

**Spark NH**  
**Developmental Screening, Referral, Diagnosis, and Services System Task Force (DSRDS)**  
**Final Report**  
**May 10, 2017**

### **Purpose**

The DSRDS Task Force was convened to:

- 1) *Determine the gaps in identifying and serving NH's young children* (birth to five years) who may have or be at risk for developmental delays or other concerns requiring timely supports and services for the child and/or family; and
- 2) *Generate recommendations* to (a) address the gaps and (b) expand the Watch Me Grow system to include evaluation, diagnosis and services for young children and their families when a concern has been identified through developmental screening or another mechanism.

### **Process**

The Task Force included representatives from the Act Early Team / Screening & Diagnosis Work Group of the NH Council on ASD, Watch Me Grow Steering Committee, Spark NH, Early Childhood Advisory Council and other participants involved in working with young children and their families.

The initial focus identified resources and gaps in services relative to early identification, referral, diagnosis and services for young children. The following list represents themes the group cited sorted into three broad categories: Public Awareness/Training; Screening/Referral/Data/ Quality Assurance; and Interagency/System.

### **Public Awareness/Training Gaps**

- **Awareness:** what is screening, when, how often, broader public knowledge, policy makers don't understand or support, lack of knowledge of where to make referrals, inconsistent (area agency? School district? private therapist? Child day clinic?)
- **Families:** lack of understanding about developmental delays, the value of screening, child developmental stages, how to access screening
- **Training:** Doctors need training on developmental delays, training WMG partners, childcare unaware of the options for screening – don't know where to refer
- **Screening results** not saved or shared (parents, providers, primary care, teachers)
- **Child care programs:** need to know about screening and working with children with challenging behaviors (connect to implementation of Pyramid model)
- **School systems** reluctant to identify children who need services, gap in participation

### **Screening/Referral/Data/QA Gaps**

- **Cultural bias:** screening tools are not validated, not reliable for reaching the culturally diverse populations in New Hampshire
- **Additional tools beyond ASQ 3 and the ASQ-SE** – if system is going to be comprehensive, need to expand options to engage other types of screening and integrate data collection
- **Time:** for providers to give the screening, score it and record data
- **Delays** – from when family completes screening, to getting notification and data being input in the system
- **Follow-up referrals for services:** Need mechanism for tracking and closing the loop on outcomes; without child ID don't know when and how often children are screened; screening data not linked to referral/service data
- **There is not always a “diagnosis” – then what?** Children who do need interventions but are not eligible, do not qualify for system services
- **After diagnosis – then what?**
- **Services pathology based in terms of eligibility**
- **Lack of capacity:** to screen, and to collect and integrate data – inconsistent statewide,
- **Reaching families:** children at home or in family/relative care (i.e. 60% of children under 5 in Monadnock region not in child care)

### Interagency/System Gaps

- **Reimbursement rate:** screening to PCP and no reimbursement for the data component, there is a perception that private insurance and Medicaid don't reimburse for screens however there is a code for billing for developmental screening
- **No unifying policy**
- **Wait time:** for referral to Child Dev clinics, to get an appointment or diagnosis, sometimes months
- **System:** transitioning from ESS to preschool, stakeholder input not being used, no linkages to follow outcomes, lack capacity to build statewide infrastructure and adequate support for current WMG sites and partners; lack of meetings and follow-up within current system
- **Unified data collection** - no single place or system collection
- **Communication and coordination** within the systems, services are not connected, diagnosis as a gateway to services
- **Lack of capacity** and ability to screen larger numbers of children and input data
- **Lack of specialized providers:** lack of EC mental health services, no DSM code under 3 (challenges for youngest children with delays), lack of providers, hearing and vision loss, developmental pediatricians, pediatric psychiatrists, developmental psychologists, feeding and swallowing supports, autism
- **Communication:** medical community not talking to providers and vice versa, Early Supports and Services to others - ECE, public schools - no one knows the process, after diagnosis no knows

what the next step is and who takes the lead, referral process, parents don't know what to do next.

- **Access to services:** inadequate or inconsistent - wait lists, regional issues where no services are available, no one place for parents to get information on screening, delivery, increases in screening leading to more referrals but no increase in resources
- **Lack of funding:** for the system, for partners to do screening, to build capacity, including the ASQ is copyright and can't go into the EMR easily
- **Family support:** behavior challenges, family support, single point of contact after diagnosis, what to do after the diagnosis
- **Transportation** – for families, transportation not available to get to the providers and clinics.

