidence-based intervention practices and community resources.

[SEP]



Family-Centered Care:

- Acknowledges the family as the constant in a child's life.
- Builds on family strengths.
- Supports the child in learning about and participating in his/her care and decision-making.
- Honors cultural diversity and traditions.
- Recognizes the importance of community-based services.
- Promotes an individual and developmental approach.
- Encourages family-to-family and peer support.
- Supports children and their families through transitions.
- Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
- Celebrates successes.

The Maternal and Child Health Bureau within the federal Department of Health and Human Services has promoted a definition of family-centered care which reads: Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice, which results in high quality services. The principles of Family-centered care also apply to the work of the Service Coordinator and other members of the Early Intervention team:

- Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role.
- Everyone respects the skills and expertise brought to the relationship.
- Trust is acknowledged as fundamental.
- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a willingness to negotiate.



Part C Family Outcomes

States are required to report on the percent of families participating in Part C who report that early intervention (EI) services have helped their family:

- Know their rights;
- Effectively communicate their children's needs; and
- Help their children develop and learn.

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All across the United States, Part C programs are required to file federal reports called Annual Performance Reports (APR) each February 1st. One of the required 11 indicators in the APR requires reporting on family outcomes. The family outcomes were designed to gather more than an opinion on satisfaction; the outcomes are designed to gather information about how Early Intervention has impacted the family. North Dakota surveys families annually to gather feedback from the families involved in Part C. The family outcome indicator is known as Indicator 4 and requires states to report on how Early Intervention services have helped families to

- Know their rights;
- Effectively communicate their children's needs; and
- Help their children learn and grow.

North Dakota makes it clear that this data reflects the support from service coordinators as well as infant development providers and other Early Intervention supports. When regional program reports are issued containing the results of the annual family survey and outcome, the report is issued to both the Regional DD Program and the specific Infant Development Program. Keeping the federal outcomes in mind as services and supports are delivered can be a point of guidance for Service Coordinators.

