DOCUMENT RESUME

ED 419 313 EC 306 397

TITLE	Abuse and Neglect of Children with Disabilities: Report and Recommendations [of the] National Symposium on Abuse and Neglect of Children with Disabilities (November 1994).
INSTITUTION	Kansas Univ., Lawrence. Beach Center on Families and Disability.; Erikson Inst. for Advanced Study in Child Development, Chicago, IL.
SPONS AGENCY	National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE	1995-00-00
NOTE	37p.
AVAILABLE FROM	National Clearinghouse on Child Abuse and Neglect Information, P.O. Box 1182, Washington, DC 20013-1182; toll-free telephone: 800-FYI-3366.
PUB TYPE	Opinion Papers (120) -- Reports - Descriptive (141)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	Change Strategies; *Child Abuse; *Child Neglect; Children; Cooperative Programs; *Disabilities; Family Problems; Guidelines; Integrated Services; *Intervention; Needs Assessment; Prevention; *Public Policy; Public Support

ABSTRACT

This report presents recommendations and outcomes of a November 1994 invitational symposium on abuse and neglect of children with disabilities. Individual sections provide a summary of the recommendations resulting from the symposium, the symposium's purposes, a list of participants and cosponsors, the meeting's charges and concerns, definitions, a statement of the extent and nature of the problem, and a listing of work groups. The 17 recommendations are organized into seven issues: (1) awareness (promote awareness within and by existing organizations and service systems); (2) prevention (provide universal prevention efforts through public health initiatives); (3) collaboration (collaborate across all professions to increase service effectiveness); (4) training (train professionals on the multiple issues regarding children with disabilities who have been abused and neglected); (5) families (increase the capacity of families to withstand stressors contributing to the abuse and neglect of children); (6) children (listen to and respect the informed preferences and priorities of children); and (7) policy (adopt a uniform child protection statute). (DB)

Abuse and Neglect of Children With Disabilities

Report and Recommendations

The National Symposium on Abuse and Neglect of Children With Disabilities—November 1994

About the Beach Center on Families and Disability

The Beach Center on Families and Disability is funded by the University of Kansas and the National Institute on Disability and Rehabilitation Research to serve as a Rehabilitation Research and Training Center. Beach Center research, training, and dissemination connect with the theme of family empowerment. Each research project supports and strengthens the motivation, resources, and skills that families who have children with special needs already have and helps communities respond better to these families.

About the Erikson Institute for Advanced Study in Child Development

The Erikson Institute for Advanced Study in Child Development is a graduate school and research center affiliated with Loyola University of Chicago. Founded in 1966, the Erikson Institute offers three academic programs: Master's and Doctoral programs in Child Development and an Infant Studies Program. As part of its commitment to expanding the number of professionals committed to working with minority children in inner-city communities, the Erikson Institute created the Bridge to Professional Leadership program, an intensive, non-degree, professional development program to assist individuals in making the transition from community human service settings to leadership positions or academic environments.

Design by Lois Weldon and Cindy Higgins. Poetry by Kirby Cobb, a Kansas City artist and incest survivor. Cobb, now a film documentary producer, recently produced *Shatterboy*, a film about abuse recovery.

Recommended citation

National Symposium on Abuse and Neglect of Children with Disabilities. (1995). *Abuse and Neglect of Children with Disabilities: Report and Recommendations*. Lawrence, KS: The Beach Center on Families and Disability, the University of Kansas, and the Erikson Institute of Chicago.

For additional copies of this report, contact:

The National Clearinghouse on Child Abuse
and Neglect Information
P.O. Box 1182
Washington, DC 20013–1182
1–800–FYI–3366

"In a free society, where wrong exists, some are guilty; all are responsible."—Anonymous

"Those in darkness sin, but those who cause the darkness are the worst sinners of all."—Victor Hugo, *Les Miserables*

Whisper Scream

The thought of a scream
crossed my lips
that came out as a whisper,
help me.

Kirby Cobb, 1995

Contents

Summary of Recommendations

1. Promote awareness within and by existing organizations and service systems.
2. Support awareness from Federal, State, and local levels through existing programs across disciplines.
3. Increase all efforts to prevent and reduce abuse and neglect incidence.
4. Use an ecological approach to understanding, preventing, and reducing maltreatment.
5. Provide universal abuse and neglect prevention efforts through public health initiatives.
6. Collaborate across all professions to increase effectiveness of services for children and families.
7. Base all prevention and intervention programs on best practices, including ongoing evaluation.
8. Train professionals on the multiple issues regarding children with disabilities who have been abused and neglected.
9. Train professionals in strategies to reduce redundancies and ineffectiveness of nonintegrated agency intervention.
10. Train for cultural competence in prevention and intervention.
11. Increase the capacity of families to withstand stressors that contribute to the abuse and neglect of children.
12. Promote inclusion.
13. Listen to and respect children's informed preferences and priorities.
14. Adopt a uniform child protection statute.
15. Enforce the Americans with Disabilities Act and existing laws relating to abuse, neglect, and disability.
16. Reauthorize laws concerning families, children, and disability.
17. Refine laws.

