High Risk Infant Follow-up

Manual of Operations

2026

CPQCC

HRIF HIGH RISK INFANT FOLLOW-UP

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PART I – CCS HRIF PROGRAM

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Mission and Goal

Children's Medical Services (CMS) Branch/California Children's Services (CCS) Program has worked with the CCS/California Perinatal Quality Care Collaborative (CPQCC) High Risk Infant Follow-up (HRIF) Quality Care Initiative to develop a web-based HRIF Reporting System to collect data for the CCS HRIF Program. The HRIF Reporting System will be able to identify quality improvement opportunities for NICUs in the reduction of long-term morbidity; allow programs to compare their activities with all sites throughout the state; allow the state to assess site-specific successes; and support real-time case management. The system, collecting data on high-risk infants up to their third birthday, enrolled in the CCS HRIF Program, will add value to the current CPQCC data already collected.

Program Background

The CCS HRIF Program was established in 1979 to identify infants who might develop CCS Program-eligible conditions after discharge from a CCS Program-approved Neonatal Intensive Care Unit (NICU). Since 1979, the CCS Program's goal of identifying neonates, infants and children who may develop a CCS Program-eligible medical condition has not changed.

The CCS Program's standards for NICUs require that each CCS Program-approved NICU ensure the follow-up of neonates and infants discharged from the NICU who have high risk for neurodevelopmental delay or disability. The CCS HRIF Program provides for three Standard Visits which include a limited number of outpatient diagnostic services for infants and children up to three years of age whose care was provided in a CCS Program-approved NICU. All three Standard Visits should occur, particularly for those neonates, infants and children identified with impairments or to be at high risk, including very low birth weight infants, even if the child has been referred to services and other resources.

Each CCS Program-approved NICU must have an organized HRIF Program for the provision of these core diagnostic services or a written agreement with another CCS Program-approved HRIF Program to provide these services.

The CCS HRIF Program revised medical eligibility criteria (P.L. 01-0606), effective July 1, 2006, with additional diagnostic services available for reimbursement. The policy in P.L. 01-1113 dated November 22, 2013, clarified the HRIF criteria for services to ensure all eligible infants have access to these diagnostic assessments. These criteria are reiterated in this manual.

P.L. 01-1113 included clarification on medical eligibility for those neonates who require direct admit to a CCS Program-approved Pediatric Intensive Care Unit (PICU), who are never admitted to a CCS Program-approved NICU, but who otherwise meet all medical eligibility criteria for HRIF services, as reiterated in, Medical Eligibility Criteria. These neonates are eligible for HRIF services.

The following are reimbursable diagnostic services:

- A Comprehensive History and Physical Examination, including neurologic assessment, usually performed at approximately 4 to 8 months, 12 to16 months, and 18 to 36 months (adjusted for chronological age). Earlier or more frequent visits (in addition to the three Standard Visits) may be determined to be medically necessary by the HRIF Program. Examinations may be completed by one of the following: a CCS Program–approved (also known as CCS Program-paneled) physician (pediatrician or neonatologist), or a pediatric nurse practitioner (PNP). A PNP functioning in this role does not require CCS Program-approval and is practicing under the direction of a physician.

- A Developmental Assessment performed at each of the three Standard Visits (4 to 8 months, 12 to 16 months, and 18 to 36 months). At the 3rd and final Standard Visit (18 to 36 months), a developmental test such as the Bayley Scales of Infant Development (BSID) 3rd edition must be performed. Earlier or more frequent assessments (in addition to the three Standard Visits) may be determined to be necessary by the HRIF Program. Each assessment during the child's three-year eligibility period may be performed by one of the following who has training in the evaluation of motor and sensory development of high-risk infants: a CCS Program-approved pediatrician or neonatologist, PNP, CCS Program-approved nurse specialist (registered nurse with a Bachelor of Science Degree in Nursing), CCS-approved physical therapist, CCS Program-approved occupational therapist, or CCS Program-approved psychologist. The PNP functioning in this role does not need to be CCS Program-approved.

- A Family Psychosocial and Needs Assessment performed during each of the child's Standard Visits by a CCS Program approved social worker, PNP or CCS Program approved nurse specialist with expertise in family psychosocial assessment. Referral shall be made to a social worker upon identification of significant social issues by a PNP or nurse specialist. Additional assessments may be determined to be necessary by the social worker, PNP, or nurse specialist.

- A Hearing Assessment, for infants:
    - **Under six months of age** who were not screened in the hospital: A referral shall be made to a Newborn Hearing Screening Program (NHSP)-certified Outpatient Infant Hearing Screening Provider for an automated Auditory Brainstem Response (ABR) hearing screen. A list of NHSP-certified screening providers is available on the NHSP website: http://www.dhcs.ca.gov/services/nhsp or by calling the NHSP toll-free number at 1-877-388-5301; **or**
    - **Over six months of age** who were not screened in the hospital: A referral shall be made to a CCS Program-approved Type C Communication Disorder Center (CDC) for a diagnostic audiology evaluation; **or**
    - Who did not pass the inpatient NICU hearing screen: A referral shall be made to a NHSP-certified Outpatient Infant Hearing Screening Provider for an automated ABR rescreen if under six months of age or to a Type C CDC for a diagnostic audiology evaluation if over six months of age; **or**
    - Who do not have a hearing loss (passed initial screen, passed rescreen, passed diagnostic evaluation) but has one or more risk factors for developing a progressive or late-onset hearing loss, (as per the most recent version of the Joint Committee on Infant Hearing Position Statement [www.jcih.org]): A referral shall be made to a Type C CDC for at least one diagnostic audiology evaluation by 24 to 30 months of age. Earlier or more frequent assessments may be indicated for infants and children at high risk.

- An Ophthalmologic Assessment performed by a CCS Program-approved ophthalmologist with experience and expertise in the retinal examination of the preterm infant. The assessments are to be done in accordance with the American Academy of Pediatrics Policy Statement Screening Examination of Premature Infants for Retinopathy of Prematurity Pediatrics, Vol. 131: Number 1, January 2013, P.189-195 and until the ophthalmologist determines the child is no longer at risk for developing retinopathy of prematurity.

Medical Eligibility Criteria

Age Criteria
A neonate, infant or child is eligible for the HRIF Program from birth up to three years of age.

Residential Eligibility
The county CCS Program is responsible for determining whether the parent or legal guardian of a HRIF Program applicant is a resident of the county per CCS Program policy.

Financial Eligibility
Financial eligibility determination is not required for HRIF Program services as the HRIF Program provides diagnostic services only. While financial eligibility is not required, insurance information shall be obtained. See page 14, for information on authorization of HRIF services and other health coverage.

Medical Eligibility
A neonate, infant or child shall be medically eligible for the HRIF Program when the infant:

A. Met CCS Program medical eligibility criteria for NICU care, in a CCS Program-approved NICU regardless of length of stay (per Numbered Letter [N.L.] 05-0502, Medical Eligibility in a CCS Program-approved NICU, or the most current N.L.).

   NOTE: Medical eligibility includes neonates who require direct admit to a CCS Program-approved PICU, who are never admitted to a CCS Program-approved NICU, but who otherwise meet all medical eligibility criteria for HRIF services in this section.

OR

B. Had a CCS Program-eligible medical condition in a CCS Program-approved NICU regardless of length of stay, even if they were never CCS Program clients during their stay (per California Code of Regulations, Title 22 Section 41515.1 through 41518.9, CCS Program Medical Eligibility Regulations).

AND

C. The birth weight was less than or equal to 1500 grams or the gestational age at birth was less than 32 weeks.

OR

D. The birth weight was more than 1500 grams **and** the gestational age at birth was 32 weeks or more **and** one of the following documented criteria was met during the NICU stay:

   1. pH less than 7.0 on an umbilical cord blood sample or a blood gas obtained within one hour of life) or an Apgar score of less than or equal to three at five minutes or an Apgar score of less than 5 at 10 minutes.
   2. An unstable infant manifested by hypoxia, acidemia, hypoglycemia and/or hypotension requiring pressor support.
   3. Persistent apnea which required caffeine or other stimulant medication for the treatment of apnea at discharge.

4. Required oxygen for more than 28 days of hospital stay and had radiographic finding consistent with chronic lung disease.
5. Infants placed on extracorporeal membrane oxygenation (ECMO).
6. Infants who received inhaled nitric oxide greater than four hours, and/or treatment during hospitalization with sildenafil or other pulmonary vasodilatory medications for pulmonary hypertension.
7. Congenital heart disease (CHD) requiring surgery or minimally invasive intervention.
8. History of observed clinical or electroencephalographic (EEG) seizure activity or receiving antiepileptic medication(s) at time of discharge.
9. Evidence of intracranial pathology, including but not limited to, intracranial hemorrhage (grade II or worse), white matter injury including periventricular leukomalacia, cerebral thrombosis, cerebral infarction or stroke, congenital structural central nervous system (CNS) abnormality or other CNS problems associated with adverse neurologic outcome.
10. Clinical history and/or physical exam findings consistent with neonatal encephalopathy.
11. Other documented problems that could result in a neurologic abnormality, such as:
    a. History of CNS infection.
    b. Documented sepsis.
    c. Bilirubin at excessive levels concerning for brain injury as determined by NICU medical staff.
    d. History of cardiovascular instability as determined by NICU medical staff due to sepsis, congenital heart disease, patent ductus arteriosus (PDA), necrotizing enterocolitis, other documented conditions.

NICU Program Responsibilities

A. Each CCS-approved NICU that has its own HRIF Program is required to have a multidisciplinary team of professionals that may include pediatricians or neonatologists, pediatric nurse practitioners (PNPs), nurse specialists, ophthalmologists, audiologists, social workers, psychologists, physical therapists, and occupational therapists. All professionals listed must be CCS-approved. The PNP only requires CCS-approval when functioning in the CCS HRIF Program as the HRIF Coordinator.

   As part of the NICU discharge planning process, the NICU must identify and refer to the CCS Program clients identified as potentially eligible for the HRIF Program.

   1. This can be accomplished by submitting Service Authorization Requests (SARs) to the appropriate County CCS Program or State Systems of Care Division (SCD) Office.
   2. The SARs are available online at the CCS Forms website, http://www.dhcs.ca.gov/formsandpubs/forms/Pages/CCSForms.aspx
   3. Click on form DHCS 4488 (New Referral of CCS/GHPP Client SAR or form DHCS 4509, Established CCS/Genetically Handicapped Persons Program Client SAR).
   4. These forms can be completed online. Print and fax to the appropriate county CCS Program or State SCD Office.

5. The approved or denied SARs for HRIF services will be mailed or faxed to the HRIF provider by the local county CCS Program or SCD Office, if the hospital facility is not approved to access online correspondence via the Provider Electronic Data Interchange (PEDI) system.
6. The facility's designated PEDI Liaison is responsible for distributing copies of the authorization to all relevant facility providers.
7. The HRIF Coordinator is responsible for distributing copies of the authorization to HRIF team members and consultants responsible for the infant's follow-up care.

B. NICU Program Referral Requirements

1. It is the responsibility of the discharging to home CCS NICU/Hospital **or the last** CCS NICU/Hospital providing care to make the referral to the HRIF Program.
2. The NICU referral process:
    1. Upon referring a neonate, infant or child to the HRIF Program, a RR Form is completed (except HRIF I.D. Number) and submitted via the web-based HRIF-QCI Reporting System (https://www.ccshrif.org/) by the discharge/referring NICU/ Hospital at time of discharge to home.
    2. As noted above in B.1, the discharging/referring NICU/Hospital will submit a SAR to the local CCS Program Office for HRIF services. (Service Code Group [SCG] 06 should be requested).

HRIF Program Responsibilities

Each HRIF Program must designate one of its team members as the HRIF Coordinator. The PNP is only required to be CCS-approved when functioning as an HRIF Coordinator.

A. As the HRIF Program is a CCS Program Special Care Center (SCC), the required team members include a CCS Program-approved: HRIF Program medical director (pediatrician or neonatologist), HRIF coordinator, ophthalmologist, audiologist, social worker, and an individual to perform the developmental assessment. Each of these professionals may be reimbursed for the diagnostic services they provide. See Program Background – A Developmental Assessment for description of the health care professionals who perform developmental assessments.

NOTE: An individual provider may simultaneously serve in more than one role on the HRIF team.

B. All HRIF Programs shall develop policies and procedures, including job descriptions assigning function responsibilities, to ensure consistent implementation of the above policy regardless of staff changes. These documents shall be available for review during CCS Program site reviews.

C. Team members of CCS Program-approved HRIF Programs are to be listed on the CCS Program HRIF SCC Directory. Names of providers must be approved by the HRIF Program Medical Director to provide services to HRIF eligible infants and children. If your NICU does not have a HRIF Program, you are required to complete the CCS Program HRIF SCC Directory form to identify your NICU and the facility that you have made arrangements with to provide HRIF services. If there are subsequent changes to the HRIF Program SCC directory, you must submit an update.
NOTE: HRIF Directory Forms are on the CCS Program website:
http://www.dhcs.ca.gov/services/ccs/Pages/HRIF.aspx#hrifdirectory

HRIF Coordinator

The HRIF Coordinator shall be a CCS Program-approved: pediatrician or neonatologist, PNP, nurse specialist, psychologist, social worker, physical therapist, or occupational therapist. The PNP only requires CCS Program-approval when functioning in the CCS HRIF Program as a HRIF Coordinator.

The coordinator has the key role in follow-up and coordination of services for eligible infants and children and their families. The specific responsibilities of the coordinator are:

A. Coordination

1. Serve as the primary person coordinating HRIF services among the local county CCS Programs, other HRIF Programs located in CCS Program-approved Regional, Community, and Intermediate NICUs, State Regional Offices, clients/families, and others in matters related to the client's HRIF services.
2. Participate in NICU discharge planning process or multidisciplinary rounds.
3. Ensure identification of HRIF eligible clients according to HRIF eligibility criteria.
4. Ensure the NICU discharge planning process includes referral and SAR submission to the County CCS Program or State SCD Office. (see NICU Program Responsibilities).
5. Ensure copies of the authorizations are distributed to HRIF team members and consultants.
6. Gather medical reports and assessments for review by team members and prepare a summary report.
7. Ensure that a copy of the summary report is sent to the local county CCS Program or State SCD Office.
8. Confer with parents regarding services provided and results of clinical evaluations and assessments of their infant or child.
9. Assist families in establishing a Medical Home for the infant or child.
10. Assist clients/families in making linkages to necessary medical and social services.
11. Ensure there is a system in place to follow-up with families including those who have missed appointments. Collect documentation of the reason for missed appointments and develop a plan of action for improving HRIF Program adherence for evaluations and assessments.
12. Provide coordination between the HRIF Program and the infant's or child's (pediatric) primary care physician, specialists, and local county CCS Program or State SCD Office when appropriate.
13. Coordinate HRIF services with the local county CCS Program and SCD Offices and other local programs.
14. Coordinate follow-up service needs among the CCS Program-approved Regional, Community and Intermediate NICUs within the community catchment area and with those NICUs that provide HRIF referrals to their agency.

B. Client Referral Services and Follow-Up

1. Ensure and document referrals are made to the Early Start (ES) Program for children who meet ES eligibility criteria. Refer to the Department of Developmental Services website for ES information: https://dds.ca.gov/General/Eligibility.cfm
2. Ensure referrals are made to the Regional Center when those services are appropriate.
3. Ensure referrals to HRIF diagnostic consultations and assessments are made with CCS Program-approved providers.
4. Ensure referrals to CCS Medical Therapy Program (MTP) are made as needed.

   Reminder: CCS Program eligibility and referral criteria for MTP are different from CCS/CPQCC HRIF data collection definitions for MTP eligibility.
5. Provide referral and resource information for other social and developmental programs within the community, as required.

C. Education Services Program

1. Provide education and outreach about the HRIF Program and services, clinical care, required documentation on transfer, and referral options, including outreach to NICUs that have a Regional Cooperation Agreement to CCS Program-approved Community and Intermediate NICU's and other community referral agencies, as appropriate.
2. Develop and provide education to parents and family members about the high-risk infant's medical condition(s), care and treatment, special needs and expected outcomes of care.
3. Provide education to parents and family members about the system of care and services (including social services) available to help them nurture, support, and care for the high-risk infant.

HRIF Program Reporting Requirements

A. The HRIF Coordinator is responsible for ensuring that data is collected and reported to State SCD, CCS Program and CPQCC. Reporting forms referenced in CCS N.L. 10-1113 and HRIF P.L 01-1113 are superseded by this P.L. The HRIF Coordinator will:

1. Coordinate the collection, collation, and reporting of required data.
2. Provide data to CCS/CPQCC Quality Care Initiative (QCI) HRIF Web-Based Reporting System. Refer to the HRIF website for reporting system information and requirements: https://www.cpqcc.org/follow/what-hrif. To view and download the Manual of Operations and reporting forms visit: https://www.cpqcc.org/follow/hrif-data-resources.

   The reporting forms include:

   - Referral/Registration (RR)
   - Standard Visit (SV)
   - Additional Visit (AV)
   - Client Not Seen/Discharge (CNSD)
3. Ensure required data is submitted accurately and in a timely fashion to the CCS/CPQCC HRIF and meets all required deadlines.

4. Review and share results of the HRIF Summary Report and the HRIF CCS Program Annual Report and the NICU Summary Report with members of the HRIF Program team, the referring NICU Medical Directors, and the NICU team.
5. In collaboration with the NICU Medical Director, ensure that the HRIF Program fully participates in the CCS Program evaluation, including submission of required information and data.

B. Required Reports for Case Management

1. A summary report of the HRIF Team Visit is required to be submitted to the local county CCS Program or State SCD Office. This information is necessary for the local county CCS Program or State SCD Office staff case management activities.
2. The HRIF Program can download a template HRIF Team Visit Report form at http://www.dhcs.ca.gov/services/ccs/Documents/hrifteamvisit.pdf or submit its own team report which shall include the required summary reporting elements.
3. A copy of the HRIF Team Visit Report and copy of the comprehensive physician report (either the template form or in lieu of this form, a dictated team report and physician report) should also be distributed to the:
    - County CCS Program or State SCD Office
    - NICU Medical Director (if the director is not directly involved with HRIF Program)
    - Medical Home (or primary care provider)
    - Other providers involved in the infant's or child's care.

Authorization of HRIF Services

A. As part of the NICU discharge planning process, the NICU must identifyand refer to the CCS Program infants identified as potentially eligible for the HRIF Program. Refer to Section IV.B regarding NICU referral and SAR submission information. The approved SARs for HRIF services will be sent to the HRIF Coordinator who is responsible for distributing copies of the authorization to all relevant HRIF team members and consultants responsible for the infant's follow- up care.

B. The HRIF Program will receive an authorization of services for SCG 06 for each infant or child determined eligible for theHRIF Program.

C. SCG 06 contains billable codes for diagnostic services provided by medical and other allied health professionals. The provider group entitled Other Allied Health Professionals includes pediatric nurse specialists, nurse specialists, psychologists, social workers, physical therapists, occupational therapists, and audiologists.

SCG 06 allows HRIF Program providers to render limited core **diagnostic services only** for a CCS Program client without the submission of a separate request for each service required. No additional codes are approved for HRIF diagnostic services.

1. Refer to the CCS Program website for HRIF SCG 06 codes anddescriptions http://www.dhcs.ca.gov/services/ccs/cmsnet/Pages/SARTools.aspx.
2. Refer to the Medi-Cal Provider Manual for the most current code list and billing

guidelines: http://files.medi-cal.ca.govpublications/masters-mtp/part2/calchildser_m00i00o03o04o07o09o11a02a04a05a06a07a08p0 0v00.doc.

3. Refer to the superseded HRIF N.L. 09-0606 for historical code descriptions for provider type and type of service http://www.dhcs.ca.gov/services/ccs/Documents/ccsnl090606.pdf.

NOTE: On July 1, 2013, the Department implemented new pricing methodology based on Diagnosis Related Groups (DRGs) for reimbursement of inpatient stays at private hospitals for both CCS Program and Medi-Cal. DRG **inpatient** reimbursement methodology does not affect CCS Program eligibility or service authorization for **outpatient** services. This includes and applies to HRIF diagnostic services.

D. At the time of the referral for HRIF authorization, an authorization for two home assessments by the HHA nurse, preferably experienced in evaluating the maternal/infant environment, may be separately authorized if needed.

1. The HRIF Program must inform the local county CCS program which HHA is to be authorized for skilled nursing home assessment(s).
2. The authorization will be for up to two home assessments during the first year.
3. These visits are only to assess the home environment. They are not to be used as the venue for the provision of HRIF diagnostic services.
4. Additional home assessments by the HRIF HHA nurse requires medical necessity justification from the HRIF Program physician.

E. When a CCS Program-eligible medical condition is discovered as part of the HRIF diagnostic assessments, the HRIF Coordinator is responsible for referring the client to the local county CCS program or State SCD Office. The program eligibility, including financial eligibility, will be determined by the local CCS program staff for treatment of the CCS Program-eligible medical condition.

If found to be eligible for the CCS Program, treatment services for the child will be separately authorized to the most appropriate CCS Program-approved provider. HRIF services (SCG 06) will continue to be authorized up to the child's third birthday. An overview of CCS Program-eligible conditions can be found on the CCS Program website at http://www.dhcs.ca.gov/services/ccs/Pages/medicaleligibility.aspx.

F. When the CCS HRIF Program staff identifies the HRIF client as having other health coverage (OHC), i.e., commercial third-party health insurance or Health Maintenance Organization (HMO), the HRIF staff must bill the OHC prior to billing the CCS Program. A denial of benefits or Explanation of Benefits (EOB) must be attached to each claim. CCS Program/Medi-Cal is the payor of last resort.

1. The State SCD Office expects HRIF clients identified as high-risk and authorized for HRIF diagnostic services to receive these services. HRIF programs that do not provide diagnostic services as authorized because the client has OHC with an unmet deductible or co-payment must notify the client's CCS Program county nurse case manager.
2. The local CCS county program county or State SCD Office staff will contact the StateHRIF Program manager to report any unresolved issues of a CCS Program HRIF client who is unable to access authorized services to assure HRIF-eligible clients receive services.

G. Provision of HRIF diagnostic services may be terminated prior to the child's third birthday if the HRIF Program indicates that the child no longer has high risk for neurodevelopmental concerns and HRIF services are no longer required. This may occur when the child is found to be doing well on neurodevelopmental examination and testing.

NOTE: If an infant who has been discharged from HRIF Program services, is later identified, prior to the third birthday, as being at risk for neurodevelopmental issues, that child may be reinstated into the HRIF Program.

Claims Submission

This section provides general guidelines for HRIF Program billing. HRIF services are reimbursable to the HRIF Program when provided by CCS Program-approved HRIF providers. Providers listed in the HRIF directory have been approved to provide services to the HRIF-eligible child.

General Requirements

1. The HRIF SCG 06 SAR only covers reimbursement of diagnosticservices (codes) included in the SCG 06.
    a. Ophthalmology diagnostic services, as listed in the SCG, may bebilled by the ophthalmologist using the SAR number.
    b. Audiology diagnostic services, as listed in the SCG, may be billedby the approved Type C CDC performing the services using the SAR number.
    c. Psychologists are only authorized to bill for limited diagnostic developmental assessment procedure codes included in SCG 06. Procedure codes that represent intervention (treatment) services are not payable with the SAR.
    d. Developmental testing procedures rendered by either a Nurse Specialist or a Physical or Occupational Therapist must be billed by the facility with the facility's outpatient Medi-Cal provider number.
2. Providers must be enrolled in the Medi-Cal Program and use their active Medi-Cal provider number on all authorized claims for all CCS ProgramHRIF clients.
3. Allied healthcare providers (e.g., physical/occupational, therapists, audiologists, and social workers) who are **employees** of a hospital or facility are exempt from the Medi-Cal provider number requirement since the facility bills for their services using the facility's Medi-Calprovider number.
4. If applicable, providers must request authorization from a client's other commercial third-party health insurance carrier or HMO prior to providing services and bill the client's other commercial health insurance carrier or HMO plan **prior** to billing the CCS Program. A denial of benefits or an EOB must be attached to each claim. CCS Program/Medi-Cal is the payor of last resort.

    NOTE: See Authorization of HRIF Service, Section E., regarding other health coverage and provision of HRIF diagnostic services.

Claims Submission

1. Providers billing for HRIF patients with a SAR issued to the SCC must adhere to the specific instructions described in the Medi-Cal Provider Manual when completing the claim form. For claim completion instructions, refer to the Medi-Cal Provider Manual.
2. For claim submission information, refer to the Computer MediaClaims (CMC) section of the Medi-Cal Program and Eligibility manual located at: http://www.medi-

cal.ca.gov/cmc_instructions.asp or call the Telephone Services Center at 1-800-541-5555.

3. Claims authorized for CCS Program/Medi-Cal children residing in Marin, Napa, San Mateo, Santa Barbara, Solano, and Yolo counties must be sent to the issuing county for approval and processing. Refer to the Medi-Cal Provider Manual, CCS Program Billing Guidelines.

NOTE: If you have any questions regarding HRIF Program services, please submit your inquiry to the State SCD office via e-mail at: hrif@dhcs.ca.gov.

Technical Support

CPQCC provides technical support for the HRIF Reporting System. Please direct all your questions and comments to HRIF Support team by submitting a ticket through CPQCC's Help Desk.