IDEA...Natural Environments

Home and Community



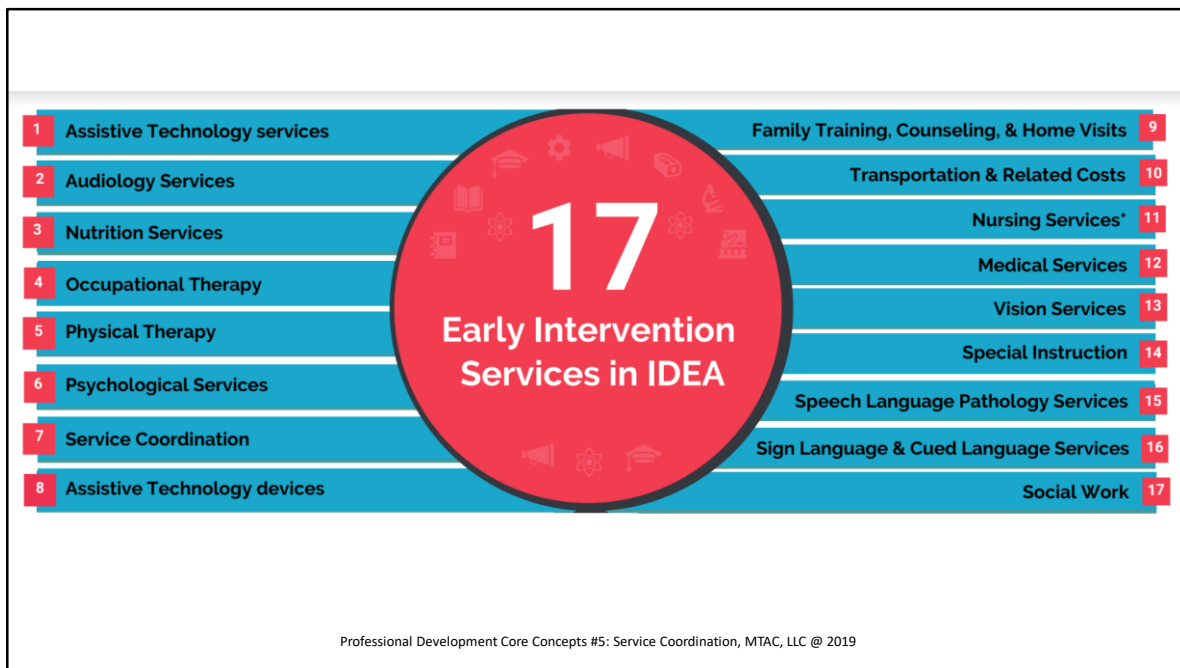
Daily Routines



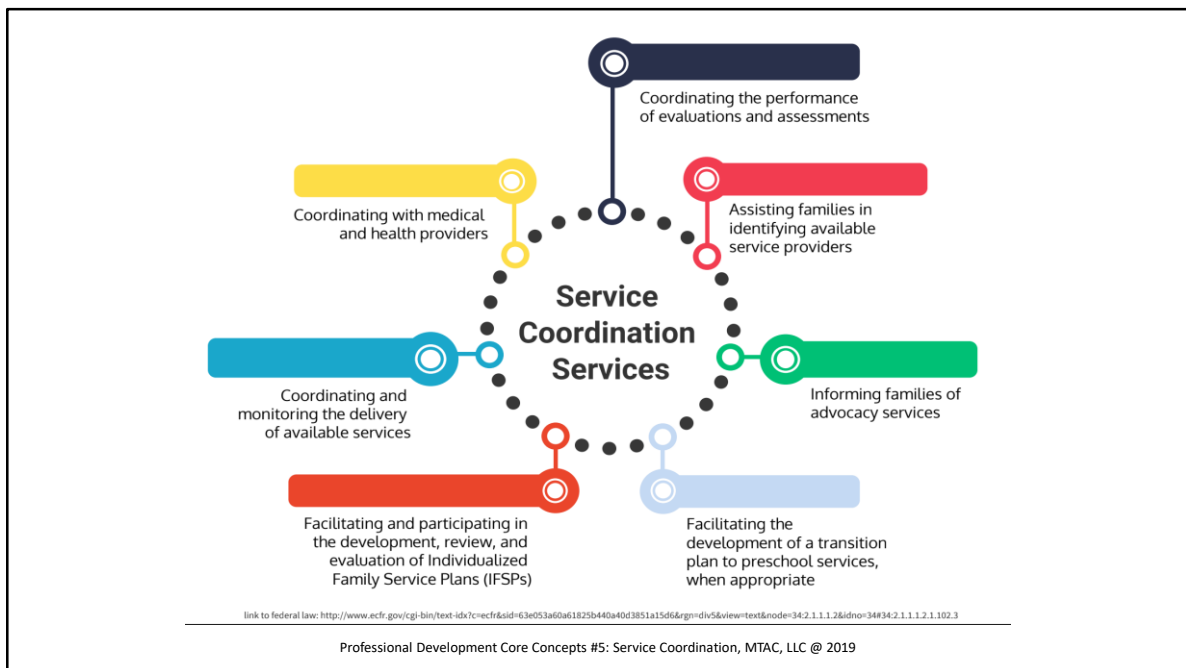
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The law states that Early Intervention services “to the maximum extent appropriate, are provided in natural environments, including the home, and community settings in which children without disabilities participate.” Therefore, the Service Coordinator meets with families in their homes or other community settings that children and families frequent. It is through the provision of home and community supports that we can truly understand and respect the uniqueness of each individual family. Being invited into the life of the family is a practice from the past that is instrumental today in providing family-centered intervention. [SEP]

As we take note of lessons from the past and present, it reinforces the value of meeting families and children where they are. It is vital that services such as service coordination and other Early Intervention supports engage children and families in their routine activities and actually go to the places where children and families live and spend time, including home and community settings.



As noted before, IDEA refers to service coordination as a core service, meaning all eligible children and their families have access to service coordination. Service coordination is one of the 17 early intervention services that are listed in the law. The next slides will provide further information about the specific tasks that are outlined in the law.



There are seven functions of service coordination that are outlined in IDEA. These functions cut across all aspects of the family’s journey through Early Intervention and thus, all activities that Service Coordinators perform in support of families throughout the process.

