

Early Developmental Screening & Community Resources

California Area Indian Health Service &
California Rural Indian Health Board, Inc. Conference
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Janice Enriquez, PhD
Clinical Psychologist

Amy Weir, MA
Psychology Doctoral Intern

UC Davis MIND Institute
Center for Excellence in Developmental Disabilities (CEDD)
Leadership Education in Neurodevelopmental and Related Disabilities (LEND)



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Objectives

- Describe screening tools for early identification of autism spectrum disorder (ASD) and referral resources.
- State at least three resources to assist IHS health professionals in education and identification of persons with intellectual and other developmental disabilities (ID/DD).
- Explain helpful connections between the Indian Health Services and the Center for Excellence in Developmental Disabilities at UC Davis MIND Inst. related to support and resources for persons with ID/DD.

Importance of Early Developmental Intervention

- Early intervention is Effective

(Wolery & Bailey, 2003; Guralnick, 1997).

- Help Children reach their full potential
 - Children with developmental disabilities benefit from intervention to reach their full potential
 - Speech and language therapy, special instruction, home visits, family support, and service coordination

(Zero to Three Policy Brief , February 2003).

Importance of Early Developmental Screenings

- Early developmental delays are often not identified in a timely way (Sices, Commonwealth Fund 2007).
- Healthcare professionals routinely overestimate developmental skills
 - 67.5% of children with delays on screening not picked up by physicians
 - Referral rates increased by 224% with screening (Hix-Small et al, Pediatrics 2007).
- Ages 0-5 are CRUCIAL for early identification

Importance of Early Developmental Screenings

- Current detection rates of developmental disorders are lower than actual prevalence rates (12-16%)
- Title V and IDEA mandate child health professionals to provide early identification and intervention for children with developmental disabilities

Does Early Identification Make A Difference?

- YES!
- Brain development is context dependent and influenced by experience/favorable environments
- Appropriate, enriched environments change both structure and function of brain connections
- Better educational, social, economic outcomes long term

Risk Factors for Delay:

Health & Developmental Concerns

- Prematurity or low birth weight
- Vision or hearing difficulties
- Prenatal exposure or other types of exposure to drugs, alcohol, or tobacco
- Poor nutrition or difficulties eating
- Exposure to lead-based paint
- Environmental factors, such as abuse or neglect

Risk Factors for Delay: Behavior & Socioemotional

- Avoids being held
- Difficult to soothe
- Lack of eye contact
- By 4-mos: Lack of cooing or smiling
- By 12-mos: Lack of single-words, social games
- By 2-years: Lack of phrase speech, social imitation
- By 3-years Lack of play with others
- Aggression, self-injurious, harms others

Definition of Developmental Delay

- Failure to reach developmental milestones at the expected age range
- Areas affected-motor, language, cognitive, personal/social
- Spectrum from mild to severe
- Transient or permanent
- Influenced by biology and environment
- Sub-optimal medical or environmental conditions puts development at risk

Developmental Areas to Screen

- 4 Major Domains of Development
 - Motor (gross and fine motor)
 - Language (articulation, expressive, receptive and nonverbal language)
 - Cognitive (verbal and nonverbal problem solving)
 - Personal/Social (social interaction, self help skills)

Surveillance, Screening, Evaluation

- Surveillance is:
 - Professional identifies developmental concerns through **observation**
- Screening is:
 - **Standardized measure** to identify children in need of intervention or further evaluation for developmental delay (at-risk)
- Developmental Evaluation:
 - A complex process aimed at identifying **specific developmental disorders** that are affecting a child.

AAP Guidelines for Developmental Surveillance and Screening

- Developmental surveillance at every well-child preventive care visit.
- Screenings:
 - Any concerns raised during surveillance
 - Administered at the 9-, 18-, and 24 or 30-month visits
 - Autism specific tool at 18 and 24 or 30 months

Pediatrics 2006/2007

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Collaborate with Parents

- Parents love to share their child's developmental skills!
- Parents provide accurate and highly valid reports about their child's development.
- In a study, 28% of parents with concerns about their child's development discussed it with their pediatrician.

Rydz et al, Journal of Child Neurology 2005

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Collaborate with Parents

- Help parents take a proactive outlook toward their child's development.

Rydz et al, Journal of Child Neurology 2005

- Evidence-based screening tools that incorporate parent reports can facilitate structured communication between parents and providers.

