Supporting Families with Infants in the Neonatal Intensive Care Unit
01/23/2024

Purpose of Today's Presentation

- Child Find: Identifying and supporting families as early as possible to make the greatest possible difference
- Supporting SPAs during the Initial Planning Process when the child is in the NICU
- Enhancing collaboration with community partners

Guest Presenter

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Smooth Way Home
Program Manager

Smooth Way Home

Smooth Way Home works to improve the social, developmental and medical outcomes of very fragile infants by enhancing the coordination of care and the quality of services provided to them as they transition from the newborn intensive care unit back to their home and community.

We do this through:

- Hospital support and transition planning
- Family support
- Fragile Infant Specialist home visitation
- Mental Health Support
- Community support
- Professional development

High Risk Perinatal Program

The High-Risk Perinatal Program (HRPP), formerly the Newborn Intensive Care Program (NICP), provides in-home community health nursing services to assist families and their newborns during the transition from the Newborn Intensive Care Unit to their home and community.

Any baby who spent at least five days in a Level II or Level III nursery qualifies to have home visits from a community health nurse or nursing support specialist through this program.

This program provides:

- Home visits from a community health nurse or nursing support specialist
- Parenting education
- Referrals to additional community resources

Differences between SWH and HRPP

- Visit frequency
- Long term vs short term
- Services available
- Feeding, lactation
- Developmental screenings
- Mental health
- Family support

The VINES program offers virtual telehealth support for families and their fragile infant after a NICU stay.

The program helps bridge the gap between a baby's discharge from the NICU and transition home to community care.

- Partnership with Smooth Way Home and Desert Neonatal Associates
- Scheduled and urgent care options
- Available for ~30 post discharge

Desert Neonatal Associates Website: https://vines.doxy.me/vines

How Smooth Way Home Can Help AzEIP Providers

- Connection with hospitals

- Medical records

- Family connections

- Support after a denial

SWH Hospitals

- Banner Desert
- Banner Estrella
- Banner Gateway
- Banner Thunderbird
- Banner University Center
- Banner University Tucson
- Tucson Medical Center

- Honor Health Shea
- Abrazo Arrowhead

- St. Joseph's
- Carondelet St. Joe's
- Northwest Medical Center
- Phoenix Children's Hospital
- Flagstaff Medical Center
- Chandler Regional Medical
- Sunrise Children's Hospital

- Valleywise

Child Find

Regulations for Part C of IDEA require each state to have a *comprehensive child find system* for the purposes of identifying, locating, and evaluating all infants and toddlers with disabilities ages birth–2 **as early as possible.**

Supporting SPAs with Initial Planning Process when infants are in the NICU

AzEIP Procedure 3.3: Initial Phone Call

- The service coordinator contacts the family as soon as possible, and no later than two (2) business days from the date the referral was received
- During the call the SC completes the following activities:
  - Confirm receipt of referral
  - Verify demographic information of child and family
  - Identify if parent or other person with whom child lives is part of ACP
  - Identify if child is involved with DCS and obtain DCS Case Manager contact information
  - Describe the purpose of early intervention and the early intervention process, including expectations for the initial visit and eligibility determination
  - share information about the following early intervention key principles
  - Verify the family's interest in proceeding with early intervention
  - Discuss how parents can prepare for the initial visit

Initial Phone Call

Service Coordinators can ask:

- Is this a good time to talk?
- Share about your child
- Child discharge date
- When would be a good time for the SC to call and meet with the family
- Family communication preferences
- Identify who the family would like to attend the initial visit
- Ensure family has contact information for the SC (don't expect the family has a pen to write it down)

How to Determine Which EI Team Supports the Family

Children in the NICU should be assigned based on the child's residence (hospital)

EI Team must identify through the initial conversation with the family which team will best support the child and family

Factors to consider in Identifying the appropriate team:

- Discharge, remembering discharge dates can change
- Continuity of Care
- Family's preference for modality of care

A child in the NICU does not alter the requirement that the Initial Planning Process must be completed within 45 days.

AzEIP Policy 3.3.2: Initial Visit

An initial visit conducted by the Service Coordinator with the family should occur within ten (10) business days from the initial AzEIP referral date to complete the following activities:

- Discuss the purpose of early intervention
- Explore the priorities and concerns of the family
- Fully and explain and provide Prior Written Notice (PWN) and procedural safeguards
- Explain the different funding sources used in early intervention
- Discuss and complete appropriate screening activities
- Obtain appropriate consents
- Discuss how child's eligibility will be determined

AzEIP Policy 3.3.5: Screening

- Screening activities are carried out to identify, at the earliest possible age, a child who is suspected of having a developmental delay and needs early intervention services.

- Screening includes parent report, observation, the gathering of information from families/caregivers and/or records indicating the results of recent and appropriate screening and **may** include the administration of appropriate instruments by personnel trained to administer those instruments.