Purposes

Early in November 1994, the National Symposium on Abuse and Neglect of Children With Disabilities was held for three purposes:

- to raise the consciousness of the public and of diverse professional communities about abuse, neglect, and maltreatment of children with disabilities
- to develop consensus recommendations on how to prevent or reduce maltreatment and how to intervene effectively when maltreatment exists
- to suggest an action plan for Congress, Federal executive agencies, professionals, State and local legislatures and executive agencies, private associations, individuals with disabilities, and family members

Participants

Seventy-seven experts, chosen for their knowledge and the difference their work had already made, assembled at the National Symposium on Abuse and Neglect of Children With Disabilities. They were:

Individuals with disabilities, including some who had experienced maltreatment

Relatives of individuals with disabilities

Community-based providers

Child protective service workers

Educators

Physicians

Mental health providers

Other health care providers

Law enforcement officials

Lawyers

Federal and State policy makers

Researchers

Cosponsors

The cosponsors collaborated to plan, fund, and implement this National Symposium. They were:

- **Institutions of higher education**

  Beach Center on Families and Disability,
  The University of Kansas

  Erikson Institute for Advanced Study in Child Development

- **Federal agencies**

  Office of Special Education and Rehabilitative Services,
  National Institute on Disability and Rehabilitation Research

  National Center on Child Abuse and Neglect

  Bureau of Maternal and Child Health,
  Department of Health and Human Services

  Administration on Developmental Disabilities,
  Department of Health and Human Services

- **Private entities**

  American Bar Association, Commission on Mental
  and Physical Disability Law

  American Academy of Pediatrics

Charges and Concerns

The very fact that so many Federal agencies and private groups sponsored the Symposium gives special credibility to the concerns and recommendations they and all the participants made.

Prologue to Zero Tolerance

Beach Center on Families and Disability, The University of Kansas, Rud Turnbull, Co-Director: "It's a mistake to blame people in the systems, but it is not a mistake to look hard at the systems within which we operate and to say, "It's not good enough, it's too late, too little of one thing, too much of another." We have to commit ourselves to a zero tolerance policy regarding maltreatment of children. Until that sense of rage rises up in us, we will continue to say, We're doing all right." I think we're not doing all right. Less able is not less worthy."

Providing A Framework

Administration on Developmental Disabilities, Bob Williams, Commissioner: "Your work in the next few days is to provide us in the Federal Government a strategic framework for addressing the interrelated challenges of maltreatment at the Federal, State, and local levels."

Bureau of Maternal and Child Health, Merle McPherson, Director, and Bonnie Strickland, Project Officer. Dr. McPherson: "Our charge here today is to not create a separate system for children with disabilities but to bring the concerns for these children into the context of what we need to do for all children. You need to concern yourselves about the way in which all services are linked together in a system of care that really supports children and families in ways they are not being supported today."

American Academy of Pediatrics, Lavdena Orr, M. D., and Michelle Zajac Esquivel, Project Manager. Esquivel: "The role of the pediatrician in the future will be more prevention-focused. With managed care, this will be dictated early on in terms of prevention and intervening early. In addition, the pediatrician will assist in developing respite services for the family so they occasionally can be relieved of some of the caretaking responsibilities, or providing help for parents and other members of the family in addition to providing help to the child with a disability."

American Bar Association, Commission on Mental and Physical Disability Law, John Parry, Director, and **Center on Children and the Law**, Howard Davidson, Director. Davidson: "Congress is presently considering the reauthorization of the Child Abuse Prevention and Treatment Act (CAPTA). Thus, attendees may need to review CAPTA's research, technical assistance, and State grant programs to see whether it makes sense for this law to more specifically address children with disabilities."

Vulnerability and Protection

Office of Special Education and Rehabilitative Services, Judy Heumann, Assistant Secretary: "When I started traveling around the country, meeting parents and hearing from them, parent after parent would talk about situations in relationship to attempting to get their child appropriate services. I just sat there saying, "'This really sounds to me like a child abuse issue. Who's taking responsibility over this?" and then learning that the system is not very functional."

National Institute on Disability and Rehabilitation Research, Kate Seelman, Director: "Children are the least able among us to protect and defend themselves against the rage of frustrated adults. We must find better ways to care for and protect our children with disabilities and their care givers. No single service system can solve all the problems that families today are experiencing. I think our successes increase as we gather together to talk about it as we are today."

Simultaneous Rage and Compassion

The Erikson Institute, Linda Gilkerson, Director of Infant Studies: "I was struck during this Symposium by the different conceptual models, the disability model of family strength and the child protection model of family risk and by the need not to polarize but to think more wholistically about the tension. There's something about the human condition that this polarization asks us to face. It asks us to face that there's love and hate, and that there's rage and compassion, in us and in the world. The ability to come to grips with negative emotions within and without, to come to grips with the dark side and truly see humanity and be there to help humanity where it is needed is a tremendous task."

Further Commitment

National Center on Child Abuse and Neglect, David Lloyd, Director, and Nainan Thomas, Project Officer. Dr. Thomas: "NCCAN is committed to seeing that the publication of the Symposium report and recommendations is widely distributed and to seeing that there is a post-Symposium work group to influence the Federal, State, and private agencies to do something about this report."

Perspectives on the Problem

To describe some of the manifold perspectives about abuse and neglect of children with disabilities, the Symposium began with three keynote presentations.

A college student who has cerebral palsy spoke candidly about her experiences with abuse and neglect.

> [People with disabilities are in a double bind:] I knew I needed this person (care giver) to get me up out of bed and keep me alive and do my breathing treatments. This person became my lifeline but was also my abuser.
>
> [People with disabilities have their own valued cultures and identities...I think it's ironic that we have this perception of dependence when dealing with people with disabilities. We are all interdependent. I am part of a very necessary growing culture of people with disabilities. We value ourselves, we don't want to be able-bodied, we want to be respected. To do that you have to realize that disability is not the problem, it's the reception to disability that becomes the problem.

Jim Garbarino, Director of Cornell's Family Life Development Center, researcher, and former President of The Erikson Institute, observed that maltreatment is a social problem.