Help Desk: www.cpqcchelp.org

Mailing Address:
Center for Academic Medicine
California Perinatal Quality Care Collaborative (CPQCC)
Neonatology – MC 5660
453 Quarry Road
Palo Alto, CA 94304

Questions and comments related to policy and procedures should be directed to the State Systems of Care Division (SCD) Office:

Email: hrif@dhcs.ca.gov
Web Address: www.dhcs.ca.gov/services/ccs/Pages/HRIF.aspx

Mailing Address:
California Department of Health Care Services
Children's Medical Services Branch
P.O. Box 997413, MS 8100
Sacramento, CA 95899-7413

PART II – HRIF REPORTING SYSTEM

The HRIF Reporting System (www.ccshrif.org) contains all of the forms necessary to refer and register an infant at an HRIF clinic and to document their visits, as well as extensive reporting tools. All forms are completed and submitted online. The forms are:

- Referral/Registration (RR) – used by the NICU staff to refer an infant
- Standard Visit (SV) – documents a standard core visit.
- Additional Visit (AV) – documents a visit deemed necessary in addition to standard core visits
- Client Not Seen/Discharge (CNSD) – documents the reason a patient was not seen (details below)

Visit the HRIF Data Resources page on the CPQCC website to download copies of the reporting forms for reference.

Reporting Forms

Referral/Registration (RR)

Eligible infants must be referred to the HRIF clinic by the discharging to home CCS-approved NICU, or the last CCS-approved NICU providing care to the infant. Referral must happen at the time of discharge to home to ensure timely follow-up.
NOTE: Only refer patients who are alive at the time of discharge to home.

Referral Process:

- Discharging NICU:
    1. Complete the RR form via the HRIF Reporting System; this will notify the HRIF Clinic that a new patient has been referred.
    2. Submit a Service Authorization Request (SAR) to the local CCS Office to authorize coverage for HRIF Program services (request Service Code Group [SCG] 06). See Authorization of HRIF Services for more information.
    3. Send a copy of the discharge summary to the HRIF Clinic.
- HRIF Clinic:
    1. Review the referred RR form for completeness if information is missing contact the referring discharging NICU.
    2. Accept the patient record via the HRIF Reporting System (all applicable information will be automatically carried forward to the Standard Visit form.)

Standard Visit (SV)

HRIF involves three core visits that take place during the following time periods:

- **Visit #1** (4 - 8 months)
- **Visit #2** (12 - 16 months)
- **Visit #3** (18 - 36 months)

NOTE: The time frames for the core visits are recommendations set by the HRIF Executive Committee; actual time frames may vary. In addition, some infants may require more visits.

- At each core visit, an SV form must be completed and submitted via the HRIF Reporting System. The **Disposition** at the end of the form **must** be completed.
- At the third and final visit (18 to 36 months), a developmental test such as the Bayley Scales of Infant Development (BSID) 3rd edition **must** be performed and reported.
- It is **highly recommended** that an Autism Spectrum Screening tool such as the MCHAT be performed between 16-30 months of age.

Incomplete Standard Visits

The most common reasons for an incomplete core visit are difficulties in obtaining a neurologic or developmental assessment. If you cannot obtain a neurologic or developmental assessment during the core visit, indicate the reason why the assessment was not performed and then schedule a return visit for the infant to complete the assessment(s). When the infant returns, the missing neurologic or developmental assessment data can be entered on the incomplete SV form. The date of the return visit should be entered in the **Date Performed** field(s).

NOTE: Patient measurements should be taken at the time when the neurologic and developmental assessments are performed. See Patient Assessment.

If situational information has changed between the incomplete core visit and the return visit, this should be updated, for example: name, address, caregiver, Child Protective Services (CPS) placement, etc.

Additional Visit (AV)

Submit an AV form if an infant requires additional visits for further assessment. Additional visits may occur before, between and/or after the recommended time frames for standard visits. This form **only** captures the date, reason (social risk, case management, concerns with neuro/developmental course or other) and disposition for the additional visit.

Client Not Seen/Discharge (CNSD)

The CNSD form should be used if:

- An infant was referred to your HRIF clinic, but clinic staff were unable to contact the infant's parent (primary caregiver) to establish an initial core visit.
- No Show: parent (primary caregiver) rescheduled (less than 24 hours) or did not show up for a scheduled core visit.
- The infant was eligible for HRIF, but the parent (primary caregiver) declined service.
- The infant expired prior to core visit, family relocated, insurance was denied, etc.
- The infant was transferred/referred to another HRIF clinic for follow-up services.

This form captures **only** the date, category, reason, and disposition for the client not seen visit.

Referral/Registration (RR) Form

Required Fields **must** be entered to save the RR form. Saved forms can be revisited later to make updates. Required fields improve the data linkages between the Maternal Database (managed by the California Maternal Quality Care Collaborative – CMQCC) and CPQCC's NICU and HRIF Databases.

Online Entry Screen

Referred HRIF Clinic (New Patient Referral Form)

Select the HRIF Clinic where the infant/child will be receiving follow-up services.

Unable To Complete Form

Use **only** when the HRIF Clinic is unable to complete the RR form, because:

- Infant/child was lost to follow-up.
- Infant/child expired prior to initial visit.
- Primary caregiver(s) refused follow-up service.

NOTE: Submit a CNSD form to clarify why the RR form is unable to be completed.

This Form Is Closed

This checkbox feature serves as an electronic signature confirmation that all available data has been entered.

HRIF Identification (ID) Number

Is a unique computer-generated number assigned to the infant/child enrolled in the HRIF Clinic.
NOTE: The HRIF ID Number is automatically generated after submission of the RR form.

Program Registration Information

California Children's Services (CCS) Number

Enter the 7-digit CCS Number of the infant/child. This number is given to the infant/child when his/her case becomes active and is assigned within a few days of the child's eligibility for CCS. If a CCS number is not assigned to the infant/child leave it blank.

NOTE: The Alpha letter T is acceptable to enter and indicates that the CCS Number is temporary. Example of a temporary CCS number T + seven-digits = T1234567.

Infant Not CPQCC NICU Eligible

Select **Infant NOT CPQCC NICU Eligible**, if the infant/child **does not** meet CPQCC's NICU eligibility criteria (See Is That Baby Eligible?) and therefore **does not** have a NICU Record ID. Enter **99999** as the NICU Record ID.

NICU Reference ID *Required Field

The NICU Reference ID is a combination of:

1. The last six digits of the Health Care Access and Information, HCAI *(formerly Office of Statewide Health Planning and Development, OSHPD)* facility ID from the discharging/referring or birth CCS-approved NICU.
2. The infant/child's NICU Record ID from the discharging/referring or birth CCS-approved NICU hospital, where the infant/child was born or admitted on or before day 28 of life.
   NOTE: The CCS-approved NICU discharging the infant/child home could also be the same facility referring the infant/child to the HRIF Clinic.

E.g., for a NICU with HCAI *(formerly OSHPD)* ID 12345 and an infant in that NICU whose NICU Record ID is 67899, the NICU Reference ID would be 12345-67899.

The HCAI *(formerly OSHPD)* ID and NICU Record ID **must** match. If you use the birth hospital's HCAI *(formerly OSHPD)* ID, then you **must** use the birth hospital's NICU Record ID.

Every CCS-approved NICU hospital has a NICU Data Contact who keeps a record of all CPQCC NICU-eligibility patients. Use the CPQCC Member Directory to identify the NICU Data Contact(s) from the discharging/referring or birth hospital. The directory is available in the navigation panel in the Reporting System.

NOTE:

- Enter **99999** or select the Infant NOT NICU Eligible checkbox, for infants who did not meet CPQCC's NICU-eligibility criteria.
- Enter **00000** for infants when a NICU Record ID has not been assigned at the time of the infant's referral to the HRIF Clinic. If a NICU Record ID is assigned to the infant later, use the Manage NICU Reference ID tool to correct the NICU Record ID.
- Enter **77777** for infants who met the CPQCC's NICU -eligibility criteria, but were never assigned a NICU Record ID.

Date of Birth *Required Field

Enter the date of birth for the infant/child using MM-DD-YYYY.

Birth Hospital *Required Field

Select the hospital where the infant/child was born.

Birth Weight *Required Field

Enter the birth weight in grams (gm). (Weight parameters 300 – 6,000 gm).

Gestational Age *Required Field

Enter the estimate of gestational age in weeks and days based on available data in medical record.

Singleton/Multiple Birth Gestation *Required Field

- Select **Singleton** for any single live birth.
- Select **Multiple** if product of multiple pregnancy and birth order.
  Multiple Gestation Information
  If Multiple Gestation is selected, indicate the infant's birth order (i.e.: first born = A, second born = B, etc.) as well as the total number of infants actually delivered (count both live born and still born infants). For example, the second infant born of triplets would be entered as 3B.

Infant's Sex *Required Field

- Select **Male** or **Female**.
- Select **Undetermined** when sex is not assigned as male or female by the time of discharge because it has been considered to be undetermined (or "ambiguous") by the clinical team. (Added Nov. 2019)
- Select **Unknown** if sex cannot be obtained.

Infant's Race / Ethnicity *Required Field

(Added Jan 2025)

NOTE:

- Selecting **Declined** or **Unknown** categories will cancel (grey out) the other race/ethnicity options.

Reporting: Starting 2027, the reporting tables and displays will be extended to include multiple race and ethnicity categories.

On March 28, 2024, the Office of Management and Budget (OMB) revised the Statistical Policy Directive No.15 (SPD 15): Standards for maintaining, collection and presenting federal data on race and ethnicity. SPD 15 has been updated to collect data using a single combined race and ethnicity and allowing for multiple responses. These revisions are intended to result in more accurate and useful race and ethnicity data across the Federal government. Reference: https://www.federalregister.gov/d/2024-06469.

Select the infant/child's race or ethnicity (check all that apply):

- Select **American Indian or Alaska Native**, individuals with origins in any of the original peoples of North, Central, and South America, including, for example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, and Maya.
- Select **Asian**, individuals with origins in any of the original peoples of Central or East Asia, Southeast Asia, or South Asia, including, for example, Chinese, Asian Indian, Filipino, Vietnamese, Korean, and Japanese.
- Select **Black or African American**, individuals with origins in any of the Black racial groups of Africa, including, for example, African American, Jamaican, Haitian, Nigerian, Ethiopian, and Somali.

- Select **Hispanic or Latino** individuals of Mexican, Puerto Rican, Salvadoran, Cuban, Dominican, Guatemalan, and other Central or South American or Spanish culture or origin.
- Select **Middle Eastern or North African**, individuals with origins in any of the original peoples of the Middle East or North Africa, including, for example, Lebanese, Iranian, Egyptian, Syrian, Iraqi, and Israeli.
- Select **Native Hawaiian or Pacific Islander**, individuals with origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands, including, for example, Native Hawaiian, Samoan, Chamorro, Tongan, Fijian, and Marshallese.
- Select **White**, individuals with origins in any of the original peoples of Europe, including, for example, English, German, Irish, Italian, Polish, and Scottish.
- Select **Other**, if the individuals' race or ethnicity is not represented by any of the above categories.
- Select **Unknown**, if the parent or primary caregiver cannot identify the infant/child's race or ethnicity. **NOTE:** If selected no other category can be checked.
- Select **Declined**, if the parent or primary caregiver refuse to declare the infant/child's race or ethnicity. **NOTE:** If selected no other category can be checked.

Hospital Discharging to Home *Required Field

Select the name of the hospital discharging the infant/child to home.

Referring CCS NICU

If the discharging hospital is **not** making the referral to the HRIF Clinic, select the name of the hospital that is making the referral. **NOTE:** The CCS NICU discharging the infant/child home could also be the same facility referring the infant/child to a HRIF Clinic.

Date of Discharge to Home *Required Field

Enter the date when the infant/child was discharged to home (Foster Care or Medical Foster Care) from your hospital (does not included transfers to another hospital) using MM-DD-YYYY.

Infant Still in Hospital

(Added Jan 2014)

Select, if the infant/child is still hospitalized in the NICU or another unit in the hospital at 8 months' chronological age.

Birth Mother's Date of Birth *Required Field

- Enter the biological or gestational carrier/surrogate mother's date of birth using MM-DD-YYYY.

  NOTE: For the maternal data items, enter maternal data on the birth mother, the woman who delivered the infant, even if she is a gestational carrier/surrogate.

  Biological Mother

The woman from whom one inherits half of one's DNA and who is the source of one's mitochondrial DNA; related by birth, cell or organism.

Gestational Carrier/Surrogate Mother

A woman who bears a child on behalf of another woman, either from her own egg fertilized by the other woman's partner, or from the implantation in her uterus of a fertilized egg from the other woman.

NOTE: A surrogate, who also donates the egg, is the biological mother.

- Select **Unknown** if the birth mother's (biological or gestational carrier/surrogate) date of birth at time of delivery is unknown.

The modification of these maternal items will improve the data linkage between the CMQCC Maternal Database with CPQCC NICU and HRIF Reporting System databases.

Birth Mother's Race / Ethnicity *Required Field

(Added Jan 2025)

NOTE:

- Selecting **Declined** or **Unknown** categories will cancel (grey out) the other race/ethnicity options.

Reporting: Starting 2027, the reporting tables and displays will be extended to include multiple race categories.

On March 28, 2024, the Office of Management and Budget (OMB) revised the Statistical Policy Directive No.15 (SPD 15): Standards for maintaining, collection and presenting federal data on race and ethnicity. SPD 15 has been updated to collect data using a single combined race and ethnicity and allowing for multiple responses. These revisions are intended to result in more accurate and useful race and ethnicity data across the Federal government. Reference: https://www.federalregister.gov/d/2024-06469

Select the birth mother's race or ethnicity (check all that apply):

- Select **American Indian or Alaska Native**, individuals with origins in any of the original peoples of North, Central, and South America, including, for example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, and Maya.
- Select **Asian**, individuals with origins in any of the original peoples of Central or East Asia, Southeast Asia, or South Asia, including, for example, Chinese, Asian Indian, Filipino, Vietnamese, Korean, and Japanese.
- Select **Black or African American**, individuals with origins in any of the Black racial groups of Africa, including, for example, African American, Jamaican, Haitian, Nigerian, Ethiopian, and Somali.
- Select **Hispanic or Latino** individuals of Mexican, Puerto Rican, Salvadoran, Cuban, Dominican, Guatemalan, and other Central or South American or Spanish culture or origin.
- Select **Middle Eastern or North African**, individuals with origins in any of the original peoples of the Middle East or North Africa, including, for example, Lebanese, Iranian, Egyptian, Syrian, Iraqi, and Israeli.
- Select **Native Hawaiian or Pacific Islander**, individuals with origins in any of the original

peoples of Hawaii, Guam, Samoa, or other Pacific Islands, including, for example, Native Hawaiian, Samoan, Chamorro, Tongan, Fijian, and Marshallese.

- Select **White**, individuals with origins in any of the original peoples of Europe, including, for example, English, German, Irish, Italian, Polish, and Scottish.
- Select **Other**, if the individuals' race or ethnicity is not represented by any of the above categories.
- Select **Unknown**, if the birth mother cannot identify a race or ethnicity. **NOTE:** If selected no other category can be checked.
- Select **Declined**, if the birth mother refuse to declare a race or ethnicity. **NOTE:** If selected no other category can be checked.

Insurance *Required Field

NOTE: The Healthy Families Program transitioned to Medi-Cal in 2013. Select **Medi-Cal** for Medi-Cal Managed Care plans.

Select **all** insurance options that apply at the time of visit:

- **CCS**
- **Commercial Health Maintenance Organization (HMO)**
- **Commercial Preferred Provider Organization (PPO)**
- **Medi-Cal**
- **Point of Service/Exclusive Provider Organization (EPO)**
- **No Insurance/Self Pay**
- **Other**
- **Unknown**

Primary Caregiver

Indicate the primary caregiver (parent/legal guardian(s) who are responsible for caring for the infant/child). If the infant/child's primary caregiver changed in the time between NICU discharge to home and the referral to the HRIF Clinic, select the category that best describes the infant/child's current living situation with his (or her) primary caregiver. **NOTE:** The Primary Caregiver is **not** the babysitter or childcare/daycare provider.

Select only **one** option.

- Select **Mother** if the infant/child lives with one biological parent and she serves as the primary caregiver in the home.
- Select **Father** if the infant/child lives with one biological parent and he serves as the primary caregiver in the home.
- Select **Both Parents** if the infant/child lives with both biological parents or same-sex partner (one partner is the biological parent) and they serve as the primary caregivers at home.
- Select **Other Relatives/Not Parents** if the infant/child lives with a relative(s) who is not the biological parent, and they serve as the primary caregiver(s) at home.
- Select **Non-Relative** if the infant/child lives with someone who is not related and not appointed by State Authority as the primary caregiver at home.

- Select **Foster Family/Child Protective Services (CPS)** if the infant/child is temporarily placed with certified, stand-in parent(s) to care for a minor infant/child who has been removed from his/her birth parents or other custodial adults by State authority as the primary caregiver at home.
- Select **Foster Family/Adoptive Family** if the infant/child through legal action has been permanently placed with guardian(s) who are not the birth (or biological) mother or father, as the primary caregiver at home.
- Select **Pediatric Subacute Facility** if the infant/child has extensive medical needs requiring continuous nursing care in a medical facility.
- Select **Other** if the infant/child's primary caregiver is not already described.
- Select **Unknown** if the infant/child's primary caregiver is not known.

Zip Code of Pediatric Subacute Facility

Enter the 5-digit zip code of the address for the pediatric subacute facility. If the zip code is not applicable, unavailable, or unknown, leave blank.

Zip Code of Primary Caregiver Residence

Enter the 5-digit zip code of the address for the primary caregiver. If the zip code is unavailable or unknown, leave it blank.
NOTE: If the 5-digit zip code is unable to be obtained or is confidential due to CPS/Foster Family situations, enter 99999 as the Zip Code of Primary Caregiver Residence.

Education of Primary Caregiver

If more than a single individual primary caregiver was selected (i.e., Both Parents), the Education of the primary caregiver should reflect the highest-level education of the individual caregivers.
NOTE: If Pediatric Subacute Facility was selected as the primary caregiver, select **Unknown** for Education of Primary Caregiver.

- Select **<9th Grade** if the primary caregiver has completed less than 9th Grade.
- Select **Some High School** if the primary caregiver has attained grade school education and some high school education (12th Grade), but no diploma.
- Select **High School Degree/GED** if the primary caregiver graduated from High School, received a diploma, or earned a General Educational Development (GED) credential.
- Select **Some College** if the primary caregiver has attained some college or university education, but no degree.
- Select **College Degree** if the primary caregiver graduated from college or university receiving an Associate degree (e.g., AA, AS) or Bachelor's degree (e.g., BA, AB, BS).
- Select **Graduate School or Degree** if the primary caregiver graduated from college or university and has attained some graduate school education or received a Master's degree (e.g., MA, MS, MSW, MBA); Doctorate (e.g., PhD, EdD) or Professional degree (e.g., MD, DO, DDS, DVM, JD).
- Select **Other** if the primary caregiver attended classes from a trade, technical, or vocational school

and/or received a certification upon completion.

- Select **Unknown** only if the infant/child lives in a chronic care facility or institution (e.g., Pediatric Subacute Facility); or if the highest level of education of the primary caregiver is not known or is unclear.
- Select **Declined** if the primary caregiver declines to give this information.

Caregiver Employment

If more than a single individual primary caregiver was selected (i.e., Both Parents), select the Caregiver Employment of the individual whose education level was provided under Education of the Primary Caregiver. If both parents have the same level of Education, please select the employment of the primary caregiver who spends the most time with the infant/child. Select only one option.
NOTE: If Pediatric Subacute Facility was selected as the primary caregiver, select Unknown for Caregiver Employment.

- Select **Full-Time** if the caregiver has a paying job that involves 35 or more (usually 40) hours of work during a week.
- Select **Part-Time** if the caregiver has a paying job that involves less than 35 hours of work during a week.
- Select **Temporary** if the caregiver is hired for contingent work, paid per the hours worked, and draws no benefits that are commonly available to regular employees.
- Select **Multiple Jobs** if the caregiver is holding more than one job either part-time or full-time.
- Select **Work from Home** if the caregiver has a work arrangement in which s/he has flexibility in working locations and hours.
- Select **Not Currently Employed** if the caregiver is without work, available to work, is currently seeking work; or chooses not to work.
- Select **Unknown** only if the infant/child lives in a chronic care facility or institution or if the caregiver's employment is not known or is unclear.
- Select **Declined** if the caregiver declines to give this information.

Primary Language Spoken at Home *Required Field

Select only **one** primary language spoken at the home as reported by the mother or primary caregiver:

- **English**
- **Spanish**
- **Arabic**
- **Armenian**
- **Cantonese**
- **Farsi/Persian**
- **Hindi**
- **Hmong/Miao**
- **Japanese**
- **Korean**
- **Mandarin**

- **Mixteco (Bajo/Alto)**
- **Mon-Khmer/Cambodian**
- **Punjabi**
- **Russian**
- **Sign Language**
- **Tagalog**
- **Thai**
- **Vietnamese**
- **Other** (describe)

Secondary Language Spoken at Home (optional)

Select only **one** secondary language spoken at the home as reported by the mother or primary caregiver.

- Select **N/A**, if a secondary language is not spoken at home.
- See **Primary Language Spoken at Home** for options.

Medical Eligibility Profile

Select **all** that apply for the infant's CCS HRIF Medical Eligibility. (***Required Field**)

Entry into the HRIF Program is available to:

- Children under three years of age who meet CCS Program HRIF medical eligibility criteria **and**
- Who met CCS Program medical eligibility criteria for NICU care **OR**
- Had a CCS Program eligible medical condition at some time during their stay in a CCS Program-approved NICU, even if they were never a CCS client.

Data should be collected on the following.

A neonate, infant or child shall be medically eligible for the HRIF Program when the infant:

A. Met CCS medical eligibility criteria for NICU care, in a CCS Program-approved NICU (regardless of length of stay) (as per Numbered Letter [N.L.] 05-0502, Medical eligibility in a CCS Program-approved NICU, or the most current N.L.). **NOTE:** Medical eligibility includes neonates who require direct admit to a CCS Program-approved PICU, who are never admitted to a CCS Program-approved NICU, but who otherwise meet all medical eligibility criteria for HRIF services in this section.

OR

B. Had a CCS Program eligible medical condition in a CCS Program-approved NICU (regardless of length of stay, even if they were never CCS clients during their stay), (as per California Code of Regulations, Title 22, Section 41515.1 through 41518.9, CCS Medical Eligibility Regulations).

AND

C. The birth weight was less than or equal to 1500 grams or the gestational age at birth was less than 32 weeks.

OR

D. The birth weight was more than 1500 grams **and** the gestational age at birth was 32 weeks or more **and** one of the following documented criteria was met during the NICU stay:

1. pH less than 7.0 on an umbilical cord blood sample or a blood gas obtained within one hour of life) or an Apgar score of less than or equal to three at five minutes or an Apgar score of less than 5 at 10 minutes.
2. An unstable infant manifested by hypoxia, acidemia, hypoglycemia and/or hypotension requiring pressor support.
3. Persistent apnea which required caffeine or other stimulant medication for the treatment of apnea at discharge.
4. Required oxygen for more than 28 days of hospital stay and had radiographic finding consistent with chronic lung disease.
5. Infants placed on extracorporeal membrane oxygenation (ECMO).
6. Infants who received inhaled nitric oxide greater than four hours, and/or treatment during hospitalization with sildenafil or other pulmonary vasodilatory medications for pulmonary hypertension.
7. Congenital heart disease (CHD) requiring surgery or minimally invasive intervention. (Added Jan 2017)
    - **Was the Norwood or a single ventricle palliation procedure performed?** (Added Jan 2018)

      Indicate if the Norwood procedure or a single ventricle palliation for hypoplastic left ventricle or hypoplastic right ventricle was performed.
        - Select **No** if the Norwood or a single ventricle palliation procedure was not performed.
        - Select **Yes** if the Norwood or a single ventricle palliation procedure was performed.
    - **CCS Cardiac Center**

      Select the CCS Cardiac Center where the patient received a surgical procedure for Congenital Heart Disease (CHD). (Added Jan 2019)
8. History of observed clinical or electroencephalographic (EEG) seizure activity or receiving antiepileptic medication(s) at time of discharge.
9. Evidence of intracranial pathology, including but not limited to, intracranial hemorrhage (grade II or worse), white matter injury including periventricular leukomalacia, cerebral thrombosis, cerebral infarction or stroke, congenital structural central nervous system (CNS) abnormality or other CNS problems associated with adverse neurologic outcome.
10. Clinical history and/or physical exam findings consistent with neonatal encephalopathy*.
11. Other documented problems that could result in a neurologic abnormality, such as:
    - History of CNS infection.
    - Documented sepsis.

- Bilirubin at excessive levels concerning for brain injury as determined by NICU medical staff.
- History of cardiovascular instability as determined by NICU medical staff due to: sepsis, congenital heart disease, patent ductus arteriosus (PDA), necrotizing enterocolitis, HIE*, other documented conditions.

Neonatal Encephalopathy and HIE

Neonatal encephalopathy is a broad term, encompassing a clinically defined syndrome involving depressed or disturbed neurologic function in the newborn, which may include a reduced level of consciousness, difficulty with initiating and maintaining respiration, abnormal tone and/or reflexes, or seizures. Neonatal encephalopathy can result from a range of etiologies. Hypoxic-ischemic encephalopathy (HIE) is responsible for many, but not all, cases of neonatal encephalopathy.

1) Russ JB, et al. Neonatal Encephalopathy: Beyond Hypoxic-Ischemic Encephalopathy. Neoreviews. 2021 Mar; 22(3): e148-e162.

REMINDER

- The discharging/referring CCS NICU/Hospital or HRIF Clinic will submit a SAR to the Local CCS Office for HRIF services. (Service Code Group [SCG] 06, should be requested). http://www.dhcs.ca.gov/services/ccs/cmsnet/Pages/SARTools.aspx
- The discharging/referring CCS NICU/Hospital will send a copy of the discharge summary to the HRIF Clinic.
- Have questions about Congenital Health Disease or Hypoglycemia eligibility criteria, visit https://www.cpqcc.org/follow/hrif-data-resources to review the clarification letters available under **California Children Services (CCS),** located at the bottom of the webpage.

