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Testimony on Issues Important for California Women & Girls September 20, 2006

My name is Margaret Dunkle. I am submitting this testimony as an individual to the California Commission for Women because of my long commitment to equality for women and girls.

By way of my background concerning issues affecting women and girls, I:

- Wrote the first comprehensive analysis on Title IX and women's athletics, which became the basis of the Title IX regulation regarding sports. In his least-read book, *Sports in America*, James A. Michener said this report "is a model of restraint, persuasion and good sense. But it also has a sharp bite."
- Co-founded and served as the first chair of the National Coalition for Women and Girls in Education, leading this effective coalition as it assured implementation of Title IX of the Education Amendments of 1972, secured passage of legislation increasing opportunities for females in vocational education, and influenced other laws and policies.
- Designed and commissioned the landmark 1992 study, *How Schools Shortchange Girls*, while I was Director of the AAUW Education Foundation.
- Conceived and drafted a 1986 federal amendment that enabled women to receive federal student financial assistance without losing eligibility for AFDC ("welfare") or Medicaid (health care) – a provision that enabled thousands of low-income women to get a higher education before this law was repealed by TANF.
- Helped to develop, testified on, and lobbied for passage of the Science and Technology Equal Opportunities Act, which became law in 1980, while national President of the Federation of Organizations for Professional Women.
- Conducted bipartisan Capitol Hill seminars on children and families (including a hands-on hearing that put policymakers in the roles of a low-income family applying for more than 20 different federal, state and local programs) as Director of the DC-based IEL Policy Exchange.

Since I have come to Los Angeles, I have focused primarily on issues affecting children and families and have, for example:

- Negotiated, on behalf of the Los Angeles Children's Planning Council, a partnership between L.A. County and the Census Bureau to get annual data for the eight Countywide Service Planning Areas (SPAs) and 69 sub-SPA areas of 100,000 to 150,000 people.
- Received the 2004 American Academy of Pediatrics' Dale Richmond Award for outstanding contributions in the field of child development.

I currently convene a large a multi-sector collaborative – the Los Angeles County Early Identification and Intervention Group – which has the goal of assuring that all children receive high-quality developmental screenings and needed follow up. This is the most important work I have done for women and children since I was a “founding mother” of Title IX 30 years ago. **Like Title IX, early identification and intervention – done right – can and will transform lives.**

I am writing to urge the Commission to adopt early identification and intervention for children who have developmental delays, disabilities or other problems (from learning, to behavioral, social-emotional and mental health) as a top priority.

Early identification and intervention is as important as it is “invisible” – analogous to the silent epidemic of breast cancer before Betty Ford had the courage to speak up. Women typically shoulder responsibility for caring for a special needs child and pick up the slack when our public and private programs fail.

At least 15% of all kids have special health care needs and more than 11% of school-age kids have problems serious enough to be in special education programs. ***These numbers mean that early identification and intervention touch almost every family.*** Nonetheless, these issues fly below the radar and generate surprisingly little attention from policymakers or the media. This lack of talk leads to a stunning lack of action, even though we know early intervention works, saving both lives and money over the long haul.

Early identification and intervention are very much women’s issues. For example:

- Women, typically the primary caregivers, are on the front line every day if they have a child who has a disability, developmental delay or other problem. It is most often the mother who raises the first red flag, and who must figure out what might be wrong, what kind of help is needed, and how to get that vital help – even as she is also likely to be exhausted from daily parenting challenges that go far beyond those posed by “normal” children.
- Girls with disabilities and delays may be identified much later than their male counterparts, especially if their disability manifests itself in “typically female” ways, such as withdrawal or being overly passive or quiet.
- Maternal depression is related to childhood disability, with children born to depressed Moms more likely to have a developmental delay or other problem, even as a depressed Mom is less able to be an effective advocate for early identification and intervention for her child.
- Many (perhaps most) marriages with a disabled child break up, typically resulting in the mother having more responsibility for her high-need child, even as she has fewer resources, less money, and less day-to-day help. Important women’s issues include not only child support and continuous health insurance coverage, but also burnout and the difficulty of holding a job while also caring for a special needs child.
- The primary parent of a child with a disability or other problem may have trouble holding down a job (much less a job with good benefits), not because she is inherently unreliable or a congenital bad employee, but because her child’s condition imposes extra demands – making her late to work when her child has a morning meltdown, being absent when there is an all-too-frequent crisis in child care or in school, and making her less flexible because she must schedule and then ferry her child to multiple appointments with intervention specialists, therapists, physicians and specialists, and other care providers.
- Children of both sexes with disabilities are more often abused than their non-disabled counterparts. In fact, children with disabilities are at least four times more likely to be in the child welfare system than a child living with one or both parents.
- Finally, the attached information shows how early identification and intervention can reduce health disparities.