> It is the accumulation of risk factors that really tells the story and does the damage. There are more and more ways in which the environment for children on average is more socially toxic. This social toxicity has to do with aggression, nastiness, violence, and desensitization through the media. All of that is at work. Vulnerable children, unless we have special intervention, will particularly suffer for it.

Bob Ammerman, Supervisor of Research and Clinical Psychology at Western Pennsylvania School for the Blind, commented about maltreatment causes and interventions in children with disabilities.

> In the past 25 years there have been three proposed pathways for increased risk in children associated with disability. They emerged early. They remain today. But only now are we really undertaking any systematic evaluation of them. The first pathway is stress due to either care giving or difficult-to-manage behavior problems. The second is disruptions in attachments between the child and the care givers. And the third is the child's increased vulnerability because of his or her disability.

Definitions

Disability refers to a physical or mental impairment that significantly limits an individual in one or more of life's major activities. Consistent with the Americans with Disabilities Act, a person has a disability if the person has such an impairment, has a history of such an impairment, or is regarded as having such an impairment.

Abuse and neglect consist of physical or mental injury, sexual abuse or exploitation, negligent treatment, or maltreatment by a person responsible for the child's welfare in circumstances in which the child's health or welfare is harmed or threatened. This is the definition that the Child Abuse Prevention and Treatment Act (CAPTA) uses.

John Parry, Director of the American Bar Association's Commission on Mental and Physical Disability Law, offered a broader definition of abuse and neglect.

> This is a limiting definition that supports a relatively rigid and harsh model of intervention based on the view that abuse and neglect is a public health concern with a criminal dimension. . . . (But) this model leads to serious conceptual problems when society tries to superimpose the disability rights model on top of it.
>
> A broader legal view of what constitutes abuse and neglect is needed that addresses persons with disabilities and the particular types of mistreatment and maltreatment common to them. Such a

> definition would include not only the more traditional aspects of abuse and neglect but also those situations in which people with disabilities are left unattended or disregarded out of ignorance, fear, hatred, lack of resources, or institutional neglect.
>
> Abuse and neglect of children with disabilities should encompass mistreatment, maltreatment, omissions, and negligence that cause substantial harm. . . including civil commitment, imprisonment, absence of care and treatment, inhumane care, forced treatment, absence of accommodations, sterilization and abortion, experimental procedures, inappropriate education, dilution of self-determination, lack of community alternatives, absence of benefits, inappropriate cessation of life support or withdrawal of care, breaches of confidentiality or privacy, victimization, negligence, inappropriate custodial care, and lack of intervention on behalf of infants and children exposed to the HIV virus.

Extent and Nature of the Problem

What is the extent and nature of abuse, neglect, and maltreatment of children with disabilities? Can maltreatment cause disability? Does a child's disability increase the risk of maltreatment? The short answer to each question is "Yes."

Children who have disabilities are at greater risk for abuse and neglect by their care givers (both families and professionals). NCCAN reports that children with disabilities experience abuse and neglect at a rate of 1.7 times higher than the rate for children without disabilities. And, yes, there has been an increase in the number of reports of abuse and neglect of children as a whole, both those with and without disabilities, over the past decade. This much, everyone agrees. But "Yes" doesn't tell the whole story.

Bob Ammerman cautioned that the NCCAN data only show that children with disabilities are overrepresented in child protective service agencies. He said that there is no evidence yet that an "average" child with a disability who lives in an "average" community is more likely to be maltreated than any other child. "We know very little about the epidemiology of incidence and prevalence; indeed, the prevalence rates vary from 3 percent to 70 percent, so we still don't know exactly what it is we're looking at."

> We don't know what unique risk might be associated with disability. Many of us feel that there is some risk, but we really have not demonstrated that in any scientific or empirical way. We don't know the specific pathways to maltreatment. Mapping out these unique pathways is something we need to work on. We also don't know about the longitudinal course of maltreatment. We see so many of these families after the fact, after they're part of child protective service systems. We don't know when the seeds are sown for the child to be at risk and which children eventually are abused and neglected. And, finally, we don't know about the effects of maltreatment on children with disabilities.

Ammerman said to look at disability not only in the child but in the parents: "We need to acknowledge that disability occurs across the family and when we provide interventions we have to look at parental disability as well."

Jim Garbarino agreed, saying that when thinking about whether or not disability causes child abuse, "It depends." Indeed, in matters of human development, "When the question is, 'Does X cause Y?' the answer is, 'It depends.'" He elaborated:

> General principles, general relationships, and general causal statements are always conditioned by that particular mix within an individual of a unique constellation of factors, variables, and characteristics. The centrality of the context is so important.
>
> Of course, community and family are two of the most important contexts. Children with early head trauma set within abusive families often learn and ultimately demonstrate that aggression. When you look at the level of

victimization in both these fields (abuse and disability), you find tremendous coprevalence.

Process and Recommendations

Participants divided into five work groups to consider what is and is not working to prevent and reduce maltreatment and to note effective interventions and policies.

- Recommend what should be done to prevent or reduce the amount of maltreatment and to effectively intervene once maltreatment has been observed.

Appendix A lists work groups and their members.

A spokesperson for each work group reported at the close of the Symposium. Other participants had opportunities to comment on the work group report.

The work groups identified seven main issues:

- Awareness
- Prevention
- Collaboration
- Training
- Families
- Children
- Policy

and made recommendations related to each. Set out on the following pages are the work groups' recommendations.

ONE

. . . .

Promote awareness within and by existing organizations and service systems.

Awareness. Unless we all become aware of the maltreatment of children with disabilities, we will not be able to understand and confront this urgent issue. We need widespread knowledge of the multiple causes and damaging effects of abuse and neglect to develop appropriate steps for preventing and reducing this problem.