Standard Visit (SV) Form

Online Entry Screen

Required Field **must** be entered to save web-based SV entry form. Saved entry forms can be recalled later to make any necessary updates.

HRIF Identification (ID) Number

Is a unique computer-generated number assigned to the infant/child enrolled in the HRIF Clinic.
NOTE: The HRIF ID Number is automatically generated after submission of the RR form.

This Form Is Closed

This checkbox feature serves as an electronic signature confirmation that all available data has been entered.

Date of Visit *Required Field

Enter the date of the core visit using MM-DD-YYYY. This is the date the infant/child was seen at the HRIF Clinic.

This Visit Was Conducted *Required Field

(Added Mar 2020 / Revised Jan 2021)

- Select **In-Person (clinic appt**) if the visit was an in-person clinic appointment.
- Select **Telehealth (audio + video observation**) if the visit was a virtual visit appointment by Telehealth, Zoom, WebEx or another audio/video application.
- Select **Phone Only** if the visit was only a telephone audio appointment.

Visit Assessment

Core Visit *Required Field

The HRIF Program has three core visits that take place during the following time periods:
Visit #1 (4-8 months), **Visit #2** (12-16 months) and **Visit #3** (18-36 months).

NOTE:

- The time periods for the core visits are only recommendations and guidelines that were decided by the HRIF Executive Committee.
- Core Visit #1 is the initial first visit to the follow-up program, even if the patient is older than 8 months corrected age.

Zip Code of Primary Caregiver

Enter the 5-dight zip code of the primary caregiver who is caring for the infant/child.
NOTE: If the 5-digit zip code is unable to be obtained or confidential due to CPS/Foster Family situations, enter **99999** as the Zip Code of Primary Caregiver Residence.

Chronological Age

Enter the infant/child's chronological age from birth in months and days.
NOTE: The Reporting System will automatically generate the chronological age. Once the form is submitted online the calculated chronological age will display in the Case History banner.

Adjusted Age

Enter the infant/child's adjusted age in months and days. The corrected age is used for an infant/child up to 3 years of age who was born prematurely and represents the age of the infant/child from the expected date of the delivery.
NOTE: The Reporting System will automatically generate the adjusted age. Once the form is submitted online the calculated adjusted age will display in the Case History banner.

Interpreter Used

Indicate if an interpreter was used to facilitate communication between the individual filling out the form or performing the assessment and the parent (or primary caregiver).

- Select **No** if no interpreter was used.
- Select **Yes** if there was an interpreter used or the HRIF Clinic staff acted as the interpret during the core visit and select the appropriate language used. Select the appropriate language interpreter. See Primary Language Spoken at Home for language options.

Insurance

NOTE: The Healthy Families Program transitioned to Medi-Cal in 2013. Select **Medi-Cal** for Medi-Cal Managed Care plans.

Select **all** insurance options that apply at the time of visit:

- **CCS**
- **Commercial Health Maintenance Organization (HMO)**
- **Commercial Preferred Provider Organization (PPO)**
- **Medi-Cal**
- **Point of Service/Exclusive Provider Organization (EPO)**
- **No Insurance/Self Pay**
- **Other**
- **Unknown**

Patient Assessment

Measurements should be taken at the time when the Neurologic and Developmental Assessments are performed.

Weight

Enter the weight in either kilograms (kg) or pounds (lbs.) and ounces (oz) recorded at time of core visit. Formats: kg (XX.XX) or lbs. (XX) oz (XX). Weight parameters 1 - 30 kg.

If **Not Collected** select the appropriate reason why the measurement was not collected: (Added Jul. 2016)

- **Not Routinely Done** if the measurement is not routinely collected in the HRIF Clinic
- **Unable to Obtain** if the measurement is not attainable.
- **Other** if the measurement was not collected and the reason was not already described.

Length

Enter the length in either centimeters (cm) or inches (in) recorded at time of core visit.

Formats: cm (XXX.X) or in (XX.XX). Length parameters 26 – 110 cm.

If **Not Collected** select the appropriate reason why the measurement was not collected: (Added Jul. 2016)

- **Not Routinely Done** if the measurement is not routinely collected in the HRIF Clinic
- **Unable to Obtain** if the measurement is not attainable.
- **Other** if the measurement was not collected and the reason was not already described.

Head Circumference

Enter the head circumference in either centimeters (cm) or inches (in) recorded at time of core visit. Formats: cm (XXX.X) or in (XX.XX). Head Circumference parameters 30 – 55 cm.

If **Not Collected** select the appropriate reason why the measurement was not collected: (Added Jul. 2016)

- **Not Routinely Done** if the measurement is not routinely collected in HRIF the Clinic.
- **Unable to Obtain** if the measurement is not attainable.
- **Other** if the measurement was not collected and the reason was not already described.

General Assessment

Is the Child Currently Receiving Breastmilk?

(Added Jan 2015)

Indicate if the infant/child is receiving breastmilk at the time of the core visit. This question is meant to determine the length of breastmilk exposure a child is receiving. **NOTE:** If a child is receiving breastmilk and solid foods, then the child will be receiving **Some** breastmilk.

- Select **Exclusively** if the infant/child is receiving only breastmilk.
- Select **Some** if the infant/child is receiving breastmilk and formula.
- Select **None** if the infant/child receives only formula.

Living Arrangement of the Infant/Child

Indicate the infant/child's current living arrangement with the primary caregiver(s). If the infant/child's living arrangement has changed since the last visit, select the appropriate category that best describes the infant/child's current living arrangement.

Select only **one** option.

- Select **Both Parents** if the infant/child lives with both biological parents and they serve as the primary caregivers at home.
- Select **One Parent** if the infant/child lives with one biological parent and he/she serves as the primary caregiver at home.
- Select **One Parent/Other Relatives** if the infant/child lives with one biological parent and with a relative(s) who are not the biological parent and they serve as the primary caregiver at home.
- Select **Other Relatives/Not Parents** if the infant/child lives with a relative(s) who is not the biological parent and they serve as the primary caregiver(s) at home.
- Select **Non-Relative** if the infant/child lives with someone who is not related and not appointed by state authorizes as the primary caregiver at home.
- Select **Foster/Adoptive Family** if the infant/child's living arrangement through legal action has been permanently placed with guardian(s) who are not the birth (or biological) mother or father, as the primary caregiver at home.
- Select **Foster Family/CPS** if the infant/child's living arrangement is temporarily placed with certified, stand-in parent(s) to care for minor children who have been removed from their birth parents or other custodial adults by state authorizes as the primary caregiver at home.
- Select **Pediatric Sub-Acute Facility** if the infant/child has extensive medical needs requiring continuous nursing care in a medical facility.
- Select **Other** if the infant/child's living arrangement is not already described.
- Select **Unknown** if the infant/child's living arrangement is not known.

Education of Primary Caregiver

(Added Jan 2014)

If more than a single individual Primary Caregiver was selected (i.e., Both Parents), the Education of the Primary Caregiver should reflect the highest-level education of the individual caregivers. If the infant/child's primary caregiver has changed since the last visit, select the appropriate category that best describes the infant/child's current primary caregiver's education.
NOTE: If Pediatric Subacute Facility was selected as the primary caregiver, select **Unknown** for Education of Primary Caregiver.

- Select **<9th Grade** if the primary caregiver has completed less than 9th Grade.
- Select **Some High School** if the primary caregiver has attained grade school education and some high school education (12th Grade), but no diploma.
- Select **High School Degree/GED** if the primary caregiver graduated from High School, received a diploma, or earned a General Educational Development (GED) credential.
- Select **Some College** if the primary caregiver has attained some college or university education, but no degree.
- Select **College Degree** if the primary caregiver graduated from college or university receiving an associate degree (e.g., AA, AS) or bachelor's degree (e.g., BA, AB, BS).
- Select **Graduate School or Degree** if the primary caregiver graduated from college or university and has attained some graduate school education or received a master's degree (e.g., MA, MS, MSW, MBA); Doctorate (e.g., PhD, EdD) or Professional degree (e.g., MD, DO, DDS, DVM, JD).
- Select **Other** if the primary caregiver attended classes from a trade, technical, or vocational school and/or received a certification upon completion.
- Select **Unknown** only if the infant/child lives in a chronic care facility or institution (e.g., Pediatric Subacute Facility); or if the highest level of education of the primary caregiver is not known or is unclear.
- Select **Declined** if the primary caregiver declines to provide this information.

Caregiver Employment

(Added Jan 2014)

If more than a single individual Primary Caregiver was selected (i.e., Both Parents), select the Caregiver Employment of the individual whose education level was provided under Education of the Primary Caregiver. If Both Parents have the same level of Education, please select the employment of the primary caregiver who spends the most time with the infant/child.

Select only **one** option. If the infant/child's primary caregiver has changed since the last visit, select the appropriate category that best describes the infant/child's current primary caregiver's employment.
NOTE: If Pediatric Subacute Facility was selected as the primary caregiver, select Unknown for Caregiver Employment.

- Select **Full-Time** if the caregiver has a paying job that involves 35 or more (usually 40) hours of work during a week.

- Select **Part-Time** if the caregiver has a paying job that involves less than 35 hours of work during a week.
- Select **Temporary** if the caregiver is hired for contingent work; paid according to the hours worked; and draws no benefits that are commonly available to regular employees.
- Select **Multiple Jobs** if the caregiver is holding more than one job either part-time or full-time.
- Select **Work from Home** if the caregiver has a work arrangement in which s/he has flexibility in working locations and hours.
- Select **Not Currently Employed** if the caregiver is without work, available to work, is currently seeking work; or chooses not to work.
- Select **Unknown** only if the infant/child lives in a chronic care facility or institution (e.g., Pediatric Subacute Facility), or if the caregiver's employment is not known or is unclear.
- Select **Declined** if the caregiver declines to provide this information.

Routine Child Care

Routine Child Care identifies the infant/child's typical weekly schedule of infant/childcare in the home or outside the home, provided by non-family members.

- Select **None**, if the infant/child does not have **Routine Child Care**. Proceed to the next category – **Caregiver Concerns of the Child**.
- Select **Yes**, if the infant/child does have **Routine Child Care**. Proceed to select **all** that apply.
- Select **Unknown** if this information cannot be obtained. Proceed to the next category – **Caregiver Concerns of the Child**.

  Indicate the current types of Routine Child Care the infant/child receives daily. If the infant/child's **Routine Child Care** changes between each core visit, select **all** the options that describe the infant/child's current routine infant/childcare at that time.
  - Select **Child Care Outside of Home** if the infant/child is cared for outside the home or home-based setting.
  - Select **Home Babysitter/Nanny** if the infant/child has regular care provided each week in his/her permanent residence.
  - Select **Not Used Routinely** if the infant/child's primary caregiver or immediate family member(s) provide the majority of care each week.
  - Select **Specialized Medical Setting** if the infant/child's medical needs require routine childcare such as in a sub-acute medical facility or skilled nursing home care on a part-time or full-time basis.
  - Select **Other** if the infant/childcare arrangement is not already described.

Caregiver Concerns of the Child

These are the concerns and priorities of the parents (or primary caregiver) about the infant/child's behavior, self-calming, interactions, habits, temperament, development, illness, problems in the environment, etc.

The social concerns and caregiver/infant concerns were developed using researched guidelines from Zero to Three (National Center for Infants, Toddlers, and Families) and their Diagnostic Manual (DC0-3R) of psychological and environmental stressors experienced from the infant's perspective that haven been demonstrated to negatively impact overall development. Most significant are disruptions in the caregiver-infant attachment relationship such as long separations & changes (divorce, incarceration, prolonged military

service, frequent changes in nannies, etc.) violence/trauma directly experienced by the infant or vicariously experienced, maternal/paternal mental illness (anxiety, depression, other psychiatric disorders).

NOTE: Parent-child relationship difficulties cluster primarily around feeding, sleeping, self-calming, and parental attunement to infant/child's needs. Open-ended questions are the most effective in obtaining information, such as what are the biggest concerns you have about your infant/child's behavior or your relationship with them?

- Select **None**, if the parent (or primary caregiver) does not have **Caregiver Concerns of the Child**. Proceed to the next section – **Interval Medical Assessments**.
- Select **Yes**, if the parent (or primary caregiver) does have **Caregiver Concerns of the Child**. Proceed to select **all** that apply.
- Select **Unknown** if this information cannot be obtained. Proceed to the next section – **Interval Medical Assessments**.

Indicate the current Caregiver Concerns of the infant/child. If the primary caregiver(s) concern of the infant/child changes between each core visits. Select **all** the options that describe the primary caregiver(s) concerns of the infant/child at that visit.

- Select **Behavioral** if the caregiver identifies infant/child behaviors that he/she does not feel competent managing or interpreting. In infancy these would include fussiness and in toddlerhood tantrums, discipline, and separation problems may be included. These behaviors may be constitutional difficulties within the infant/child, a lack of attunement on the parent's part, or need for education or training.
- Select **Calming/Crying** if the caregiver assessment includes infant/child's difficulty with self-soothing/calming when distressed and crying. Ask questions like, "how does your infant/child calm her/himself down?"
- Select **Feeding & Growth** if the caregiver identifies problems with the infant/child's weight gain and/or nutritional intake, including quantity, difficulty swallowing or gagging, adjustment to texture, transitioning to oral feeds or solid foods, food restrictiveness, etc. Include behavioral problems at meals including tension between the caregiver and infant/child, power struggles, and developmental appropriateness of self-feeding is included.
- Select **Frequent Illness** if the caregiver reports frequent illness such as the result of chronic diseases such as asthma, or frequent or persistent infections.
- Select **Gastrointestinal/Stooling/Spitting-up** if the caregiver identifies concerns with the infant/child's gastrointestinal system, i.e., stooling concerns, feeding intolerance (such as reflux), etc. (Added Jan. 2010)
- Select **Hearing** if the caregiver identifies concerns about infant/child hearing, including listening or attending to sounds or voices.
- Select **Medications** if the caregiver identifies any concerns about the infant/child's medications, e.g., how to give medications, reaction to medications, etc. (Added Jan. 2010)
- Select **Motor Skills, Movement** if the caregiver identifies concern about infant/child's lack of age-appropriate gross or fine motor ability, balance, quality of movement, etc.
- Select **Pain** if the caregiver reports that the infant/child has signs and symptoms such as crying, rapid breathing, rapid heart rate, muscle tension, etc.
- Select **Sensory Processing** if the caregiver identifies problems with the infant/child regulating his/her behavior or positive/negative emotions at home, with specific adults, peers, certain circumstances, or environments.
- Select **Sleeping/Napping** if the caregiver identified problems getting the infant/child to sleep, staying asleep, duration of sleep, or duration of naps.
- Select **Speech & Language** if the caregiver expresses concerns about infant/child's communication

abilities, both expressive and receptive. These may include gesture and nonverbal communications, receptive language, and verbal expression of wants and needs.

- Select **Stress** if the caregiver acknowledges significant level of his/her own stress in the care giving relationship with the infant/child, often exacerbated by environmental risk factors and/or reduced emotional wellbeing (depression, anxiety) that interferes with functioning. Present as an open-ended question such as How are you doing? Which validates interest in them as an important part of their child's wellbeing).
- Select **Vision** if the caregiver identifies concerns about the infant/child's vision. Parents may report symptoms such as sensitivity to light, squinting, jerky eye movements, poor eye contact, etc.
- Select **Other** if the caregiver concern is not already described.

Interval Medical Assessment

Does the Child Have a Primary Care Provider?

A health care professional (General/Family Practitioner, Pediatrician, Nurse Practitioner), who acts as the first point of consultation for the infant/child. (Added Jan. 2012)

- Select **No**, if the infant/child does not have a Primary Care Provider.
- Select **Yes**, if the infant/child does have a Primary Care Provider.
- Select **Unknown**, if this information cannot be obtained.

Does the Primary Care Provider Act as the Child's Medical Home?

(Added Jan 2012)

The health care professional (identified as the primary care provider) provides what is defined as a Medical Home, per The American Academy of Pediatrics (AAP).

- Select **No**, if the primary care provider does not act as the infant/child's Medical Home.
- Select **Yes**, if the primary care provider does act as the infant/child's Medical Home.
- Select **Unknown** if this information cannot be obtained.

The American Academy of Pediatrics (AAP) believes that the medical care of infants, children, and adolescents ideally should be accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. It should be delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a partnership of mutual responsibility and trust with them. These characteristics define the medical home. The American Academy of Pediatrics, Policy Statement: The Medical Home, Pediatrics Vol. 110 No. 1 (July 2002), 184-186.

Hospitalizations Since Last Visit

If this is the infant/child's first core visit, indicate whether the infant/child has been hospitalized since NICU discharge and prior to the first HRIF Clinic core visit. If this is the second or third Core visit, indicate if the infant/child was hospitalized between HRIF Core assessment visits.

NOTE: A hospitalization is defined as admission and at least an overnight stay in the hospital. This should be distinguished from a long emergency room visit or urgent care outpatient clinic visit that may or may not have been over night during interviews with the family.

- Select **No** if the infant/child has not been hospitalized since the last visit. Proceed to the next category – **Surgeries Since Last Visit.**
- Select **Yes** if the infant/child has been hospitalized since the last visit and enter the number of hospitalizations since the last visit (hospitalization limit: 1-15). Proceed to select **all** reasons that apply during the time of hospitalizations:
    - **Gastrointestinal Infection(s)**
    - **Meningitis Infection(s)**
    - **Nutrition/Inadequate Growth**
    - **Respiratory Illness**
    - **Seizure Disorder**
    - **Urinary Tract Infection(s)**
    - **Other Infection(s)**
    - **Other Medical Rehospitalizations**
    - **Unknown**

    EXAMPLE: Patient had 2 hospitalizations: Nutrition/Inadequate Growth and Gastrointestinal and Meningitis Infections.

Hospitalization Reasons	1	2
Gastrointestinal Infection(s)		√
Meningitis Infection(s)		√
Nutrition/Inadequate Growth	√	

- Select **Unknown** if this information cannot be obtained. Proceed to the next category – **Surgeries Since Last Visit**.

Surgeries Since Last Visit

Indicate whether the infant/child had any surgeries, since NICU discharge and prior to the first HRIF Clinic core visit and/or if the infant/child had any surgeries between HRIF Clinic core assessment visits.

- Select **No**, if the infant/child had no surgeries since the last visit. Proceed to the next category – **Medications Since Last Visit**.
- Select **Yes**, if the infant/child has had surgeries since the last visit and enter the number of surgeries since the last visit. Surgery Limit: 1-15. Proceed to Select **all** surgeries that apply.
    - **Cardiac Surgery**
    - **Circumcision, Gastrostomy Tube Placement**
    - **Inguinal Hernia Repair**
    - **Retinopathy of Prematurity**
    - **Shunt/Shunt Revision**

- **Tracheostomy**
- **Tympanostomy Tubes**
- **Other ENT Surgical Procedures**
- **Other Gastrointestinal Surgical Procedures**
- **Other Genitourinary Surgical Procedures**
- **Other Neurosurgical Procedures**
- **Other Surgical Procedures**
- **Unknown**

- Select **Unknown** if this information cannot be obtained. Proceed to the next category – **Medications Since Last Visit**.

Medications Since Last Visit

If this is the infant/child's **first core visit,** select the pertinent medications the infant/child has taken since NICU discharge and is taking now. If this is the child's **second core visit,** select all the medications the child has taken since the first core visit and is taking now. If this is the child's **third core visit,** select all the medications the child has taken since the second core visit and is taking now.

NOTE: The purpose of this question is to capture the significant and/or consistent medications that the child is taking or has taken during the intervals described. Occasional use of acetaminophen, ibuprofen, or over the counter cough or cold medications should not be captured.

- Select **No**, if the child has had no medications since the last visit. Proceed to the next category – **Equipment Since Last Visit**.
- Select **Yes**, if the infant/child has had medication since the last visit. Proceed to select **all** medications that apply.
  - **Actigall**
  - **Allergy Medication** (Added Jan 2024)
  - **Anti-Reflux Medication**
  - **Anti-Seizure Medication**
  - **Antibiotics/Antifungal**
  - **Antihypertensive**
  - **Caffeine, Cardiac Medications**
  - **Chest Physiotherapy (daily)**
  - **Chest Physiotherapy (inter.)**
  - **Diuretics**
  - **Inhaled Bronchodilators (daily)**
  - **Inhaled Bronchodilators (inter.)**
  - **Inhaled Steroids (daily)**
  - **Inhaled Steroids (inter.)**
  - **Levothyroxine** (Added Jan 2024)
  - **Nutrition Supplements – Enteral Nutrition and Dietary Supplements**
  - **Oral Steroids**
  - **Oxygen**
  - **Viagra (Pulmonary Hypertension)**
  - **Synagis/Palivizumab or Beyfortus/Nirsevimab** (Revised Jan 2024)

- **Other**
- **Unknown**

NOTE:

- There are two selections under Nutrition Supplements: Enteral Nutrition is for special formulas and Dietary Supplements is for vitamins, minerals, modulars and other nutrition additives. (Added Jan. 2010)
- Select **Oxygen** for infants receiving oxygen after discharge. Only enter the infant's chronological post-natal age, if the oxygen was discontinued.

- Select **Unknown**, if this information cannot be obtained. Proceed to the next category – **Equipment Since Last Visit**.

Equipment Since Last Visit

If this is the infant/child's **first core visit,** select all the equipment the infant/child has received since NICU discharge and is using now. If this is the infant/child's **second core visit,** select all the equipment the infant/child has received since the first core visit and is using now. If this is the infant/child's **third core visit,** select all the equipment the infant/child has received since the second core visit and is using now.

- Select **No**, if the infant/child is not using any equipment since the last visit. Proceed to **Medical Services Review**.
- Select **Yes**, if the infant/child has been using equipment since the last visit. Proceed to select **all** equipment that applies.
  - **Apena/CR Machine**
  - **Braces/Castings/Orthotics**
  - **Enteral Feeding Equipment**
  - **Helmet**
  - **Nebulizer**
  - **Ostomy Supplies**
  - **Oxygen Supplies** e.g. Nasal Cannula/Oxygen Tank (Added Jan. 2022)
  - **Tracheostomy**
  - **Ventilator/CPAP/BiPAP**
  - **Wheelchair**
  - **Other**
  - **Unknown**

  NOTE: Enteral Feeding Equipment includes NG/NJ Tube Feeding Equipment and Gastrostomy and Feeding Equipment. (Added Jan. 2012)

- Select **Unknown** if this information cannot be obtained. Proceed to **Medical Services Review**.

Medical Services Review

Is the Child Receiving or Being Referred for Medical Services?

Complete the following if the child has received or has been referred to medical services prior to the current evaluation/HRIF assessment:

- Select **No**, if the infant/child is not receiving or being referred for Medical Services. Proceed to **Neurosensory Assessment**.
- Select **Yes**, if the infant/child is being referred for Medical Services. Select the **Medical Services** below.

If the infant/child is receiving or being referred for medical services between standard visits, indicate the status of each medical service for the infant/child. Select **Receiving** as the status, even if the infant/child is no longer receiving at time of visit.

- **Allergy/Immunology** (Added Jan 2021)
- **Audiology**
- **Cardiology**
- **Craniofacial**
- **Dermatology** (Added Jan 2024)
- **Endocrinology**
- **Gastroenterology**
- **Hematology/Oncology**
- **Metabolic/Genetics**
- **Nephrology**
- **Neurology**
- **Neurosurgery**
- **Ophthalmology**
- **Orthopedic**
- **Otolaryngology (ENT)**
- **Pulmonology**
- **Surgery**
- **Urology**

Select the appropriate status for **each** medical service:

- **Does Not Need**
- **Receiving**
- **Complete**, if the infant/child no longer needs the service. (Added Jan 2010)
- **Referred at Time of Visit**
- **Referred, but Not Receiving – Missed Appointment**
- **Referred, but Not Receiving – Visit Pending** (Added Jan 2010)
- **Referred, but Not Receiving – Re-Referred**, if the infant/child initially was referred did not receive and now being re-referred for services. (Added Jan 2012)
- **Referred, but Not Receiving – Insurance / HMO Denied**
- **Referred, but Not Receiving – Parent Declined /Refused Service**
- **Referred, but Not Receiving – Service Not Available**

- **Referred, but Not Receiving – Other / Unknown Reason**

- Select **Unknown** if this information cannot be obtained. Proceed to **Neurosensory Assessment**.

Neurosensory Assessment

Vision Assessment History

Does the Child Have History of Retinopathy of Prematurity (ROP)?

(Added Jan 2012)

- Select **No**, if the infant/child does not have history of ROP. Proceed to **Does the Child Have a Visual Impairment?**
- Select **Yes**, if the infant/child does have history of ROP.
  If **Yes**, was selected because the infant/child has history of ROP, indicate if **Eye Surgery and/or Treatment with Anti-VEGF (i.e., Avastin)?** was performed.
  - Select **No** if eye surgery was not performed.
  - Select **Yes** if eye surgery was performed.
  - Select **Scheduled** if eye surgery is scheduled to be performed.
  - Select **Unknown** if this information cannot be obtained.

  Location of ROP
  If **Yes**, was selected because the infant/child has history of ROP, indicate the location of the ROP:
  - **Unilateral**
  - **Bilateral**
  - **Unknown** if this information cannot be obtained.

Does the Child Have Visual Impairment?

