This guide outlines hospital-to-home transition guidelines to ensure a successful transition of an at-risk infant. Interagency planning is discussed, with the benefits for families, hospitals, and infant-toddler service providers highlighted. Steps that transition planners should follow to ensure a sound transition plan are provided. Useful suggestions are made by hospital-community transition planning teams. Information is provided on the following topics: identifying and monitoring potentially eligible children; referring eligible children to the community; facilitating the transition from hospital to home; supporting the family role in transition; formulating a family transition plan; initiating the referral to community programs; and providing community feedback to the referring hospital. Screening and evaluation issues are also discussed. An infant at-risk criteria checklist and an infant at-risk referral/discharge notification form are attached. Contains references for families, planners, and physicians. (CR)
A newborn baby is rushed by helicopter to a Neonatal Intensive Care Unit (NICU) at a hospital many miles away from his family's home. Suddenly the family members of the premature and critically ill infant experience shock and must confront an uncertain future.

Purpose

This manual and the Hospital to Home Transition Guidelines have been developed to assure that local planners, including hospital personnel, have accurate and practical information to design, implement and evaluate their own transition procedures. These procedures will allow them to work together to:

- address each family's needs during the child's hospitalization.
- provide a smooth transition when the family brings the child home.
- utilize the hospital and community service providers' expertise to meet an array of individual needs.
- coordinate child assessments and other hospital and community procedures to eliminate duplication.
Interagency Planning

Benefits of Transition Planning
Communitywide planning for transitions from hospital to community services provides basic procedures, which guide hospital and community service providers as they plan transitions with individual families.

Benefits for Families:
- Smooth transitions
- Improved access to services
- Increased support
- No interruptions in services
- Reduced stress

Benefits for Hospitals and Infant-Toddler Service Providers:
- Improved coordination
- More uniform transition practices
- Increased efficiency
- Decreased duplication
- Written procedures to guide practice
- Methods to evaluate transitions

Steps to Initiate a Community Transition Planning Team
First, assess the need to revise, update or develop a community transition plan. Ask families of children recently hospitalized how they feel about the transition home from the hospital. How were their family needs met during the child's hospital stay? After they left the hospital, were families able to access the community services available to themselves and the child? What suggestions do they have to improve the transition?

Second, ask hospital and community service providers if there is an established line of communication between hospital and community services. Do providers know whom to contact to make referrals or to obtain information? Do they know when a referral is appropriate? Is hospital staff aware of eligibility criteria for community programs to make wise decisions about referrals? How do hospital and community service providers support families during the child's hospitalization? What suggestions do providers have to improve transitions?

You can never get enough reassurance. I was terrified because I'd never known anyone who had a premie before. The other parents were nice, but we never talked about what we felt inside. I wished there was a support group or class of some kind.

Topeka parent

If the assessment supports a need for transition planning, then gather a team of family members and service providers who are dedicated to improving the transition. Service providers should represent all agencies that are providing services to families and infants. Team members need support from the agency administration to have the necessary time and authority to make procedural decisions.

Partners for Hospital to Home Community Transition Planning Teams
- FAMILY MEMBERS (whose children have been recently hospitalized)
- HOSPITAL (administration, unit staff, social work department)
- HEALTH DEPARTMENT (Maternal and Infant Program, Healthy Start)
- INFANT-TODDLER SERVICES (local interagency coordinating council representative, service providers)
- OTHER KEY PEOPLE (important to families or instrumental in the community)
Hospital to Home
Transition Guidelines

The Hospital to Home Transition Guidelines were developed by the Hospital to Home Transition Workgroup of the Bridging Early Services Transition Taskforce. This group was established and supported by the Kansas Coordinating Council on Early Childhood Developmental Services.

PURPOSE:

To provide families, hospital service providers and community Infant-Toddler Service systems with a more uniform hospital to home transition plan for children receiving Infant-Toddler and "at-risk" referrals in Kansas.