As a reminder, the federal law states that the functions of service coordination are as follows:

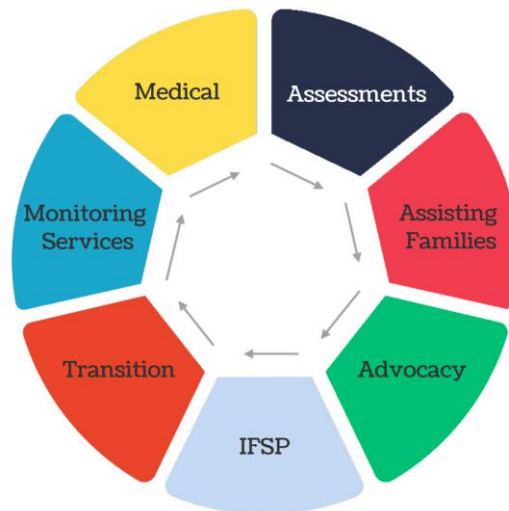
- Coordinating the performance of evaluations and assessments
- Facilitating and participating in the development, review, and evaluation of Individual Family Service Plans (IFSPs)
- Assisting families in identifying available service providers
- Coordinating and monitoring the delivery of available services
- Informing families of advocacy services
- Coordinating with medical and health providers
- Facilitating the development of a transition plan to preschool services, when appropriate

We will review the functions of service coordination as they are described in IDEA. You will gain more detailed information on the various tasks that Service Coordinators

complete as they partner with families throughout this training.^[11]

Each service coordination function will be supported by references to DEC Recommended Practices that support the function. The Division of Early Childhood (DEC) Recommended Practices are an “initiative that bridges the gap between research and practice, offering guidance to parents and professionals who work with young children who have or are at risk for developmental delays or disabilities.” (<http://www.dec-speds.org/dec-recommended-practices>).

But what does Service Coordination look like in ND?



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When thinking about service coordination, it is helpful to be mindful about what “coordination” means. Coordination is defined as the organization of different elements or activity so as to enable the parts of the system to work together. In reality, it is a cooperative effort to have an effective relationship. You will see in upcoming slides that the words “guide” and “navigator” are used in relation to service coordination and the duties of Service Coordinator.

Each situation may be a bit different. In some situations, the Service Coordinator and Early Interventionist work together closely with Early Intervention when supporting families across the 7 service coordination roles. In other situations, the Service Coordinator takes more of the lead. As with any effective relationship, each region needs to be clear about who is doing what parts of these roles to assure that the family receives true service coordination.

It is important to remember that coordination does not happen without partnership. All team members work together with the family to build bridges that facilitate communication and advocacy for families. Service Coordinators work alongside Early Intervention providers as part of a team to ensure that the provision of all Part C services meets the needs of the

family. As with any effective relationship, each team needs to communicate about who is doing which part of these roles to assure that the family receives true service coordination.

The Service Coordinator has the Ultimate Responsibility.



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In North Dakota, designated Service Coordinators have the responsibility to assure the 7 coordination services support families. In summary, how families are supported is often a cooperative endeavor between the Service Coordinator and Early Interventionist that varies by region. The bottom line, is that the Service Coordinator must ensure that the 7 roles are fulfilled.

Outcomes of Service Coordination

A series of studies conducted by the Research and Training Center (RTC) on Service Coordination has identified nine interrelated outcomes that should be achieved as a result of high-quality service coordination. These outcomes are listed in Table 4.2 from *Working With Families of Young Children with Special Needs* edited by R.A. McWilliam. Copyright 2010 by The Guilford Press.

- Families have access to support, information, and education to address their individual needs.
- Families are able to communicate the needs of their child.
- Families make informed decisions about services, resources, and opportunities for their child.
- Agencies and professionals are coordinated.
- Children and families receive quality service.
- Children and families participate in supports and services that are coordinated, effective, and individualized to their needs.
- Families acquire and/or maintain a quality of life to enhance their well-being.
- Families meet the special needs of their child.
- Children's health and development are enhanced.