Center for Disease Control

SURVEILLANCE & SCREENING TOOLS

Parents' Evaluation of Developmental Status (PEDS)

- Evidence based surveillance tool for children birth-8 years
 - Sensitivity/specificity 70-80%
- 10 questions for each well child visit
 - Interview or parent completed (5th grade reading)
 - 2-10 minutes to complete
 - Easy to score
 - English/Spanish versions

PEDS- Developmental Milestones (DM)

- Milestones in each of 5 domains for each age encounter (6-8 items/encounter)
- Completed by parents or health professional
- Can be used in combination with PEDS (16-18 items per encounter) or following concerns on PEDS

Ages and Stages Questionnaire (ASQ-3) (2009)

- 21 Questionnaires span interval from 1- 66 months
- Parent administered and completed (4-6th grade reading level) in 10-15 minutes
- Scoring takes 1-5 minutes
- Available in English, Spanish, (2nd edition in French)
- Reproducible
- Online management (new)

ASQ Organization

- 30 questions/form: 6 questions in each of 5 developmental areas (gross motor, fine motor, problem-solving, communication, personal-adaptive skills)
- Questions progress developmentally within the domain, so easier tasks are presented before harder tasks

Scoring ASQ

- Must have all responses completed
- A domain can't be scored if >2 unanswered questions
 - If <2 unanswered items, then average the sum of the answered items in the section and add to the sum for an estimated score for that domain (twice if needed)
- If more advanced items marked “yes,” then earlier items marked “not yet” or “sometimes” can be changed to “yes”
- Yes = 10, Sometimes = 5, No = 0
- Plot on bar graph on Summary Sheet

ASQ Interpretation

- Share scores indicating typical development with parents
- Refer a child when a score falls below the cut off in any particular area
- Closely follow or consider referral for borderline scores, especially if other risk factors or if parent has indicated concern
- Don't alarm parent, just explain the score indicates further evaluation is in order

Ages & Stages Questionnaires: Social-Emotional (ASQ:SE)

- 8 Questionnaires span interval from 6 - 60 months
- Parent administered and completed (4-6th grade reading level) in 10-15 minutes
- Scoring takes 1-5 minutes
- Available in English, Spanish
- Reproducible

Ages & Stages Questionnaires: Social-Emotional (ASQ:SE)

- General areas screened: Personal-Social
(self-regulation, compliance, communication, adaptive functioning, autonomy, affect, and interaction with people)

Autism Spectrum Disorders

- Prevalence of ASD is increasing internationally
 - 1/68 in 2014 in the US according to CDC

Surveillance and Screening Algorithm: Autism Spectrum Disorders

- Perform Surveillance
- Score 1 for Each Risk Factor:
 - Sibling with ASD
 - Parental Concern
 - Other Caregiver Concern
 - Pediatrician Concern

Johnson et al, Pediatrics 2007

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Surveillance and Screening Algorithm: Autism Spectrum Disorders

- Score of zero, routine well child care and screen at 18 and 24 month well child visits
- Score of 1
 - Administer ASD Specific Screening Tool, refer or follow up as indicated
- Score of >1
 - Refer and provide education materials, follow up appointment and audiology referral

ASD Screening

- ASD specific (18-24 months)
 - M-CHAT-R/F
 - Social Communication Questionnaire (SCQ)
 - ASQ language, self-help and social-emotional

M-CHAT-R/F

(Robins, Fein, & Barton, 2009)

- AAP recommends screening for autism at the 18 **AND** 24 month visit
- Screening tool designed for toddlers age 16-30 months

M-CHAT-R is a great screening tool

- Pros
 - Brief
 - Free at mchatscreen.com
 - Available in ~40+ languages, though not all have undergone validity/reliability studies
 - High sensitivity
- Cons
 - High sensitivity leads to false positives

Follow-up Questionnaire

- Developed to help reduce number of false positives
- Even if the child is not eventually diagnosed with ASD, a positive screen may be due to other developmental delays

Scoring

- For all items except 2, 5, and 12 response of “NO” indicates ASD risk
- No longer with “critical items”
- Now cumulative number of failed items constitute score

Low Risk (Score of 0-2)

- If the child is younger than 24 months of age, rescreen after 2nd birthday
- No further action required unless surveillance indicates risk for ASD

Medium Risk (Score of 3-7)

- Follow up interview needed
- If score remains 2 or higher, the screen is positive and should be referred to audiology, early intervention services and for a diagnostic evaluation
- If score is 0-1, child has screened negative, no further action required unless surveillance indicates risk for ASD. Continue to screen at 24 month WCC (if applicable) and schedule 30 month (or sooner) check up