Media coverage to date has typically sought to sensationalize the beatings, sexual molestation, starvation, and other maltreatment of children. Sensationalized accounts mask the scope and nature of the problem.

One task we face is to raise the awareness of every person at every level of our society. Another task is to focus that awareness so that appropriate actions are taken to prevent or reduce the maltreatment of all children, whether with or without disabilities.

Accordingly, we recommend:

Of all Federal funds used to support public and professional awareness of child abuse (whether in block grants or allocations to and through Federal agencies), a minimum of 10 percent should be devoted to disability issues.

> Another area is providing incentives to the corporate and public relations community to help sponsor child abuse and disability awareness. (Combined Group)

- Media should be involved in the advocacy issues surrounding families and their children with disabilities who have experienced abuse and neglect.

> I think the media is pretty guilty of fostering a lot of paternalistic attitudes toward persons with disabilities and denying issues like sexuality, whether it's overt or covert or implicit. So we have to educate them about the realities of being a person with a disability and the vulnerabilities of children. (Child Protective Services Group)

TWO

Support awareness from the Federal, State, and local level through existing programs across disciplines.

- Link child abuse and neglect programs to disability programs and train existing child abuse and neglect staff about disability issues.

> Maintain the community system as a focal point. Keep in mind that the strengths and uniqueness of communities themselves will guide and define the development of successful programs. (Merle McPherson)
>
> We need to deal with the tremendous invisibility of disability issues within abuse and neglect topics. (Policy Group)
>
> Set up communication exchanges through conferences, newsletters, journal articles, research, publications, etc. (Community Service Providers Group)

- Make Federal funding available for multidisciplinary training and supervision so that professionals will be acutely conscious about the maltreatment of children with disabilities.

> Funding should be given to target awareness of the need of services for professionals and individuals in existing programs. And I think if the funding isn't set up in a way that it encourages that collaboration, the result is probably going to be more separation instead of greater inclusion. (Community Service Providers Group)

- Develop and support a rehabilitation research and training center.

> We need funding for model treatment demonstration programs with a means of communicating successful efforts to community-based organizations. (Community Service Providers Group)

THREE

Increase significantly all efforts to prevent and reduce the incidence of abuse and neglect.

Prevention. We need to move beyond intervention efforts—beyond a reactive posture—into a more preventive, proactive approach as we address the needs of children who have disabilities and approach who might be or already have been abused and neglected. Prevention of child abuse and neglect includes a reduction in the risk for abuse and neglect.

To date, most of our resources have been focused on intervention efforts to decrease the chances that abuse and neglect of children will be repeated. Programs and resources are generally made available to children and families and other care givers after abuse or neglect has occurred.

We want to increase prevention efforts for all children. In doing so, we will increase efforts that will reduce the risk for children who have a disability. In addition, our prevention efforts must specifically focus on the unique characteristics of the lives and environments of children with a disability.

Accordingly, we recommend:

- Adopt prevention measures: home visitors, family support, prenatal and postnatal support for parents, and Parent-to-Parent programs.

> ...we always include child abuse in any prevention program. (Policy Group)
>
> Require Federal agencies that deal with substance abuse and chemical addiction to collaborate with agencies that fund programs for children with disabilities who have been abused. (Combined Group)
>
> . . .link domestic violence to child abuse. (Policy Group)
>
> I have some new thoughts about using the word prevention. . .talk about risk reduction instead, because I think it keeps us ever wary that there is a risk, that perpetrators who want to perpetrate are going to do it regardless of whatever protections we put up there. (Nora Baladerian)

> ...find some accountability through evaluating and reviewing the near misses—the children who lived—and really start to take this seriously. We can do this by coat-tailing on the child death review teams that are now existent in 39 States. (Nora Baladerian)

> We had a very, very potent and eloquent spokesperson for the Parent-to-Parent movement in our group, who talked a lot about the importance of that sort of connection, where parents can call up, talk to another parent. She mentioned that there were many times when she had folks on the other end of the phone who basically said, 'I'm so overwhelmed, I don't know what to do. I'm afraid I'm going to abuse my child.' And even though the Parent-to-Parent Program isn't an extensively child abuse and neglect program, it certainly functions in that regard. (Combined Group)

FOUR

Use an ecological approach to understanding, preventing, and reducing maltreatment

Researchers Garbarino and Ammerman made a single, straightforward recommendation: Use the ecological model.

This model links maltreatment to several interrelated variables: the child, the family, the community, and social and policy contexts. This is the same point that John Parry made when he urged a broader legal perspective on abuse and neglect. Without understanding and then evaluating interventions based on our knowledge of the ecology of maltreatment, we will take less than effective steps toward prevention.

FIVE

Provide universal prevention efforts through public health initiatives.

- Recognize public health implications and intervene as though abuse and neglect were health issues, without abridging individual due process rights.

> I think we really need to work on the issue of abuse and disabilities being a public health issue and get it in with managed care and primary care issues. We have to hammer it home as a basic public health care issue. (Patricia Sullivan)

SIX

Collaborate across all professions to increase service effectiveness.

Collaboration. We see the problem of serving children who have been abused or neglected and who have disabilities as a "shared" problem in two respects. First, many different disciplines are involved in prevention, reduction, intervention, and policy-making related to abuse and neglect of children. Second, children with disabilities typically are served by more than one discipline.

We recognize that collaboration among individuals and agencies increases the effectiveness of programs and reduces the expenditure of resources for redundant services. Collaboration among all professionals and families and other care givers ensures that there is a sharing of the relevant expertise related to the abuse and neglect of children who have disabilities.

Accordingly, we recommend:

- Share information across service systems so that families at risk for abusing and neglecting of children with disabilities can be identified and appropriately served.