This slide outlines a list of 9 interrelated outcomes that were identified through work by the Research and Training Center on Service Coordination. As noted earlier, all states are responsible to report out on the following three family outcomes:

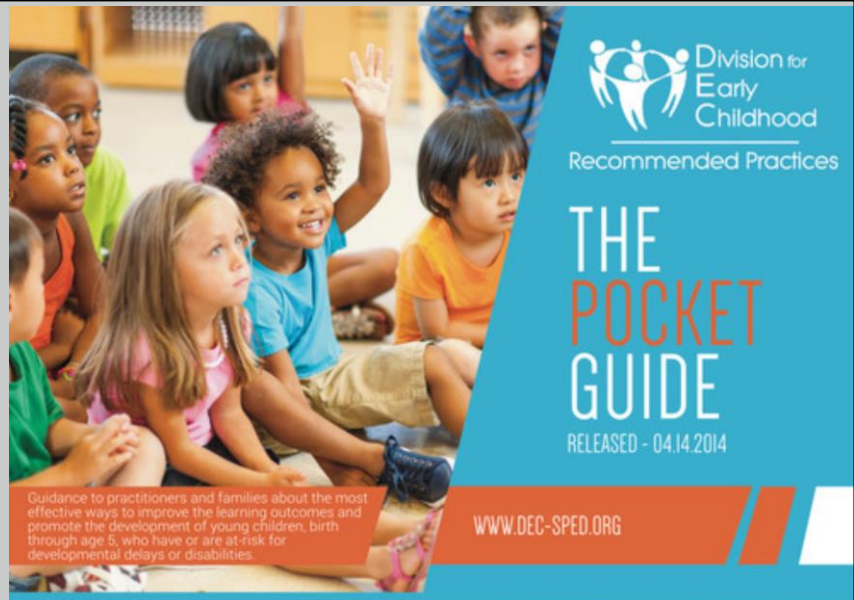
- Know their rights;
- Effectively communicate their children's needs; and
- Help their children learn and grow.

You can see the alignment of these federal outcomes within the nine that are outlined on this slide. Beyond the federal outcomes, we can see that outcomes regarding well-coordinated services and quality of life guide Service Coordinators to consider how supports beyond just the Part C services come into play.

If the functions outlined in IDEA and in the previous slide result in these outcomes for families, then Service Coordinators know that the strategies they use are in line with a family's needs. Each family requires their own set of strategies and practices implemented along different timelines or in different methods of delivery. Also, families change with their children. As their children grow and learn, families' needs change, so it's important that Service Coordinators and other Early Intervention personnel have a

way to “check in” with a family on a regular basis in regards to the outcomes above.

DEC Recommended Practices



<http://www.dec-sped.org/dec-recommended-practices>

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The Division of Early Childhood (DEC) Recommended Practices are an “initiative that bridges the gap between research and practice, offering guidance to parents and professionals who work with young children who have or are at risk for developmental delays or disabilities.” (<http://www.dec-sped.org/dec-recommended-practices>). DEC Recommended Practices were “developed to provide guidance to practitioners and families about the most effective ways to improve the learning outcomes and promote the development of young children, birth through age 5, who have or are at-risk for developmental delays or disabilities.

<http://www.dec-sped.org/dec-recommended-practices>

DEC alignment with Service Coordination functions



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We will now explore the 7 functions of a Service Coordinator as outlined in IDEA and highlight relevant DEC Recommended Practices that align with the functions. The application of the Recommended Practices to the various service coordination functions are not exclusive as many of the Recommended Practices are relevant. As we move through the functions, we've also included some suggested outcomes. Again this is not an exhaustive list as we understand different children and families will and should experience different outcomes.

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Coordinating the Evaluations and Assessments

Suggested Outcomes

- Families can identify why evaluations and assessments are being done
- Families understand their rights relating to evaluations, assessments, and consent for evaluations
- Families can identify the role and function of each professional involved with evaluations and assessments
- Families have written reports that are understandable and accessible to them
- Families do not incur a charge for evaluations and/or assessments

Related DEC Recommended Practices

- F1. Practitioners build trusting and respectful partnerships with the family through interactions that are sensitive and responsive to cultural, linguistic, and socio-economic diversity
- A1. Practitioners work with the family to identify family preferences for assessment processes
- A2. Practitioners work as a team with the family and other professionals to gather assessment information
- A11. Practitioners report assessment results so that they are understandable and useful to families

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Service coordinators can see themselves as a guide or a navigator for families who find themselves with a child who is eligible for ND Part C Early Intervention services. The first Early Intervention professional a family meets is a Service Coordinator. They may have just found out about their child's diagnosis or still be unclear why they are being referred. This means that entry into a service delivery system can feel overwhelming to a family. Imagine yourself in a brand new country where no one speaks the same language that you do and you know that you have some important work to accomplish. What's the most helpful to you? Written directions in your language? Pictures? Someone who goes with you to your next destination? Someone who checks that you got there? Someone who calls ahead to make sure the people at your destination understand your needs? A picture of who you'll meet?