High Risk (Score 8-20)

- Refer immediately to audiology, early intervention services and for a diagnostic evaluation

Instructions

- Parents to keep in mind how the child USUALLY behaves
- If you have seen your child do the behavior a few times, but he/she does not usually do it, then please answer no
- Use follow-up questions for failed responses

ASD Specific Screening

- SCQ-Social Communication Questionnaire
(*Requires consultation with professional with expertise in standardized assessments)
 - 39 item parent report
 - High sensitivity(85%) and specificity (75%) in standardization sample of children >4yr, lower (68%/41%) in 18-48 months

Early Intervention: Assisting and Supporting Families

- Refer the family promptly for a more complete developmental assessment
- Present any statements about long term prognosis carefully
 - inform parents that prognoses are based on data for groups of children
 - Snapshot in time
- Subsequent medical visits
 - ask questions about the child's early intervention services and the child's progress

Spiker & Hebbeler 1999

Key Points

- Developmental delays are missed without routine screening
- ASD are increasing in prevalence
- Early identification of DD and ASD important for long term outcome
- Reliable screening instruments available
- ASD screening recommended as routine part of developmental surveillance and screening

Summary

- Developmental Surveillance at every visit
- Developmental Screening at 9, 18, 24-30 months
- Autism Screening at 18 and 24-36 months
- Make appropriate referrals simultaneously
 - Vision, hearing
 - Speech evaluation
 - PT/OT evaluation
 - Early Intervention/Regional Center
 - Local School District (IEP)
 - Diagnostic Evaluation (Child Development, Psychology)

Case Example

- Video & Example

Call to Action

- Application in your Clinics:
 - Screening is easy and effective in clinical setting
 - ALL staff can be trained!
 - Clinic nurses can lead this effort
 - Measures to consider in your clinic:
 - MCHAT-R/f
 - ASQ
 - Learning more about developmental disabilities is important.
- Additional information and resources:
 - UC Davis MIND Summer Institute Conference
 - UC Davis LEND program
 - Autism Speaks
 - Be an advocate!

EARLY DEVELOPMENTAL SCREENING & INTERVENTION RESOURCES

Resources

- CA Early Start Services
 - Dept. of Developmental Services
 - Department of Education
 - Partnership with:
 - Families
 - Professionals
 - Family Support
 - Coordination of Services



800.515.BABY
www.dds.ca.gov/earlystart

Resources

- CA Early Start Services
 - Statewide
 - Accessible within:
 - Regional Centers
 - County Office of Ed.
 - Local School District
 - Health/Social Service agencies
 - Family Resource Networks



800.515.BABY
www.dds.ca.gov/earlystart

Early Start Services

- ▶ assistive technology, including devices or services
- ▶ audiology or hearing services
- ▶ family training, counseling, and home visits
- ▶ health services necessary for a child to benefit from other early intervention services
- ▶ medical services for diagnosis and evaluation only
- ▶ nursing services
- ▶ nutrition services
- ▶ occupational therapy
- ▶ physical therapy
- ▶ psychological services
- ▶ service coordination (case management)
- ▶ social work services
- ▶ special instruction
- ▶ speech and language services
- ▶ transportation and related costs necessary for a child to receive services
- ▶ vision services



**THE EARLIER WE START,
THE FARTHER THEY'LL GO**

Because all babies are different, they rarely do the same thing at exactly the same age. As a result, it's not unusual for families to have questions or concerns about their child's development. You may wonder:

Why isn't my son sitting up?

Why isn't my daughter crawling?

*Why can't anyone understand
what my son is saying?*

Is my child's hearing/vision normal?

It's important to keep in mind that all children develop differently and at their own pace. If you have concerns about your child's development, call your child's primary health care provider, community health clinic, or 800/515-BABY for early intervention services in your area. You can also visit our website at www.dds.ca.gov/earlystart or e-mail us at earlystart@dds.ca.gov.

Call
800/515-BABY
or visit
www.dds.ca.gov/earlystart
e-mail:
earlystart@dds.ca.gov

For more information, call your local regional center,
education agency, or family resource center.

REGIONAL CENTER

PHONE

LOCAL EDUCATION AGENCY

PHONE

FAMILY RESOURCE CENTER

PHONE



for Infants
and
Toddlers
with
Disabilities
and their
Families

California Early Start is an interagency system
of coordinated early intervention services
administered by the Department of Developmental
Services in collaboration with the California
Department of Education.