- Select **No**, if the infant/child does not have a visual impairment per a specialized clinical exam or parent report. Proceed to **Hearing Assessment History**.
- Select **Yes**, if the infant/child does have a visual impairment per a specialized clinical exam or parent report.
- Select **Unknown**, if unable to answer the question **Does the Child Have a Visual Impairment?**
  If **Unknown** was selected, then answer the next question **Why is Visual Impairment Unknown?**
  Select one of the options provided:
  - **Exam Results Unknown**
  - **No Ophthalmology Exam Performed**
  - **Needs Referral for Exam**
  - **Referred for Exam**
  - **Not Received**
  - **Referred, but Service Not Available**
  - **Referred, but Parent Declines/Refuses Service**
  - **Referred, but Insurance/HMO Denied**
  - **Referred, but Missed Appointment**

- **Referred for Functional Vision Assessment**
- **Functional Vision Assessment in Progress**

A. Impairment Due To

If **Yes**, was selected because the infant/child has a visual impairment, select all type(s) of impairment(s) that apply at the time of the core visit:

- **No, Type of Visual Impairment at Visit**
- **Strabismus**
- **Cataract**
- **Retinoblastoma**
- **Cortical Visual Impairment**
- **Refractive Errors**
- **Nystagmus**
- **ROP**
- **Other** if the type of visual impairment is not already described.
- **Unknown** if the type of visual impairment is not known.

Indicate if **Eye Surgery** was performed for either **Strabismus**, **Cataract**, or **Retinoblastoma** if one of these impairment(s) was selected**.**

- Select **No** if eye surgery was not performed.
- Select **Yes** if eye surgery was performed.
- Select **Scheduled** if eye surgery is scheduled to be performed.

B. Location of Impairment

If **Yes**, was selected because the infant/child has a visual impairment, indicate the location of the impairment. Select location of impairment:

- **Unilateral**
- **Bilateral** for the location of the impairment.
- **Unknown** if this information cannot be obtained.

C. Corrective Lens(es) Recommended

If **Yes**, was selected because the infant/child has a visual impairment, indicate if **Corrective Lens(es) Recommended** at the time of the core visit.

- Select **No** if corrective lens(es) were not recommended by the Ophthalmologist or noted in the medical record.
- Select **Yes** if corrective lens(es) were recommended by the Ophthalmologist or noted in the medical record.
- Select **Unknown** if unable to determine whether corrective lens(es) was recommended by the Ophthalmologist or noted in the medical record.

D. Corrective Lens(es) Used

If **Yes**, was selected because the infant/child has a visual impairment, indicate if **Corrective Lens(es) Used** at the time of the core visit.

- Select **No** if corrective lens(es) is not used by the infant/child.

- Select **Yes** if corrective lens(es) is used by the infant/child.
- Select **Unknown** if unable to determine whether the infant/child is using the corrective lens(es).

E. Is There Functional Vision?

(Added Jan 2012)

Blindness is defined as visual acuity of less than 20/400, or corresponding visual field loss to less than 10 degrees, in the better eye with best possible correction. Legal blindness is defined at 20/200 and less than 20 degrees of Visual Field. Visual acuity of 20/200 and 20/70 are considered low vision. **NOTE:** 20/400 is in Snellen unit and 6/120 is equivalent at measured at 6 feet.

- Select **Yes** if infant/child has functional vision and is not blind.
- Select **No** if the infant/child has no functional vision (blindness) or has recently loss functional vision.
  If **No** was Selected because the infant/child has no functional vision (blindness) or has recently loss functional vision, indicate the location of blindness:
  - **Unilateral**
  - **Bilateral**
  - **Unknown**
- Select **Unknown** if this information cannot be obtained.

Hearing Assessment History

Does the Child Have a Hearing Loss (HL)?

- Select **No** if the infant/child does not have a hearing loss per a specialized clinical exam or parent report. Proceed to **Neurologic Assessment**.
- Select **Yes** if the infant/child does have a hearing loss per a specialized clinical exam or parent report.
- Select **Unknown Hearing Loss** the proceed to the next question **Why is Hearing Loss Unknown?**
  Select one of the options provided:
  - **Exam Results Unknown**
  - **No Audiology Exam Performed**
  - **Needs Referral for Exam**
  - **Referred for Exam, Not Received**
  - **Referred, but Service Not Available**
  - **Referred, but Parent Declines/Refuses Service**
  - **Referred, but Insurance/HMO Denied Services**
  - **Referred, but Missed Appointment**

- Select **Hearing Assessment in Progress** if the infant/child's hearing assessment is in progress and you are unable to select the prior options of **No**, **Yes**, or **Unknown Hearing Loss**. Proceed to **Neurologic Assessment**.

  A. Is There Loss in One or Both Ears?
  If **Yes**, was selected because the infant/child has a hearing loss, indicate the location of the hearing loss. Select either **One** or **Both** if the infant/child has documented hearing loss in one or both ears.
  - Select **Assessment in Progress** if an assessment has not been completed to determine if the infant/child has any evidence of hearing loss.
  - Select **Unknown** if this information cannot be obtained (or if unable to determine if the infant/child has any evidence of hearing loss).

  B. Does the Child use an Assistive Listening Device (ALD)?
  If **Yes**, was selected because the infant/child has a hearing loss, indicate if the infant/child uses an assistive listening device.
  - Select **No** if there is documentation that an ALD was not recommended.
  - Select **Yes, ALD Recommended and Received** if there is documentation or communication by the parent (or primary caregiver) that an ALD was recommended and received.
  - Select **Yes, ALD Recommended, but not Received** if there is documentation or communication by the parent (or primary caregiver) that an ALD was recommended, but not received.
  - Select **Unknown** if unable to determine whether an ALD was recommended by the Audiologist or noted in the medical record.

  C. Type of ALD(S) Used
  If **Yes**, **ALD Recommended and Received** was selected for **Does the Child Use an Assistive Listening Device (ALD)**, select **all** the type(s) of ALD(s) the child uses:

  - **Bone Anchored Hearing Aid (BAHA)**
  - **Cochlear Implant**
  - **FM System**
  - **Hearing Aid**
  - Select **Other** if the type of ALD is not already described.
  - Select **Unknown** if the type of ALD is not known.

Neurologic Assessment

Was a Neurologic Exam Performed During This Core Visit? *Required Field

- Select **No** if the infant/child did not have a neurologic exam performed during this core visit. Leave the **Date Performed** blank.
  If **No** was selected for **Was a Neurologic Exam Performed?** then answer the next question **Reason Why Exam NOT Performed**.
  Select one of the options provided:
  - **Acute Illness**
  - **Behavior Problems**

- **Examiner Not Available**
- **Known SEVERE Developmental Disability**
- **Primary Caregiver Refused**
- **Primary Language**
- **Significant Sensory Impairment/Loss**
- **Other Medical Condition**
- **Other**

- Select **Yes** if the infant/child had a neurologic exam performed during this current core visit. Enter the Core visit date performed for the neurologic exam using **MM-DD-YYYY**. NOTE: The Reporting System has a **Same as Date of Visit** checkbox, if selected it will automatically input the date of visit.

> If you cannot obtain a neurologic assessment during the core visit, schedule a return visit for the infant to complete the assessment(s) and indicate the reason why the assessment was not performed. When the infant returns for the missing neurologic assessment, data can be entered on the incomplete SV Form. The date of the return visit should be entered in the **Date Performed** field, using **MM-DD-YYYY.** NOTE: Enter the new weight, height, and head circumference measurements in the Patient Assessment section.

This Part of the Visit Was Done By *Required Field

(Added Jan 2021)

- Select **In-Person** if the visit was an in-person clinic appointment.
- Select **Telehealth (audio + video observation**) if the visit was a virtual visit appointment by Telehealth, Zoom, WebEx or another audio/video application.
- Select **Phone Only** if the visit was only a telephone audio appointment.

Summary of Neurologic Assessment

- Select **Normal** if the infant/child's neurologic assessment exam indicates the infant/child is normal. If **Normal** is selected, proceed to **Developmental Assessment**.
- Select either **Abnormal** or **Suspect** if the infant/child's neurologic assessment exam indicates the infant/child is abnormal or suspect.
  If **Abnormal** or **Suspect** is selected, select the appropriate responses for **(A.) Oral Motor Function**, **(B.) Muscle Tone**, **(C.) Is There Scissoring of the Legs on Vertical Suspension**, **(D.) Deep Tendon Reflexes**, **(E.) Persistent Primitive Reflexes Present**, **(F.) Abnormal Involuntary Movements Present**, and **(G.) Quality of Movement and Posture**.

A. Oral Motor Function

If **Abnormal** or **Suspect** was selected for neurologic assessment exam, indicate the status of the assessment for **each Oral Motor Function**. Make sure that the infant/child is demonstrating age-appropriate responses for the oral motor functions of **Feeding**, **Swallowing**, and **Management of Secretions** by selecting **one** of the options:

- **Normal**
- **Abnormal** (includes excessive drooling, poor coordination of suck and swallow, inability to chew in children with molars).

- **Suspect**
- **Unable to Determine** if unable to establish, assess, or determine any of the above.

B. Muscle Tone

If **Abnormal** or **Suspect** was selected for neurologic assessment exam, indicate the status of the assessment for **Muscle Tone** listed for **each** region **Neck, Trunk, Right Upper Limb, Left Upper Limb, Right Lower Limb,** and **Left Lower Limb** by selecting **one** of the options:

- **Normal**
- **Increased** (Hypertonic)
- **Decreased** (Hypotonic)
- **Suspect** if you suspect muscle tone is hypertonic or hypotonic.
- **Unable to Determine**, unable to establish, assess, or determine any of the above.

C. Is There Scissoring of the Legs on Vertical Suspension?

(Added Jan. 2013)

If **Abnormal** or **Suspect** was selected for neurologic assessment exam, indicate if there is persistent scissoring (crossing of the legs) when the infant/child is vertically suspended (supported under arms).

- Select **No**, if there is no scissoring of the legs on vertical suspension present.
- Select **Yes**, if there is scissoring of the legs on vertical suspension present.

D. Deep Tendon Reflexes

If **Abnormal** or **Suspect** was selected for neurologic assessment exam, indicate the status of the assessment for **Deep Tendon Reflexes** listed for **each** region **Right Upper Limb** or **Left Upper Limb** by selecting only **one** of the options:

- **Normal** if the deep tendon reflex is between 1+ and 2+.
- **Increased** if the deep tendon reflex is 3+, usually with clonus or asymmetrical.
- **Decreased** if the deep tendon reflex < 1+.
- **Suspect** if you suspect DTR is increased or decreased, but you are not certain. (Added Jan 2012)
- **Unable to Determine**, unable to establish, assess, or determine any of the above.
  Indicate the status of the assessment for **Deep Tendon Reflexes** listed for **each** region **Right Lower Limb** and **Left Lower Limb** by selecting only **one** of the options:
  - **Normal** if the deep tendon reflex is between 1+ and 2+.
  - **Increased** if the deep tendon reflex is 3+ or greater.
  - **Decreased** if the deep tendon reflex < 1+.
  - **Clonus** (5 beats or more is considered abnormal).
  - **Suspect** if you suspect DTR is increased or decreased, but you are not certain.
  - **Unable to Determine**, unable to establish, assess, or determine any of the above.

> **Clonus:** is a series of involuntary muscular contractions due to sudden stretching of the muscle (rapidly flexing the foot upward, in dorsiflexion). Only sustained clonus (5 beats or more) is considered abnormal.

E. Are Persistent Primitive Reflexes Present?

In particular Moro > 4 months adjusted age and Fencer (ATNR) > 6 months adjusted age.

- Select **No**, if there are no persistent primitive reflexes present.
- Select **Yes**, if there are persistent primitive reflexes present.
- Select **Unknown**, if this information cannot be obtained.

F. Are Abnormal Involuntary Movements Present?

- Select **No**, if there are no abnormal involuntary movements present.
- Select **Yes**, if there are abnormal involuntary movements present.
  If **Yes**, was selected; select **all** that apply: **Ataxia**, **Choreoathetoid**, or **Tremors**.
- Select **Unknown** if this information cannot be obtained.

G. Quality of Movement and Posture

If **Abnormal** or **Suspect** was selected for neurologic assessment exam, indicate the quality of movement and posture. (Added Jan. 2013)

- **Normal**
- **Abnormal** includes any of the following: extensor posturing, abnormal posturing of limb, asymmetric movement/laterality (favoring 1 side of body) or motor incoordination.
- **Suspect** if you suspect quality of movement and posture, but you are unsure.
- **Unable to Determine** if unable to establish, assess, or determine any of the above.

Functional Assessment

Indicate the functional assessment of the infant/child for **Bimanual Function**, **Right Pincer Grasp**, and **Left Pincer Grasp** by selecting only **one** of the options:

NOTE: Only complete Right and Left Pincer Grasp if the infant/child is >= 15 months adjusted age.

- Select **Normal**
- Select **Abnormal**, if any of the following are present: lack of bimanual integration ≥ 4 months adjusted age or lack of grasp at > 9 months adjusted age and lack of fine pincer at >15 months adjusted age.
- Select **Suspect** if you are unsure.
- Select **Unable to Determine**, if unable to establish, assess, or determine any of the above.

Cerebral Palsy (CP)

As presented by Bax, et al. (1) cerebral palsy is a broad descriptive term encompassing a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems.

Early Detection of Cerebral Palsy
In response to concerns around potential delay in cerebral palsy (CP) diagnosis and therefore possible delay in data-driven interventions, a large working group of international experts and parent stakeholders published guidelines for early CP detection and based on a systematic review of the evidence (2, 3). This included a comprehensive review and recommendations regarding standardized assessment tools at different timepoints (see Appendix C Figure from Novak et al, JAMA Pediatrics 2017 in the Part III – Appendices section of the manual). Since then, publications have described implementation of this approach in single sites and organizational systems (4). In addition, recent publications have further described best practice guidelines for communicating with parents when diagnosis of a disability is made.

We are aware that some California sites have launched integration of standardized assessments to optimize early CP detection. Therefore, we have expanded the Standard Visit queries regarding CP diagnosis to earlier ages aligned with questions about standardized assessments used.

Was Early Detection of High-Risk Cerebral Palsy Made at this Visit?

(Added Jan 2024 / Rev Jul 2025)

Complete if the child is less than 18 months adjusted age.

- Select **No**, if the infant/child does not have cerebral palsy. Proceed to **Developmental Assessment.**
- Select **Yes**, if the infant/child cerebral palsy assessment indicates High Risk or Definite.

Select the Assessment Used to Arrive at Early Detection of High-Risk Cerebral Palsy:

(Added Jan 2024 / Rev Jul 2025)

Proceed to select **all** assessments used.

- **Alberta Infant Motor Scale (AIMS)**
- **Developmental Assessment of Young Children (DAYC)**
- **General Movements Assessment (GMA)**
- **Hammersmith Infant Neurological Examination (HINE)**
- **Motor Assessment of Infants (MAI)**
- **Magnetic Resonance Imaging (MRI)**
- **Neurologic exam with GMFCS assessment**
- **Neuro Sensory Motor Development Assessment (NSMDA)**
- **Test of Infant Motor Performance (TIMP)**
- **Other** (text field)

For the purposes of the HRIF Reporting System, the focus has been on everyday motor function [an approach in concert with international proposals and reports for consistency in neurodevelopmental follow up structures for high-risk infants (5)] at 18 months adjusted age or older. As such, the definition of cerebral palsy will be based on having abnormalities in both areas 1 and 2 below:

1. **Definite abnormalities observed in neuromotor exam**, which includes passive muscle tone, deep tendon reflexes, coordination, and movement (6).
2. **A delay in motor milestones**. This would be reflected as abnormalities in functional gross motor skills for age, including head and neck and/or trunk postural function abnormalities, and/or upper limb or lower limb gross motor skills.

In addition, abnormalities in protective reactions (parachute, lateral protective reactions) and primitive reflexes may be present.

Does the Child Have Cerebral Palsy (CP)?

Complete if the child is ≥ 18 months adjusted age.

- Select **No**, if the infant/child does not have cerebral palsy. Proceed to **Developmental Assessment.**
- Select **Yes**, if the infant/child has cerebral palsy.
- Select **Suspect**, if the infant/child is suspected to have cerebral palsy. (Added Jan 2013)
  If **Yes** or **Suspect** was selected, select the appropriate responses for **Gross Motor Function Classification System (GMFCS).**
- Select **Unable to Determine**, if unable to determine whether the infant/child has cerebral palsy.

Gross Motor Function Classification System (GMFCS)

For children with cerebral palsy, the severity of functional motor abilities and limitations should be further characterized. The Gross Motor Function Classification System (GMFCS) is a widely used and validated scale, arranged by age bands.

If **Yes** or **Suspect** was selected for identifying the infant/child has cerebral palsy at the time of the core visit, select the child's **Gross Motor Function Classification System (GMFCS)** level for the appropriate adjusted age grouping (18 - 24 months adjusted age **or** 24 – 36 months adjusted age). Baxter, P. (2008). *The Definition and Classification of Cerebral Palsy. Developmental Medicine and Child Neurology, 49(s109), 1-44.*

Infants 18 - 24 months of age (adjusted age)

- Select **Level I** if infant/child walks without the need for any assistive mobility device.
- Select **Level II** if infant/child maintain floor sitting but may need to use his/her hands for support to maintain balance. Infant/child creeps on his/her stomach or crawls on hands and knees. Infant/child may pull to stand and take steps holding on to furniture.
- Select **Level III** if infant/child maintain floor sitting when the low back is supported. Infant/child rolls and creeps forward on his/her stomach.
- Select **Level IV** if infant/child has head control but trunk support is required for floor sitting. Infant/child can roll to supine and may roll to prone.
- Select **Level V** if physical impairments limit voluntary control of movement. Infant/child is unable to maintain antigravity head and trunk postures in prone and sitting. Infant/child requires adult assistance to roll.
- Select **Unsure/Unable to Determine** if you cannot adequately complete the evaluation to assess.

Infants 24 - 36 months of age (adjusted age)

- Select **Level I** if infant/child floor sits with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Infant/child walks as the preferred method of mobility without the need for any assistive mobility device.
- Select **Level II** if infant/child floor sits but may have difficulty with balance with both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Infant/child pulls to stand on a stable surface. Infant/child crawls on hand and knees with a reciprocal pattern, cruise holding onto furniture, and walks using an assistive mobility device as preferred methods of mobility.
- Select **Level III** if infant/child maintains floor sitting often with W-sitting and may require adult assistance to assume sitting. Infant/child creeps on his/her stomach and crawls on hands and knees as his/her primary methods of self-mobility. Infant/child may pull to stand on a stable surface and cruise short distances. Infant/child may walk short distances indoors using a hand-held mobility device and adult assistance for steering and turning.
- Select **Level IV** if infant/child floor sits when placed but is unable to maintain alignment and balance without use of his/her hands for support. Infant/child frequently requires adaptive equipment for sitting and standing. Self-mobility for short distances is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.
- Select **Level V** if physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, infant/child has no means of independent movement and is transported.
- Select **Unsure/Unable to Determine** cannot adequately complete the evaluation to assess.

1) Bax M, Goldstein M, Rosenbaum P, Leviton A, Paneth N, Dan B, et al. Proposed definition and classification of cerebral palsy, April 2005. Dev Med Child Neurol. 2005; 47(8):571-6.
2) Novak I, Morgan C, Adde L, et al. Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment. JAMA Pediatr. 2017 Sep 1;171(9):897-907.
3) Spittle AJ, Morgan C, Olsen JE, Novak I, Cheong JLY. Early Diagnosis and Treatment of Cerebral Palsy in Children with a History of Preterm Birth. Clin Perinatol. 2018 Sep;45(3):409-420.
4) Maitre NL, Damiano D, Byrne R. Implementation of Early Detection and Intervention for Cerebral Palsy in High-Risk Infant Follow-Up Programs: U.S. and Global Considerations. Clin Perinatol. 2023 Mar;50(1):269-279.
5) Novak I, Morgan C, McNamara L, Te Velde A. Best practice guidelines for communicating to parents the diagnosis of disability. Early Hum Dev. 2019 Dec;139:104841.
6) Report of a BAPM/RCPCH Working Group. Classification of health status at 2 years as a perinatal outcome. January 2008. British Association of Perinatal Medicine. http://www.bapm.org
7) Amiel-Tison C, Ellison P. Birth asphyxia in the full-term newborn: Early assessment and outcome. Dev Med Child Neurol. 1986;28(5):671-82.
8) Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Dev Med Child Neurol. 1997; 39(4):214-23.
9) GMFCS – Expanded and Revised, Can Child Centre for Childhood Disability Research (Palisano R, 2007). http://motorgrowth.canchild.ca/en/GMFCS/resources/GMFCS-ER.p

Developmental Core Visit Assessment

Was a Developmental Assessment Screener or Test Performed During This Core Visit? *Required Field

- Select **No** if the infant/child did not have a developmental screener or developmental test performed during this core visit. Leave the **Date Performed** blank.
    - If **No** was selected for **Was a Developmental Screener or Test Performed during this Core Visit?** then answer the next question **Reason Why Assessment NOT Performed.** Select one of the options provided:
        - **Acute Illness**
        - **Behavior Problems**
        - **Examiner Not Available**
        - **Known Severe Developmental Disability**
        - **Primary Caregiver Refused**
        - **Primary Language**
        - **Significant Sensory Impairment/Loss**
        - **Other Medical Condition**
        - **Other**
- Select **Yes** if the infant/child did have a developmental assessment screener or developmental assessment test performed during this core visit. Enter the date the developmental screener or developmental test was performed using **MM-DD-YYYY**. NOTE: The system has a **Same as Date of Visit** checkbox, if selected it will automatically input the date of visit.

If you cannot obtain a developmental assessment during the core visit, schedule a return visit for the infant to complete the assessment(s) and indicate the reason why the assessment was not performed. When the infant returns, the missing developmental assessment data can be entered in the incomplete SV form. The date of the return visit should be entered into the **Date Performed** field, using **MM-DD-YYYY.** NOTE: Enter the new weight, height, and head circumference measurements in the Patient Assessment section.

This Part of the Visit Was Done By *Required Field

(Added Jan 2021)

- Select **In-Person** if the visit was an in-person clinic appointment.
- Select **Telehealth (audio + video observation**) if the visit was a virtual visit appointment by Telehealth, Zoom, WebEx or another audio/video application.
- Select **Phone Only** if the visit was only a telephone audio appointment.

Developmental Assessment Screeners

Determine the appropriate developmental assessment screener to be performed during the infant/child's adjusted age (corrected for prematurity) core visit. **NOTE:** Developmental Assessment Screeners **cannot** be used in the last or third (18 to 36 month) core visit.

Scores / Cutoffs for each Developmental Screener

	Standard	Scale	T
Mean (M)	**100**	**10**	**50**
Standard Deviation (SD)	**15 = 1**	**3 = 1**	**10 = 1**

Ages and Stages Questionnaire 3rd Edition (ASQ-3)

(Added Jan 2022)

See Appendix B. Ages & Stages Questionnaire 3rd Edition - General Information document in the Part III – Appendices section of this manual.

This screener is scored using raw scores for each domain (Communication, Gross Motor, Fine Motor, Problem-Solving and Personal-Social).

- Select the appropriate **Scoring Zone** for the ASQ-3:
  - **On Schedule** if the score for that area falls within the unshaded (higher score range) zone.
  - **Monitor** if the score for that area falls within the lightly shaded (middle score range) monitoring zone. This represents 1-2 standard deviations below the mean for that age-based questionnaire.
  - **Below** if the score for that area falls within the darkly shaded (low score range) zone. This represents 2 standard deviations below the mean for that age-based questionnaire.
- Select **Unable to Assess** if the infant/child was uncooperative during the screening or if this information cannot be obtained.
- Select **Did Not Assess** if the domain is not used for the infant/child's developmental assessment.

Bayley Infant Neurodevelopmental Screener (BINS)

This screener is scored using raw scores.

- Select the appropriate range for the **Overall Classification** for the BINS Screener:
  - **Low Risk** if the raw score falls within the low-risk range on the table for the child's age in months.
  - **Medium Risk** if the raw score falls within the medium risk range on the table for the child's age in months.
  - **High Risk** if the raw score falls within the high-risk range on the table for the child's age in months.
- Select **Unable to Assess** if the infant/child was uncooperative during the screening or if this information cannot be obtained.
- Select **Did Not Assess** if the domain is not used for the infant/child's developmental assessment.

Battelle Developmental Inventory Screening Test, 2nd Edition (BDIST)

This screener is scored using raw scores for each domain (Adaptive, Personal-Social, Communication, Motor, and Cognitive).

- Select the appropriate range for each domain:
    - Select **Pass** if the raw score is greater than the negative 1.5 cut score for the child's age in months.
    - Select **Refer** if the raw score is less than or equal to the negative 1.5 cut score for the child's age in months.
- Select **Unable to Assess** if the infant/child was uncooperative during the screening or if this information cannot be obtained.
- Select **Did Not Assess** if the domain is not used for the infant/child's developmental assessment.

Bayley Scales of Infant and Toddler Developmental Screener III (Bayley III)

This screener is scored using raw scores for each domain (Cognitive, Receptive Language, Expressive Language, Fine Motor, and Gross Motor) which are converted into **Competent**, **Emerging** and **At Risk** categories using cut-score ranges found in the table appropriate for the child's age in months and days.

- Select the appropriate range for each domain:
    - **Competent** if the raw score falls within the competent range on the table for the child's age in months and days.
    - **Emerging** if the raw score falls within the emerging range on the table for the child's age in months and days.
    - **At Risk** if the raw score falls within the at-risk range on the table for the child's age in months and days.
- Select **Unable to Assess** if the infant/child was uncooperative during the screening or if this information cannot be obtained.
- Select **Did Not Assess** if the domain is not used for the infant/child's developmental assessment.

Bayley Scales of Infant and Toddler Developmental Screener 4 (Bayley 4)

(Added Nov 2019)

This screener is scored using raw scores for each domain (Cognitive, Receptive Language, Expressive Language, Fine Motor, and Gross Motor) which are converted into **Low Risk**, **Borderline Risk** and **High Risk** categories using cut-score ranges found in the table appropriate for the child's age in months and days.

