

Stereotyped Behavior in Autism and Improving Developmental Screening in Primary Care Practices

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Video Project with Dr. Gary Stobbe at Children's Autism Center

Patient #1 K. M.

1. Videos from preschool and initial assessment for developmental delay in 1992 and 1993, age 4 and 5 years
2. Video interview of K.M., age 22, by Dr. Stobbe at Children's Autism Clinic May 2011

K.M.

- Birth by c-section for fetal distress, unremarkable early development (though family noted he wasn't cuddly and didn't smile)
- Language regressed age 18-24 months
- Noted to have stereotypies like hand-flapping and running laps around room
- ROS– trouble sleeping, bruxism (teeth-grinding) and restrictive eating
- Fam Hx– Asperger's/bipolar on dad's side, pediatric epilepsy on mom's
- Diagnosed PDD-NOS age 3 at CHDD, confirmed 1 year later
- Made progress with early intervention (EEU)
- Around 11 years old developed catastrophic affective storms → MED

K.M. Videos from 1992-2011



Lorna B

- Female with intellectual disability and autism-like behaviors
- Late to walk and only used monosyllabic words when talking
- Stereotyped behaviors as early as age 3, clasping fingers over her nose
- History of hypotonia and unusual facial features
- Special education and speech therapy and completed high school in self-contained. Reads at 3rd grade level now.
- Later diagnosed with Smith-Magenis syndrome at age 22

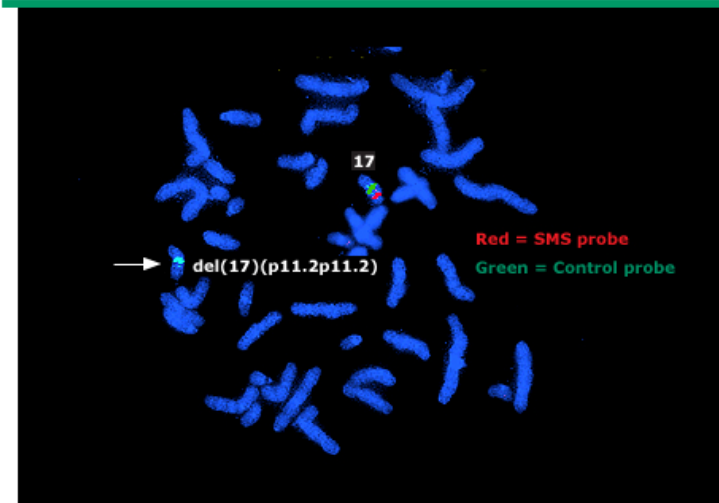
Smith-Magenis Syndrome

Facial features include brachycephaly, midface hypoplasia, broad nasal bridge, and prominent jaw.

Self-injury, including biting, hitting, head banging, and skin picking, is very common.

Repetitive upper body squeeze or self-hugging is a behavioral trait that may be unique to Smith-Magenis syndrome. People also compulsively lick their fingers and flip pages of books and magazines (a behavior known as "lick and flip").

Smith-Magenis syndrome



The Smith-Magenis (SMS) syndrome is typified by a microdeletion of chromosome band 17p11.2. The green control probe, used in FISH analysis of a patient's chromosome spread is present in both the paternal and maternal chromosomes 17. The red probe, however, that is designed to hybridize to the commonly deleted SMS region only fluoresces on a single chromosome. This finding strongly supports the diagnosis of SMS.

Courtesy of Athena Cherry, Stanford Hospital and Clinics.

L.B. (ages 3-22)



