

# OC Children's Screening Registry

## Overview of OC Children's Screening Registry

### Healthy Tomorrows Partnership for Children Program Award

The Healthy Tomorrows Partnership for Children Program is a collaborative effort between the American Academy of Pediatrics and Maternal Child Health Bureau that distributes grants to promote community planning and problem solving at the local level.

In March 2014, Help Me Grow Orange County was awarded a Healthy Tomorrows Partnership for Children Program grant. The purpose of the grant is to support the creation of a Developmental Screening Network (DSN), as well as the creation of a Developmental Screening Registry (OC Children's Screening Registry) to improve physician engagement and cross-sector collaboration, link electronic health records among Orange County service providers, and reach out to pediatricians to encourage them to regularly use developmental screening tools and refer children for evaluation and treatment when needed.

### OC Children's Screening Registry

The OC Children's Screening Registry is an online database designed to enable primary health care providers and community-based providers to view and/or enter developmental and behavioral screening data and share information on referrals and outcomes. The OC Children's Screening Registry has been developed to accommodate four screening tools (Ages and Stages Questionnaires (ASQ) -Third Edition, ASQ: Social Emotional-2, Parents Evaluation of Developmental Status and Modified Checklist for Autism in Toddler, Revised with Follow-up).

### Developmental Screening Network

The Developmental Screening Network (DSN) is a collaborative structure of community stakeholders, the primary purpose is to support improved care coordination and connection to developmental services among local service providers serving children birth through eight years.

The DSN has met on a monthly basis since its inception to oversee the development of the Registry. To facilitate this process, the DSN established a subcommittee - the Confidentiality Work Group - to identify barriers to registry utilization, find solutions, examine laws, and outline a methodology that will increase success of the OC Children's Screening Registry.

### Framework for Use of OC Children's Screening Registry Data

The screening information is designed to help clinical and community based providers proactively identify children with at-risk developmental screening results, reduce duplication of screening efforts, and assist in connecting families with appropriate resources. Information shared may include demographic information (name, date of birth, sex); developmental screening results; and services (types and/or outcomes of referrals made).

**Administrative:** Help Me Grow is the data administrator of the OC Children’s Screening Registry. Help Me Grow will have access to screening information collected on children in the registry for purposes of evaluation, support, and maintenance. Help Me Grow may report aggregate information (*no individuals or individual-level health information will be identified*) from a service provider, group of service providers, or across all service providers. The one exception could be that a participant location such as zip code could be used for purposes of graphing service delivery. Help Me Grow may work with additional data administrators that may only see registry information for purposes of providing technical support for the registry or to authorized service providers, quality assurance for the program, or for removing authorization to share child information.

**Service Provider:** There are two levels of child information access within the OC Children’s Screening Registry. First, is the data collected and entered by each Service Provider and second is the screening data collected by another service provider, but common to both parties.

- **Service Provider Own-entered Child Data.** Service Providers may use the data they collect and enter into the registry for internal purposes only. Providers may prepare and disseminate reports of their own aggregate data for use in program planning and reporting.
- **Screening Results Collected from Another Service Provider.** One of the benefits of the screening registry is to provide a continuum of care for a child between service providers. Individual child screening results on each tool can be viewed within the registry between service providers IF certain conditions are in place:
  1. Service Provider is considered a Treating Provider AND the Service Provider has a treatment relationship with the Child that would warrant a benefit to the child if screening results were shared: **OR**
  2. Service Provider is NOT a Treating Provider, but has obtained a written, valid HIPAA Authorization from the child’s parent/guardian to allow access to view general screening results obtained from another provider. An example of such valid HIPAA Authorization is available on the Help Me Grow website.
  3. Not all Participants utilizing the OC Children’s Screening Registry will have access to view records from other Service Providers.

**Child Data Protections:** Participating in the OC Children’s Screening Registry is voluntary. A parent not wishing to participate may opt out of the registry without any consequences to receiving services. Participant’s staff are subject to follow guidelines set forth by the Health Insurance Portability and Accountability (HIPAA) and California Health and Safety Codes 130200 (AB211) and 1280.15 (SB541) which require the protection and confidential handling of protected health information. All client records are confidential and are protected in a HIPAA compliant, secure database that will only be accessed by authorized OC Children’s Screening Registry users and Help Me Grow staff for administrative purposes. Child data will be maintained in the OC Children’s Screening Registry for Data Entry Only Participants until the child reaches 8 years of age, at which time data sharing expires and additional access to this record would require parental/guardian authorization. Child data will be maintained in the OC Children’s Screening Registry for Treating Providers until the child reaches 17 years of age, at which time data sharing expires and additional access to this record would require parental/guardian authorization. A request may be made to discontinue sharing information within a child’s record at any time by submitting a written Request to Remove Confidential Information to Help Me Grow at: 2500 Red Hill Ave, Suite 290, Santa Ana, CA 92705.