There are high-quality, cheap, short developmental screening tools that respect and draw on what parents/mothers know to identify whether or not a child might have a disability, delay or other problem. **Two of the best developmental screening tools are PEDS (Parent’s Evaluation of Developmental Status) and the Ages and Stages Questionnaires (ASQ).** Yet most pediatricians do not use any tool regularly, much less a high-quality one.

Attached is an article that I wrote with Lou Vismara, MD (a consultant to the California Legislature, working with Senator Perata) that describes many of these issues in more depth.

Below are eight recommendations for consideration by the Commission:

1. Adopt early identification of, and intervention for, children with developmental delays, disabilities and other problems as a top priority of the California Commission for Women. *(Administrative)*
2. Partner with First 5 CA, the new Blue Ribbon Commission on Autism, the LA County Early Identification and Intervention Group (and perhaps the Ad Council, relevant state and county agencies, and local First 5 Commissions as well) to launch a massive public information campaign for parents and families to do developmental screening (either in their pediatrician's office or in another setting). This campaign should also help parents follow up with their physician or Regional Center when screening indicates a likely problem. (Tools like PEDS and ASQ identify 70-80% of the kids **with** problems and rule out 70-80% of kids **without** problems. This is twice as good as a physician's clinical assessment.) An important part of this public information campaign would be to support parents (in practice, mostly mothers) and families by, for example, advocating the use of high-quality screening tools (such as PEDS and ASQ) that rely on parental observations to spot possible problems. *(Administrative, Budget)*
3. Identify all current federal, state and local programs that are (or could) fund early identification (developmental screening) in California. Find out if these programs are using high-quality tools (not just eyeballing kids or using a home-made checklist), and if children with problems actually receive needed early intervention (Early Start or Part C of IDEA, which provides services for kids age 0-36 months, or early special education for kids ages 3-5). Based on this analysis, identify and advocate for policy changes to increase the effectiveness of, and coordination among, these programs. Note that this study must include multiple departments, including Health Services, Education, Mental Health, DCFS and DDS. *(Study)*
4. Look at the gender participation in the various programs that identify and/or serve people (children, adults or both) with disabilities, developmental delays and other problems. Pay special attention to cross-tabulations by race-ethnicity and gender: For example, there may be an identification or service problem for Asian girls/women (but not Asian boys/men, or not white girls/women, or not Latino boys/men). Identify disparities that may be due to bias and that do not reflect the real incidence of the condition. Recommend improvements in outreach and services to fix these disparities. *(Study, Administrative)*
5. Assure that early developmental screening with a high-quality instrument (not just for the kids in Pre-K programs but also for their younger and older siblings up to age 8) is a required part of all Pre-K programs. Also structure this requirement so that effective intervention quickly follows identification of problems. *(Legislative, Administrative, Budget)*
6. Work with the Department of Health Services to revamp the contracts with health care providers and intermediaries to assure that high-quality developmental screenings are done on all children, that there are quick and appropriate referrals when needed, and that physicians and plans are rewarded for making these improvements. These contracts include both Med-Cal/Medicaid and the CHIP program. *(Administrative, Budget)*
7. Increase state support for the federally required Early Start program (Part C, IDEA and Pre-School Special Education for kids ages 3-5) by disproportionately infusing **new money** into these programs. Even though the federal per-child amount received for school-age children in special education programs is more than double that for younger children (0-3 and 3-5), I do **not** recommend reducing funding for school-age children with disabilities to fund intervention for children not yet in school: Rather, channel the lion's share of **new funding** to these youngest children who need help. *(Budget)*
8. Actively support effective implementation of the provisions in the federal Child Abuse Prevention and Treatment Act (CAPTA) and IDEA that require a process for referring kids age 0-36 months in the child welfare system to early intervention.

If it would be helpful to you, I would be glad to provide additional information and involve the other wonderful people in LA County who are working on these issues, perhaps facilitating a conversation with the Los Angeles County Early Identification and Intervention Group, which I convene.

Thank you. I very much appreciate this opportunity to offer testimony to the California Commission on Women. I hope we can work together to improve early identification and intervention for California children.