Initial Visit

Initial Visit
- Introduction of the team members and their roles
- Confirm the child's and both parents information such as name and last name etc.
- Discuss the purpose of the Early Intervention
- Allow the family time to ask questions about the program and provide clarification as needed
- Discuss with the family about the Child and Family Rights
- Learn about the family concerns and priorities such as what is the family and child's immediate needs (is it learning about the child's diagnosis a priority, or medical equipment)?
- Ask about the newborn screening results
- How will the family be supported by the team while the child is still in the hospital and a discharge date has not been identified
- Explain how services will look different from the hospital to the home setting
- A team lead is identified, frequency of visits is discussed based on what works best for the family

Arizona Newborn Health Screening

- Newborn screenings check babies for serious but rare and mostly treatable health conditions at birth.
- It includes blood, hearing and heart screening.
- 35 conditions are currently being screened in Arizona
- There are three parts to newborn screening:
  - Blood Test
  - Hearing Screening
  - Heart Screening

Arizona | Newborn Screening

AzEIP Policy 3.5: Eligibility Determination

A child may be determined eligible for AzEIP by:

- A review of medical or other records documenting that the child has
  - An established condition or
  - A significant developmental delay in one or more developmental domains
- Completion of a multidisciplinary evaluation covering all developmental areas that establishes the child has a significant developmental delay in one or more of the developmental domains.

AzEIP Policy 3.4.1(b): Established Condition

Established conditions are defined as a diagnosed physical or mental condition that has a high probability of resulting in a significant developmental delay.

*Please refer to [AzEIP Eligibility Criteria for Established Conditions Technical Assistance Bulletin](#) for more details

Eligibility - Record Review

Record Review may be completed during IPP to identify if a child meets AzEIP eligibility criteria based on an AzEIP established condition or a significant developmental delay.

Record Review Considerations When Child is in the Hospital:

- Who can assist in obtaining records?
  - Family
  - Hospital with Consent to Share
  - Smooth Way Home with Consent to Share
- Established Condition
  - Will this lead to a significant delay?

Eligibility - Evaluation

Evaluation Considerations When Child is in the Hospital:

- Modality
  - In person
    - Check with hospital before you schedule with the fami
    - Any special permission to evaluate in NICU
  - Virtual or Hybrid
    - Is family comfortable and is it safe to handle the child
    - Will any hospital staff be present to assist
- Participants
  - Child/Family
  - Evaluators (AzEIP TBEIS Providers)
  - Hospital Staff
  - Others requested by family
- Informed Clinical Opinion
  - May be used when evaluators determine a child has a significant developmental delay that is not reflected in the evaluation tool(s)

AzEIP Policy 3.7: Child and Family Assessment (CFA)

- AzEIP partners with families to understand their unique resources, priorities, concerns, and interests related to their child's development and the activities and settings in which the child and family spend time.

- AzEIP ensures the family provides written consent to conduct the child assessment prior to conducting the assessment.

- The child and family assessment guides and documents this discovery process and ensures that the role of early intervention in the life of each family is specifically tailored to meet the priorities of each family.

- The voluntary, family-directed assessment is conducted to identify the family's resources, priorities, and concerns and the supports and services necessary to enhance the family's capacity to meet the developmental needs of the child in early intervention.

- The child and family assessment must be sufficiently comprehensive to develop a summary of the child's present level of development for the IFSP. Therefore, if needed, the multidisciplinary team may use a broad-spectrum assessment tool (i.e., criterion- referenced).

Child and Family Assessment

Things to consider if the child is still in the hospital during the CFA process:

- What does the family's schedule look like, when do they visit
- Do they have other children at home
- What supports do they have in place and how are those supports assisting them (family, friends, hospital staff, other agencies)
- What does the child and family need in order to discharge home
- What is the current discharge plan
- What are the families concerns regarding transitioning home
- Remembering things can change often and CFA may need to be updated several times, especially when they are discharged from the hospital.

AzEIP Procedure 3.8:
Child Outcome Summary (COS)

The Service Coordinator

- Discusses the Child Outcomes Summary (COS) process
- Captures on the IFSP Child Indicators Summary form how the child's development, across all domains, affects his/her participation and engagement in:
  - Positive social and emotional development, including relationships
  - Acquisition and use of knowledge and skills
  - Use of appropriate behavior to meet his/her needs.
- The data gathered from the child and family assessment may also be used to complete the COS process

Child Outcome Summary (COS)

Describing COS to families

- Gives a snapshot of where your child is now based on his/her chronological age
- Updated every six months so we can see growth
- Helps us review outcomes to see what we can do as a team to help your child

Child Outcome Summary (COS) continued

Tips for COS Ratings Discussions with Families of Children in NICU

- COS discussions build on Child and Family Assessment - pick activities from CFA to gather more information
- Use open ended questions and focus on what the child is doing
  - Tell me what it looks like when…changing diaper, during feeding, you enter the room or talk to the baby
  - How does your baby let you know when they don't like something? What calms/soothes your baby?
- Share praise, positivity, encouragement for even the simplest successes (e.g., moving eyes when holding him, different types of cries)

AzEIP Procedure 3.9.6: IFSP Outcomes

The IFSP team develops participation-based outcomes that reflect the family's priorities and interests, and the routines and activities with which they would like support from early intervention and documents the outcomes and strategies on the IFSP Outcomes page.

