

Parents as Partners in Autism Research

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AMERICA'S CHILDREN - SPECIAL EDITION: "WE'RE IN A NATIONAL STATE OF EMERGENCY"

COURIER NEWS

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CRISIS IN AMERICA: Thousands of Children Reported Missing

THOUSANDS SIMPLY VANISHED

*WORST NATIONAL CRISIS
ON RECORD*

*PARENTS LOOKING TO GOVERNMENT
FOR IMMEDIATE ANSWERS*

Parents throughout the country awoke this morning to find that their children had vanished overnight! 911 operators report hundreds of thousands of calls received from parents nationwide. The National Guard has been called in to initiate around the clock search efforts.. The American Red Cross mobilized ...

Why Parents as Partners?

- n Contribute unique community experiences, adds passion and urgency to the discussion
- n Ensures that the human dimensions of disease are incorporated into scientific considerations, program policy, investment strategy and research focus
- n Provide a critical and informed panel of consumers who have the capacity to integrate multiple disciplines and perspectives

Opportunities and Models for Partnership

- n Autism Advisory Boards
- n Integration Panels
- n Autism Research Inventories
- n Community Based Research

Autism Advisory Boards

- n Recommended in the Combating Autism Act as an essential mechanism to emphasize the human side of autism research and ensure Federal resources are used wisely
- n Serve to review, critique, inform and direct autism research initiatives at the National Institutes

Integration Panels

- n Recommended by the Institute of Medicine in 1993 to the Department of Defense
- n Establishes consumer participation in research strategy and funding by active participation on scientific and programmatic peer review panels
- n Utilized by Congressionally Directed Medical Research Programs (CDMRP) and the newly established Autism Spectrum Disorder Research Program (ASDRP)

Autism Research Inventories

- n Both public and private autism research initiatives make significant contributions
- n Coordination is essential to identify overlaps and under funded areas of investigation
- n Develop mechanisms for collaborations in an effort to share resources and accelerate the translation of scientific findings into clinical interventions

Community Based Research Initiatives

- n The Autism community is flush with research opportunities
- n The Autism Research Institute has reports of over 1,000 children recovering from autism using biomedical interventions
- n Clinical data mining offers the potential to identify clues to etiology, heterogeneity and effective treatments

Summary of New Directions

- n Acknowledge Autism as a National emergency
- n Shift research focus from genetics to environment and bed to bench
- n Embrace stakeholders as equal partners in research
- n Devise new ways to partner, share ideas and work together in a collaborative effort in the areas of policy, science and research

Closing Thoughts

- n “Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed it’s the only thing that ever has.” *Margaret Mead*