**When you have questions
about your child's
development**



**A FAMILY INTRODUCTION TO
CALIFORNIA
EARLY
START**

**for Infants
and Toddlers
with Disabilities
and Their
Families**



DEPARTMENT OF DEVELOPMENTAL SERVICES

Early Start Services

- Who is Eligible?
 - 0-36 mos.
 - Significant Developmental Delay
 - Cognitive
 - Social/Emotional
 - Communication
 - Adaptive
 - Physical
 - Hearing
 - Vision



800.515.BABY
www.dds.ca.gov/earlystart

Early Start Services



800.515.BABY
www.dds.ca.gov/earlystart

- Who is Eligible?
 - <24-mos: 33% delay in one or more areas of development
 - ≥24-mos:
 - 50% delay in one or more areas of development OR
 - 33% delay in 2 or more areas of development

Early Start Services



800.515.BABY
www.dds.ca.gov/earlystart

- Who provides services:
 - Regional Center OR
 - Local Education Agency
 - Vision, hearing, severe orthopedic impairment

Early Start Services



CALIFORNIA EARLY START

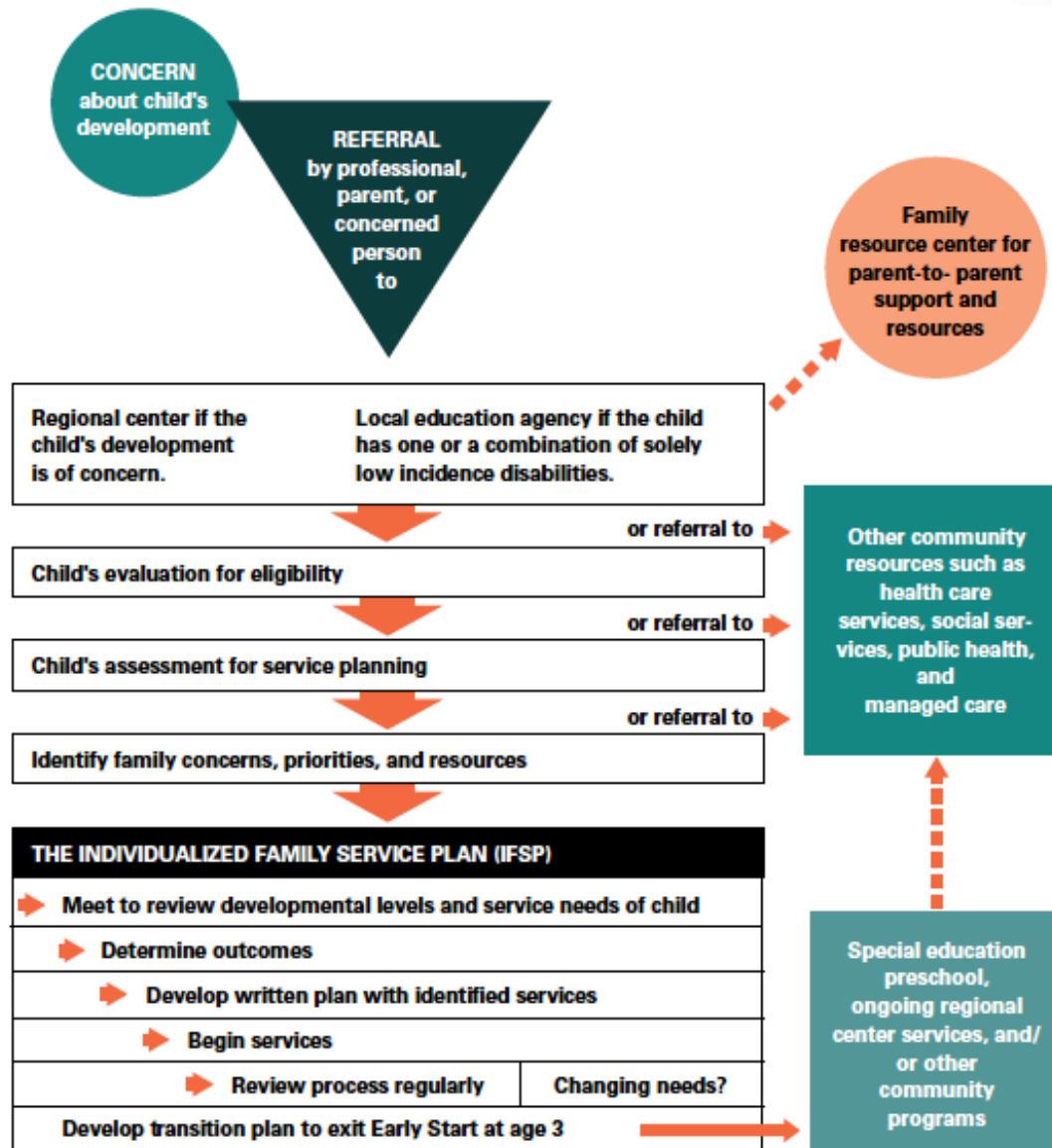
Regional Centers by County

800.515.BABY

www.dds.ca.gov/earlystart



For more information,
please refer to the *Central
Directory of Early Intervention
Resources* located at www.dds.ca.gov/earlystart
or call 800/837-4337.



EARLY START REFERRAL PROCESS

Family & Provider Resources

Resources for Families

- Family Resource Centers
- Warmline Family Resource Center
 - Free Resource for families
 - Parent support
 - Trainings
 - Consultation
 - Ages 0-26-years
 - Located in 26 counties of CA
 - Staffed by Parents



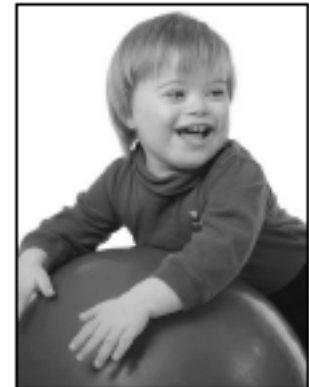
Providing
resources & support to families
of children and youth with
special needs.

Email: warmline@warmlinefrc.org

2424 Castro Way
(Physical Address)
Sacramento, CA
95818
916-455-9500

Toll Free:
844-455-9517

Español:
916-922-1490



Open:
Monday-Friday: 9am - 5pm

CENTERS FOR DISEASE CONTROL AND PREVENTION'S “Learn the Signs. Act Early.”

Patty Schetter, MA, BCBA

Coordinator of Autism Education Initiatives

CEDD at the MIND Institute

pschetter@autismandbehavior.com

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Learn the Signs. Act Early.