> We want to facilitate communication among concerned professionals. We want to look for ways of cross-pollinating and creating opportunities for inviting people to contribute across those typical disciplinary boundaries, to facilitate communication among concerned professionals, to set up communication exchanges through conferences, newsletters, journal articles, research, publications, etc. (Community Service Providers Group)
>
> The issue was brought up that persons with disabilities who are battered have no place to go that has special facilities, special access if you use a wheelchair, if you cannot communicate in a traditional way. Legal advocacy, media, education ...should be knowledgeable about the resources in the community. Natural support also is necessary. (Community Service Providers Group)
>
> Collaboration is emphasized at the State level between developmental disability planning councils, State protection agencies and advocacy agencies, and education agencies. (Combined Group)

- Create interdisciplinary teams to serve families at risk and include experts on disabilities and child abuse as team members.

> There's no one professional group that has all the wisdom associated with this problem. (Combined Group)
>
> We felt a multisystems approach was important: You don't just treat the child, you don't just treat the family, you don't just think of the child and the family with relationship to one organization, but instead to the total community. (Combined Group)
>
> A disability liaison position should be created in each child abuse agency to provide case-by-case consultation to front-line child abuse staff regarding disability. (Combined Group)

- Recognize and try to reconcile the creative tension between different models and missions.

> People in the child welfare business look at families in a much different way than people in the developmental disabilities and the mental health fields look at them. In DD and MH, we look at families as being strong and able to be supported. In child welfare, families are looked at in a very much more pathological way. But the tension between the child abuse model and the disability empowerment model is a creative tension that provides more protection in services for the child, rather than less. We don't believe we can take one model over the other. But we need to find a way to integrate the two models so that we have the best of both, the protection-of-the-child model and the empowerment-of-the-disability model. (Policy Group)

- Create demonstration projects that emphasize multisystem collaboration.

> We have the exceptional family member program within all the Armed Forces now and a program called STOMP, Specialized Training of Military Parents, because we have unique needs

> that the outside communities don't have. (Gene Bastian)

SEVEN

Base all prevention and intervention programs on best practices, including ongoing evaluation.

- Evaluate programs' effectiveness and disseminate their results.

> If we're going to have demonstration programs, it's essential that there's a good evaluation component so not only does it provide a service to people, but also it's going to help guide what happens in the future. (Community Service Providers Group)

> ...what we need to do is not view research as something separate, but as an integral part of everything that we do. (Bob Ammerman)

> We need funding for model treatment demonstration programs with a means of communicating successful efforts to community-based organizations...We see programs that appear to be really good and have a lot of potential that exist for 3 years and disappear and nobody follows up. (Community Service Providers Group)

EIGHT

Train professionals on the multiple issues regarding children with disabilities who have been abused and neglected.

Training. We see cross-discipline training as a key effort to provide effective prevention and intervention efforts for children who have disabilities and have been abused or neglected. Yet, few of us have the training necessary to address the multiple issues in the abuse or neglect of children who have disabilities. The training usually provided is discipline specific and contributes to the continuation of fragmented and uncoordinated services for these children and for their families.

We have encountered many dedicated professionals whose training has been focused specifically on the issues of abuse and neglect or on those related to disability. This fact impedes our awareness, prevention, reduction, and intervention efforts. The increasing cultural diversity of our country adds to the complexity of these issues. We who are knowledgeable about these issues have gained that knowledge through our own efforts and experience.

We recommend training that brings professionals together from all relevant disciplines to create cross-disciplinary approaches to intervention and prevention.

NINE

Train professionals in strategies to reduce redundancies and ineffectiveness of nonintegrated agency intervention.

Accordingly, we recommend:

- Training should focus on issues surrounding disabilities and abuse and neglect, including identification of children who have disabilities and have been abused or neglected; appropriate prevention and intervention for these children and for their families; and the relationship between the abuse or neglect of children and other forms of family violence.

- Disability training should be included as part of broader diversity training in many different settings, and disability, abuse and neglect training should be incorporated into existing programs rather than offered separately.

> To put disabilities generally and disability and abuse issues into the Court Appointed Special Advocate (CASA) and Guardian Ad Litem (GAL) training manuals would be a very concrete recommendation, since they just got new funding. (Bev Jackson)
>
> We need to have better protocols for interviewing individuals who are abused and neglected, especially persons who have communication disorders and who have difficulty expressing themselves and who have difficulty identifying what has happened to them. (Community Service Providers Group)
>
> Standards have to exist for those people who are doing outreach to homes, but also standards for community-based group home living and monitoring. (Policy Group)
>
> Professionals trained in abuse don't know about disabilities. They may not have access to training. They may not know what those discrete or overt or obvious signs are, and they may not know where persons with disabilities who are abused can go to for help. Training school is really important. (Combined Group)
>
> We should give emphasis to the type of training the national judicial college has done through no less than three State Justice Institute grants in the last 3

years. This training has been accessible to the courts,

ADA, and victims, witnesses, and defendants with mental retardation; and these training activities are excellent examples of getting at high-level policy makers in a model that is set up to replicate these curriculums. (Forensic Group)

We talk about staff turnover; we have to look at it as how do we keep the good people and not just how do we provide incentives for everybody to stay. We have to provide incentives for good people to stay. (Community Service Providers Group)

A problem is that the fatality review board, for example, says they wouldn't know whether a child who had died had a disability or not unless there were very obvious physical anomalies in the child. (Policy Group)

- Multidisciplinary coordination and collaboration.

We must have multidisciplinary training and supervision on an ongoing basis to the various professional groups that are involved—legal, medical, CPS, special education, early intervention. (Combined Group)

TEN

Train for cultural competence in prevention and intervention efforts.