Coordinating the Evaluations and Assessments



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Service Coordinators have a responsibility within IDEA to assure that families understand their rights and procedural safeguards under the law. As families enter Early Intervention, for most of them, this will be the first time that they hear about IDEA and a description of their rights. Most people are used to getting legalese, such as a HIPPA form, when they get services from professionals, but starting to build a wealth of knowledge at the beginning of what IDEA does for individuals with disabilities is critical for families. It is possible that they will be navigating IDEA services for many years to support their child.

Understanding the learning styles, cultural preferences, and adult learning needs of family members is important in order to maximize a family's ability to understand their rights, participate in the evaluation/assessment process, and finally to use the information provided by the evaluation and/or assessment to help their child learn and grow. As Service Coordinators work to understand the individual needs of a family, relationships and partnerships start to form as families realize that their strengths and differences are valued. These relationships are nurtured through consistent follow-through and asking for feedback on whether the support is helpful.

As noted in the analogy to traveling in a country different from your own, having

information about who will be coming into a family's home, what their expertise is, and how families can prepare for the evaluation and/or assessment can be helpful. Having access to phone numbers and names, knowing what to do if they need to cancel or change an appointment, as well as what the next steps will be toward getting services are all helpful strategies to increase participation and engagement with families in the evaluation and/or assessment process.

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Facilitating and participating in the development, review, and evaluation of Individualized Family Service Plans (IFSPs)

Suggested Outcomes

- Families learn about parent prior notices and understand their rights relating to IFSP development and reviews
- Families can report they were instrumental in developing outcomes and service plans for them and their child
- Families have written materials and a final copy of the IFSP that are understandable and accessible to them

Related DEC Recommended Practices

- TC 2. Practitioners and families work together as a team to systematically and regularly exchange expertise, knowledge, and information to build team capacity and jointly solve problems, plan, and implement interventions
- F4. Practitioners and the family work together to create outcomes or goals, develop individualized plans, and implement practices that address the family's priorities and concerns and the child's strengths and needs

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Even though Service Coordinators and other Early Intervention staff are focused on the timeline of 45 days to complete an Individual Family Service Plan (IFSP) after referral, we have to make sure that families have the information they need to participate fully in creating the IFSP. Although staff have been on many teams and sat through the development of hundreds of IFSP's, in most cases, this will be the family's first opportunity to be part of a team and to develop a plan that supports their child's growth and learning.

What adult learning techniques can you use to increase family understanding and engagement? The information that families have to grasp includes understanding their rights and procedural safeguards surrounding the notification and participation in the IFSP, as well as the knowledge that the IFSP, is truly a legal document that secures a plan for service delivery. They also need information regarding their role as a team member. Being a team member means that personal information about their child and family is as critical to the development of an IFSP as the expertise a professional brings to a team. For example, while a physical therapist knows about motor development in an infant, a family knows what motivates an infant to move. Families often look to professionals as the expert and downplay their knowledge. Finally, families need to learn that strengths, interests, and motivations are more critical to the development of an IFSP than are the

deficits. Families need to be coached to think about what they and their child are doing well, what they like to do, and what gets them excited about learning.

Focusing on adult learning styles, means that service coordinators and other Early Intervention professionals must be culturally competent and sensitive to any accommodations that need to be made in both verbal and written communication. This must be true throughout the Early Intervention experience for children and families.