The journey of your child's early years includes many developmental milestones for how he or she plays, learns, speaks, and acts.

Look inside to learn what to look for in your child. Talk with your child's doctor about these milestones.

Not reaching these milestones, or reaching them much later than other children, could be a sign of a developmental delay.

If you have concerns about your child's development and live within the greater Sacramento Area, here is who you can call for further support:

**Parent Training and Information Center
WarmLine Family Resource Center**
916.455.9500 or 844.455.9517
warmlinefrc.org

Alta California Regional Center
916.978.6400
www.altaregional.org

Developmental milestones adapted from Caring for Your Baby and Young Child: Birth to Age 5 (AAP 2009) and Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents (AAP 2003).

Special Education Local Plan Areas (SELPA)
Sacramento County Office of Education - SELPA
916.226.2500
scoe.net/services/id510/Pages/default.aspx

Elk Grove Unified - SELPA
916.686.7780
blogs.egusd.net/specialed/

Sacramento City School District - SELPA
916.643.9163
scsd.edu/special-education

San Juan Unified School District - SELPA
916.971.7525
sanjuan.edu/Page/292

Folsom Cordova Unified School District - SELPA
916.284.9007
fousd.org/Domain/637

Placer County Office of Education - SELPA
530.869.6030
placercoe.k12.ca.us/departments/selpa/Pages/default.aspx

Yolo County SELPA
530.668.3787
ycoe.org/SELPA

Colusa County Office of Education: Special Education
530.458.8891
ccoe.net/SpecialEducation

El Dorado County Office of Education: SELPA
530.295.2228
edcoe.k12.ca.us/departments/selpa/index.html

Nevada County Superintendent of Schools
530.265.0611
nevco.k12.ca.us

Sutter County SELPA
530.822.2900
sutter.k12.ca.us/Content/SELPA/home.aspx

Yuba County SELPA
530.749.4873
yuba.net/edservices/selpa/Pages/default.aspx

Tahoe Alpine SELPA
530.541.2860 x 226/248

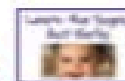
Sierra County
530.993.4465

Track Your Child's Developmental Milestones



Your child's early development is a journey. Use this map of milestones to know what to look for along the way.