Select the appropriate range for each domain:

- Select **Low Risk** if the raw score falls within the low-risk range on the table for the child's age in months and days.
- Select **Borderline Risk** if the raw score falls within the borderline risk range on the table for the child's age in months and days.
- Select **High Risk** if the raw score falls within the high-risk range on the table for the child's age in months and days.

- Select **Unable to Assess** if the infant/child was uncooperative during the screening or if this information cannot be obtained.
- Select **Did Not Assess** if the domain is not used for the infant/child's developmental assessment.

NOTE: In May 2023, Persons Assessments announced that post-publication research on the Bayley 4 and the Bayley 4 Screening Test highlighted performance concerns with the normative information for the Cognitive, Language, and Motor Scales data. Reference the original Important Bayley 4 announcement.

Pearson Assessments has updated norms and conversion tables, and the reliability, and validity information. The Q-global system was updated on June 28, 2023, incorporating new normative data in the e-scoring, and new Bayley 4 Administration Manuals were shipped July-August 2023.

The Capute Scales / The Cognitive Adaptive Test - Clinical Linguistic and Auditory Milestone Scale Screener (Capute/CAT-CLAMS)

This screener is scored using standard scores for each domain (Language Auditory (CLAMS), Cognitive Adaptive (CAT), Full Scale Capute).

- **Enter the score** at the appropriate range for each domain:
  - **Normal** if the standard score is greater than or equal to (≥ 85 or less (<) than 1 SD from the mean.
  - **Borderline** if the standard score is between 71 to 84 or between 1 to 2 SD below the mean.
  - **Deficient** if the standard score is less than or equal to (≤) 70 or greater (>) than 2 SD below the mean.
- Select **Unable to Assess** if the infant/child was uncooperative during the screening or if this information cannot be obtained.
- Select **Did Not Assess** if the domain is not used for the infant/child's developmental assessment.

Warner Initial Developmental Evaluation of Adaptive and Functional Skills (WIDEA-FS)

(Added Jan 2021)

See Appendix A. WIDEA-FS Materials in the Part III – Appendices section of this manual for supporting materials for the WIDEA-FS screening tool.

This screener is scored using standard scores for each domain (Self-Care, Mobility, Communication and Social Cognition).

- **Enter the score** at the appropriate range for each domain:
  - Self-Care (<= 68)
  - Mobility (<= 36)
  - Communication (<= 52)
  - Social Cognition (<= 44)
- Select **Unable to Assess** if the infant/child was uncooperative during the screening or if this information cannot be obtained.
- Select **Did Not Assess** if the domain is not used for the infant/child's developmental assessment.

1) Peyton C, Msall ME, Wroblewski K, Rogers EE, Kohn M, Glass HC. Concurrent validity of the Warner Initial Developmental Evaluation of Adaptive and Functional Skills and the Bayley Scales of Infant and Toddler Development, Third Edition. Dev Med Child Neurol. 2020 Nov 18. doi: 10.1111/dmcn.14737. Epub ahead of print. PMID: 33206384.
2) Mulkey SB, Arroyave-Wessel M, Peyton C, Bulas DI, Fourzali Y, Jiang J, Russo S, McCarter R, Msall ME, du Plessis AJ, DeBiasi RL, Cure C. Neurodevelopmental Abnormalities in Children With In Utero Zika Virus Exposure Without Congenital Zika Syndrome. JAMA Pediatr. 2020 Mar 1;174(3):269-276. doi: 10.1001/jamapediatrics.2019.5204. Erratum in: JAMA Pediatr. 2020 Mar 1;174(3):305. PMID: 31904798; PMCID: PMC6990858.

Other/Not Listed Screener

Domains available for **Other/Not Listed Screener** include: Cognitive, Expressive Language, Receptive Language, Communication, Language Composite, Gross Motor, Fine Motor, Motor Composite, Personal-Social, Adaptive, or Other Domain. **NOTE:** Enter the name of the **Other Domain** if the domain is not already listed.

- Enter the **Full Name** of the Other/Not Listed Screener used for assessment of the infant/child.
- Select the appropriate range for each domain of this screener: **Normal**, **Mild/Moderate**, or **Significant**.
- Select **Unable to Assess** if the infant/child was uncooperative with the screening or if this information cannot be obtained.
- Select **Did Not Assess** if the domain is not used for the infant/child's developmental assessment.

The following are score ranges:

Standard Scores

- Within Normal Limits ≥ 85 (1 SD from the mean)
- Mild/Moderate Delay 71 - 84 (between 1-2 SD below the mean)
- Significant Delay ≤ 70 (2 SD below the mean)

Scale Scores

- Within Normal Limits ≥ 7 (1 SD from the mean)
- Mild/Moderate Delay 5 - 6 (between 1-2 SD below the mean)
- Significant Delay ≤ 4 (2 SD below the mean)

T Scores

- Within Normal Limits ≥ 40 (1 SD from the mean)
- Mild/Moderate Delay 31 - 39 (between 1-2 SD between the mean)
- Significant Delay ≤ 30 (2 SD below the mean)

Raw Scores

- Within Normal Limits if raw score is less than (<) 1 SD from the mean
- Mild/Moderate Delay if the raw score is between 1 to 2 SD below the mean
- Significant Delay if the raw score is greater than (>) 2 SD below the mean

Developmental Assessment Tests

Determine the appropriate developmental assessment test to be performed during the infant/child's adjusted age (corrected for prematurity) core visit. **NOTE:** A Developmental Assessment Test **must** be used in the last or third (18 to 36 month) core visit.

Scores / Cutoffs for each Developmental Test

	Standard	Scale	T
Mean (M)	**100**	**10**	**50**
Standard Deviation (SD)	**15 = 1**	**3 = 1**	**10 = 1**

Bayley Scales of Infant and Toddler Development III (Bayley III)

(Hardcopy/Computer)
This test is scored using both standard scores and scale scores.
Standard Scores are used for 5 domains (Cognitive Composite, Language Composite, Motor Composite, Social-Emotional Composite, and Adaptive-Behavioral Composite).
Scale Scores are used for 4 sub-domains (Receptive Language, Expressive Language, Fine Motor, and Gross Motor).

- **Enter the score** at the appropriate range for each domain.
- Select **Unable to Assess** if the infant/child was uncooperative during the test or if this information cannot be obtained.
- Select **Did Not Assess** if the domain/scale is not used for the infant/child's developmental assessment.

The following are the score ranges:

Standard Scores
Domains: Cognitive Composite, Language Composite, Motor Composite, Social-Emotional Composite, and Adaptive-Behavioral Composite.
NOTE: score values must be between 45 – 155.

- Within Normal Limits ≥ 85 (1 SD from the mean)
- Mild/Moderate Delay 71 - 84 (between 1-2 SD below the mean)
- Significant Delay ≤ 70 (2 SD below the mean)

Scale Scores
Domains: Receptive Language, Expressive Language, Fine Motor, and Gross Motor.
NOTE: score values must be between 1 – 19.

- Within Normal Limits ≥ 7 (1 SD from the mean)
- Mild/Moderate Delay 5 - 6 (between 1-2 SD below the mean)
- Significant Delay ≤ 4 (2 SD below the mean)

Bayley Scales of Infant and Toddler Development 4 (Bayley 4)

(Hardcopy/Computer) (Added in Nov 2019)

This test is scored using both standard scores and scale scores.
Standard Scores are used for 5 domains (Cognitive, Language, Motor, Social-Emotional, and Adaptive-Behavioral).
Scale Scores are used for 4 sub-domains (Receptive Language, Expressive Language, Fine Motor, and Gross Motor).

- **Enter the score** at the appropriate range for each domain.
- Select **Unable to Assess** if the infant/child was uncooperative during the test or if this information cannot be obtained.
- Select **Did Not Assess** if the domain/scale is not used for the infant/child's developmental assessment.

The following are the score ranges:

Standard Scores
Domains: Cognitive, Language, Motor, Social-Emotional, and Adaptive-Behavioral.
NOTE: score values must be between 45 – 155.

- Extremely High/Very Exceptional (> 129)
- Very High/Exceptional (120 – 129)
- High Average (110 – 119)
- Average (90 – 109)
- Low Average (80 - 89)
- Very Low/Borderline (70 - 79)
- Extremely Low (< 70)

Scale Scores
Domains: Receptive Language, Expressive Language, Fine Motor, and Gross Motor.
NOTE: score values must be between 1 – 19.

- Very High/Exceptional (> 13)
- High Average (12 - 13)
- Average (9 - 11)
- Low Average (8)
- Very Low/Borderline (6 - 7)
- Extremely Low (< 6)

NOTE: In May 2023, Persons Assessments announced that post-publication research on the Bayley 4 and the Bayley 4 Screening Test highlighted performance concerns with the normative information for the Cognitive, Language, and Motor Scales data. Reference the original Important Bayley 4 announcement.

Pearson Assessments has updated norms and conversion tables, and the reliability, and validity information. The Q-global system was updated on June 28, 2023, incorporating new normative data in the e-scoring, and new Bayley 4 Administration Manuals were shipped July-August 2023.

Battelle Developmental Inventory, 3rd Edition Test (BDI-3)

This test is scored using both standard scores and scale scores.
Standard Scores are used for 5 domains (Adaptive, Personal-Social, Communication, Motor, and Cognitive).
Scale Scores are used for 4 sub-domains (Receptive Language, Expressive Language, Fine Motor, and Gross Motor).

- **Enter the score** at the appropriate range for each domain.
- Select **Unable to Assess** if the infant/child was uncooperative during the test or if this information cannot be obtained.
- Select **Did Not Assess** if the domain/scale is not used for the infant/child's developmental assessment.

The following are the score ranges:

Standard Scores
Domains: Adaptive, Personal-Social, Communication, Motor, and Cognitive

- Accelerated Development (130-155)
- Advanced Development (120-129)
- High Average (110-119)
- Average (90-109)
- Low Average (80-89)
- Mild Developmental Delay (70-79)
- Significant Developmental Delay (45-69)

Scale Scores
Domains: Receptive Language, Expressive Language, Fine Motor, and Gross Motor

- Accelerated Development ()
- Advanced Development ()
- High Average ()
- Average ()
- Low Average ()
- Mild Developmental Delay ()
- Significant Developmental Delay ()

Revised Gesell and Amatruda Developmental and Neurologic Examination Test (Gesell)

This test is scored using standard scores for each domain (Language Development, Fine Motor, Gross Motor, Personal-Social, and Adaptive).

- **Enter the score** at the appropriate range for each domain.
- Select **Unable to Assess** if the infant/child was uncooperative during the test or if this information cannot be obtained.
- Select **Did Not Assess** if the domain/scale is not used for the infant/child's developmental assessment.

The following are the score ranges:

Standard Scores
Domains: Language Development, Fine Motor, Gross Motor, Personal-Social, and Adaptive

- Within Normal Limits ≥ 85 (1 SD from the mean)
- Mild/Moderate Delay 71 - 84 (between 1-2 SD below the mean)
- Significant Delay ≤ 70 (2 SD below the mean)

Mullen Scales of Early Learning – AGS Edition Test (Mullen)

This test is scored using both standard scores and T scores.
Standard Score is used for 1 domain (Early Learning Composite).
T Scores are used for 4 scales (Visual Perception, Receptive Language, Expressive Language, Fine Motor, and Gross Motor).

- **Enter the score** at the appropriate range for each domain.
- Select **Unable to Assess** if the infant/child was uncooperative during the test or if this information cannot be obtained.
- Select **Did Not Assess** if the domain/scale is not used for the infant/child's developmental assessment.

The following are the score ranges:

Standard Scores
Domain: Early Learning Composite

- Within Normal Limits ≥ 85 (1 SD from the mean)
- Mild/Moderate Delay 71 - 84 (between 1-2 SD below the mean)
- Significant Delay ≤ 70 (2 SD below the mean)

T Scores
Domains: Visual Perception, Receptive Language, Expressive Language, Fine Motor, and Gross Motor

- Within Normal Limits ≥ 40 (1 SD from the mean)
- Mild/Moderate Delay 31 - 39 (between 1-2 SD below the mean)
- Significant Delay ≤ 30 (2 SD below the mean)

The Developmental Assessment of Young Children 2nd Edition (DAYC-2)

(Added Jan 2021)

This test is scored using standards scores for each domain (Cognitive, Communication, Social-Emotional, Physical Development and Adaptive Behavior).

- **Enter the score** at the appropriate range for each domain.
- Select **Unable to Assess** if the infant/child was uncooperative during the test or if this information cannot be obtained.
- Select **Did Not Assess** if the domain/scale is not used for the infant/child's developmental assessment.

The following are the score ranges:

Standard Scores
Domains: Cognitive, Communication, Social-Emotional, Physical Development and Adaptive Behavior

- Very Superior (> 130)
- Superior (121 – 130)

- Above Average (111 – 120)
- Average (90 – 110)
- Below Average (80 – 89)
- Poor (70 - 79)
- Very Poor (< 70)

Developmental Profile 3 and 4 (DP-3 and DP-4)

(Added Jan 2021)

This test is scored using standard scores for each domain (Physical, Adaptive Behavior, Social-Emotional, Cognitive and Communication).

- **Enter the score** at the appropriate range for each domain.
- Select **Unable to Assess** if the infant/child was uncooperative during the test or if this information cannot be obtained.
- Select **Did Not Assess** if the domain/scale is not used for the infant/child's developmental assessment.

The following are score ranges:

Standard Scores
Domain (Physical, Adaptive Behavior, Social-Emotional, Cognitive and Communication)

- Well Above Average (> 130)
- Above Average (116 – 130)
- Average (85 – 115)
- Below Average (70 – 84)
- Delayed (< 70)

Other/Not Listed Test

Domains/scales available for **Other/Not Listed Test** include: Cognitive, Expressive Language, Receptive Language, Language Composite, Gross Motor, Fine Motor, Motor Composite, Personal-Social, Adaptive, or Other Domain. **NOTE:** Enter the name of the **Other Domain** if the domain is not already listed.

- Enter the **Full Name** of the Other/Not Listed Test used for assessment of the infant/child.
- Select the appropriate range for each domain/scale of this test: **Normal**, **Mild/Moderate**, or **Significant**.
- Select **Unable to Assess** if the infant/child was uncooperative during the testing or if this information cannot be obtained.
- Select **Did Not Assess** if the domain/scale is not used for the infant/child's developmental assessment.

The following are score ranges:

Standard Scores

- Within Normal Limits ≥ 85 (1 SD from the mean)
- Mild/Moderate Delay 71 - 84 (between 1-2 SD below the mean)
- Significant Delay ≤ 70 (2 SD below the mean)

Scale Scores

- Within Normal Limits ≥ 7 (1 SD from the mean)
- Mild/Moderate Delay 5 - 6 (between 1-2 SD below the mean)
- Significant Delay ≤ 4 (2 SD below the mean)

T Scores

- Within Normal Limits ≥ 40 (1 SD from the mean)
- Mild/Moderate Delay 31 - 39 (between 1-2 SD below the mean)
- Significant Delay ≤ 30 (2 SD below the mean)

Raw Scores

- Within Normal Limits if raw score is less than (<) 1 SD from the mean
- Mild/Moderate Delay if the raw score is between 1 to 2 SD below the mean
- Significant Delay if the raw score is greater than (>) 2 SD below the mean

Autism Spectrum Screen (Optional)

As per the Johnson CP and the AAP statement Identifying infants and young children with developmental disorders in the medical home (Pediatrics, 2006): For general developmental screening and surveillance, the ***AAP recommends administering a standardized autism-specific screening tool on all children at the 18-month preventive care visit.*** The AAP Autism Expert Panel responded to the statement with a commentary that suggested a repeat screening be per- formed at 24 months of age to identify those who may regress after 18 months of age.

(1) Johnson, CP, Myers SM. *Identification and Evaluation of Children with Autism Spectrum Disorders. Pediatrics.2007;*120(5):1183-1215

(2) Council on Children with Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, Medical Home Initiatives for Children With Special Needs Project Advisory Committee. *Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening. Pediatrics.*2006;118:405.

Does the Child have a Diagnosis of Autism Spectrum Disorder?

(Added Jan 2024 / Revised Jan 2025)

- Select **No** if the infant/child has not been diagnosed with autism spectrum disorder. Proceed to – **Was an Autism Spectrum Screen Performed During This Visit**?
- Select **Yes** if the infant/child has been diagnosed with autism spectrum disorder. Proceed to – **Early Start (ES) Program**.

Was an Autism Spectrum Screen Performed During This Visit?

(Revised Jan 2022) *Complete if the Child is ≥ 16 months adjusted age.*

- Select **No** if the infant/child did not have an Autism Spectrum Screen performed during this core visit. Proceed to **Early Start (ES) Program**.
- Select **Yes** if the infant/child did have an Autism Spectrum Screen performed during this core visit. Complete the **Autism Spectrum Screen** questions below.

  Select the autism spectrum **Screening Tool Used**:

  - Modified Checklist for Autism in Toddlers (M-CHAT)/ Modified Checklist for Autism in Toddlers - Revised with Follow Up (M-CHAT-RF)
  - Communication and Symbolic Behavior Scales Developmental Profile (CSBS-DP)
  - Other/Not Listed.

  Select the autism spectrum **Screening Results**:

  - **Pass**
  - **Did Not Pass**

  Select the **Risk Level** if the infant/child **Did Not Pass** the **M-CHAT-RF**: (Added Jan 2022)

  - **Low Risk**, if the score is 0 - 2
  - **Medium Risk**, if the score is 3 - 7
  - **High Risk**, if the score is 8 - 20

Was the Child Referred for Further Autism Spectrum Assessment?

- Select **No** if the infant/child was not referred for further autism spectrum assessment. Proceed to **Early Start (ES) Program**.
- Select **Yes** if the infant/child was referred for further autism spectrum assessment.

Was an ASD diagnosis made at this visit (i.e. concurrent DBP evaluation)?

(Added Jan 2025)

NOTE: This data item was added for those HRIF Program sites that conduct comprehensive CCS-paneled Developmental Pediatrics and/or psychology evaluations at the time of the infant/child's HRIF standard core visit. This is **not an expectation** for HRIF Program clinic visits.

- Select **No** if the infant/child was not diagnosed with autism spectrum disorder (ASD) at this visit concurrent with a Developmental Behavioral Pediatrics (DBP) or psychology evaluation. Proceed to **Early Start (ES) Program**.
- Select **Yes** if the infant/child was diagnosed with autism spectrum disorder (ASD) at this visit concurrent with a Developmental Behavioral Pediatrics (DBP) or psychology evaluation. Complete the **How was the diagnosis made** question.

  How was the diagnosis made:
  Select the appropriate evaluation instrument used to make the ASD diagnosis:
  - Autism Diagnostic Observation Schedule (ADOS)

- Other Diagnostic Tools
- Other Clinical Evaluation

Early Start (ES) Program

(Revised Jan 2018/2022)

The Early Start Program is California's response to federal legislation ensuring that early intervention services for infants and toddlers with disabilities and their families are provided in a coordinated, family-centered network.

Is the Child Currently Receiving Early Intervention Services Through Early Start (Regional Center and/or Local Educational Agency [LEA])?

The Local Educational Agency (LEA) is a public board of education or other public authority legally constituted within a state for either administrative control or direction of, or to perform a service function for, public elementary or secondary schools in a city, county, township, school district, or other political subdivision of a state, or for a combination of school districts or counties as are recognized in a state as an administrative agency for its public elementary or secondary schools.

Select only **one** option that applies at the time of core visit.

- Select **Yes** if the infant/child is currently receiving services.
- Select **No, Complete** if the infant/child received the service and the service is no longer required (Added Jan 2022)
- Select **No, Not Required** if the infant/child is not receiving services.
- Select **No, Referred at Visit** if the infant/child is being referred at the time of visit or was initially referred but did not receive the service and is being referred again.
- Select **No, Referral Failure** if the infant/child was referred in the past, but not picked up for services.
- Select **No, Pending Services** if the infant/child was referred but is currently pending an appointment.
- Select **No, Parent Refused** if the parents refused the service.
- Select **No, Determined Ineligible by ES** if the infant/child was referred, but ES determined them ineligible for services.
- Select **Unknown** if this information cannot be obtained.

Medical Therapy Program (MTP)

(Added Jan 2013 / Revised Jan 2018/2022)

The Medical Therapy Program (MTP) is a special program within California Children's Services that provides physical therapy (PT), occupational therapy (OT) and medical therapy conference (MTC) services for children who have handicapping conditions, generally due to neurological or musculoskeletal disorders.

Is the Child Currently Receiving Services Through CCS Medical Therapy Program (MTP)?

Select only **one** option that applies at the time of core visit.

- Select **Yes** if the infant/child is currently receiving services
- Select **No, Complete** if the infant/child received the service and the service is no longer required (Added Jan 2022)
- Select **No, Not Required** if the infant/child is not receiving services
- Select **No, Referred at Visit** if the infant/child is being referred at the time of visit or was initially referred but did not receive the service and is being referred again.
- Select **No, Referral Failure** if the infant/child was referred in the past but not picked up for services.
- Select **No, Pending Services** if the infant/child was referred but is currently pending an appointment
- Select **No, Parent Refused** if the parents refused the service.
- Select **No, Determined Ineligible by MTP** if the infant/child was referred, but MTP determined them ineligible for services.
- Select **Unknown** if this information cannot be obtained.

Special Services Review

(Revised Jan 2010/2012/2022)

Is the Child Receiving or Being Referred for Special Services Because of the Current Evaluation / HRIF Assessment?

- Select **No** if the infant/child is not receiving or being referred for special services. Proceed to **Resources and Social Concerns**.
- Select **Yes** if the infant/child is receiving or being referred for special services.
- Select **Unknown** if this information cannot be obtained. Proceed to **Resources and Social Concerns**.

If the infant/child is receiving or being referred for special services, select both the status of each special service **and** one service provider for the infant/child. If there is more than one service provider, select the provider most frequently used.
Special Services include:

- **Behavior Intervention**
- **Feeding Therapy**
- **Infant Development Services**
- **Hearing Services**
- **Nutritional Therapy**
- **Occupational Therapy (OT)**
- **Physical Therapy (PT)**
- **Speech/Language Communication**
- **Social Work Intervention**
- **Visiting, Public Health, and/or Home Nursing**
- **Vision Services**

Listed below are the status choices for **each** Special Service:

- **Does Not Need**
- **Receiving**
- **Receiving – Increase Frequency** if the infant/child requires more utilization of the service. (Added Jan 2022)
- **Complete** if the infant/child no longer needs the service. (Added Jan 2010)
- **Referred at Time of Visit**
- **Referred, but Not Receiving – Missed Appointment**
- **Referred, but Not Receiving – Waiting List**
- **Referred, but Not Receiving – Re-Referred** initially referred and did not receive, now re-referred for services. (Added Jan 2012)
- **Referred, but Not Receiving – Insurance/HMO Denied**
- **Referred, but Not Receiving – Service Not Available**
- **Referred, but Not Receiving – Service Cancelled** (Added Jan 2010)
- **Referred, but Not Receiving – Parent Declined/Refused Service**
- **Referred, but Not Receiving – Other/Unknown Reason**

Behavior Intervention

- Select the appropriate **status** of the infant/child receiving (or being referred) for behavior intervention services.
- Select **one** service provider:
    - **Early Intervention Specialist**
    - **Licensed Clinical Social Worker**
    - **Psychologist**
    - **Other**
    - **Unknown**

Feeding Therapy

- Select the appropriate **status** of the infant/child receiving (or being referred) for feeding therapy services.
- Select **one** service provider:
    - **Early Intervention**
    - **Specialist**
    - **Certified Lactation Consultant**
    - **Home Health Agency**
    - **Occupational Therapist**
    - **Physical Therapist**
    - **Public Health Nurse**
    - **Registered Dietitian**
    - **Registered Nurse**
    - **Speech/Language Pathologist**
    - **Other**
    - **Unknown**

Infant Development Services

Also referred to as Infant Stim or Infant Stimulation

- Select the appropriate **status** of the infant/child receiving (or being referred) for Infant Development Services.
- Select **one** service provider:
    - **Early Intervention Specialist**
    - **Licensed Clinical Social Worker**
    - **Occupational Therapist**
    - **Physical Therapist**
    - **Psychologist**
    - **Registered Nurse**
    - **Medical Social Worker (MSW)**
    - **Speech/Language Pathologist**
    - **Other**
    - **Unknown**

Hearing Services

- Select the appropriate **status** of the infant/child receiving (or being referred) for hearing services.
- Select **one** service provider:
    - **Audiologist**
    - **Early Intervention Specialist**
    - **ENT**
    - **Speech/Language Pathologist**
    - **Teacher of the Deaf**
    - **Other**
    - **Unknown**

Nutritional Therapy

- Select the appropriate **status** of the infant/child receiving (or being referred) for nutritional services.
- Select **one** service provider:
    - **Certified Lactation Consultant**
    - **Public Health Nurse**
    - **Physician**
    - **Registered Dietitian**
    - **Registered Nurse**
    - **Other**
    - **Unknown**

Occupational Therapy (OT)

- Select the appropriate **status** of the infant/child receiving (or being referred) for occupational services.