TARGET POPULATION:

Two groups of children and their families should be considered: 1) all children meeting Infant-Toddler Services eligibility criteria, and 2) children identified as being "at-risk" because of biological or environmental reasons.

STEPS:

Seven steps should be followed by transition planners to ensure a sound transition plan.
1. Identify and monitor eligible children.
2. Refer eligible children to the community.
3. Facilitate the transition from hospital to home.
4. Support the family role in transition.
5. Formulate a family transition plan.
6. Initiate the referral to community programs.
7. Provide community feedback to the referring hospital.

Five Kansas hospital-community transition planning teams worked together to test the Hospital to Home Guidelines. Here are their suggestions:

- Hold transition planning team meetings at the hospital.
- Involve a parent whose child was a patient of a key physician.
- Make personal visits to key medical and agency staff.
- Involve both administrators and direct service providers.
- Allow involvement to be one-time or ongoing.
- Ask to make presentations at Grand Rounds, staff inservices, subsection meetings and interagency meetings.
- Learn the terminology used by various agency and hospital staff.
- Allow time for representatives from each agency and hospital to explain the services they provide.
- Use sticky notes to chart each step of transition to visualize how a family proceeds from hospital into community services, rearrange and add sticky notes to improve the process and then put it in writing.
- Use a case review approach to evaluate a recent transition.
- Involve a member of the hospital forms committee—either as a team member or as a reviewer—to evaluate proposed forms.
- Start with medical and agency forms and procedures that are in place—review and adapt them to meet Infant-Toddler Services requirements. (Example: modify the hospital care plan to include the requirements of an interim Individualized Family Service Plan [IFSP].)
- Prepare to institute an Individualized Family Service Plan (IFSP) or interim IFSP to meet family needs while the child is still hospitalized.
- Coordinate hospital social services with community-based services to provide for family needs during the child's hospitalization (information, transportation, child care for other children).
- Plan ahead with community agencies so that family support services, such as transportation and respite care, may be accessed on an immediate, emergency basis.
1. Identify and Monitor Potentially Eligible Children

Each hospital unit that serves children potentially eligible for Infant-Toddler Services will be responsible for developing a process to identify and monitor those children. This monitoring may be accomplished by an individual or a team. It is suggested that the individual or individuals chosen for this task be familiar with developmental issues. The Infant At-Risk Criteria Checklist may be used to determine whether a referral to Infant-Toddler Services or a Discharge Notification for screening and monitoring is appropriate.

"The discharge planning tool that we used before didn't have a place for referrals. Someone could have written a note at the end of it—if he remembered. We are now getting to know all of the community service providers, but before we didn't know who we were talking to. This team has made everyone more accountable and responsible."

Mindy Graham, RN; Asbury Regional Medical Center Nursery, Salina

Definitions

Referral — a transfer of information to determine eligibility, initiate or continue early intervention services. KAR 28-4-550(d)

Medical personnel should refer children ages birth through 2 who have a diagnosed mental or physical condition that has a high probability of resulting in developmental delay. Examples of mental or physical conditions are listed in the Infant At-Risk Criteria Checklist (reprinted on pg. 5).

• Referrals shall be made when concerns are identified and a need for evaluation is established. KAR 28-4-551(d)
• A referral shall be made within two working days. Parent permission shall not be required for this initial referral. KAR 28-4-551(e)

Discharge Notification — a notification to be made during preparation for discharge when an infant or toddler is at-risk for developmental delay because of biological or environmental reasons. These children are not eligible for the statewide Kansas Infant-Toddler Services. Notifications from hospitals assure that regular contacts are maintained with the family so the child can be monitored through the local ongoing screening program.

Parental permission is not required for this initial notification. Examples of biological and environmental risk factors are listed in the Infant At-Risk Criteria Checklist (reprinted on pg. 9).

Referrals and discharge notifications should be sent to the family's county health department, the community's designated Infant-Toddler Services referral contact person and the primary care physician.