- Cultural competence in both identification of abuse or neglect and intervention.

Professionals should be culturally and ethnically sensitive. (Community Service Providers Group)

ELEVEN

Increase the capacity of families to withstand stressors contributing to the abuse and neglect of children.

Families. We recommend that professionals work with families to increase their capacities to withstand the forces contributing to abuse and neglect of children. Rather than regarding families as blame-worthy, we want to recognize and build the strengths of those families. We further recognize that the behavior of families is often a function of the characteristics of the community and support they are able to access.

We also know that there are times when this presumption must be overcome and the child must be removed either temporarily or permanently. It is sometimes difficult but necessary to distinguish those families who can be supported and deterred from abuse and neglect from those who cannot. Should the presumption apply to the latter, what criteria help distinguish the former from the latter, and is it appropriate to make these distinctions? These questions beg careful research and policy consideration. When removal occurs, there is, in a very real sense, a failure—not necessarily a failure of the family but rather a failure of society to build the family's capacity not to abuse or neglect the child.

We assert that three considerations—family behavior, family freedom, and family intactness—justify a special effort to build families' capacities to care for but not maltreat their children.

Accordingly, we recommend:

- Emphasize family support priorities.

> We have to be more supportive of families—family-centered, community-centered, advocacy-minded. This means we have to provide an array of services prenatally. (Combined Group)

- Ensure continuity of care.

> There is great difficulty in finding out-of-home care for children with disabilities. It's bad enough when you have to take a child without a disability out of the natural family into foster care or other kinds of arrangements. But when you take a child with a disability out of a family you really may cause some serious damage. Continuity for many of these children is enormously important, and the experience of being in three or four foster homes for a child with mental retardation or other kind of disability may be very difficult. (Combined Group)

- Foster informal supports.

> Parent-to-Parent training is very important so we can link up parents of children with disabilities immediately, get some sort of

> mentorship system started, and help parents have an understanding of the expectations and the stresses involved. (Child Protective Services Group)

- Provide information about and referral to services.

> A lot of the solutions to these problems need to be on a person-to-person level and on a community level, and a lot of the big agency approaches don't really support that. They take the place of that and sometimes you sort of win the battle and lose the war. (Community Service Providers Group)

- Offer service brokerage.

> As we move into more managed care kinds of situations, we may end up balkanizing or decentralizing a lot of services into discrete little places, and we may be back to making families be their own case managers in order to access those services. (Combined Group)

- Educate for parenting.

> I think parenting classes in junior high and high school are not too early to look at issues around parenting and appropriate parenting, reasons for having a child, and issues for young parents who are at greater risk for having children with disabilities and for producing disabilities and harm. (Child Protective Services Group)

- Advocate for families and children.

> One of the main reasons I'm here as an attorney with the Michigan Protection and Advocacy Services is because of the withholding of medically appropriate treatment for seriously ill children. There's this huge current coming now of health care rationing

> that asserts that we don't need to be treating these kinds of people. But if we don't, their quality of life is horrible. (Lisa Gigliotti)

- Increase respite services.

> Respite care. There's not enough respite care. (Child Protective Services Group)

- Encourage family-based decision making, especially the participation of fathers.

> ...it's not just a woman's problem. We have to have paternal involvement projects and have to have policy, like family leave policies, that child care should be a division of labor. (Policy Group)

Children. A major issue for children with disabilities is the professional approach that is often disrespectful of their priorities and preferences and can result in the children's powerlessness and vulnerability. We know that these situations increase the opportunities for and the risks of abuse or neglect to children who have disabilities.

We know that the voice of a single child is often not heard in the chorus of surrounding adults. This is particularly true when that child has a disability and may be unable to communicate easily. We must take extreme means to ensure that these children are heard, understood, and heeded.

We recommend that children who have disabilities be provided with the resources they need to take their rightful place in society and that they be recognized as equal and participating citizens in that society.

Accordingly, we recommend:

TWELVE

Promote inclusion.

- Provide children the most appropriate inclusive environment while also recognizing that some families are opposed to the most inclusive settings and services. Still, inclusion is preferable to the alternatives.

> ...the greater the inclusion, the less the risk...
>
> I think at the very basic level we need to think both about specific programs in areas like helping people improve communication skills, sexuality training, etc. We also need to create environments in which people are encouraged to use those skills. I think we still have environments in which people are taught to communicate in the therapy room, but discouraged from communicating in real life, etc. That kind of dichotomy creates a false perception that we're helping people by teaching them to communicate when in fact the real message that they're getting is you only speak when you're spoken to. (Community Service Providers Group)

THIRTEEN

Listen to and respect the informed preferences and priorities of children.

- Provide self-determination and self-advocacy training.

> Educate people with disabilities regarding their rights and their responsibilities under IDEA, ADA, etc. (Forensic Group)
>
> Train children with disabilities in the use of personal assistance services. (Forensic Group)
>
> Developmentally appropriate child safety and assault prevention programs should be integrated into school curricula. (Forensic Group)

Policy. Legislation, such as the Individuals with Disabilities Education Act and the Americans with Disabilities Act, has improved the lives of children with disabilities and their families. However, many provisions or aspects of State and Federal child welfare protection policies and laws need immediate attention. It is imperative that abuse and neglect of children with disabilities be addressed by all persons who implement policies affecting children and families. Thus, policy makers and their constituents should:

FOURTEEN

Adopt a uniform child protection statute.

- Adopt a uniform child protection statute.
- Enforce the Americans with Disabilities Act (ADA).