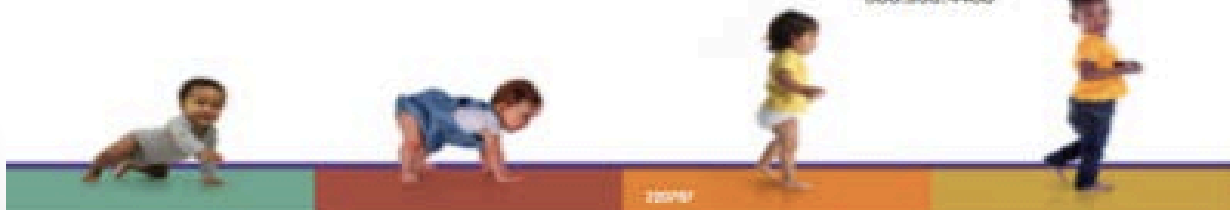
For parents of children from birth to 4 years



Centers for Disease Control and Prevention
www.cdc.gov/ActEarly
1-800-CDC-DEFO

Department of Health and Human Services
Centers for Disease Control and Prevention

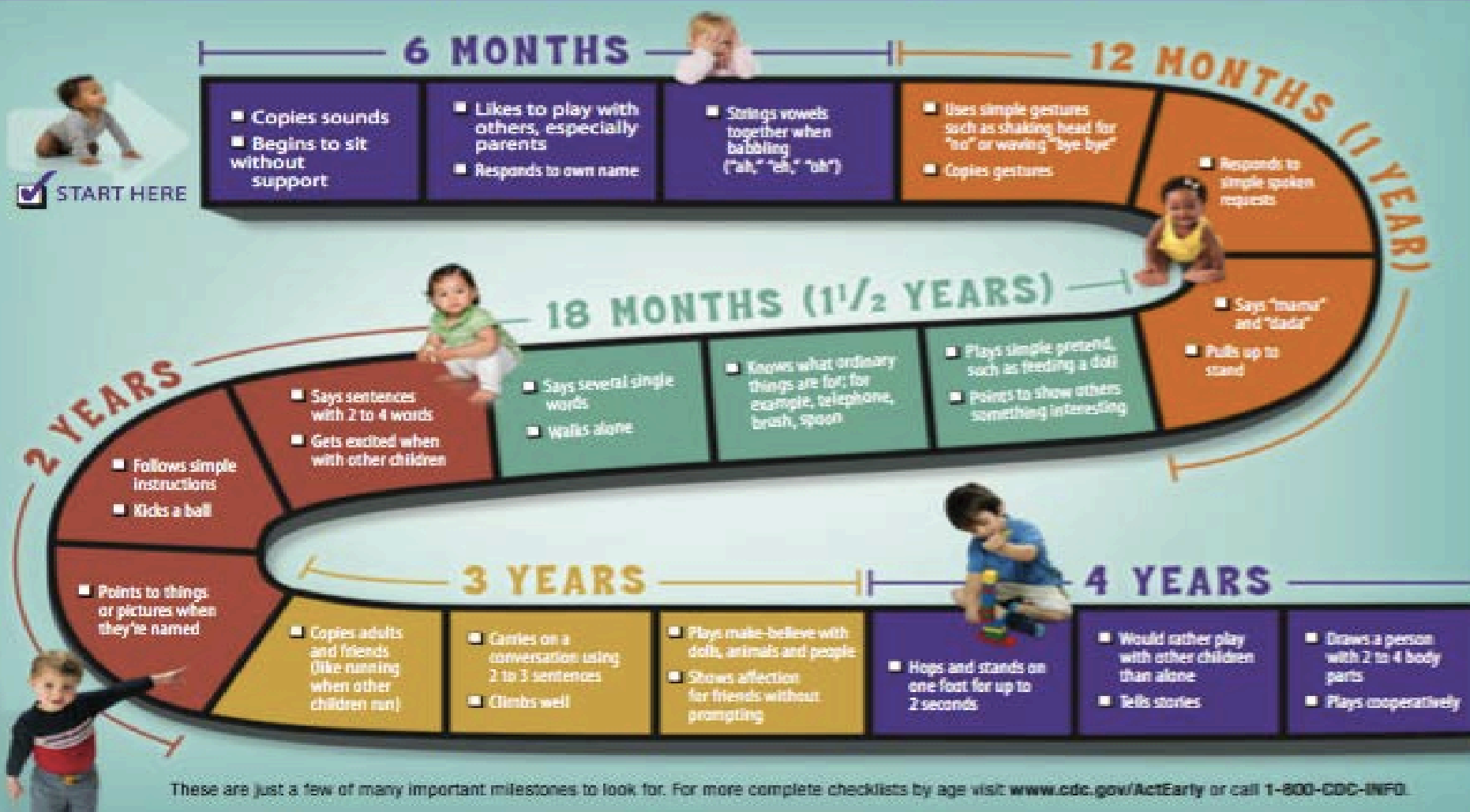
Learn the Signs. Act Early.