"I think the Level III NICU is identifying more children. They are looking at kids and saying, 'I think this is a Part II,' and they are noting on the bottom of the referral sheet why that child is a referral—low birth weight, hypertonia or whatever. I appreciate that because it helps to know why the decision was made."

Pam Herrman, Early Childhood Special Educator; Russell Child Development Center/ St. Catherine's Hospital, Garden City
Infant At-Risk Criteria Checklist

REFERRAL TO INFANT-TODDLER SERVICES CRITERIA

(Referral to community contacts to be made within 2 working days of identification of concerns)

Children ages birth through 2, who have a diagnosed mental or physical condition that has a high probability of resulting in developmental delay, are eligible for early intervention services. The delay may or may not be exhibited at the time of diagnosis, but the natural history of the disorder includes the need for early intervention services. Examples of such conditions include but are not limited to:

1. CHROMOSOMAL DISORDERS ASSOCIATED WITH DEVELOPMENTAL DELAY (including but not limited to Trisomy syndromes, Fragile X Syndrome, Cri du Chat, De Lange Syndrome, Osteogenesis Imperfecta, Apert Syndrome)

2. CONGENITAL AND ACQUIRED SYNDROMES AND CONDITIONS ASSOCIATED WITH DEVELOPMENTAL DELAY (including but not limited to cleft lip and palate, microcephaly, macrocephaly, myelomeningocele, seizures, cerebral palsy, muscular dystrophy, intracranial or intraventricular hemorrhage, periventricular leukomalacia, hypoxic ischemic encephalopathy, diabetes, meningitis, neurofibromatosis, intracranial tumors or abnormal neurological exam at discharge)

3. SENSORY IMPAIRMENTS (including but not limited to visual impairment, congenital cataract, coloboma, retinopathy of prematurity, hearing impairment)

4. INBORN ERRORS OF METABOLISM (including but not limited to PKU, Galactosemia, Cystic Fibrosis, Sickle Cell disease, Tay-Sachs disease, Maple Syrup disease)

5. DISORDERS SECONDARY TO EXPOSURE TO TERATOGENIC SUBSTANCES (including but not limited to drug or alcohol exposure in utero (infant toxic), Fetal Alcohol Syndrome, congenital or acquired infectious such as Cytomegalovirus, Rubella, Herpes, Toxoplasmosis)

6. SEVERE ATTACHMENT DISORDERS (including but not limited to failure to thrive requiring medical intervention and/or hospitalization)

7. A COMBINATION OF RISK FACTORS THAT, TAKEN TOGETHER, MAKES DEVELOPMENTAL DELAY HIGHLY PROBABLE (including but not limited to a combination of these factors: prematurity <30 weeks, very low birthweight <1500 grams, small or large for gestational age, length of hospital stay in newborn period >45 days, family history of hearing impairment, apnea, prolonged ventilation)

DISCHARGE NOTIFICATION CRITERIA

(Notification to community contacts to be made in preparation for dismissal)

Children ages birth through 2, who are at risk of developmental delay because of biological or environmental reasons, can be provided with early intervention services including tracking and monitoring. Services are optional based on local discretion and funding.

1. BIOLOGICAL RISK FACTORS (including but not limited to low birthweight 1500-2500 grams, >30 weeks gestation, asphyxia, respiratory distress, maternal diabetes)

2. ENVIRONMENTAL RISK FACTORS (including but not limited to evidence of family history of child abuse or neglect, lack of physical or social stimulation, high level of family disruption or maternal age less than 17 years)
2. Refer Eligible Children to the Community

Once it is determined during hospitalization that a referral to Infant-Toddler Services is appropriate, the referral needs to be made within two working days according to federal and state regulations. A Discharge Notification for screening and monitoring may be made in preparation for discharge. Parental permission is not required for either referral or notification of discharge. The local Infant-Toddler Services interagency representative will then contact the family to determine the interest in participating in services and to identify any family needs for community support prior to the child's discharge.