- Select **one** service provider:
    - **Occupational Therapist**
    - **Other**
    - **Unknown**

Physical Therapy (PT)

- Select the appropriate **status** of the infant/child receiving (or being referred) for physical intervention services.
- Select **one** service provider:
    - **Physical Therapist**
    - **Other**
    - **Unknown**

Speech/Language Communication

- Select the appropriate **status** of the infant/child receiving (or being referred) for speech/language communication services.
- Select **one** service provider:
    - **American Sign Language**
    - **Early Intervention Specialist**
    - **Teacher of the Deaf**
    - **Speech/Language Pathologist**
    - **Other**
    - **Unknown**

Social Work Intervention

- Select the appropriate **status** of the infant/child receiving (or being referred) for social Work intervention services.
- Select **one** service provider:
    - **Licensed Clinical Social Worker**
    - **Marriage and Family Therapist**
    - **Psychologist**
    - **Physician**
    - **MSW**
    - **Other**
    - **Unknown**

Visiting, Public Health and/or Home Nursing

- Select the appropriate **status** of the infant/child receiving (or being referred) for visiting, public health and/or home nursing services.
- Select **one** service provider:
    - **Licensed Vocational Nurse**
    - **Physician**

- **Public Health Nurse**
- **Registered Nurse**
- **Other**
- **Unknown**

Vision Services

- Select the appropriate **status** of the infant/child receiving (or being referred) for vision services.
- Select **one** service provider:
  - **Low Vision Specialist (Optometrist**)
  - **Low Vision Specialist (Ophthalmologist)**
  - **Occupational Therapist**
  - **Orientation & Mobility Specialist**
  - **Physical Therapist**
  - **Teacher of the Visually Impaired**
  - **Other**
  - **Unknown**

Social Concerns and Resources

(Revised Jan 2021)

The Social Concerns and Resources section provides a framework to identify multiple sources of psychosocial or environmental stressors experienced by an infant/child and his/her family, noting severity and duration.

Caregiver – Child Disruptions or Concerns

Choose one of the options if intervention is necessary; in the instance that the infant/child's primary caregiver is a single parent, divorced, has a prolonged separation (incarceration, military service), multiple changes in caregivers/daycare, or the caregiver has a chronic illness.

- Select **No**
- Select **Already Receiving Services** (Added Jan 2025)
  If the child/family is currently receiving intervention services prior to the clinic visit.
  NOTE: if additional intervention services are needed at the time of the clinic visit, select the appropriate "**Yes"** option below.
- Select **Yes, Referral Not Necessary**
- Select **Yes, Referred to Social Worker**
- Select **Yes, Referred to Other Community Resources**

Economic/Environmental Concerns/Stressors

Choose one of the options if intervention is necessary; in the instance that the primary caregiver has housing insecurity, lack of resources, money issues, insurance (or high co-pay), lack of reliable transportation for medical needs.

- Select **No**
- Select **Already Receiving Services** (Added Jan 2025)
  If the child/family is currently receiving intervention services prior to the clinic visit.
  NOTE: if additional intervention services are needed at the time of the clinic visit, select the appropriate "**Yes"** option below.
- Select **Yes, Referral Not Necessary**
- Select **Yes, Referred to Social Worker**
- Select **Yes, Referred to Other Community Resources**

Community & Relationship Concerns

Choose one of the options if intervention is necessary; in the instance that the child/primary caregiver does not have perceived emotional support from family/friends, a supportive and safe intimate relationship, safe neighborhood, and resources for needs.

- Select **No**
- Select **Already Receiving Services** (Added Jan 2025)
  If the child/family is currently receiving intervention services prior to the clinic visit.
  NOTE: if additional intervention services are needed at the time of the clinic visit, select the appropriate "**Yes"** option below.
- Select **Yes, Referral Not Necessary**
- Select **Yes, Referred to Social Worker**
- Select **Yes, Referred to Other Community Resources**

Parent – Child Concerns

Choose one of the options if intervention is necessary; if the child/primary caregiver has problems regarding feeding and growth, calming, behavior, sleep, and other.

- Select **No**
- Select **Already Receiving Services** (Added Jan 2025)
  If the child/family is currently receiving intervention services prior to the clinic visit.
  NOTE: if additional intervention services are needed at the time of the clinic visit, select the appropriate "**Yes"** option below.
- Select **Yes, Referral Not Necessary**
- Select **Yes, Referred to Social Worker**
- Select **Yes, Referred to Other Community Resources**

Food Insecurity

(Added Jan 2021)

Choose one of the options if intervention is necessary; in the instance that the primary caregiver within the past 12-months: Worried whether their food would run out before they got money to buy more OR the food they bought just didn't last and they didn't have money to get more. NOTE: Some families receiving food and nutrition services such as CalFresh Food or Women, Infants and Children (WIC) may experience food insecurities.

- Select **No**
- Select **Already Receiving Services** (Added Jan 2025)
  If the child/family is currently receiving intervention services prior to the clinic visit.

NOTE: if additional intervention services are needed at the time of the clinic visit, select the appropriate "**Yes"** option below.

- Select **Yes, Referral Not Necessary**
- Select **Yes, Referred to Social Worker**
- Select **Yes, Referred to Other Community Resources**

Child Protective Services (CPS)

Is a Child Protective Services (CPS) Case Currently Opened?

Select one option that applies at the time of core visit.

- Select **No**
- Select **Yes** if CPS referral is pending or currently opened
- Select **Referred at Time of Visit**

Other Medical Conditions

Has the Child's Immunizations Schedule Ever Been Delayed?

(Added Jan 2021)

Select one option that applies at the time of core visit.

- Select **No**
- Select **Yes**
- Select **Unknown** if this information cannot be obtained.

Were There Additional Medical Conditions Identified That May Impact the Child's Outcome?

(Added Jan 2018)

Select one option that applies at the time of core visit.

- Select **No** if there are no additional medical conditions identified.
- Select **Yes** if there are additional medical conditions identified that may impact the child's outcome.

  Select **all categories** that apply and **provide a description** of the diagnosis:

  - **Cardiovascular and Circulatory**
  - **Endocrine and Metabolic**
  - **Eye, Ear, Nose**
  - **Gastrointestinal and Hepatobiliary**
  - **Genetic**
  - **Hematologic, Immunology, or Oncologic/Neoplasm**

- **Infectious Diseases**
- **Injuries, Accident, or Poisoning**
- **Renal and Genitourinary Tract**
- **Respiratory System**
- **Nervous System**
- **Other**

Including categories and text field for specificity, we hope to identify other diagnoses and disorders that may impact outcomes and resource utilization above and beyond the initial HRIF eligibility criteria-related diagnoses.

Disposition *Required Field

(Revised Jan 2015/2016)

Disposition is the status of the need for continued follow-up care for this infant/child after the visit.

Select only one option that applies at the time of core visit.

- Select **Scheduled to Return** if the infant/child will be scheduled for another follow-up core visit at the HRIF Clinic.
- Select **Completed HRIF Core Visits, Scheduled to Return** if the child has completed the three HRIF follow-up core visits, before the child's third birthday and is scheduled to return for additional resources. (Added Jul 2016)
- Select **Will Be Followed by Another CCS HRIF Program** if the infant/child is transferred and receiving follow-up care from another CCS HRIF Clinic. Learn How to Transfer a Record to Another CCS HRIF Clinic?
- Select **Discharged, Graduated** if the infant/child has completed the three HRIF Program follow-up core visits and has reached the 3-year age limit. In the case, no further data will be submitted on this infant/child to CMS/CCS.
- Select **Discharged, Family Moving Out of State/Country** if the family is moving out of state/country. In the case, no further data will be submitted on this infant/child to CMS/CCS. (Added Jan 2015)
- Select **Discharged, Will Be Followed Elsewhere** if the infant/child will be receiving follow-up care from a Non-CCS HRIF Program in California. In the case, no further data will be submitted on this infant/child to CMS/CCS.
- Select **Discharged, Closed Out of Program** if the HRIF Clinic has determined that the infant/child is no longer needs to be followed within a CCS HRIF Program. In the case, no further data will be submitted on this infant/child to CMS/CCS.
- Select **Discharged, Family Withdrew Prior To Completion** if the infant/child's primary caregiver(s) decides not to return or continue follow-up core visits in a CCS HRIF Program, before the final (3rd) visit or the child's third birthday. In the case, no further data will be submitted on this infant/child to CMS/CCS.
- Select **Discharged, Completed HRIF Core Visits, Referred for Additional Resources** if the child has completed the three HRIF Program follow-up core visits, has reached the 3-year age limit and is referred for additional resources. In the case, no further data will be submitted on this infant/child to CMS/CCS.

Additional Visit (AV) Form

Required Fields **must** be entered to AV entry form. Saved forms can be revisited later to make updates.

Online Entry Screen

HRIF Identification (ID) Number

Is a unique computer-generated number assigned to the infant/child enrolled in the HRIF Clinic.
NOTE: The HRIF ID Number is automatically generated after submission of the RR form.

This Form Is Closed

This checkbox feature serves as an electronic signature confirmation that all available data has been entered.

Date of Additional Visit *Required Field

Enter the date of the additional visit using MM-DD-YYYY. This is the date the infant/child was seen at the HRIF Clinic.

This Visit Was Conducted *Required Field

(Added Mar 2020 / Revised Jan 2021)

- Select **In-Person** if the visit was an in-person clinic appointment.
- Select **Telehealth (audio + video observation**) if the visit was a virtual visit appointment by Telehealth, Zoom, WebEx or another audio/video application.
- Select **Phone Only** if the visit was only a telephone audio appointment.

Reason For Additional Visit *Required Field

Indicate the reason for the infant/child's additional visit to the HRIF Clinic.

- Select **Social Risk** if there are concerns regarding any disruption with the primary caregiver(s), such as divorce, military, etc., strained family relationship, poor economic status, and/or safety issues.
- Select **Concern with Neuro/Developmental Course** if the infant/child needs additional assessment of Neurologic or Developmental status.
- Select **Case Management** if the infant/child needs additional access to, linking with, referring to, or coordinating and/or monitoring of services.
- Select **Other** if the reason for the additional visit is not already described. Use the text field to type in the reason that best describes why the infant/child needed an additional visit.

Disposition *Required Field

(Revised Jan 2015)

Disposition is the status of the need for continued HRIF for this infant/child after the visit.

Select only **one** option that applies at the time of core visit.

- Select **Scheduled to Return** if the infant/child will be scheduled for another follow-up core visit at the HRIF Clinic.
- Select **Will Be Followed by Another CCS HRIF Clinic** if the infant/child is transferred and receiving follow-up care from another CCS HRIF Clinic. Learn How to Transfer a Record to Another CCS HRIF Clinic?
- Select **Discharged, Graduated** if the infant/child has completed the three HRIF Program follow-up core visits and has reached the 3-year age limit. In the case, no further data will be submitted on this infant/child to CMS/CCS.
- Select **Discharged, Family Moving Out of State/Country** if the family is moving out of state/country. In the case, no further data will be submitted on this infant/child to CMS/CCS. (Added Jan 2015)
- Select **Discharged, Will Be Followed Elsewhere** if the infant/child will be receiving follow-up care from a Non-CCS HRIF Program in California. In the case, no further data will be submitted on this infant/child to CMS/CCS.
- Select **Discharged, Closed Out of Program** if the HRIF Clinic has determined that the infant/child is no longer needs to be followed within a CCS HRIF Program. In the case, no further data will be submitted on this infant/child to CMS/CCS.
- Select **Discharged, Family Withdrew Prior To Completion** if the infant/child's primary caregiver(s) decides not to return or continue follow-up core visits in a CCS HRIF Program, before the final (3rd) visit or the child's third birthday. In the case, no further data will be submitted on this infant/child to CMS/CCS.
- Select **Discharged, Completed HRIF Core Visits, Referred for Additional Resources** if the child has completed the three HRIF Program follow-up core visits, has reached the 3-year age limit and is referred for additional resources. In the case, no further data will be submitted on this infant/child to CMS/CCS.

Cerebral Palsy (CP)

(Added 2025)

As presented by Bax, et al. (1) cerebral palsy is a broad descriptive term encompassing a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems.

Early Detection of Cerebral Palsy
In response to concerns around potential delay in cerebral palsy (CP) diagnosis and therefore possible delay in data-driven interventions, a large working group of international experts and parent stakeholders published guidelines for early CP detection and based on a systematic review of the evidence (2, 3). This included a comprehensive review and recommendations regarding standardized assessment tools at different timepoints (see Appendix C Figure from Novak et al, JAMA Pediatrics 2017 in the Part III – Appendices section of the manual). Since then, publications have described implementation of this approach in single sites and organizational systems (4). In addition, recent publications have further described best practice guidelines for communicating with parents when diagnosis of a disability is made.

We are aware that some California sites have launched integration of standardized assessments to optimize early CP detection. Therefore, we have expanded the Standard Visit queries regarding CP diagnosis to earlier ages aligned with questions about standardized assessments used.

Was Early Detection of High-Risk Cerebral Palsy Made at this Visit?

Complete if the child is less than 18 months adjusted age.

- Select **No**, if the infant/child does not have cerebral palsy. Proceed to **Developmental Assessment.**
- Select **Yes**, if the infant/child cerebral palsy assessment indicates High Risk or Definite.

Select the Assessment Used to Arrive at Early Detection of High-Risk Cerebral Palsy:

Proceed to select **all** assessments used.

- **Alberta Infant Motor Scale (AIMS)**
- **Developmental Assessment of Young Children (DAYC)**
- **General Movements Assessment (GMA)**
- **Hammersmith Infant Neurological Examination (HINE)**
- **Motor Assessment of Infants (MAI)**
- **Magnetic Resonance Imaging (MRI)**
- **Neurologic exam with GMFCS assessment**
- **Neuro Sensory Motor Development Assessment (NSMDA)**
- **Test of Infant Motor Performance (TIMP)**
- **Other** (text field)

For the purposes of the HRIF Reporting System, the focus has been on everyday motor function [an approach in concert with international proposals and reports for consistency in neurodevelopmental follow up structures for high-risk infants (5)] at 18 months adjusted age or older. As such, the definition of cerebral palsy will be based on having abnormalities in both areas 1 and 2 below:

3. **Definite abnormalities observed in neuromotor exam**, which includes passive muscle tone, deep tendon reflexes, coordination, and movement (6).
4. **A delay in motor milestones**. This would be reflected as abnormalities in functional gross motor skills for age, including head and neck and/or trunk postural function abnormalities, and/or upper limb or lower limb gross motor skills.

In addition, abnormalities in protective reactions (parachute, lateral protective reactions) and primitive reflexes may be present.

Does the Child Have Cerebral Palsy (CP)?

Complete if the child is ≥ 18 months adjusted age.

- Select **No**, if the infant/child does not have cerebral palsy. Proceed to **Developmental Assessment.**
- Select **Yes**, if the infant/child has cerebral palsy.
- Select **Suspect**, if the infant/child is suspected to have cerebral palsy. (Added Jan 2013)
  If **Yes** or **Suspect** was selected, select the appropriate responses for **Gross Motor Function Classification System (GMFCS).**
- Select **Unable to Determine**, if unable to determine whether the infant/child has cerebral palsy.

Gross Motor Function Classification System (GMFCS)

For children with cerebral palsy, the severity of functional motor abilities and limitations should be further characterized. The Gross Motor Function Classification System (GMFCS) is a widely used and validated scale, arranged by age bands.

If **Yes** or **Suspect** was selected for identifying the infant/child has cerebral palsy at the time of the core visit, select the child's **Gross Motor Function Classification System (GMFCS)** level for the appropriate adjusted age grouping (18 - 24 months adjusted age **or** 24 – 36 months adjusted age). Baxter, P. (2008). *The Definition and Classification of Cerebral Palsy. Developmental Medicine and Child Neurology, 49(s109), 1-44.*

Infants 18 - 24 months of age (adjusted age)

- Select **Level I** if infant/child walks without the need for any assistive mobility device.
- Select **Level II** if infant/child maintain floor sitting but may need to use his/her hands for support to maintain balance. Infant/child creeps on his/her stomach or crawls on hands and knees. Infant/child may pull to stand and take steps holding on to furniture.
- Select **Level III** if infant/child maintain floor sitting when the low back is supported. Infant/child rolls and creeps forward on his/her stomach.
- Select **Level IV** if infant/child has head control but trunk support is required for floor sitting. Infant/child can roll to supine and may roll to prone.
- Select **Level V** if physical impairments limit voluntary control of movement. Infant/child is unable to maintain antigravity head and trunk postures in prone and sitting. Infant/child requires adult assistance to roll.
- Select **Unsure/Unable to Determine** if you cannot adequately complete the evaluation to assess.

Infants 24 - 36 months of age (adjusted age)

- Select **Level I** if infant/child floor sits with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Infant/child walks as the preferred method of mobility without the need for any assistive mobility device.
- Select **Level II** if infant/child floor sits but may have difficulty with balance with both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Infant/child pulls to stand on a stable surface. Infant/child crawls on hand and knees with a reciprocal pattern, cruise holding onto furniture, and walks using an assistive mobility device as preferred methods of mobility.
- Select **Level III** if infant/child maintains floor sitting often with W-sitting and may require adult assistance to assume sitting. Infant/child creeps on his/her stomach and crawls on hands and knees as his/her primary methods of self-mobility. Infant/child may pull to stand on a stable surface and cruise short distances. Infant/child may walk short distances indoors using a hand-held mobility device and adult assistance for steering and turning.
- Select **Level IV** if infant/child floor sits when placed but is unable to maintain alignment and balance without use of his/her hands for support. Infant/child frequently requires adaptive equipment for sitting and standing. Self-mobility for short distances is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.
- Select **Level V** if physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, infant/child has no means of independent movement and is transported.
- Select **Unsure/Unable to Determine** cannot adequately complete the evaluation to assess.

10) Bax M, Goldstein M, Rosenbaum P, Leviton A, Paneth N, Dan B, et al. Proposed definition and classification of cerebral palsy, April 2005. Dev Med Child Neurol. 2005; 47(8):571-6.
11) Novak I, Morgan C, Adde L, et al. Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment. JAMA Pediatr. 2017 Sep 1;171(9):897-907.
12) Spittle AJ, Morgan C, Olsen JE, Novak I, Cheong JLY. Early Diagnosis and Treatment of Cerebral Palsy in Children with a History of Preterm Birth. Clin Perinatol. 2018 Sep;45(3):409-420.
13) Maitre NL, Damiano D, Byrne R. Implementation of Early Detection and Intervention for Cerebral Palsy in High-Risk Infant Follow-Up Programs: U.S. and Global Considerations. Clin Perinatol. 2023 Mar;50(1):269-279.
14) Novak I, Morgan C, McNamara L, Te Velde A. Best practice guidelines for communicating to parents the diagnosis of disability. Early Hum Dev. 2019 Dec;139:104841.
15) Report of a BAPM/RCPCH Working Group. Classification of health status at 2 years as a perinatal outcome. January 2008. British Association of Perinatal Medicine. http://www.bapm.org
16) Amiel-Tison C, Ellison P. Birth asphyxia in the full-term newborn: Early assessment and outcome. Dev Med Child Neurol. 1986;28(5):671-82.
17) Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Dev Med Child Neurol. 1997; 39(4):214-23.
18) GMFCS – Expanded and Revised, Can Child Centre for Childhood Disability Research (Palisano R, 2007). http://motorgrowth.canchild.ca/en/GMFCS/resources/GMFCS-ER.p

Autism Spectrum Screen (Optional)

(Added Jan 2025)

As per the Johnson CP and the AAP statement Identifying infants and young children with developmental disorders in the medical home (Pediatrics, 2006): For general developmental screening and surveillance, the ***AAP recommends administering a standardized autism-specific screening tool on all children at the 18-month preventive care visit.*** The AAP Autism Expert Panel responded to the statement with a commentary that suggested a repeat screening be per- formed at 24 months of age to identify those who may regress after 18 months of age.

(1) Johnson, CP, Myers SM. *Identification and Evaluation of Children with Autism Spectrum Disorders. Pediatrics.2007;*120(5):1183-1215

(2) Council on Children With Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, Medical Home Initiatives for Children With Special Needs Project Advisory Committee. *Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening. Pediatrics.*2006;118:405.

Has a Diagnosis of Autism Spectrum Disorder Been Made?

- Select **No** if the infant/child has not been diagnosed with autism spectrum disorder. Proceed to – **Was an Autism Spectrum Screen Performed During This Visit**?
- Select **Yes** if the infant/child has been diagnosed with autism spectrum disorder. Proceed to – **Early Start (ES) Program**.

Was an Autism Spectrum Screen Performed During This Visit?

Complete if the Child is ≥ 16 months adjusted age.

- Select **No** if the infant/child did not have an Autism Spectrum Screen performed during this core visit. Proceed to **Early Start (ES) Program**.
- Select **Yes** if the infant/child did have an Autism Spectrum Screen performed during this core visit. Complete the **Autism Spectrum Screen** questions below.

  Select the autism spectrum **Screening Tool Used**:

  - Modified Checklist for Autism in Toddlers (M-CHAT)/ Modified Checklist for Autism in Toddlers - Revised with Follow Up (M-CHAT-RF)
  - Communication and Symbolic Behavior Scales Developmental Profile (CSBS-DP)
  - Other/Not Listed.

  Select the autism spectrum **Screening Results**:

  - **Pass**
  - **Did Not Pass**

  Select the **Risk Level** if the infant/child **Did Not Pass** the **M-CHAT-RF**: (Added Jan 2022)

  - **Low Risk**, if the score is 0 - 2
  - **Medium Risk**, if the score is 3 - 7
  - **High Risk**, if the score is 8 - 20

Was the Infant Referred for Further Autism Spectrum Assessment?

- Select **No** if the infant/child was not referred for further autism spectrum assessment. Proceed to **Early Start (ES) Program**.
- Select **Yes** if the infant/child was referred for further autism spectrum assessment.

Was an ASD diagnosis made at this visit (i.e. concurrent DBP evaluation)?

(Added Jan 2025)

NOTE: This data item was added for those HRIF Program sites that conduct comprehensive CCS-paneled Developmental Pediatrics and/or psychology evaluations at the time of the infant/child's HRIF standard core visit. This is **not an expectation** for HRIF Program clinic visits.

- Select **No** if the infant/child was not diagnosed with autism spectrum disorder (ASD) at this visit concurrent with a Developmental Behavioral Pediatrics (DBP) or psychology evaluation. Proceed to **Early Start (ES) Program**.
- Select **Yes** if the infant/child was diagnosed with autism spectrum disorder (ASD) at this visit concurrent with a Developmental Behavioral Pediatrics (DBP) or psychology evaluation. Complete the **How was the diagnosis made** question.

  How was the diagnosis made:
  Select the appropriate evaluation instrument used to make the ASD diagnosis:
  - Autism Diagnostic Observation Schedule (ADOS)
  - Other Diagnostic Tools
  - Other Clinical Evaluation

Client Not Seen/Discharge (CNSD) Form

Required Fields **must** be entered to CNSD entry form. Saved forms can be revisited later to make updates.

Online Entry Screen

HRIF Identification (ID) Number

Is a unique computer-generated number assigned to the infant/child enrolled in the HRIF Clinic.
NOTE: The HRIF ID Number is automatically generated after submission of the RR form.

This Form Is Closed

This checkbox feature serves as an electronic signature confirmation that all available data has been entered.

Date Client Not Seen/Discharged *Required Field

- If the infant/child is lost to follow-up. Enter the last attempted date to contact the family to schedule an appointment. Use the date format MM-DD-YYYY.
- Enter the date the infant/child was a no show. Use the date format MM-DD-YYYY.
- Enter the date the infant/child expired prior to the core visit, family relocated, insurance denial, etc. Use the date format MM-DD-YYYY.
- Enter the date when the infant/child was transferred/referred to another HRIF Clinic for follow-up services. Use the date format MM-DD-YYYY.

NOTE: A core visit rescheduled or canceled (24 hours prior) **does not** constitute as a no show.

Category *Required Field

Select the appropriate category, describing why the infant/child was not seen at the HRIF Clinic.

- Select **No Appointment Scheduled**, if the infant/child was referred to HRIF, but the staff were unable to establish an initial core visit.
- Select **Core Visit Appointment Scheduled**, if the infant/child was on the schedule, but not seen.
- Select **Discharged**, if the infant/child will be referred to another CCS HRIF Clinic or other program (Non-CCS HRIF Program) for follow-up services.

Reason For Client Not Seen/Discharge *Required Field

(Revised Mar 2021)

Indicate the reason why the infant/child was not seen at the HRIF Clinic.

- Select **Appt Cancelled/COVID-19 Related** if the infant/child is scheduled for standard visit and the parent (caregiver) cancelled/rescheduled the appointment to prevent the risk of Coronavirus/ COVID-19 spread in the state of California or due to other COVID-19 related reasons such as: In

home distance learning; no childcare/daycare for other children in the household; family/household member diagnosed with coronavirus. (Added Mar 2021)

- Select **Infant Illness** if the infant/child is ill on the day of the appointment but will be rescheduled for another visit.
- Select **Infant Hospitalized** if the infant/child is hospitalized on the day of the appointment but will be rescheduled for another visit.
- Select **Infant Referred to Another HRIF Clinic** if the HRIF Coordinator has contacted the other HRIF clinic and has shared the infant's records accordingly.
- Select **Infant/Family Moved Within California** if the family cannot make the appointment due to moving from their primary residence and have changed city or county within California.

> NOTE: The HRIF Coordinator should try to link the family to an HRIF clinic in their new location.

- Select **Infant/Family Moved Out of State** if the family lives or is moving out of state or country.

> NOTE: The HRIF Coordinator should try to link the family to an HRIF clinic in their new location.

- Select **Infant Expired** if the infant/child has died.

> NOTE: The HRIF Coordinator should note in the chart that the infant/child has expired and close the case.

- Select **Parent Illness** if the caregiver was ill and was unable to bring the infant/child to the appointment.
- Select **Parent Refused i**f the family believes the infant/child does not need the services provided by the HRIF Program.

> NOTE: The HRIF Coordinator should contact the family to determine the reason for refusing the appointment and work with the family to encourage them to appear for appointments.

- Select **Parent Competing Priorities** if the primary caregiver cannot bring the infant/child to the appointment for the following reasons: work schedule, family issues, forgetfulness, etc.