Assisting families in identifying available service providers

Suggested Outcomes

- Families can report that they understand who is available to support their child and family and how they will be paid
- Families identify their service coordinator as a partner in getting services and supports in place
- Families can report that they know how to resolve conflicts or change service providers if they feel this will benefit them and their child

Related DEC Recommended Practices

- L13. Leaders promote efficient and coordinated service delivery for children and families by creating the conditions for practitioners from multiple disciplines and the family to work together as a team
- F2. Practitioners provide the family with up-to-date, comprehensive and unbiased information in a way that the family can understand and use to make informed choices and decisions

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IDEA lists seventeen distinct services that should be considered during IFSP development. The law also is clear that this list is not exhaustive. Service Coordinators need to familiarize themselves with the list of services to ensure that IFSP outcomes are supported by the professionals that are needed to address achieving the outcome. This should never be limited to the staff that are available in a given service agency or because a certain service has never been provided. In some situations, teams need to think outside of the box to meet the service delivery needs. Service Coordinators need to work closely and partner with families to get the service delivery team in place. Partnership does not mean just handing a parent a brochure or a phone number, nor does it mean completely taking over the coordination. An example of partnership may look like a service coordinator calling ahead to a service provider to get the specific name of an intake worker and best times to call, then passing this information on to the family to make the actual appointment. Following up to make sure the connection happened is crucial.

Coordinating and monitoring the delivery of available services

Suggested Outcomes

- Services listed as Part C Early Intervention services on the IFSP are started when stated on the IFSP
- Families can report that they know how to resolve conflicts or change service providers if they feel this will benefit them and their child
- Progress on IFSP outcomes is documented and recognized by the family and the service providers

Related DEC Recommended Practices

- TC5. Practitioners and families may collaborate with each other to identify one practitioner from the team who serves as the primary liaison between the family and other team members based on child and family priorities and needs
- E1. Practitioners provide services and supports in natural and inclusive environments during daily routines and activities to promote the child's access to and participation in learning experiences

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Once the IFSP service plan is in place, Service Coordinators work with families to assure that services are started in a timely manner. Timely initiation of services is one of the indicators that states must report on annually to the federal Office of Special Education Programs.

Early Intervention service providers are often referred to as Early Intervention professionals, home visitors, or therapists. Because families have a right to know that the services on their IFSP are being fulfilled, it's important that families can identify the professional background of the providers that support their IFSP. Families should also have clear knowledge about the additional services that are referenced under IDEA, so that as new developmental needs and concerns arise, they understand that they can ask for an IFSP review to consider the outcomes and which services are needed. Written instructions on how to resolve conflicts and/or change service providers should be provided to parents with accommodations for any adult learning needs they might have. If conflicts arise, service coordinators need to assure that families have support to resolve these conflicts either via themselves or by referring the family to other advocacy organizations.

Informing families of advocacy services

Suggested Outcomes

- Families have a variety of resources to inform their choices and address their needs
- Families actively ask questions, provide information, and are engaged in all aspects of working with professionals to support their child
- Families have opportunities to provide input into how services and supports are created and/or enhanced
- Families can report that their child and family's needs are met

Related DEC Recommended Practices

- F10. Practitioners inform families about leadership and advocacy skill-building opportunities and encourage those who are interested to participate
- L3. Leaders develop and implement policies, structures, and practices that promote shared decision making with practitioners and families
- TC4. Team members assist each other to discover and access community-based services and other informal and formal resources to meet family-identified child or family needs