The Task Force divided into three subgroups to identify possible solutions to address the gaps. These groups considered options that build on the history and success of both Watch Me Grow and Act Early initiatives cognizant of the resource and fiscal limitations of the current system.

The work groups generated recommendations for a comprehensive early identification, referral, and services system. After vetting the recommendations with several constituencies, a final draft was prepared for the Task Force. A survey was created that asked for members' intuitive responses to the feasibility of implementation on a five-point scale. The recommendations were sorted and presented to the Task Force in April 2017. Three final categories for implementation were used - Short term, Midterm and Long-term based on clustering of responses.

The Task Force met on April 25 and reviewed the process. As an exercise in encouraging continuing momentum, we began to identify which agency or organization might take leadership for ongoing work. After the meeting representatives from Act Early and WMG added information and clarification of some of the recommendations and lead agencies. An Addendum to this report contains the collective input (DSRDS Task Force Recommendations: Notes).

## Summary

It was apparent in the final review that priorities need to be established. Consensus emerged that a specific entity was necessary to take responsibility for follow-up. The group agreed that Act Early was the appropriate agent to pick up the System Building work. WMG Management Team and Steering Committee will incorporate those recommendations that fall within the scope of work for WMG and participate in future Act Early follow-up at a system level. The goal is to focus on providing accountability and resources to implement those recommendations where interagency collaboration can work.

The **Act Early** Team will expand membership to include representation from Project LAUNCH, the Child Development Bureau, SPARK NH policy perspective, FCESS, NH Family Voices, parent ASD, Office of Student Wellness, Office of Children's Behavioral Health and others as appropriate. The DOE representative will be available to answer questions and keep informed of the work.

To build a sustainable comprehensive system in New Hampshire there is a need to develop an overarching policy to support the infrastructure that is needed. Funding is a significant gap. Data are not

available to accurately report on the needs for screening and follow-up services. Eventually, requests to the legislature and other potential funders will be critical to support the work. It is recommended that Spark NH reach out to policy leaders and develop a plan of action to obtain funding for policy development and an analysis of the finances needed to address long-term recommendations. The role of New Futures should be explored.

### **Reflection**

I include some thoughts based on my observations working with the groups, talking with other stakeholders, and analyzing our findings.

The capacity of Family Resource Centers is an issue. Although screening is an expectation of those funded by DCYF, there are concerns that there is not adequate funding of staff to sustain the model. There are perceptions that it is a stretch to fulfill these expectations - data entry and fidelity to the model are in question. For those not funded by DCYF there is no formal mechanism to engage them in a comprehensive system.

There are serious equity issues that are often regionally based. Not all young children are in care. It was reported that in one region approximately 60% are not in childcare or Head Start. Screening needs to involve medical and health providers. If not direct screening having the knowledge and information to refer is imperative. Communities of Practice are a model to bring together critical partners. Work locally to involve pediatric providers, health care, and FRC (both DCYF funded and others).

What could be the continuing role of Behavioral Health, Home Visiting Programs, and Child Care Aware? How might the Wellness Commission, VNA, The NH Children's Trust, Home Schooling Association, and the Healthy Homes Initiative be engaged?

The recommendation that New Hampshire Family Voices be the primary resource for referrals and follow-up will need to be fully integrated.

Suggest working sessions to share work plans, reporting, MOU's, and performance standards across agencies and stakeholders involved in providing services and supports for young children and their families. This would create transparency, sharing accomplishments, data, and facilitate requests for support.

The extent of the recommendations may appear overwhelming, yet there is overlap within the categories. As the Act Early Team and Watch Me Grow set new goals, priorities will emerge. The WMG Crosswalk and Act Early Blueprint Action Steps were folded into the recommendations. The original two documents will need to be updated and combined in some form to represent the larger system efforts. Much can be accomplished through communication and collaboration.