> NOTE: The HRIF Coordinator should work with the family to schedule a HRIF appointment that will not be a conflict with other obligations and to educate the family on the importance of these follow-up services.

- Select **Parent Declines Due to Cost** if the family cannot afford to bring the infant/child to the HRIF Program due to insurance deductibles (co-pays/share of cost).
- Select **Insurance Authorization Problems** if the family has been unsuccessful in securing insurance authorization for HRIF services.

> NOTE: The HRIF Program will work with the family to secure insurance authorization for the HRIF Services.

- Select **CCS Denied** if the local (county) CCS Program office denied the infant/child for HRIF services.

- Select **Clinic Visit Considered Unnecessary** if the family was informed that HRIF services are not needed by the infant/child's health care professional (General/Family Practitioner, Pediatrician, Nurse Practitioner).
- Select **Lack of Transportation** if the family has mechanical issues with the car; no bus route available; no neighborhood support for securing a ride to the appointment; etc.

> **NOTE:** The HRIF Coordinator should contact the family and attempt to secure transportation for the next scheduled appointment.

- Select **Lost to Follow-up** if unable to initiate contact with the family after multiple attempts.
- Select **Unable to Contact** if the HRIF Coordinator is not able to get in contact (phone, letter, email, etc.) with the family to schedule an appointment after multiple attempts.

> **NOTE:** The HRIF Coordinator should inform the infant/child's pediatrician that the family is not responding, and they are unable to contact the family.

- Select **Other** if the reason the infant/child was not seen has not already been described. Use the text field to type in the reason that best describes why the infant/child was not seen.
- Select **No Show/Reason Unknown** if no specific reason is available or known for why the infant/child was not seen.

Disposition *Required Field

(Revised Jan 2015)

Disposition is the status of the need for continued follow-up care for this infant/child after missing a scheduled appointment.

Select only **one** option that applies at the time the infant/child was not seen.

- Select **Scheduled Appointment** if the infant/child has been scheduled for a return follow-up core visit.
- Select **Will Schedule Appointment** if the infant/child will be scheduled for a return follow-up core visit.
- Select **Will Be Followed by Another CCS HRIF Program** if the infant/child is transferred and receiving follow-up care from another CCS HRIF Clinic. Learn How to Transfer a Record to Another CCS HRIF Clinic?
- Select **Discharged, Family Moving Out of State/Country** if the family is moving out of state/country. In the case, no further data will be submitted on this infant/child to CMS/CCS. (Added Jan 2015)
- Select **Discharged, Will Be Followed Elsewhere** if the infant/child will be receiving follow-up care from a Non-CCS HRIF Program in California. In the case, no further data will be submitted on this infant/child to CMS/CCS.
- Select **Discharged, Closed Out of Program** if the HRIF Clinic has determined that the infant/child is no longer needs to be followed within a CCS HRIF Program. In the case, no further data will be submitted on this infant/child to CMS/CCS.

PART III – APPENDICES

Appendix A. WIDEA-FS Materials

The Warner Initial Developmental Evaluation of Adaptive and Functional Skills

(WIDEA-FS TM) ▪ Version 15 ▪ November 1, 2015

Michael E. Msall, Colleen Peyton, Nancy Lyon, Kathleen Mariano

➢➢➢ **How often can your child do the following without help?** **Subject #:**_____

1 = Never 2 = Sometimes, infrequent 3 = Most of the time 4 = All of the time

I. Self-Care: Feeding	
1. Easily drinks formula or breast milk	
2. Easily swallows baby food	
3. Chews solid food	
4. Finger feeds	
5. Eats using a spoon	
6. Drinks from cup without a lid	
7. Eats using a fork	
II. Self-Care: Dressing	
1. Holds arms up so you can put shirt on	
2. Removes socks	
3. Pulls pants down	
4. Pulls up a zipper once it is started	
5. Puts on t-shirt	
6. Removes all clothes	
III. Self-Care: Diaper Awareness	
1. Indicates a wet diaper	
2. Indicates a soiled diaper	
3. Voids into potty chair or toilet	
4. Sits on potty chair and has bowel movement	
Subtotal Self-Care Domain (max=68)	

IV. Mobility	
1. Rolls both ways	
2. Maintains sitting without support	
3. Crawls short distance	
4. Walks few feet with assistance (cruises)	
5. Scoots/crawls 10 feet or moves his/her wheelchair 10 feet	
6. Walks 10 feet independently	
7. Crawls up stairs	
8. Gets on and off a chair	
9. Walks up stairs with hand held	
Subtotal Mobility Domain (max=36)	

V. Communication	
1. Understands words for people in immediate family (mommy, daddy) (R)	
2. Demonstrates 2 syllable babbling (baba)(E)	
3. Understands words for some common objects (R)	
4. Gestures a social greeting (wave, blow a kiss) (E)	
5. Carries out a 1 step oral request with gesture (pick up toy, cup) (R)	
6. Uses single words or signs to request or communicate (E)	
7. Carries out a 1 step oral request without gesture (R)	
8. Identifies one body part (R)	
9. Identifies three or more body parts (R)	
10. Points at pictures (R)	
11. Has at least 10 words or 10 signs (E)	
12. Combines words or signs to make needs known (E)	
13. Names pictures (E)	
Subtotal Communication Domain (max=52)	

VI. Social Cognition	
1. Plays “peek-a-boo”, “patty cake”, or “so big”	
2. Looks for object dropped out of sight	
3. Initiates social contacts with peers	
4. Takes turns rolling a ball	
5. Imitates another child	
6. Recognizes familiar song	
7. Starts mechanical toy or computer	
8. Can pretend play with doll or toy	
9. Turns pages in a book	
10. Points at pictures when you read a story	
11. Helps with simple household tasks	
Subtotal Social Cognition Domain (max=44)	

TOTAL SCORE ☐

Total Items: 50 ▪ Maximum Score: 200

Tema #:_____

Warner IDEA-FS ™

Evaluación evolutiva inicial de las habilidades adaptativas y funcionales de Warner · Versión 7

Michael E. Msall, Nancy Lyon, Colleen Peyton, Ron Espinal

¿Con qué frecuencia su hijo(a) realiza las siguientes actividades sin ayuda?

1 = Nunca **2** = A veces, infrecuente **3** = Most of the time **4** = Casi siempre

I. Cuidado personal: Alimentación	
1. Toma fácilmente la leche de fórmula o de pecho	
2. Traga con facilidad alimentos para bebé	
3. Mastica alimentos sólidos	
4. Come usando los dedos de las manos	
5. Come usando una cuchara	
6. Bebe de un vaso sin tapa	
7. Come usando un tenedor	
II. Cuidado personal: Vestirse	
1. Levanta los brazos para que usted le coloque una camiseta	
2. Se saca las medias	
3. Se baja los pantalones	
4. Termina de subir un cierre	
5. Se pone una camiseta	
6. Se saca toda la ropa	
III. Cuidado personal: Control de esfínteres	
1. Avisa cuando el pañal está mojado	
2. Avisa cuando el pañal está sucio	
3. Orina en orinal para bebés o en inodoro	
4. Se sienta en el orinal para bebés y defeca	
Subtotal Área Cuidado Personal (máx=68)	

IV. Movilidad	
1. Se vira hacia ambos lados	
2. Se mantiene sentado sin apoyo	
3. Gatea distancias cortas	
4. Camina una distancia de pocos pies con ayuda (pasea)	
5. En una silla de ruedas, se desplaza, o se mueve una distancia de 10 pies	
6. Camina hasta 10 pies, sin ayuda	
7. Gatea hacia arriba en las escaleras	
8. Sube y baja de una silla	
9. Sube las escaleras llevado de la maño	
Subtotal Área Movilidad (máx=36)	

V. Comunicación	
1. Comprende las palabras que identifican a las personas de su familia inmediata (R)	
2. Demuestra parloteo de 2 sílabas (E)	
3. Entiende palabras para nombrar algunos objetos comunes (R)	
4. Realiza gestos de saludo (E)	
5. Responde a instrucciones orales de un paso con apoyo gestual (R)	
6. Se comunica o pide usando una palabra o gestos (E)	
7. Responde a instrucciones orales de 1 paso sin apoyo gestual (R)	
8. Identifica una parte del cuerpo (R)	
9. Identifica tres o mas partes del cuerpo (R)	
10. Apunta a figuras con el dedo (R)	
11. Tiene por lo menos 10 palabras o 10 señales (E)	
12. Combina palabras o señales para expresar sus necesidades (E)	
13. Nombra figuras (E)	
Subtotal Área Comunicación (máx=52)	

VI. Habilidades sociales	
1. Juega a las escondidas (peek-a-boo), a batir palmas, y mostrar como es de grande	
2. Busca objetos que han caído fuera de su área visual	
3. Inicia contacto social con sus compañeros	
4. Espera su turno para hacer rodar una pelota	
5. Imita a otro niño	
6. Reconoce canciones familiares	
7. Enciende juguetes mecánicos, o Computadoras	
8. Puede jugar a hacer de cuenta con una muñeca o juguete	
9. Pasa las páginas de un libro	
10. Señala las figuras cuando le leen un cuento	
11. Ayuda con una tarea simple en el hogar	
Subtotal Área habilidades sociales: (máx=44)	

*** Total ítems: 50
*** Puntaje máx. 200

PUNTAJE TOTAL

University of Chicago IRB approval April 2005

WIDEA-FS Results of Typical Children (N = 548)

			WIDEA-FS Domain														
			WIDEA-FS Total			Self-care			Mobility			Communication			Social Cognition		
Ages (months)	**No. of Boys**	**No. of Girls**	**Mean**	**Median**	**SD**	**Mean**	**Median**	**SD**	**Mean**	**Median**	**SD**	**Mean**	**Median**	**SD**	**Mean**	**Median**	**SD**
0 – 3.9	43	31	55.2	54.0	4.0	21.6	21.0	2.9	9.1	9.0	0.4	13.3	13.0	0.9	11.2	11.0	1.1
4 – 6.9	29	39	65.1	61.5	16.1	24.6	23.0	4.8	12.0	11.0	4.1	15.1	13.0	5.1	13.3	11.0	4.2
7 – 9.9	27	23	85.0	87.0	15.0	28.4	28.0	5.1	18.7	18.0	4.5	19.6	19.5	4.3	18.5	17.0	4.6
10 – 12.9	34	29	109.4	106.0	16.5	33.3	32.0	4.3	25.6	26.0	5.6	25.9	26.0	5.4	24.6	23.0	5.9
13 – 15.9	34	23	131.7	131.0	18.2	36.9	35.0	5.2	31.5	32.0	3.8	33.2	31.0	8.1	29.5	29.0	6.5
16 – 18.9	18	19	152.0	151.0	15.9	40.9	39.0	7.1	34.6	35.0	1.9	41.4	43.0	6.8	35.1	35.0	5.5
19 – 21.9	18	19	164.6	168.0	16.9	45.6	45.0	6.4	35.2	36.0	1.6	45.9	49.0	6.7	37.8	39.0	6.1
22 – 24.9	19	23	171.7	171.5	9.6	47.0	47.0	6.1	35.3	36.0	1.8	50.0	51.0	3.0	39.5	40.5	3.4
25 – 27.9	11	16	179.3	181.0	11.5	52.4	53.0	8.9	35.7	36.0	0.9	50.4	52.0	3.6	40.7	42.0	3.6
28 – 30.9	17	16	183.0	184.0	10.0	54.5	55.0	7.8	35.8	36.0	0.7	51.0	52.0	2.5	41.7	43.0	3.4
31 – 33.9	16	13	186.2	190.0	11.8	58.6	59.0	8.2	35.6	36.0	1.7	50.9	52.0	3.1	41.1	42.0	3.0
34 – 36.9	16	15	190.2	191.0	7.3	60.2	60.0	6.2	35.8	36.0	1.1	51.8	52.0	0.5	42.3	44.0	2.3
> 37	0	0	0	0	-	0	0	0	0	0	-	0	0	0	0	0	-

Self care:

Age group (months)	N	Mean	SD	p5	p10	p25	p50	p75	p95
0-4.9	100	22	4	18	18	20	21	24	28
5-5.9	20	26	5	20	20	23	23	29	37
6-6.9	22	26	3	22	23	23	25	27	30
7-7.9	17	25	4	17	19	23	25	27	33
8-8.9	15	28	3	23	23	24	28	30	33
9-9.9	18	32	5	26	26	28	32	35	43
10-10.9	16	33	4	28	28	29	32	35	41
11-11.9	18	32	4	24	28	30	32	34	43
12-12.9	29	34	4	29	30	31	33	36	41
13-15.9	57	37	5	29	31	34	35	40	48
16-18.9	37	41	7	31	34	37	39	44	58
19-21.9	37	46	6	37	38	41	45	50	56
22-24.9	42	47	6	39	39	42	47	50	57
25-30.9	60	54	8	40	42	48	54	61	65
31-36.9	60	59	7	44	51	57	60	66	68

Mobility:

Age group (months)	N	Mean	SD	p5	p10	p25	p50	p75	p95
0-4.9	100	10	3	9	9	9	9	9	12
5-5.9	20	12	3	9	9	9	11	13	18
6-6.9	22	14	3	10	11	11	13	16	18
7-7.9	17	16	4	9	12	12	15	18	27
8-8.9	15	19	3	15	15	16	18	22	25
9-9.9	18	22	3	15	15	21	22	24	27
10-10.9	16	22	5	15	15	19	21	25	35
11-11.9	18	23	4	18	18	20	24	26	33
12-12.9	29	29	4	20	21	27	30	33	36
13-15.9	57	32	4	22	24	31	32	34	36
16-18.9	37	35	2	32	32	33	35	36	36
19-21.9	37	35	2	31	32	35	36	36	36
22-24.9	42	35	2	32	34	35	36	36	36
25-30.9	60	36	1	35	35	36	36	36	36
31-36.9	60	36	1	35	36	36	36	36	36

Communication:

Age group (months)	N	Mean	SD	p5	p10	p25	p50	p75	p95
0-4.9	100	13	4	13	13	13	13	13	16
5-5.9	20	15	4	13	13	13	14	16	26
6-6.9	22	15	2	13	13	13	15	17	19
7-7.9	17	17	4	13	13	14	16	22	23
8-8.9	15	19	4	13	14	17	19	22	26
9-9.9	18	22	4	18	18	20	22	24	33
10-10.9	16	22	3	16	17	19	22	24	33
11-11.9	18	24	3	18	20	21	25	27	29
12-12.9	29	29	3	18	20	21	25	27	29
13-15.9	57	33	8	21	23	27	31	39	49
16-18.9	37	41	7	31	32	35	43	47	51
19-21.9	37	46	7	35	36	43	49	51	52
22-24.9	42	50	3	45	46	49	51	52	52
25-30.9	60	51	3	45	48	51	52	52	52
31-36.9	60	52	2	50	50	52	52	52	52

Social cognition:

Age group (months)	N	Mean	SD	p5	p10	p25	p50	p75	p95
0-4.9	100	11	3	11	11	11	11	11	13
5-5.9	20	14	5	11	11	11	12	16	25
6-6.9	22	14	2	11	11	11	14	16	18
7-7.9	17	15	3	11	11	14	15	17	22
8-8.9	15	18	3	14	14	16	17	20	25
9-9.9	18	22	5	14	16	18	22	24	32
10-10.9	16	22	4	16	17	19	21	23	34
11-11.9	18	23	3	17	18	20	23	25	30
12-12.9	29	28	6	19	19	22	27	32	41
13-15.9	57	29	7	20	22	24	29	34	41
16-18.9	37	35	6	26	28	31	35	39	44
19-21.9	37	38	6	26	29	35	39	43	44
22-24.9	42	39	3	34	35	37	41	42	44
25-30.9	60	41	3	34	35	40	42	44	44
31-36.9	60	42	3	36	38	40	43	44	44

WIDEA-FS percentile scores by age group and domain among 548 children with typical Development

From Peyton C, Wroblewski K, Park J, Crisante C, Mariano K, Syon N, Baker C, Rogers B, Rolstacher J, Carter, F, Msall, M. Validity of WIDEA-FS: A daily activity criterion checklist for infants and toddlers. *Pediatric Research* 2020

Concurrent validity of the Warner Initial Developmental Evaluation of Adaptive and Functional Skills and the Bayley Scales of Infant and Toddler Development, Third Edition

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PUBLICATION DATA

Accepted for publication 12th October 2020.

Published online

ABBREVIATIONS

Bayley-III	Bayley Scales of Infant and Toddler Development, Third Edition
WIDEA-FS	Warner Initial Developmental Evaluation of Adaptive and Functional Skills

AIM To determine the concurrent validity of the Warner Initial Developmental Evaluation of Adaptive and Functional Skills (WIDEA-FS), a criterion-specified questionnaire that assesses a child's adaptive skills in everyday contexts, and the Bayley Infant and Toddler Scales of Development, Third Edition (Bayley-III).

METHOD In a prospective cohort study, 431 WIDEA-FS and Bayley-III assessments were completed among 341 children, aged 10 to 36 months corrected age (158 females, 183 males; median [interquartile range] gestational age at birth 32wks [29–38]), monitored in a high-risk neonatal intensive care unit follow-up clinic.

RESULTS WIDEA-FS scores were significantly associated with Bayley-III scores in all domains. Lower scores on the WIDEA-FS were significantly associated with an increased risk of adverse developmental performance on all Bayley-III scales. The association was strongest for motor and language Bayley-III scores when tested at <30 months of age, and for cognitive Bayley-III scores when tested at ≥30 months of age.

INTERPRETATION The WIDEA-FS has concurrent validity with the Bayley-III and may be a useful tool in high-risk follow-up settings.

Infants born preterm, with a history of neonatal encephalopathy or other neurological conditions, are at increased risk of adverse neurodevelopmental functioning and require close follow-up in the first years of life.[1] Early identification of children with atypical development prompts referral to targeted intervention services designed to maximize functional outcomes at the time of greatest brain plasticity.[2,3] Therefore, valid and effective screening tools are essential to promote identification of children at risk of adverse neurodevelopmental outcomes.

One of the most commonly used tools for evaluating the neurodevelopment of children aged <42 months old is the Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-III).[4] An experienced and reliable examiner can administer the Bayley-III in approximately 1 hour. The results of the Bayley-III can be used to identify children who would benefit from early intervention services. However, extensive implementation in clinics and research studies remains limited because of the time requirement, the need for an in-person visit by a trained examiner, and the associated high cost for families and health care centers.

The Warner Initial Developmental Evaluation of Adaptive and Functional Skills (WIDEA-FS) was developed to simplify the assessment process for infants at high-risk of neurodevelopmental disability aged up to 37 months.[5,6] The WIDEA-FS is a 50-item, criterion-specified questionnaire designed to assess a child's adaptive skills,[6] including mobility, communication, social cognition, and self-care (e.g. feeding, drinking, diaper awareness) skills. The WIDEA-FS takes only 10 to 15 minutes to administer and can be conducted by either parents or individuals who have observed the child's performance during daily routines.[6] Because the WIDEA-FS can be conducted by telephone, families with children at high risk of neurodevelopmental disabilities that live in remote areas may benefit from reduced travel times and costs associated with in-person follow-up visits.

The objective of our study was to determine the ability of WIDEA-FS to identify children at risk of neurodevelopmental delay or disability, that would justify additional developmental assessments or intervention services. More specifically, concurrent validity was calculated by comparing the WIDEA-FS to Bayley-III.

What this paper adds

- WIDEA-FS mobility, communication, and social cognition domains are concurrently valid in infants at high-risk for neurodevelopmental disability.
- Bayley-III motor, language, and cognitive composite scores are concurrently valid in the same group.
- The WIDEA-FS mobility and communication domains may be most clinically useful in children <30 months.

METHOD

We conducted a cross-sectional study, using a sample of children consecutively enrolled in a state mandated University of California San Francisco Benioff Children's Hospital Intensive Care Nursery Follow-Up Program between February 2015 and June 2018.

Participants

The children were prospectively recruited at between 10 and 36 months corrected age from the follow-up program. Eligibility criteria included any of the following: preterm birth (gestational age <32wks), neonatal encephalopathy, persistently and severely unstable (prolonged hypoxia, acidemia, hypoglycemia and/or hypotension requiring pressor support, persistent pulmonary hypertension of the newborn requiring inhaled nitric oxide for >4 hours, extracorporeal membrane oxygenation), intracranial pathology, or other neurological pathology, according to the California Children's Services program guidelines. Written informed parental consent was obtained for each child and ethical approval for the study was granted by the institutional review board of the University of California San Francisco.

Bayley-III

At between 10 to 36 months' corrected age, motor, language, and cognitive outcomes were assessed with the Bayley-III[4] as part of clinical care in the follow-up program. Standard assessments are conducted at three of four possible time points: 12, 18, 24, or 30 months, depending on risk factors. The Bayley-III assesses the child's developmental level of gross and fine motor skills, receptive and expressive communication, how the child relates to objects, memory, and concept formation.[4] The assessments were performed by either a child psychologist or a qualified pediatric nurse practitioner trained in Bayley-III assessment. The mean of each composite score of the Bayley-III is 100 (standard deviation 15) points. We designated children with composite scores of ≤85 as being at risk of adverse neurodevelopmental outcomes. Some children in the cohort were tested at more than one time-point, with a minimum of 6 months between assessments.

WIDEA-FS

The WIDEA-FS is a 50-item check list designed to describe the emerging functional skills in the domains of a child's mobility (nine items), communication (13 items), social cognition (11 items), and self-care (17 items) (Appendix S1, online supporting information). The WIDEA-FS was designed to assess criterion-specific activities, representing a child's daily routine. The domains of the WIDEA-FS were originally created by a multidisciplinary team with varied expertise in the daily activities of children. The choice of items was based on activities that occur on a daily basis and were developed by an interdisciplinary team of health, rehabilitation, early childhood, and psychology professionals. They were chosen based on domains considered essential activities from historic adaptive assessments, including the Vineland Adaptive Behavior Scales,[7] the Pediatric Evaluation of Disability Inventory,[8] the WeeFIM,[9] the Battelle Developmental Inventory,[10] and items used in early childhood assessments of motor, manipulative, communicative, and cognitive skills. The WIDEA-FS is an evaluative measure of a child's performance from observation, parent, or professional report from criterion items developed using Delphi methodology.[11] The purpose of the WIDEA-FS is to describe how children with diverse developmental delays, disability, and special health-care needs are progressing in becoming independent in basic feeding, mobility, communication, and social interaction skills. The individual items were selected based on their relationship to meaningful everyday tasks that parents could easily observe or participate in with the child. Each item consists of an operationally defined task that is part of an everyday activity and is rated on a scale of 1 (never performs task) to 4 (always performs task). Examples of test items from each subscale include: 'maintains sitting without support' (mobility), 'demonstrates two-syllable babbling' (communication), 'looks for an object dropped out of sight' (social cognition), and 'chews solid food' (self-care). The total score ranges from 50 to 200 points. Once a child achieves the maximum score in each domain, they demonstrate that basic skills have been achieved. The WIDEA-FS has been validated in a population of typically developing children[12] and has been used as an outcome measure in children with Krabbe disease,[13] children with prenatal exposure to Zika virus,[14] and in children with a history of neonatal encephalopathy.[15] In this study, the WIDEA-FS was completed either in person or via telephone within 1 month of the Bayley-III assessment.

Statistical analysis

Data were analyzed with Stata, version 15 (StataCorp LLC, College Station, TX, USA). When comparing the WIDEA-FS and the Bayley-III, we compared the following domains to one another: WIDEA-FS mobility to Bayley-III motor, WIDEA-FS communication to Bayley-III language, and WIDEA-FS social cognition to Bayley-III cognitive.

To examine the relationships between WIDEA-FS and the Bayley-III, we used three analytical methods: Spearman's rank correlation, a receiver operating characteristic curve, and sensitivity and specificity analyses. First, the Spearman's rank correlation association between the score on the WIDEA-FS and each Bayley-III domain was analyzed. Second, the area under the receiver operating characteristic curve was calculated, using the trapezoidal rule as a measure of the ability of the WIDEA-FS to discriminate between children with and without risk of adverse neurodevelopmental outcomes on the Bayley-III. This was done separately at the time-points listed above, and an overall area under the receiver operating characteristic curve was calculated using the 'somersd' package in Stata (which allows for the clustering of multiple observations per patient). Finally, for the calculation of sensitivity and specificity, a cut-off point was chosen based on maximizing the Youden's index[16] (sensitivity+specificity–1) of the WIDEA-FS score with the Bayley-III composite scores of no more than 85 as the criterion standard; 95% confidence intervals (CIs) were constructed for these estimates based on the binomial distribution. A second set of cut-off points was also calculated, where applicable, for instances when sensitivity was ≥90%.

RESULTS

There were 431 (WIDEA-FS and Bayley-III) assessments completed among 341 children (158 females, 183 males; median [interquartile range] gestational age at birth 32wks [29–38]). Two children had WIDEA-FS assessments at >37 months and were excluded. This left 429 assessments among 341 children (260 with one assessment, 74 with two assessments, and seven with three assessments; Table S1, online supporting information). Demographic and clinical characteristics of the participants are listed in Table 1. Mean scores on the WIDEA-FS and Bayley-III at time-points 10 to <18 months, 18 to <24 months, 24 to <30 months, and ≥30 months are listed in Table 2. The mean Bayley-III scores fell within the average range at all tested time-points. There was no difference in results based on the order of test administration (WIDEA-FS first compared with Bayley-III first).