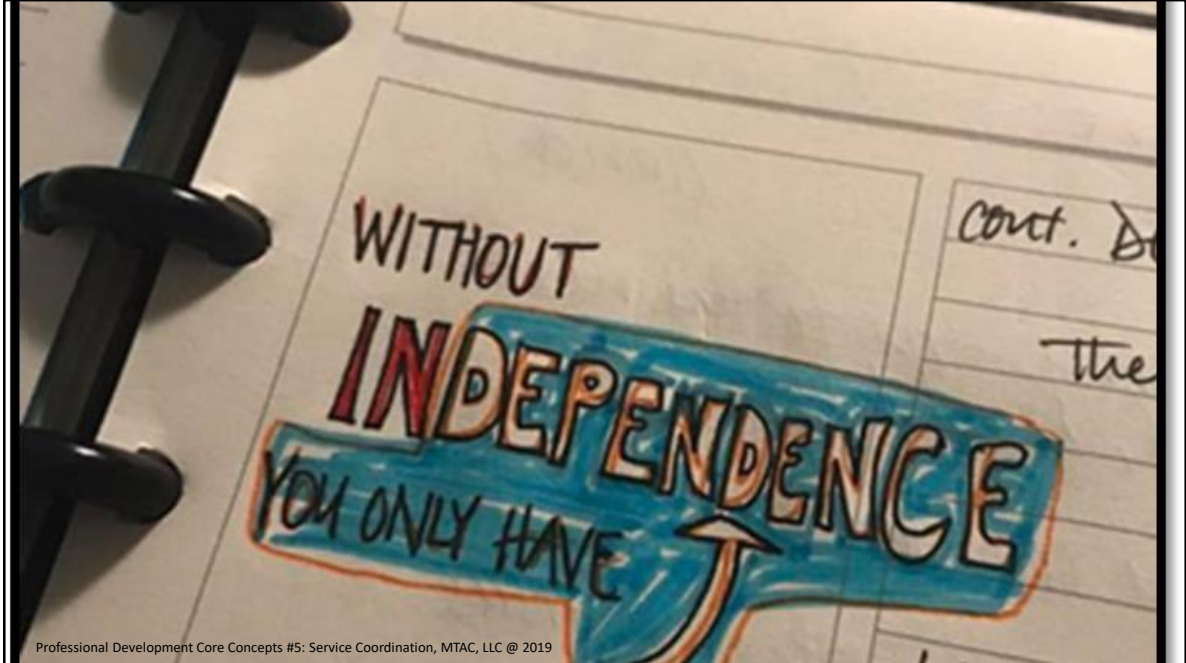
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Advocacy is the act of seeking support or a cause on someone's behalf. Families who have infants and/or toddlers who are eligible for Early Intervention services are often faced with becoming advocates for their child and having to exercise a leadership role for possibly the first time in their lives. Having opportunities for leadership training and advocacy skill-building are resources that should be included in discussions around family needs. These opportunities can include connecting with other parents that have had similar experiences, learning about family-based, family support organizations, and having family outcomes that keep the team focused on the need for advocacy skill-building.

Service coordination agencies and other Early Intervention providers should think about opportunities to include families in decision-making around policies, structures, and practices. Including families in decision-making should not be taken lightly. Accessibility considerations such as time of meetings, reimbursement for costs, adult learning styles, and consistent feedback are all important in assuring that shared decision-making is genuine and valuable.

One possible opportunity for shared decision-making around Early Intervention may be involvement in a state's interagency coordinating council (ICC). Presently, IDEA requires

that the state have a council to advise and assist the state lead agency in making decisions about the state's Part C system. A state's council must dedicate at least 20% of their membership to family members who have children under 12 and who have had a child/children in Early Intervention. North Dakota's Inter-Agency Coordinating Council (ICC) requires 30% family membership and tries to include a parent from each region.



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We're taking this photo break, to remind everyone that the goals of service coordination as part of the ND Part C Early Intervention system is to lean on the strengths and inherent potential of young children and their families to learn and grow beyond those that support them. (Photo credit: Sarah Carlson)

Coordinating with medical and health providers

Suggested Outcomes

- Releases of information are in place for coordinating services and families understand the purpose of the releases and how to revoke the releases if necessary
- Families can report that they have access to care coordination within their systems of service delivery
- Families can talk about the full array of services that are available to them and can make choices when needed

Related DEC Recommended Practices

- F3. Practitioners are responsive to the family's concerns, priorities, and changing life circumstances
- F7. Practitioners work with the family to identify, access, and use formal and informal resources and supports to achieve family-identified outcomes or goals

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Collaborating with a child's medical professionals and other related service providers, like outpatient pediatric therapy providers, is key to developing and implementing a comprehensive IFSP. Assuring that releases of information are in place and helping families to understand how these will be used and their right to retracting the releases is another step in educating families about their rights and procedural safeguards. Families will just be learning how to coordinate all of their services. Learning about medical home as defined by the American Academy of Pediatrics (<https://www.aap.org/en-us/professional-resources/practice-transformation/medicalhome/Pages/home.aspx>) and how medical, developmental, and family supports can be coordinated can be considered as a family outcome on the IFSP.