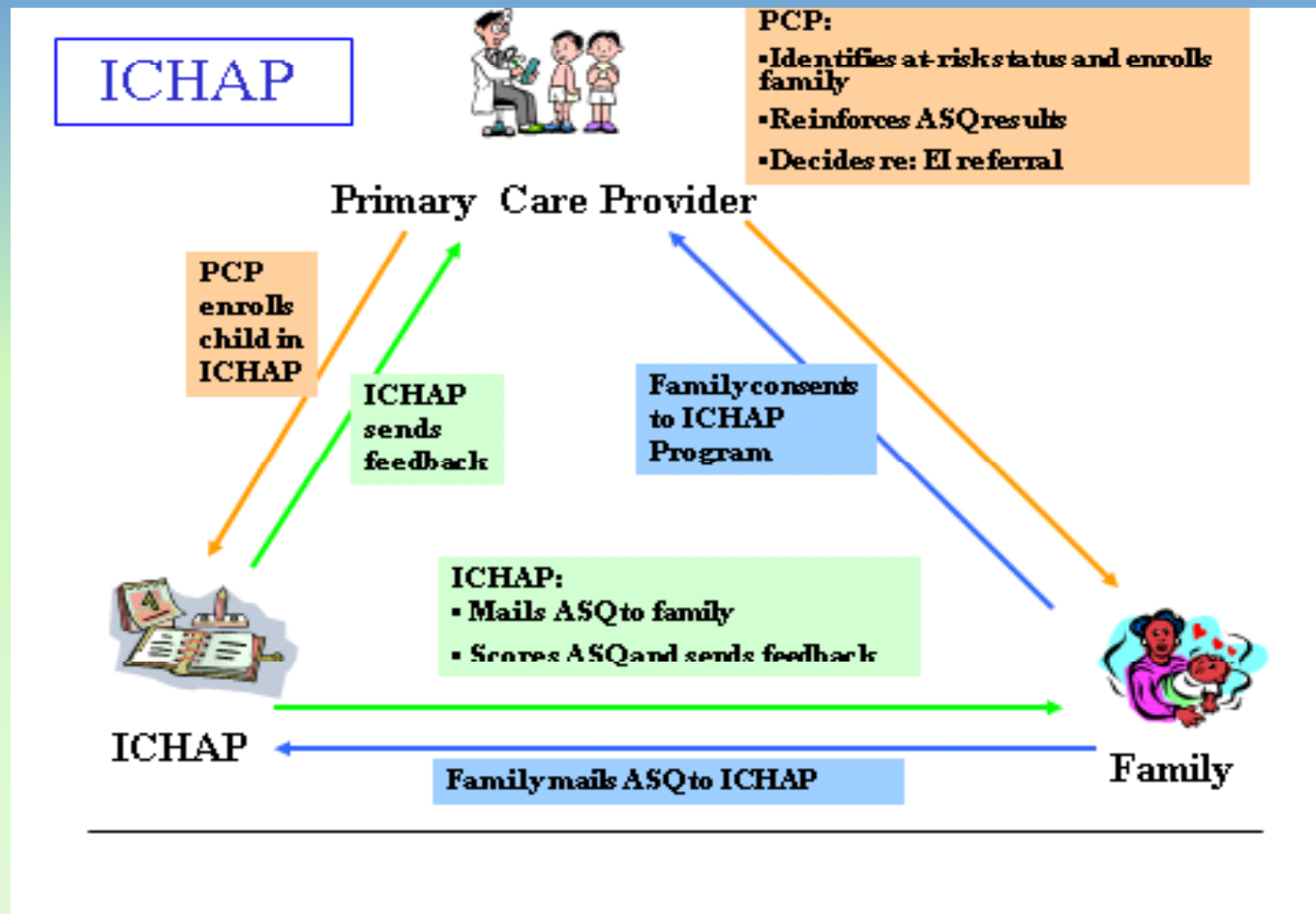
Developmental Screening

- Approached by Dr. TeKolste to help facilitate Family Medicine and Primary Care Physician involvement in state-wide developmental screening effort
- Meetings with WWAMI Family Medicine Residency Network Director and Faculty to strategize how to incorporate residency training in the developmental screening effort

Washington State Developmental Screening

ICHAP = Infant
and Child Health
Assessment
Program

ASQ =
Ages and Stages
Questionnaire



Components for Universal Developmental Screening for Children 0-? Years in Washington State

Universal reach to parents of youngest children

Public Awareness: Developmental screening seen as social norm, similar to car seat use.
Family entry into Screening Program
Family linked to Medical Home, if not already

A Means to Administer, Score and Track Developmental Screens

Developmental Screen completed
(by parent/guardian access or by facilitator)
Child entered into tracking system - referrals, next screening