Eligibility for Services

According to the *Procedure Manual for Infant-Toddler Services in Kansas*, eligibility for Infant-Toddler Services may be established in any of these four ways:

- 25% delay or 1.5 standard deviations below the mean in one of the following developmental areas: cognitive, physical, communication, social or emotional, adaptive.

- OR 20% delay or one standard deviation below the mean in two or more of the following developmental areas: cognitive, physical, communication, social or emotional, adaptive.

- OR clinical judgment of a multidisciplinary team that concludes a developmental delay exists when tests are not available or do not reflect the child's actual performance.

- OR a diagnosed mental or physical condition that has a high probability of resulting in developmental delay. The delay may or may not be exhibited at the time of diagnosis, but the natural history of the disorder includes the need for early intervention services.

Child Find activities. (d) Referrals through child find shall be made when concerns are identified and a need for evaluation is established. (e) A referral shall be made within two working days. Parental permission shall not be required for this initial referral. KAR 28-4-551
3. Facilitate the Transition from Hospital to Home

Each community's local interagency coordinating council for Infant-Toddler Services (LICC) will develop a systematic plan in collaboration with local and regional hospitals to facilitate the transition from hospital to home. The LICCs and hospitals, in partnership with the families, will identify individuals to support families during this transition. Each LICC will designate a central point of contact for all referrals. A list of contact persons from LICCs across the state will be made available to hospital referral sources.

Questions to be answered in each community transition plan:

1. When the local contact person receives a referral or notification of discharge from a hospital, how will the family be contacted? If the infant will remain in the NICU for a period of time, how will contact be made? How will the initial contacts differ between referrals and notices of discharge? How will information about the benefits of Infant-Toddler Services and other community services be shared with families in a supportive and nonintrusive way?

2. When an infant with an established mental or physical condition is referred, what will be the process to document eligibility? What evaluation will be conducted by the hospital staff? How can this information be used to document eligibility? How will the clinical judgement of medical personnel be documented?

3. Who will be the Family Service Coordinator or interim coordinator?

4. What will be the process to write an IFSP or interim IFSP? Will the process be different if the infant continues to be hospitalized?

5. What community and hospital services will be available to support the family during the time of hospitalization? How will local family support services coordinate with hospital social work or family support services? How will information about family support services be shared with the family?

6. How will follow-up contacts be made if a family declines Infant-Toddler Services at the time of hospitalization or at the time of transition?
4. Support the Family Role in Transition

Family members or designated caregivers, such as grandparents or foster parents, will have opportunities to participate in formulating a plan for the child’s transition to the home. Families or caregivers may decide the level of involvement in transition planning.

“This is an example of a family where the parents are challenged with disabilities. Our contact with the family started prior to dismissal so that we could make the transition more effective. We knew there were a lot of needs, so we started very early on with the baby. The baby and family were in full services before he was a month out of the hospital. It was just a very quick process. We were able to get involved early and work with all the agencies who were going to be involved—the developmental program, ARC and other community agencies. We worked with all of them prior to dismissal, through dismissal and then after dismissal, too. Plus, we worked with them through the baby’s ongoing medical needs, including re-hospitalization.”

Donna Delaney, Family Services Coordinator; Rainbows United, Wichita

5. Formulate a Family Transition Plan

Each hospital will be responsible for establishing a process for developing a transition plan with the family. The Infant At-Risk Referral/Discharge Notification and the Infant At-Risk Criteria Checklist forms have been developed to guide the transition plan. They will provide necessary information, yet maintain confidentiality. These forms are suggested, but each community may wish to adapt them or use other forms that better fit local needs.

“I would like the local agencies to contact the families to just say, ‘We’re here and looking forward to visiting with you. If you have any problems or questions before we meet, don’t hesitate to call us.’ Once we were out of the hospital’s hands, there was a need for professional support.”