Example of Region Customized Brochure for greater Sacramento Area

Your Child's Early Development is a Journey

Check off the milestones your child has reached and share your child's progress with the doctor at every visit.



Resources for Parents

- California Regional Centers
 - dds.ca.gov/rc/rclist.cfm
 - 0-3 Early Intervention Program
 - ALTA (916) 978-6400
- Early Start Program in California (0-36 months)
 - dds.ca.gov/EarlyStart/ESQuestionAnswers.cfm
 - 800-515-BABY
- Warmline Family Resource Center
 - warlinefrc.org
 - (916) 922-9276
- First 5 Sacramento (parenting/school readiness resources)
 - first5sacramento.net
- California Children Services
 - dhcs.ca.gov/services/ccs/Pages/ProgramOverview.aspx

Resources for providers

- http://www.firstsigns.org/screening/tools/rec.htm#dev_screens (free M-CHAT and more)
- www.dbpediatrics.org/mchat.pdf (free M-CHAT)
- <http://www.brightfutures.org/mentalhealth/pdf/tools.html> (free mental health toolkit; AAP has one also for purchase)
- National Dissemination Center for Children with Disabilities <http://www.nichcy.org> (info on IDEA, fact sheets on disabilities, resources, and more)
- <http://www.autismspeaks.org/video/glossary.php> (video glossary-ASD and normal behaviors)

Resources for Providers

- AAP Algorithm for Developmental Surveillance and Screening (2006) Pediatrics 118:405-420
- Identification and evaluation of children with ASD
Johnson et al (2007) Pediatrics 120:1183-1215
- *AAP: Autism: Caring for Children with ASD: A Resource toolkit for clinicians*
- CDC Learn the Signs Act Early

Community & University Collaborations



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Center for Excellence in Developmental Disabilities

Community Advisory Council

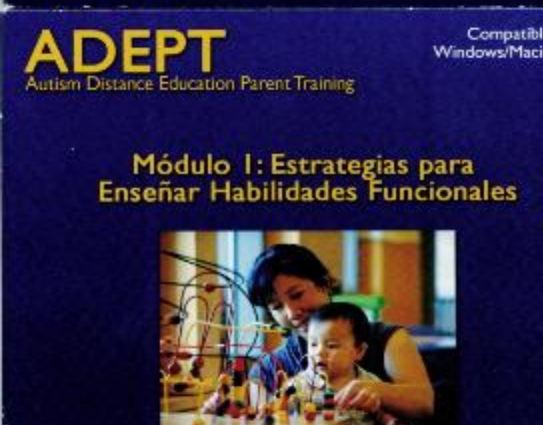
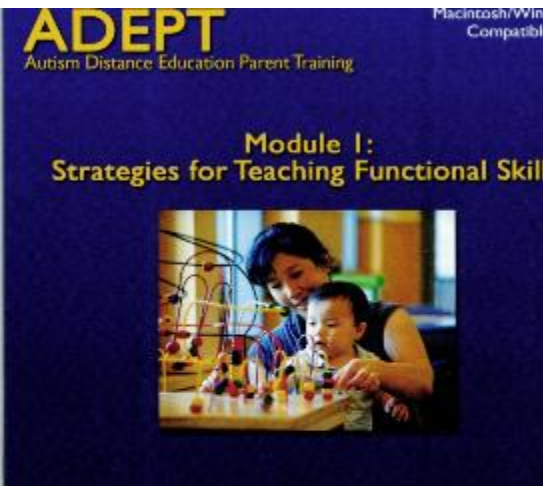
Consumers and family
members (50%)
CA DD Network Partners
State Council on DD
UCLA/USC UCEDDs
Disability Rights CA
State and Local agencies
serving the DD community



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Autism Initiatives



- **ADEPT Autism Distance Education Parent Training**
- Parenting modules available online
- Utilized statewide for Regional Center training
- Included in curricula by psychology training programs nationally
 - Teaching functional skills
 - Positive behavior supports
 - English and Spanish versions
 - Korean version in production