Respectfully submitted,

Tessa McDonnell

Task Force Facilitator

## Task Force Recommendations

### System Building/Interagency Coordination

Short term
1. Develop MOU templates for interagency collaboration and data sharing.
2. Replicate/adapt the NJ Act Early resource that maps the “Next Steps for Developmental Services.”
3. Create and maintain a master list of partners and their affiliates involved in screening.
4. Share strategic plans of organizations, agencies, and departments involved in developmental screening.
5. Document how many agreements sites have, when they are updated, and ensure they are correctly posted on the Watch Me Grow website. Assure MOU transparency and accountability.
6. Create a single point of contact in regions by position (not individual).
Mid Term
7. Re-examine the business plan of CT’s Help Me Grow system with an analysis of the resources needed to implement the model with fidelity in NH.
8. Develop a one-page “Summary Report” form that would record screening, referrals and follow-up and a process to document collaboration, referral agency, and outcome; share with community partners.
9. Conduct an analysis of the benefits and barriers of other evidenced-based developmental screening tools and weigh them as additional pieces of the broader system in NH.
10. Assure that annual and federal reports from agencies accountable for screening contain shared information and are consistent and comprehensive.
11. Connect agencies so that they can better coordinate to provide resources to families and help them navigate the system.
Long Term
12. Request that the Office of Medicaid Insurance and Policy consider a review of network adequacy for pediatric specialty care services.
13. Establish an executive-level infrastructure to support a unified early childhood system.
14. Develop a policy for measuring child and system-level outcomes related to DSRDS.

**Funding**

Short Term
1. Promote communication across health and education teams in local communities with sufficient funding to support them (model communities of practice).
Mid Term
2. Fund a PR Consultant to develop and create a campaign for WMG, with the goal to reach all families and providers from early care, medical and other sectors.
3. Incentivize providers through private insurers.
4. Explore alternative funding sources for providers who fall outside the eligible health provider network (Early learning, family resource centers, school districts via DOE).
Long Term
5. Increase funding to expand child development clinics and other specialty providers to increase capacity.
6. Fund the Early Childhood Quality Rating System that includes implementation of standards for child screening in child care programs.
7. Review and consider applications for funding streams that would allow NH to engage in unified data collection with a single point of entry/collection and/or links across data systems.
8. Increase reimbursement rates for screening through Medicaid and private insurers.

**Data**

Short Term
1. Use the Child Care Aware NH Professional Registry and the CDC Watch Me Grow for data on trainings to monitor how many NH people have taken training.
2. Encourage the development and use of a data dictionary for data collection across systems to facilitate future linkages.
Mid Term
3. Ensure programs report all data collected on the ASQ and ASQ-SE in a timely manner (define).
Long Term
4. Develop mechanism for data to be collected, shared, and accessible so that gaps are identified, adequate resources are allocated, services needed are provided and work is accomplished across service sectors (ESS, DOE, community agencies including children born, children screened, related services, etc.) Create a Qualitative data dashboard.

5. Include developmental screening data from systems other than Watch Me Grow with a clear methodology for obtaining data and a mechanism for importing to Welligent or another system as needed. (Ex. Electronic Medical Record, EDHI (hearing and vision screenings), and Welligent systems used by other Home Visiting programs.)
6. Explore the feasibility of implementing a single unique identifier assigned at birth to longitudinally track children. (ex. Start with EDHI newborn screening).
7. Establish an integrated, cross-agency statewide Early Childhood Data System to improve program effectiveness and child and family outcomes.

**Quality Assurance**

<b>Short Term</b>
1. Provide frequent, consistent, and comprehensive overviews to the FRC’s and WMG partners – collect data, compile, and distribute as summary reports on a quarterly basis.
2. Ensure the WMG Quality Assurance Standards are being followed for measuring quality, including scope and reach, fidelity to tool, monitoring, culturally responsive system and the "closing of the circle" (screening, referral, and response).
3. Create standard reporting on referrals and eligibility to ESS and other services as listed in the database including enrollment data, follow-up, and outcome.
<b>Mid Term</b>
4. Build fidelity across screeners.
5. Create and implement a process to eliminate duplicative records for children (ex. data is entered within a specified time, birth date checked.)
6. Create a process to collect family input regarding what quality is for them.
<b>Long Term</b>
7. Create an "easy" way to have a snapshot of the system and impact on stakeholders – develop a mechanism to identify trends, emerging issues. – dashboard of metrics and outcomes (long term impact with longitudinal data) how well are we doing with the process, what are the outcomes for children and families, use the data to look at the gaps in service.

**Public Awareness, Outreach, and Communication**

<b>Short Term</b>
1. Share best practices (in and out-of-state) and success stories to build mentoring and role modeling across the system.

2. Create and implement a public relations campaign for WMG, with the goal to reach all families and providers from early care, medical and other sectors. (PowerPoint to introduce the system to families and professionals or create a podcast, funding, and expertise to deliver an app and support website. roll out to focus on the online version, including social media messaging, ads for radio, television, newspaper)
3. Identify entity to coordinate sending out a message every month.
4. Use successful family stories with the focus on engaging and promoting the growth and development of children and benefits to the families.
5. Review where and how WMG information is displayed and distributed.
6. Increase parent communication. Leverage existing resources (Text for Babies, VROOM).
<b>Mid Term</b>
7. Coordinate the WMG system with all partners and agencies who provide information about developmental screening. Embed and simplify message with other organizations with similar initiatives.
8. Explore using the United Way 211 Resource line or Community Health Centers as the central place to get information on screening.
9. Ensure sustainability in local work plans to keep screening in the forefront.