Salina mother

6. Initiate the Referral to Community Programs

Once the Infant At-Risk Referral/Discharge Notification has been completed, it will be sent to 1) the family’s county health department; 2) the community’s local Infant-Toddler Services contact; and 3) the primary care physician. The Infant-Toddler Services contact person has the responsibility to coordinate services with the health department and the primary care physician. It is also the responsibility of the Infant-Toddler Services contact person to provide families with information about all relevant community options.
Infant at-Risk Referral/Discharge Notification

Date ________________________________

Personal Data:

Name of Infant ___________________________

Gender ________________________________

Mother __________________________________

Marital Status __________________________

Relationship to infant ____________________

Significant Other _________________________

Relationship to infant ____________________

Address __________________________________

County ________________________________

City/State/ZIP ___________________________

Home Phone (_______) ______________________

Language _______________________________

Work Phone (_______) ______________________

Infant History:

Date of Birth ____________________________

Birthweight _____________________________ grams

Birthlength ____________________________ cm.

Gestational Age _______________ weeks by exam

Apgars 1 & 5 min. __________ & __________

Retinopathy of prematurity exam results: ________________________________

Suggested follow-up: ________________________________

Hearing screen results: ________________________________

Suggested follow-up: ________________________________

Hospital Social Worker: ________________________________

Neonatologist: ________________________________

Apnea Monitor ________________________________

F/U Appointments ________________________________

Feeding ________________________________

______________________________

Weight _____________________________ grams

Infant's Physician: ________________________________

Phone: (_______) ________________________________

Discharge diagnoses ________________________________

______________________________

______________________________

Community Health Department ________________________________

Part H Referral ________________________________

Part H Notification of Discharge ________________________________

Home Health Nurse ________________________________

Community Based Services ________________________________

Hospital Outpatient Clinics ________________________________

Neonatal Follow-up Clinic ________________________________

Child Protective Services ________________________________

Special Health Services ________________________________

Thank you,

Name ________________________________

Position ________________________________

Infant at-Risk Referral/Discharge Notification Form
"We are seeing families who did not want services initially come back two and three months later. They are calling back and saying ‘We are ready now,’ or ‘Let’s do this again.’"

Donna Delaney, Family Service Coordinator; Rainbows United, Wichita

### 7. Provide Community Feedback to the Referring Hospital

Kansas hospitals wish follow-up information in order to monitor the progress of infants who spent time in their NICUs. A feedback report provides the referring hospital with feedback from the referring community agency. The receiving agency will be expected, with parental consent, to provide feedback to the hospital contact person and the infant's physician.

A feedback report provides the referring hospital with feedback from the referring community agency. The receiving agency will be expected, with parental consent, to provide feedback to the hospital contact person and the infant's physician.

**Feedback Report Form**

<table>
<thead>
<tr>
<th>Type and Date of Contact (please check)</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>J Phone/date</td>
<td></td>
</tr>
<tr>
<td>J Home visit/date</td>
<td></td>
</tr>
<tr>
<td>J Office visit/date</td>
<td></td>
</tr>
<tr>
<td>J Letter/date</td>
<td></td>
</tr>
<tr>
<td>J Other (please specify)</td>
<td></td>
</tr>
</tbody>
</table>

Parental permission is necessary to release this information: Consent for release of information obtained:

- J Yes
- J No

**Parental feedback**

Feedback Report Form

Please complete the feedback report when a plan has been established and mail or fax copies of this form to the source of this referral and the infant's physician.

Parental permission is necessary to release this information: Consent for release of information obtained:

- J Yes
- J No

Current Medical/Developmental Concerns:

Date

Infant's Name

Parent's Names

Current Address

Current Phone

Current Physician

Referral for comprehensive evaluation

Referral for comprehensive evaluation

Re-admission to hospital?

Current Family Concerns

Agency

Address

Phone

Screening services being offered

Healthy Start Program

Individualized Family Service Plan (IFSP) in place

J Yes

J No

Services being offered

J Healthy Start Program

J Individualized Family Service Plan (IFSP) in place

J Literature sent to family

J Enrolled in developmental program

J Ultrasound screening

J Other (please specify)

J Yes

J No

"I can say I was real nervous at first, because I saw such a high percentage of parents declining services. But they were going to get lost. We are encouraged to see that families aren't getting lost, but they are equipped to find their way back if they have concerns. It gives that ownership to them. It is a family driven service, we are not mandating it."