• A Means to Provide Results to Providers and to Families

- **Providers** in system automatically informed that results are available
- **Regional Coordinator/Case Manager** regularly reviews results for children in their region and tracks that each child's family receives results in appropriate manner,

A Means of Care Coordination to Link Children to a Continuum of Services

Regional Coordinator/Case Mgr

In coordination with the medical home, assesses need for support services/interventions, & results of referrals
Follow-up to assure connection to services, determine family satisfaction,

Community Awareness of and Connection to Information and Services

Regional Coordinator

Identify gaps and barriers, Update resources
Increase community resources awareness

Components for Universal Developmental Screening for Children 0-3 Years in Washington State

Public Awareness Campaign and Provider Campaign

Developmental screening seen as social norm, similar to car seat use



Family Entry into Screening Program:

- Signs up for Washington State Screening Program & (optional) CHLD Profile mailings,
- Completes permission and release of information form,
- Indicates 'Need to Know' care providers who can access results (Medical Home, Head Start Program, Foster Care, etc.), and
- Completes first age-appropriate screening tool

Screening system entry point:

- Enrolls family in screening management system and tickler system
- Connects family with medical home, if needed



Parent receives prompt that child is due for screening:

- Tickler file reminder from on-line system
- Health information mailings
- Provider gives reminder (health care, child care, home visitor, other)
- PSA announcements provide prompt

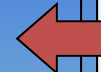


**On-line Developmental Screen done
(by parent/guardian access or by facilitator) Resulting
in:**

- Providers in system automatically informed that results are available
- Regional Coordinator/Case Manager, in coordination with the medical home regularly reviews results for children in their region and tracks that each child's family receives results in appropriate manner, need for support services/interventions, & results of referrals

Where is online access?

- Home or care site computer
- Computer with Home visitor or case worker
- Library
- Facilitated by phone interview w/ child development hotline, Navigator, or another provider with computer access
- Paper format and hand entered
- Kiosks at malls?
- Cell phones?
- Others?



Child developing typically, No family needs –

- Medical Home provider or other agreed upon provider reviews with parents
- Family provided information on developmental activities
- Tickler file notifies parents of next screening date
- Family also receives CHILD Profile mailing with reminder

Child needs monitoring and/or Family has needs

- Medical Home provider reviews with parents
- Child flagged at next screening age for careful monitoring of results
- Developmental activities provided
- Follow up contact with family to assess for potential supports and services
- Tracking and care coordination for any referrals

Child needs further assessment:

- Medical Home provider reviews with parents
- Early intervention referral
- Medical follow-up/subspecialty referral for further evaluation
- Family linked to information and supports
 - Information about the assessment process and diagnosis, if appropriate
 - Family support groups

Regional Coordinator/Case Mgr

Follow-up to assure connection to services, determine family satisfaction, identify gaps and barriers, update resources

Ongoing Efforts

- LEND and State Implementation Grant focus
 - LEND and MCH trainee interest
 - CAM –
 - STAT training
 - Developmental Screening
 - Other outreach – Family medicine, MHLN teams

Workgroups:

- Now:
 - System
 - Care Coordination/Community Resources (Chairing this Workgroup)
 - Data system/Registry
 - Reaching All Populations
 - (Information Technology)
- Later
 - Marketing, Fiscal, Evaluation

System: Components

- Universal reach to parents of our youngest children,
- A means to administer, score and track screens,
- A means to provide results to providers and to families,
- Community awareness of and connection to a spectrum of information and services as dictated by screening results, and
- A means of care coordination to link children to a continuum of services

Medical Homes: Screening System 'Mandates'

- Support primary health care providers who:
 - Screen at all ages on site
 - Screen at some ages on site and not at other ages
 - Do not screen
- Not a substitute for Well Child Check
- Work load/priorities during patient visit
- Provide Care Coordination - linkage to services and follow-up (DPIP)

Thank You

- Dr. Gary Stobbe and patients K.M., L.B., and their families
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- Dr. Julie Osterling—Eval and videotapes for KM
- Dr. Katherine TeKolste
- Rebecca Davis-Suskind, MPH
- Brother-in-law Tom Porter, Power Point extraordinaire