**Screening**

<b>Short Term</b>
1. Finalize and distribute the WMG Implementation Guide.
2. Conduct an environmental scan or survey of the tools healthcare providers are using including how data is collected and stored.
3. Explore opportunities to increase access to programs and services, such as online screening, telehealth, and others.
4. Engage families as partners including families that have a culturally diverse background to assist with increasing screening by peers.
<b>Mid Term</b>
5. Inventory what other tools the Family Resource Centers use to collect data and where the data is stored.
<b>Long Term</b>



- |   |
|---|
| 6. Create a network of screeners fluent in multi languages. |
|---|

### Referral to Resources, Services, and Support

Short Term
1. Identify and implement best practices in communicating road maps to resources for parents, including follow-up and support groups.
2. Include WMG status on the agenda of quarterly meetings for Comprehensive Family Support Services programs.
3. Provide support to programs and partners with quarterly face-to-face regional meetings (such as those happening in Monadnock), and post summaries and reports on the WMG website.
4. Use family and partner testimonies to normalize process.
5. Ensure partner sites know what resources are available, where to find the resources, and how to make referrals. Ex. mentor or role model site assigned to help.
Mid Term
6. Ensure care coordinators connect and follow-up with families.
7. Support resources for Family Resource Centers to enter follow-up information, create incentives for entering data in Welligent.
8. Support sites to be culturally and linguistically competent so that referrals accommodate and meet the family's needs.
Long Term
9. Support child care programs, who seek an advanced quality rating in the new QRIS system, with full implementation of the WMG model.

### Training and Technical Assistance

Short Term
1. Provide training on having difficult conversations with families. Embed the Strengthening Family approach in conversations with families (different languages).
2. Increase training on data input – including monitoring and access.
3. Share best practices – this is how we do it successfully.
4. Provide training for navigators/care coordinators to help families maneuver the system (SMS, ESS, area agencies, partners in health).

5. Promote the value of being a WMG site and the process to enter a MOA, encourage childcare sites to sign up for WMG before staff are trained.
Mid Term
6. Incorporate healthy homes, other home visiting programs with United Way 211.
7. Provide trainings to child care and schools on the ASQ and SE, why use it, what the results mean, how and when to refer, and how to share the information with families.
8. Provide “on demand” training on Ages and Stages ASQ, Question 3, and Social Emotional tool
9. Create Train the Trainer model.
Long Term
10. Explore training modalities to build capacity of the system (online, face-to-face, webinars).
11. Create tiered training models for implementation in programs, agencies, child care centers etc. with administration and staff.
12. Embed developmental screening and Watch Me Grow into college programs and internships to build professional capacity for those entering the field.
13. Update information for providers on the process for billing and provide training statewide. (Medical code 96110 for billing.)
14. Train people in the culturally diverse population to provide the screeners to their families and other diverse community members.

## Task Force Members

Rae Sonnenmeier, UNH, Dept. of Communication Sciences & Disorders

Nancy Evans, Child Health Services, Child Development Clinic

Joelle Martin, Early Education and Policy Advocate

Jenn Pineo, NH Family Voices

Jen Doris, Special Medical Services

Janet Clark, Child Health Services, Child Development Clinic

Holly Tutko, UNH, Institute for Health Policy and Practice

Betsy Humphreys, UNH, NH-ME LEND Program

Liz Collins, Special Medical Services

Diana Dorsey, Special Medical Services (formerly, currently DOE)

Dee Dunn Tierney, Special Medical Services

Nina Sand-Loud, Dartmouth-Hitchcock Medical Center

Kristine Arbor, Moore Center

Kim Firth, Endowment for Health

Debra Nelson, Head Start State Collaboration Office

Laura Milliken, Spark NH

Conor Murphy, Watch Me Grow, AmeriCorps VISTA

Krisha Dubreuil, Child Development Bureau

Michelle Lewis, Parent Information Center

Ruth Littlefield, Bureau of Special Education, DOE

Mark Vallone, Epping School District

Cathy McDowell, Family Resource Center, Gorham

Lara Quiroga, Project LAUNCH

Christina D'Allessandro, Moms Rising NH

Chris Motika, Title I, DOE

Sue Watson, Prevention Technical Assistance

Marjorie Droppa, Monadnock United Way

Tessa McDonnell, Facilitator, Spark NH