Dey Fleming, RN; Wesley Medical Center NICU, Wichita

Donna Delaney, Family Service Coordinator; Rainbows United, Wichita

"We are seeing families who did not want services initially come back two and three months later. They are calling back and saying ‘We are ready now,’ or ‘Let’s do this again.’"

Donna Delaney, Family Service Coordinator; Rainbows United, Wichita

Donna Delaney, Family Service Coordinator; Rainbows United, Wichita

Donna Delaney, Family Service Coordinator; Rainbows United, Wichita

Donna Delaney, Family Service Coordinator; Rainbows United, Wichita
Screening and Evaluation Issues

Many questions have been raised about screening and evaluating infants who have been in an NICU.

A child with a condition that is an established risk for developmental delay shall be considered eligible and in need of services, and shall be referred for evaluation and assessment without a screening. 

KAR 28-4-553(b)

When the NICU team refers an infant with an established risk factor from the criteria checklist, the infant is automatically eligible for Infant-Toddler Services. Evaluation information is gathered to document the diagnosis to establish eligibility.

A review of the evaluations performed in the hospital may provide all or most of the information needed in the five developmental domains:

1. Physical development—including
   a. Health (including nutritional status)
   b. Vision
   c. Hearing
   d. Motor
2. Cognitive development
3. Communication development
4. Social and emotional development
5. Adaptive development

In the event of exceptional circumstances—such as a prolonged hospital stay—it may be impossible to complete the evaluation and IFSP within the required 45 days. In such cases, an interim IFSP shall be used.

An interim IFSP includes:
1. The name of the family service coordinator who will be responsible for implementation of the interim IFSP, as well as coordination with other agencies and persons.
2. The early intervention services that are needed immediately by the child and family.
3. Documentation of the reasons that the 45-day time requirement has not been met.
4. Parental signature indicating their knowledge of, and agreement to, the desire to begin services before evaluation or the delay in completing the evaluation.
Suggested Resources

Resources for Families

Videos:
- Families Together, Inc. (1993). Early childhood video. Families Together Parent Center, 501 Jackson, Suite 400, Topeka, KS 66603, 800-264-6343. (Note: This video provides basic information about infant-toddler services and family support)

Guide for the McClusky-Fawcett & O'Brien videos:

Handbooks:

Resources For Planners:


Resources To Share with Physicians:


HOSPITAL TO HOME: A GUIDE FOR TRANSITION PLANNERS was produced by the Bridging Early Services Transition Taskforce, a committee of the Coordinating Council on Early Childhood Developmental Services in Kansas. Funds were contributed by Infant-Toddler Services/Kansas Department of Health and Environment, Bridging Early Services Transition Project Outreach/Associated Colleges of Central Kansas, and the Coordinating Council on Early Childhood Developmental Services.

Editor: Cynthia Shotts. Contributors: Vicky Bonilla, Nicki Bradbury, Janie Bradley, Melanie Campbell, Brenda Coppel, Suzanne Chapel-Miller, Donna Delaney, Joanie Dinsmore, Debbie Fleming, Janiece Gonzalez, Pam Herren, Barbara Jackson, Dr. Valerie Kirschen, Kathy Johnson, Dr. Becky Rodgers, Sharon Rosenkotter, Rita Ryan, Deb Salisbury, Mary Schulte, Marilyn White, and Project Continuity

Photographic credits: Cal Schumacher, Hays Area Children's Center, and Wesley Medical Center


Additional copies of Hospital to Home: A Guide for Transition Planners may be obtained from the Make a Difference Information Network, 800-332-6262; Infant-Toddler Services, 913-356-6135; or Bridging Early Services Transition Project Outreach, 316-241-7754.