> We need a better understanding of what ADA accommodations in the courtroom may look like for some of these children. (Forensic Group)

FIFTEEN

Enforce American with Disabilities Act and existing laws relating to abuse, neglect, and disability.

- Enforce existing laws.

> We have to get better compliance with existing Federal and State laws, by agencies involved in investigation and adjudication, wherever abuse and neglect occurs. (Forensic Group)

SIXTEEN

Reauthorize laws concerning families, children, and disability.

- Reauthorize Federal legislation concerning families and children with disabilities, such as the Individuals with Disabilities Education Act, Federal Family Support Program, Child Abuse Prevention and Treatment Act, and Adoption Assistance and Child Welfare Act.

> ...it would be nice to have some specific provisions in this reauthorized legislation that create a mandate that issues of disability and maltreatment are addressed in some more appropriate way. (Community Services Providers Group)
>
> Because of tribal sovereignty, ADA is not typically embraced on all reservations and so what we want to do is encourage tribes to make a decision to pick up some elements or create a similar kind of environment or requirement to ADA. (Ela Yazzie-King)

- Fully fund and staff all programs dealing with children and families.

> When you look longitudinally at what we're spending, it might be a lot better to start looking at putting some of that up front to begin identifying at-risk children at the point of birth and try to focus services to the families to try and help them along, before they get to the point where they are identified as neglectful or abusive parents and we throw them back into this other system. (Symposium Participant)

SEVENTEEN

Refine laws.

- Improve criminal and civil justice systems in their response to children with disabilities who experience maltreatment.

> We need alternative court procedures and alternative dispute resolution procedures for child witnesses who have disabilities. (Forensic Group)
>
> ...the justice system is not particularly child-friendly, not particularly family-friendly and again certainly has not a clear sense of what legal accommodations might be needed. (Forensic Group)

- Create special teams to prosecute cases of abuse and neglect.

> Abuse and neglect of children with disabilities is not adequately investigated or prosecuted. (Forensic Group)
>
> We need better access to law enforcement and CPS records. (Forensic Group)

- Require a child's disability status to be clearly noted in records.

> Records aren't kept by CPS on disability issues. (Child Protective Services Group)

- Enact whistle-blower protection laws, antiretaliation laws, and liability-exemption laws.

> There is fear of recrimination about reporting. I think that even for parents who are aware that their child with a disability's being abused poses a real problem, because if they pull that child out of that system, where do they go? There are fewer options for people with disabilities.
>
> So it's a fear of recrimination that the person who is providing care will not be there. (Child Protective Services Group)
>
> ...CPS workers are afraid of a liability question that if they identify children as having a disability and

> the child really doesn't have a disability, that they can be sued by the parents by having misidentified...their child. (Nora Baladerian)

- Require certification standards and background checks for every person who has professional contact with children, including those with disabilities.

> Monitoring standards have to exist for those people who are doing outreach to family homes and community-based group home living. (Policy Group)

National Symposium Work Groups

Community

Judith Allen, Coordinator Child Protective Services, University of Chicago Hospitals, Chicago, IL; **Herbert Cohen,** Director, Rose Kennedy Center, University Affiliated Program, Bronx, NY; **Kay Conklin,** Missouri Planning Council, Jefferson City, MO; **Michelle Zajac Esquivel,** Project Manager, American Academy of Pediatrics, Division of Child and Adolescent Health, Elk Grove, IL; **Beverly Roberson Jackson,** Director of Public Policy, Zero to Three, Arlington, VA; **Linda Mitchell,** Research Assistant, Beach Center on Families and Disability, University of Kansas, Lawrence, KS; **Christine Pawleski,** Assistant Professor, Brooklyn College, Brooklyn, NY; **Dick Sobsey,** Director, Abuse and Disability Project, University of Alberta, Edmonton, Alberta, Canada; **Raymond Starr, Jr.,** Developmental Psychologist/Author, University of Baltimore, Baltimore, MD; **Susan Vilardo,** Education Specialist, MOCSA, Kansas City, MO; **Ela Yazzie-King,** M.R.S. Coordinator/Advocate, Indian Children's Program, Fort Defiance, AZ.

Child Protective

Robert Ammerman, Supervisor, Research and Clinical Psychology, Denver, Western Pennsylvania School for Blind Children, Sewickley, PA; **Mary Carrasco,** Director, Family Intervention Center, Children's Hospital of Pittsburgh, Pittsburgh, PA; **Christine Coughlin,** Advocate, Tempe, AZ; **Michael Crocker,** Program Director, Lexington Abuse and Disabilities Program, Jackson Heights, NY; **Aggie Floyd,** Project Manager for the National Resource Center on Child Abuse and Neglect, Denver, CO;

Lili Frank Garfinkel, Coordinator of the Juvenile Justice Project, PACER Center, Minneapolis, MN;

Phil Newsom, Bureau Chief for Intake Services, Prince George's County Department of Social Services, Hyattsville, MD;

Kaia Skaggs, Beach Center on Families and Disability, University of Kansas, Lawrence, KS;

Maria Synodi, State Agency Liaison, Birth-to-Three, Connecticut State Department of Children and Families, Middletown, CT;

Nainan Thomas, Ph.D., Federal Project Officer, National Center on Child Abuse and Neglect, Washington, DC;

Vicki Turbiville, Research Project Director, Beach Center on Families and Disability, University of Kansas, Lawrence, KS.