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Community Service and Outreach



- Reducing health disparities
 - Southeast Asian, Hispanic and African American Community outreach projects for early screening and intervention, family supports and education, sibling workshops
 - Vamos a platicar/Let's Talk
 - African American Parent Support Group
 - Health care transition for adolescents/young adults to adult providers
 - Packard Foundation funding

Community Service and Outreach

- Reducing Health Disparities
 - Family Navigator support for families of children with developmental disabilities during hospitalization
 - Pediatric Care Coord.
 - AAP webinar series
 - Family Resource Center
 - Bilingual staff



Autism Initiatives

- Special Studies Program in ASD
 - Educators, service providers, parents
 - Face to face now online



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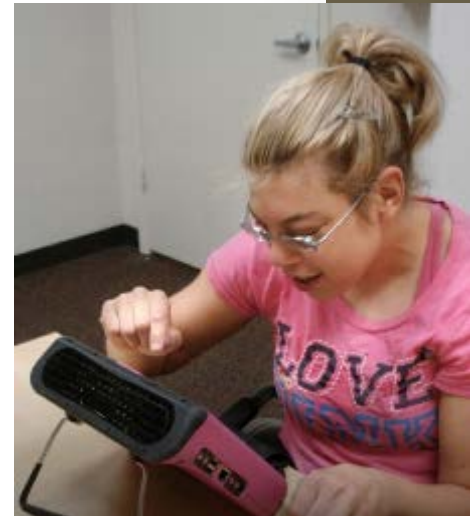
Community service and outreach

- Assistive Technology Consortium
 - School districts, Department of Education and Rehabilitation, community programs
 - Promotion of assistive technology use to enhance quality of life and classroom inclusion
 - Teacher and family training

Resource Fairs

Community of Practice

AT Certification Course for Educators



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Community Service and Outreach



- Transition projects
 - CA Community of Practice for Transition
 - Think Transition Work Group
 - monthly training series and support for families/educators
 - information sharing for community members and professionals
- Employment
 - Internships in MIND Resource Center
 - Legislative Advocacy
 - Employment First
 - Self-Determination

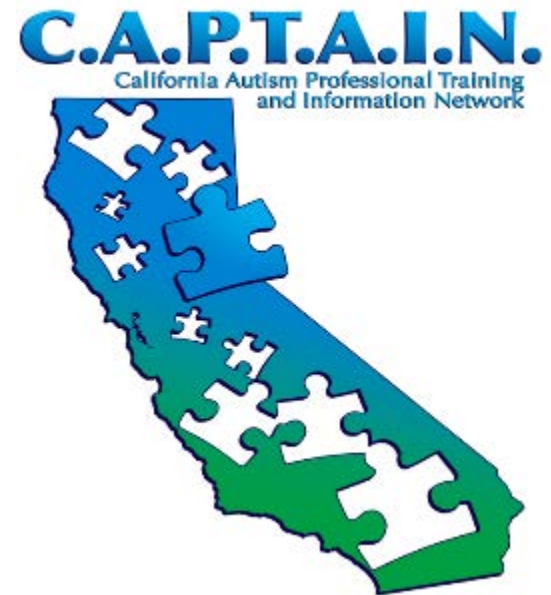
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Autism Initiatives

- CA Autism Professional Training and Information Network
 - Interagency collaboration
 - SELPAs/Dept of Ed Dx Centers
 - Regional Centers
 - Family Resource Centers
 - Training in evidence-based interventions in ASD
 - Preschool through high school



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Northern CA. LEND: Leadership Education in Neurodevelopmental and Related Disabilities

Training future leaders in the maternal and child health field

HRSA funded program

Director: Sally Rogers, PhD

Co-Director: Aubyn Stahmer

LEND Program



- Graduate level, interdisciplinary training for clinicians, family members, self-advocates and policy makers
- Learn about Neurodevelopment and Leadership
- Emphasis on underserved populations in California
- NOW Recruiting:
 - Graduate students in health and public health professions & post-graduate professionals who are committed to learning more about developmental disabilities and want to be visionary leaders
 - Some paid positions. NO cost to trainees
 - Email: jenriquez@ucdavis.edu (916) 703-0457

For more information, questions, and support for your clinic setting

- Contact:
- Dian Baker RN, Pediatric Nurse Practitioner, PhD
- Professor of Nursing at Sacramento State



- dibaker@csus.edu

Thank You!