Child and Family Outcomes

Name of the person the outcome is for	An action verb	The context within the outcome will be practiced or	The priority this outcome is addressing
Juan	will eat	enough food	so he can gain weight and not have surgery
Sanjay	will play	with his toys and his sister	during bath time while sitting up in the tub
Sarah	will learn	about her daughter's diagnosis	so that she can describe to her extended family

Outcomes

- Are connected to the CFA
- Written without acronyms or jargon
- Routines/activity based
- Include the
  - Name of the person the outcomes is for, an action verb,
  - Context within the outcome will be practiced or the priority this outcomes is addressing

IFSP Outcomes

IFSP Outcomes

- Are based on the concerns and worries the family identifies at the creation of the IFSP
- Address what the family would like to see happen over the next few months to six months
- Should be achievable during the duration of the IFSP
- May include family outcomes that help the family around topics such as
  - Their child's diagnosis
  - About the medical equipment
  - Supports needed after hospital discharge
- Identify what is the family's biggest worry.

The team identifies child and family outcomes by

- Actively listening to the family
- Asking open ended questions
- Ensuring they are specific and child-centered and/or family-focused with their collaboration and input of information surrounding the sensitivity/delicacy of the NICU situation.

Supporting Children and their Families while in the NICU

- Utilization of Family Outcomes
  - Assist families with obtaining resources needed for discharge
  - Supporting families in learning about their child
- Non-Direct Support from Team Lead

AzEIP Policy 3.8.4(d): IFSP Services & Supports

The early intervention services based on **peer-reviewed research** and **resources necessary to meet the unique needs of the child and family** to achieve those outcomes or results. For each early intervention service, the IFSP must include:

- Actual Location
- Length (length of time during each session)
- Duration (dates for the initiation of each service and anticipated duration)
- Frequency (number of sessions)
- Intensity (Individual or group)
- Method of delivery each service

IFSP Services & Supports

- IFSP Services are based on what the family needs at the time of the IFSP
- If a child is in the hospital, they may need to have their services updated once they have returned home as the hospital supports will have changed

AzEIP Policy 3.8.4(e): Other Services

The following are the federal components required in an IFSP:

Other services, including medical or other services the child or family needs or is receiving through other sources, but that are neither required nor funded under IDEA, Part C, early intervention.

For services not currently being provided, include a description of the steps the service coordinator or family will take to secure those other services

Community Resources and Services for Families

Community Resources and Services:

- Healthy Families
- High Risk Perinatal program
- Raising Special Kids
- Smooth Way Home
- VINES: Virtual Neonatal Support Program
- DDD
- ALTCS
- Social Security
- WIC

General Resources:

- Housing
- Transportation
- Insurance
- Parent Support Groups
- Information about their child's diagnosis or condition
- Nursing
- Medical Equipment
- Legal Issues
- Transition home from Hospital

Specific Reminders from Presentation

- The earlier delays are identified and treated, the more likely the child will be able to reach their potential later in life.
- A child in the NICU does not alter the requirement that the Initial Planning Process must be completed within 45 days.
- Initial Visits screenings must include parent report, observation, gathering information from families/caregivers and or records indicating the results of recent and appropriate screenings. They **may** include the administration of an appropriate screening tool..
- Child and Family Outcomes are statements describing changes and benefits that the family would like to see for their child and their family.
- Family outcomes are vital in supporting the family as well as the child.
- An initial visit must be completed for all children prior to determining AzEIP eligibility.
- IFSP teams are encouraged to consider if it may be appropriate to write an IFSP for a shorter duration for a newborn or very young infant during the initial planning process.

General Reminders

- Transfers are submitted to RSK if a child is transferring from
  - One region to another region
  - Within region to another contractor with AzEIP approval
- Please make sure SCs are careful about Twin Documentation and keep their records separate and the use of their names and pronouns used (he/she) within reports, consents, contact logs, etc, etc
- Please make sure SCs are doing the I-TEAMS to FOCUS Push for DDD Eligibility Team to proceed with determination process
- Services provided in an ABA clinic or ABA school are not considered natural environment and will require a justification statement.

Resources we would like to share

Arizona Policy Manual
Arizona Procedure Manual
AzEIP Eligibility Criteria for Established Conditions Technical Assistance Bulletin
AzEIP Billing Manual
DES Program and Service Contact Numbers
Arizona Child Care Resources and Referral
Newborn Screening Arizona Department of Health Services
Healthy Families
High Risk Perinatal Program
Raising Special Kids
Smooth Way Home
VINES: Virtual Neonatal Support Program
Division of Developmental Disabilities
Arizona Long Term Care System
Social Security Income
Women, Infants and Children (WIC)
DES Program and Service Contact Numbers
Arizona Child Care Resources and Referral

Thank you for attending!

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