Combined

Nora Baladerian, Co-Founder and Chair, Disability Abuse and Personal Management Project, National Coalition on Abuse and Disability, Los Angeles, CA;

Valerie Bradley, President, Human Services Research Institute, Cambridge, MA;

María Chávez, Director, Children, Youth, and Families Department, Community Planning, Santa Fe, NM;

Edith Freeman, Professor, School of Social Welfare, University of Kansas, Lawrence, KS;

Linda Gilkerson, Director of Infant Studies, Erikson Institute, Chicago, IL;

John Parry, Director American Bar Association, Commission on Mental and Physical Disability Law;

Illiana Hernández, Family Support Coordinator, Parent to Parent-Miami, Miami, FL;

Lavdena Orr, Director, Division of Child Protection, Children's National Medical Center, Washington, DC.

JoAnn Jaco Plucker, Assistant Director, National Resource Center on Child Sexual Abuse, Huntsville, AL;

Roseann Rafferty, Project Officer, National Institute on Disability and Rehabilitation Research, Washington, DC;

Ann Turnbull, Co-Director, Beach Center on Families and Disability, University of Kansas, Lawrence, KS.

Forensics

Sherri Ash, Special Assistant, Administration on Developmental Disabilities;

Amy Buchele-Ash, Research Attorney, Beach Center on Families and Disability, University of Kansas, Lawrence, KS;

Gene Bastian, Parent/Team Advocate for Special Kids, Irvine, CA;

Howard Davidson Director, American Bar Association, Center on Children and the Law;

Gissele Acevedo-Franco, Director of Multi-Cultural Outreach, Protection and Advocacy, Monrovia, CA;

Lisa Gigliotti, Staff Attorney, Michigan Protection and Advocacy Service, Lansing, MI;

Daniel Guiney, Chicago Police Department, Chicago, IL;

Sarah Kaplan, ABA Center on Children and the Law;

Diane Lipton, Director, Family Advocacy Program, Disability Rights Education and Defense Fund, Berkeley, CA;

Holly Riddle, Director, Council on Developmental Disabilities, Department of Human Resources, Raleigh, NC;

Shirley Robinson, Pediatric Psychologist, Civitan International Research Center, Birmingham, AL;

Patricia Sullivan, Director, Center for Abused Children with Disabilities, Boys Town National Research Hospital, Omaha, NE;

Molly Romer Witten, Clinical Psychologist, Michael Reese Hospital, Chicago, IL.

Policy

Barbara Bates, Research Coordinator, National Center on Child Abuse and Neglect, Washington, DC; **Ira Burnim,** Legal Director, Judge David Bazelon Center for Mental Health Law, Washington, DC; **Sharon Davis,** Director, Department of Research and Program Services, ARC, Arlington, TX; **Gary DeCarolis,** Branch Chief, Center for Mental Health Services, Rockville, MD; **Barbara Huff,** Executive Director, Federation of Families for Children's Mental Health, Alexandria, VA; **Ellen Kagen,** Senior Program Specialist, Mental Health Services Program for Youth, Washington, DC; **Barbara Smith,** Executive Director, Council for Exceptional Children, Division for Early Childhood, Pittsburgh, PA; **Denise Kane,** Office of Inspector General, Department of Children and Family Services, Chicago, IL; **Siobahn Sullivan,** Research Analyst, Developmental Disabilities Project, National Conference of State Legislatures, Denver, CO; **H. Rutherford Turnbull, III,** Co-Director, Beach Center on Families and Disability,University of Kansas, Lawrence, KS; **Virginia Williams,** Senior Advisor/Associate Director, Community Planning, Georgetown University-UAP, Washington, DC.

Other Resources

Buchele-Ash, A., & Mitchell, L. (1995). *Child Abuse and Neglect of Children with Disabilities: A Compilation of Legal and Social Readings*. Lawrence, KS: Beach Center on Families and Disability, The University of Kansas.

Buchele-Ash, A., Turnbull, H.R., & Mitchell, L. (1995). Forensic and Law Enforcement Issues in the Abuse and Neglect of Children With Disabilities. *Mental and Physical Disability Law Reporter*, 19(1), 115-121.

Davidson, H. (1994). Legal Issues Related to Abuse and Neglect of Children With Disabilities. *Mental and Physical Disability Law Reporter*, *18*(6), 707.

National Symposium on Abuse and Neglect of Children With Disabilities. (1994). *Advance Literature*. Lawrence, KS: Beach Center on Families and Disability, The University of Kansas, and the Erikson Institute of Chicago.

Parry, J.W. (1994). Executive Summary and Analysis. *Mental and Physical Disability Law Reporter*, *18*(6), 614-621.

Turnbull, H.R., Buchele-Ash, A., & Mitchell, L. (1994). *Abuse and Neglect of Children With Disabilities: A Policy Analysis*. Lawrence, KS: Beach Center on Families and Disability, The University of Kansas.

National Symposium Report Contributors

Joint Planning Committee:
Sherri Ash - Administration on Developmental Disabilities
Michelle Zajac Esquivel - American Academy of Pediatrics
Joan Gaffney - National Center on Child Abuse and Neglect
Linda Gilkerson - Erikson Institute
John Parry - American Bar Association
Roseann Rafferty - National Institute on Disability and Rehabilitation Research
Bonnie Strickland - Bureau of Maternal and Child Health
Nainan Thomas - National Center on Child Abuse and Neglect
H. Rutherford Turnbull, III - Beach Center on Families and Disability

In addition, the following assisted in planning, advance materials, site coordination, and report contributions:

Beach Center
Amy Buchele-Ash, Marilyn Fender, Ben Furnish, Cindy Higgins, Terese Maier, Linda Mitchell, Crissy Shade, Tom P. Tronsdal, Vicki Turbiville, Ann Turnbull, H. Rutherford Turnbull, III, Amy Turnbull (volunteer), and Lois Weldon.

Erikson Institute
Jim Garbarino, Linda Gilkerson, and Daria Zvetina.

NOTICE

REPRODUCTION BASIS