Young children and families are constantly changing, therefore Service Coordinators should always be considering whether there are new partners external to Early Intervention that need to be brought in as partners. Families should be able to report that they have been informed that the best Early Intervention experience is one where there is a clear connection between all of the services that support them and their child.

Navigating various systems of support, such as Early Intervention, health care payment sources, financial benefits, medical providers, and other public providers like other home

visiting programs, can be overwhelming. Developing eco-maps or providing binders that keep all of the information organized can be helpful tools for families to manage the demands associated with having an infant and/or toddler who live with delays, disabilities, and/or special health care needs.

Facilitating the development of a transition plan to preschool services, when appropriate

Suggested Outcomes

- Every IFSP of a child over the age of two years, five months has transition-focused outcomes, which are regularly updated as the child ages toward the age of 3
- Families can report the various options available to them and their child at least 90 days before their child's 3rd birthday
- Providers that will be responsible for services and/or supports to the child and family after 3 are part of the team at least 90 days before the child's 3rd birthday
- Families understand all of the implications of the transition out of Early Intervention

Related DEC Recommended Practices

- F6. Practitioners engage the family in opportunities that support and strengthen parenting knowledge and skills and parenting competence and confidence in ways that are flexible, individualized, and tailored to the family's preferences
- TR2. Practitioners use a variety of planned and timely strategies with the child and family before, during, and after the transition to support successful adjustment and positive outcomes for both the child and family.

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IDEA is clear about the responsibility of the Part C system to make sure that families don't face any surprises when their child turns 3 and exits from the Early Intervention system. Furthermore, IDEA designates the responsibility of facilitating the development of the transition plan within the IFSP. Making sure that the transition plan is in place, the local and state educational agency has been notified of the child, and that a transition conference has been held prior to 90 days of a child exiting from Early Intervention are all data elements that are annually reported to the federal Office of Special Education.

Updating the IFSP to reflect the various actions, strategies, and outcomes that are current to the transition plan is critical for families to monitor that all of the steps are happening. IFSP teams need to be particularly sensitive to a family's need for information related to IDEA Part B procedures, community resources, family support, financial benefits, and additional advocacy supports.

Transition is one of the most critical opportunities for families to learn about their procedural safeguards and the protections under IDEA. They will be faced with meeting with new teams of people, participating in meetings with a large number of professionals they don't know, signing unfamiliar paperwork, and experiencing processes that may seem completely foreign to what they have already experienced. If

parent-to-parent supports or use of ND's Experienced Parent Program has not been accessed prior to this time, this is an excellent time for this additional support to help with the need for learning and emotional support.

Transition is also a time for celebration and recognition that relationships will change. Families and Early Intervention staff create incredible bonds during the time a child is in services. IFSP teams should think about how to take time to celebrate the work that they accomplished together as well as ways to say good-bye. It will be helpful to think about new ways to add in emotional and informational supports for families that will now be missing or changing supports.

Family's journey through EI



**Brian &
Caitlin V.**

“Because our baby girl was born with major medical complications, it was so important that we had Early Intervention supports as soon as she was born. The information we received helped us emotionally prepare for our daughter’s arrival and future well-being, as well as prepare ourselves finally through various programs available to children with special needs.”

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“Because our baby girl was born with major medical complications, it was so important that we had Early Intervention supports as soon as she was born. The information we received helped us emotionally prepare for our daughter’s arrival and future well-being, as well as prepare ourselves finally through various programs available to children with special needs.”

This quote was used for the North Dakota Early Intervention Happy Birthday celebration. In reading the words of the family, we can understand the weight of responsibility that service coordinators carry in supporting families in the journey of advocacy for their family.



“The informality of family life is a blessed condition that allows us to become our best while looking our worst.” Morgan Kennedy

We’d like to end this presentation by asking you to remember that each child and their family brings the richness of their unique approach to life and that as we enter their lives, we need to embrace their informality and the chaos that is true for every family with young children. We encourage you to perfect and own your professional knowledge and skill and apply the art of blending that expertise with the wealth of potential that each child and family brings into the relationship. As you help families appreciate themselves and the strengths they bring, keep in mind the words from Morgan Kennedy: “The informality of family life is a blessed condition that allows us to become our best while looking our worst.”