WIDEA-FS scores are associated with Bayley-III scores at multiple time-points

The WIDEA-FS scores were significantly related to Bayley-III scores for all compared domains in at least two tested time-points. When comparing WIDEA-FS mobility scores to Bayley-III motor scores, there was a significant association at every time-point; the greatest association occurred at 10 to <18 months (Table 3). There were significant associations between communication scores and Bayley-III language scores at all time-points, with the greatest association in children tested at 18 to <24 months (Table 3). When comparing the WIDEA-FS social cognition score to the Bayley-III cognitive composite score, significant associations were seen at 10 to <18 months and at ≥30 months (Table 3).

Table 1: Demographic and clinical characteristics of 341 children who received concurrent WIDEA-FS and Bayley-III testing

Characteristic	*n*=341
Female sex, *n* (%)	158 (46)
Gestational age at birth (wks), median (IQR)	32 (29–38)
Birthweight (g), median (IQR)	1500 (1109–3000)
Primary diagnosis for high-risk follow-up eligibility *n*, (%)	
Preterm birth	195 (58)
Neonatal encephalopathy	62 (18)
Unstable infant	46 (14)
Intracranial pathology	20 (6)
Other neurological pathology	18 (5)
Destination after NICU discharge *n*, (%)	
Home	315 (95)
Residential care	1 (<1)
Transfer to another hospital	15 (5)

WIDEA-FS, Warner Initial Developmental Evaluation of Adaptive and Functional Skills; Bayley-III, Bayley Scales of Infant and Toddler Development, Third Edition; IQR, interquartile range; NICU, neonatal intensive care unit.

Lower WIDEA-FS scores are associated with increased risk of adverse outcome on the Bayley-III

The association between WIDEA-FS score subdomains and risk of adverse (≤85) Bayley-III composite scores was strongest when comparing WIDEA-FS mobility and Bayley-III motor, and WIDEA-FS communication and Bayley-III language for time-points measured at <30 months. In addition, the association between WIDEA-FS social cognition score and risk of adverse (≤85) Bayley-III cognitive score was strongest when tested at ≥30 months of age (Table 3).

Sensitivity and specificity of the WIDEA-FS for Bayley-III

The sensitivity and specificity of the WIDEA-FS scores, calculated using Youden's index, for predicting Bayley-III composite scores of ≤85 at all four time-points, and cut-off point scores that yield at least 90% sensitivity are listed in Table 4.

Bayley-III motor scale

For the WIDEA-FS mobility scale, at 10 to <18 months, a cut-off point of 34 yielded a sensitivity of at least 90% for predicting a Bayley-III motor score of ≤85; however, when the WIDEA-FS mobility was tested at other ages, there was no cut-off point that provided a sensitivity of 90% (Table 4). From 24 to ≥30 months of age, a cut-off point of 36 on the WIDEA-FS mobility scale yielded the best combination of specificity and sensitivity to Bayley-III motor scores.

Bayley-III language scale

WIDEA-FS communication cut-off scores of 30 and 48 yielded sensitivity of at least 90% in predicting Bayley-III language scores of ≤85 at 10 to <18 months and 18 to

Table 2: Concurrent mean Bayley-III and median WIDEA-FS scores of 341 children at four standardized follow-up time-points

	10 to <18mo	18 to <24mo	24 to <30mo	≥30mo
Number of children receiving assessment *n* (%)	166 (40)	112 (26)	45 (11)	106 (25)
Bayley-III composite, mean (SD) [% with ≤85 score][a]				
Cognitive	102 (14) [11]	101 (13) [14]	106 (21) [11]	103 (16) [13]
Language	100 (13) [9]	95 (13) [18]	98.8 (19) [13]	97 (15) [18]
Motor	94 (16) [28]	98 (13) [15]	98.4 (18) [18]	95.6 (14) [17]
WIDEA-FS raw scores, median (IQR)[b]				
Self-care (68 max)	38 (34–42)	45 (40–50)	53 (46–57)	58 (52–63)
Mobility (36 max)	31 (24–35)	36 (34–36)	36 (35–36)	36 (36–36)
Communication (52 max)	34 (27–43)	51 (38–50)	51 (48–52)	52 (49–52)
Social cognition (44 max)	34 (29–39)	39 (31–41)	40 (37–43)	41 (37–43)

The time-points represent the ages of the children when they were tested. [a]Percentage with ≤85 score indicates the percentage of children scoring at least 1SD below the mean on the Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-III) composite score. [b]Warner Initial Developmental Evaluation of Adaptive and Functional Skills (WIDEA-FS) medians are presented as raw scores.
IQR, interquartile range.

Table 3: Relationship between WIDEA-FS scores and adverse Bayley-III composite scores in 341 children who received concurrent testing

	10 to <18mo	18 to <24mo	24 to <30mo	≥30mo
ROC curve area (95% CI)				
WIDEA-FS mobility and Bayley-III motor	0.82 (0.75–0.90)	0.81 (0.69–0.93)	0.91 (0.77–1.0)	0.61 (0.49–0.73)
WIDEA-FS communication and Bayley-III language	0.92 (0.85–0.98)	0.82 (0.71–0.94)	0.79 (0.61–0.98)	0.70 (0.55–0.85)
WIDEA-FS social cognition and Bayley-III cognitive	0.76 (0.64–0.89)	0.55 (0.39–0.71)	0.64 (0.36–0.91)	0.83 (0.71–0.94)
Spearman's correlations and *p*				
WIDEA-FS mobility and Bayley-III motor	0.59, <0.001	0.40, <0.001	0.41, <0.01	0.27, <0.01
WIDEA-FS communication and Bayley-III language	0.55, <0.001	0.66, <0.001	0.65, <0.001	0.51, <0.001
WIDEA-FS social cognition and Bayley-III cognitive	0.28, <0.001	–0.03, 0.77	0.26, 0.09	0.33, <0.001

The time-points represent the ages of the children when they were tested with the Warner Initial Developmental Evaluation of Adaptive and Functional Skills (WIDEA-FS) and the Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-III). ROC, receiver operating characteristic.

<24 months respectively (Table 4). At 24 to <30 months, a cut-off score of 52 yielded 100% sensitivity to a Bayley-III language score of ≤85. Using the Youden's index, the highest combination of sensitivity and specificity to the Bayley-III language score occurred at 10 to <18 months of age.

Bayley-III cognitive scale

WIDEA-FS social cognition cut-off points between 40 and 44 yielded sensitivities of at least 90% in prediction of a Bayley-III cognitive score of ≤85 for the four age groups tested (Table 4). Using Youden's index, the specificity of WIDEA-FS social cognition score was higher in each age group as compared to sensitivity for Bayley-III cognitive composite score (Table 4).

WIDEA-FS mobility and communication scores and Bayley-III motor and language scores

Because some children achieved the maximum score for the WIDEA-FS mobility and communication scores at earlier ages than other children (Table 2), we next examined whether there were differences between mean Bayley-III scores among those children who achieved the maximum WIDEA-FS scores compared to those who did not at the following time-points: 18 months to <24 months, 24 months to <30 months, and ≥30 months. Children who had not achieved the maximum WIDEA-FS mobility score had lower Bayley-III motor scores at all time-points compared to children who did achieve the maximum score (18–<24mo: −10, 95% CI −15 to −4; 24–<30mo: −18, 95% CI −34 to −2; ≥30mo: −12, 95% CI −21 to −3). In similar fashion, children who had not achieved the maximum WIDEA-FS communication score also had lower mean Bayley-III language composite scores at all time-points (18–<24mo: −12, 95% CI −19 to −5; 24–<30mo: −22, 95% CI −32 to −13; ≥30mo: −12, 95% CI −17 to −7).

DISCUSSION

In this prospective study of infants at high-risk for neurodevelopmental disability, we demonstrated concurrent validity between the WIDEA-FS and Bayley-III by finding significant correlations between scores on the WIDEA-FS mobility, communication, and social cognition domains and the Bayley-III motor, language, and cognitive composite scores. The WIDEA-FS was also able to establish differences between children who had normal motor, language, and cognitive Bayley-III scores from those who were at risk of adverse motor, language, and cognitive outcomes (≤85). While the WIDEA-FS mobility and communication domains had good concurrent validity with the Bayley-III language and motor domains, the concurrent validity between the WIDEA-FS social cognition domain and Bayley-III cognitive domain was less robust.

The age at which greater proportions of children were able to achieve the maximum scores on the WIDEA-FS followed a typical early neurodevelopmental sequence with

Table 4: Specificity and sensitivity of WIDEA-FS in predicting Bayley-III in 341 children who received concurrent testing

		10 to <18mo		18 to <24mo		24 to <30mo		≥30mo	
Bayley-III	WIDEA-FS	Sp	Se	Sp	Se	Sp	Se	Sp	Se
Motor	Mobility	YI cut-off point 25		YI cut-off point 35		YI cut-off point 36		YI cut-off point 36	
		89 (82–94)	62 (46–76)	81 (72–88)	71 (44–89)	87 (71–96)	88 (47–100)	87 (78–93)	33 (13–59)
		90% cut-off point 34							
Language	Communication	YI cut-off point 27		YI cut-off point 43		YI cut-off point 52		YI cut-off point 49	
		87 (80–92)	87 (60–98)	75 (65–83)	80 (56–94)	51 (35–68)	100 (54–100)	87 (78–93)	53 (29–76)
		90% cut-off point 30		90% cut-off point 48		90% cut-off point 52			
Cognitive	Social cognition	YI cut-off point 31		YI cut-off point 33		YI cut-off point 38		YI cut-off point 36	
		74 (67–81)	72 (47–90)	85 (77–92)	31 (11–59)	77 (61–89)	60 (15–95)	89 (81–95)	62 (32–86)
		90% cut-off point 40		90% cut-off point 44		90% cut-off point 44		90% cut-off point 42	
	Self-care	YI cut-off point 37		YI cut-off point 44		YI cut-off point 42		YI cut-off point 58	
		65 (57–73)	83 (59–96)	58 (48–68)	63 (35–85)	87 (73–96)	60 (15–95)	59 (49–70)	85 (55–98)
		90% cut-off point 49		90% cut-off point 53		90% cut-off point 60		90% cut-off point 60	

The first raw score cut-off point is based on Youden's index (YI) and the second reported raw score cut-off point provides a sensitivity of at least 90% when available (95% confidence intervals are reported for all values). The time-points represent the ages of the children when they were tested with the Warner Initial Developmental Evaluation of Adaptive and Functional Skills (WIDEA-FS) and the Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-III). Sp, specificity, Se, sensitivity.

more children first reaching the maximum score on the mobility domain (from 18–24mo) than the communication domain (from 24–30mo), and finally the social cognition domain (≥30mo), possibly representing the emergence of executive functioning. This suggests that the domains of the WIDEA-FS may be most clinically useful at age-specific time-points, which reflect the skillset of the child at that time.

We calculated sensitivities and specificities using Youden's index at all time-points. The WIDEA-FS was designed to measure basic functional competencies of a child and was not intended as a replacement for more extensive assessments that measure more complex developmental skills. However, if the goal of the clinician is to use the WIDEA-FS to screen children who will need to receive a more detailed, in-person neurodevelopmental assessment, we recommend that the clinician consider using the 90% sensitive cut-off scores (when available) to identify children who will need a full Bayley-III assessment. For the mobility domain of the WIDEA-FS, we recommend using this test between 10 to <18 months of age because there appears to be a ceiling affect after this age and there is a provided cut-off score of 34, which provides a 90% sensitivity to a Bayley-III motor score of ≤85. For the same reasons, we recommend using the WIDEA-FS communication scale from 10 to 24 months of age with the cut-off scores of 30 at 10 to <18 months of age and 48 at 18 to <24 months of age. The social cognition domain of the Bayley-III may be most useful to clinicians in screening for cognitive functioning at ≥30 months of age. Clinicians using the 90% sensitive cut-off scores should be aware that many children who are recommended for more detailed evaluation may have Bayley-III scores >85, as maximizing sensitivity will yield a lower specificity for children who will score in the average range.

Although we present a large cohort of children at risk of adverse neurodevelopmental outcome, our recommendations are limited by the fact that relatively few of the children included scored ≤85 on the Bayley-III, therefore, our 90% sensitive cut-off threshold may be higher than in other samples of children with lower Bayley-III scores. In addition, by calculating sensitivity and specificity at various time-points, there are fewer assessments performed in each age grouping. Consequently, the confidence intervals are larger, especially in age groupings where few children scored ≤85 on the Bayley-III.

It is important for clinicians working with high-risk infants to identify those at greatest risk for adverse neurodevelopmental outcome in order to direct intervention and study the effects of previous treatment. However, it is not always possible for families to complete Bayley-III testing, which requires a visit with a skilled tester and participation of the child. Additionally, follow-up programs may need to prioritize assessments based on space and practitioner availability. The WIDEA-FS is a novel way to screen children via parent interview, as it can be administered easily by a variety of professionals. The WIDEA-FS can also be used in person or over the phone and takes 15 minutes or less to complete. While there are domain-specific ceiling effects at various ages, the WIDEA-FS can detect delays in children who are not able to achieve the maximum scores (at the above age-specified time-points), screening those children who are at highest risk of severe disability. Therefore, the WIDEA-FS can be used easily as either a part of a battery of developmental tests or when other, more extensive testing, is unavailable. This test may

also be used remotely and may be of benefit to families who have limited resources to travel to a pediatric medical center or are burdened by traveling a great distance to receive follow-up care.

The Ages and Stages Questionnaire has administration time and methods similar to the WIDEA-FS, and has been compared to the Bayley-III in general and high-risk populations,[17–19] with moderate specificity and a lower sensitivity in identifying infants at highest risk. The WIDEA-FS and Ages and Stages Questionnaire have been successfully used together[13] in order to provide a more comprehensive evaluation and to increase compliance of families in need of ongoing monitoring.

A large number of WIDEA-FS and Bayley-III assessments were completed in this study and the majority of children tested (75%) had only one assessment included in our analysis. To better understand the ability of the WIDEA-FS to predict long-term neurodevelopment, it may be beneficial to compare longitudinal WIDEA-FS assessments with outcomes at school age. The WIDEA-FS, especially the self-care and social cognition domains, may measure executive competencies which are more accurately assessed later in development.

The WIDEA-FS, which is designed to quickly measure the functional independence of a young child, may be a practical alternative to repeated Bayley-III testing of children who require long-term monitoring. This study establishes concurrent validity between the WIDEA-FS mobility and communication domains and the Bayley-III motor and language scales in a cohort of high-risk infants at 10 to 36 months corrected age.

ACKNOWLEDGEMENTS

The authors thank the providers at the University of California San Francisco Benioff Children's Hospital Intensive Care Nursery Follow-Up Program for their assistance with the study, as well as Sili Liu, Manogna Manne, Rebecka Craig, and Bria Bailey for their assistance with data collection and WIDEA-FS testing. This study was supported by the National Institutes of Health Eunice Kennedy Shriver National Institute of Child Health and Human Development R03HD090298. The authors have stated that they had no interests that might be perceived as posing a conflict or bias.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

SUPPORTING INFORMATION

The following additional material may be found online:

Appendix S1: The WIDEA-FS.

Table S1: Age distribution of children at WIDEA-FS and Bayley-III testing

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Appendix B. Ages & Stages Questionnaire 3rd Edition - General Information

AGES & STAGES QUESTIONNARE 3rd EDITION GENERAL INFORMATION

I. INTRODUCTION

To provide options for screening instruments that can be done by telehealth or parent questionnaires, the CPQCC CCS HRIF QCI is adding the Ages and Stages Questionnaire 3rd edition (ASQ-3). The ASQ-3 is a screener but provides scores in five areas:

- Communication
- Gross Motor
- Fine Motor
- Problem Solving
- Personal-Social

The ASQ-3 was developed as a parent/primary caregiver questionnaire that can also be administered by phone. It is also available in several languages including Spanish. Visit the ASQ webpage: https://agesandstages.com/products-pricing/asq3/ to learn more about the screening tool.

Below is an overview of ASQ-3 key points for questionnaire selection, administration, and scoring. Also refer to ASQ-3 User's Guide (particularly Chapter 6) for further information.

A. **Questionnaire Selection**

The age range encompassed by the ASQ-3 is 1-66 months. It is critical to select the correct questionnaire for the correct age range. ASQ-3 kits include paper masters of the 21 age-based questionnaires and scoring sheets as well as CD-ROM with printable PDF questionnaires. To obtain accurate scores, the correct age interval questionnaire must be used as the questions individually tailored to relate to age-based skill acquisition.

For the purposes of the CPQCC CCS HRIF, **corrected age for prematurity should be used as per usual guidelines.** The following table will guide selection of appropriate ASQ-3 questionnaire (see also ASQ-3 User's Guide, page 67, Table 6.1 for complete information):

Table 6.1. ASQ-3 age administration chart

Child's age	Use this ASQ-3
1 month 0 days *through* 2 months 30 days	2 month
3 months 0 days *through* 4 months 30 days	4 month
5 months 0 days *through* 6 months 30 days	6 month
7 months 0 days *through* 8 months 30 days	8 month
9 months 0 days *through* 9 months 30 days	9 or 10 month[a]
10 months 0 days *through* 10 months 30 days	10 month
11 months 0 days *through* 12 months 30 days	12 month
13 months 0 days *through* 14 months 30 days	14 month
15 months 0 days *through* 16 months 30 days	16 month
17 months 0 days *through* 18 months 30 days	18 month
19 months 0 days *through* 20 months 30 days	20 month
21 months 0 days *through* 22 months 30 days	22 month
23 months 0 days *through* 25 months 15 days	24 month
25 months 16 days *through* 28 months 15 days	27 month
28 months 16 days *through* 31 months 15 days	30 month
31 months 16 days *through* 34 months 15 days	33 month
34 months 16 days *through* 38 months 30 days	36 month
39 months 0 days *through* 44 months 30 days	42 month
45 months 0 days *through* 50 months 30 days	48 month
51 months 0 days *through* 56 months 30 days	54 month
57 months 0 days *through* 66 months 0 days	60 month

[a]May use the 9 or 10 month ASQ-3 with children in this age range.

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B. **Administration**

The ASQ-3 can be administered by phone or telehealth administration, sending, or giving the questionnaire to parent/primary caregiver for completion, and/or in person.

- Information on scores from the five areas will be obtained for CPQCC CCS HRIF purposes.
- The "Overall" section at the end of the questionnaires will NOT be obtained. HRIF sites may however wish to obtain that information for their own site-specific clinical information.

The ASQ-3 has a total of 30 questions (6 questions in each of the 5 areas) and takes 10-15 minutes to complete. The HRIF teams may wish to introduce both the general purpose of the questionnaire and response options to the parent/primary caregiver. Possible points to include are an explanation of the yes/ sometimes/not yet response options, that there are no "right" or "wrong" answers, and that different children develop differently.

The parent/primary caregiver should also be advised that some skills asked about may include activities with certain toys or equipment – like playing with balls (throwing, kicking) and blocks, stringing beads or similar, looking at drawings or making them, looking at a picture book, walking upstairs, etc. Because not all of these may be routine, the HRIF team may advise the parent to try activities with the child before answering.

C. **Scoring**

- Scoring the ASQ-3 takes ~3-5 minutes.
- Each response to items on the questionnaire should be scored as follows:
    - Yes = 10
    - Sometimes = 5
    - No = 0
- Add all scores within each developmental area to assign separate scores to each area: Communication, Gross Motor, Fine Motor, Problem Solving, Personal-Social.
    - As there are 6 questions in each area, the maximum total for each area = 60.
- Dealing with missing responses:
    - An area should NOT be scored if there are more than 2 responses are unanswered in that area.
    - Area scores may be adjusted for missing items up to 2 items as per the below table (also see ASQ-3 User's Guide, page 72, Table 6.2). Find the total score from COMPLETED items on the left-hand column ("Area score"). Follow to the right to determine the adjusted score if 1 item or 2 items are unanswered.

Area score	Adjusted area score–1 item omitted	Adjusted area score–2 items omitted
50	60	–
45	54	–
40	48	60
35	42	52.5
30	36	45
25	30	37.5
20	24	30
15	18	22.5
10	12	15
5	6	7.5
0	0	0

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II. COMPLETING HRIF DATA ENTRY

Each area score should be calculated and assessed in the context of the SCORING GRID that is included in and specific to each age-based questionnaire.

Select the appropriate **Scoring Zone** for the ASQ-3. See below example from ASQ-3 User's Guide, page 70, figure 6.5.

- **On Schedule** if the score for that area falls within the unshaded (higher score) zone.
- **Monitor** if the score for that area falls the lightly shaded (middle score range) monitoring zone. This represents 1-2 standard deviations below the mean for that age-based questionnaire.
- **Below** if the score for that area falls within the darkly shaded (low score range) zone. This represents 2 or more standard deviations below the mean for that age-based questionnaire.

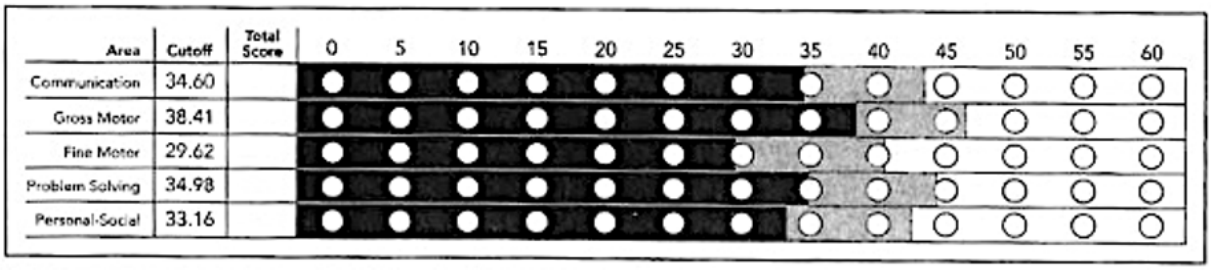
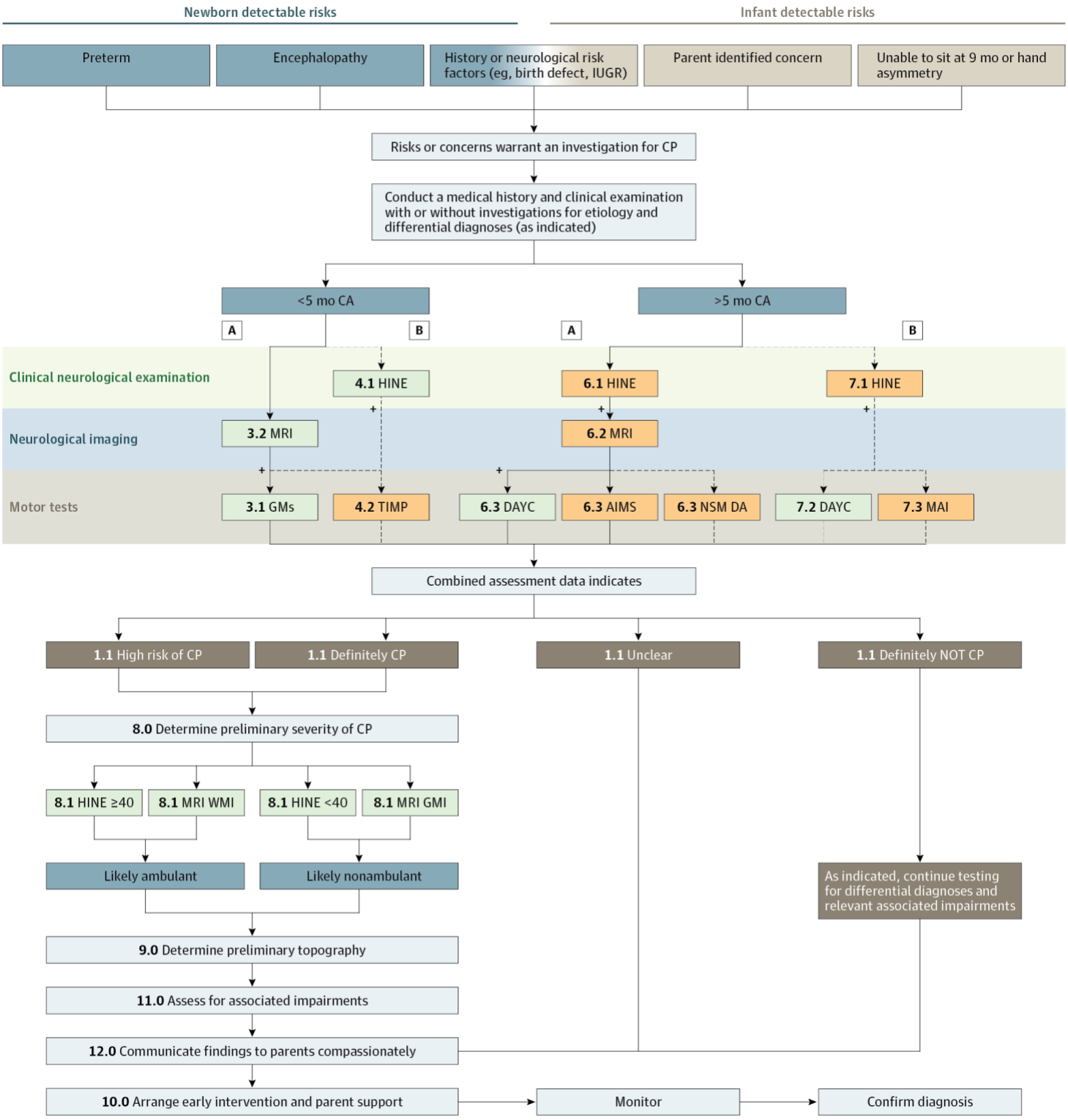


Figure 6.5. The section of the ASQ-3 Information Summary sheet designed to record area scores. (In this illustration, the 4 month summary sheet is shown. For each ASQ-3 interval, the Cutoff column on the summary sheet shows the cutoff scores for that particular interval.)

Appendix C. Figure form Novak et al, JAMA Pediatrics 2017



From: Novak I, et al. Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment. *JAMA Pediatr*. 2017;171(9):897-907