Rule Out Abuse Campaign
Physician Education Program

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Rule Out Abuse Campaign: A Call for Help

Today is May Day 2016. On this day, recognizing a call for help, we are asking people to spread the word about the Rule Out Abuse Campaign. We are seeking to increase awareness that abuse happens to children and adults with disabilities. Our specific target audience is the health and mental health profession. We are seeking to increase awareness of those who provide health and mental health services to children and adults with intellectual and developmental disabilities...or any disability for that matter.

All our materials are online on our homepage at www.disabilityandabuse.org. There are four documents:

1. An endorsement letter from Dr. Vincent Felitti, the co-principal investigator of the ACES program, that through their research found that those who experienced adverse childhood events continued to suffer throughout their lifetime in the domains of psychological, social and physical repercussions.

2. The Rationale letter, that explains the genesis of the Rule Out Campaign.

3. Part One of the Rule Out Abuse information packet.


What we seek is relatively simple: asking health practitioners to add “abuse” to their list of conditions that they review when analyzing symptoms presented by their patient or the parents/caregivers of their patients.

Please help us celebrate the launch of the Rule Out Abuse Campaign, by forwarding this letter to physicians, mental health and other health practitioners to more quickly identify signs of abuse and take appropriate action.

Sincerely,

The Disability and Abuse Team
Dear Fellow Health Practitioners:

This letter is to let you know that I support the Rule Out Abuse Campaign that was developed by Dr. Nora Baladerian of the Disability and Abuse Project of the Spectrum Institute.

As you know, I and many other medical researchers and practitioners, are well aware of the traumatic events that children experience and that these events affect them both at the time they occur and well into adulthood.

Dr. Baladerian has pointed out that this awareness has not specifically included the effects of such trauma on children and adults with disabilities. They are abused at rates much higher than the generic population. At the lowest, it is 3.4 times the rate of abuse in the general population. As health practitioners, we should be aware of the incidence and prevalence of abuse and maltreatment among those with intellectual and developmental disabilities and other disabilities.

Dr. Baladerian informed me of her concern that across the nation, when she is involved in cases of abuse of children and adults with developmental disabilities, she has found time and again that the parents have taken them to their specialist physicians and mental health practitioners with their list of changes they have noted in their children, but health professionals have not linked the symptoms of abuse presented by the parents to abuse. When the parents learn, either from law enforcement or the press that abuse that has been occurring in these programs, they invariably say, “Now it all makes sense.” Dr. Baladerian wants the list of changes the parents observe and report to their physicians to be analyzed so that the possibility of abuse as a contributing factor is included in the constellation of causes that are considered. Although the reason abuse is not considered in such cases is unclear, Dr. Baladerian wishes the medical community to be proactive in filling the gap, increasing awareness that abuse may be the cause of the symptoms list presented.

I encourage you and your professional colleagues to respond positively to Dr. Baladerian’s offer to make presentations to your programs, read the materials she has made available, and design an informational program in your arena to add the Rule Out Abuse practice to your existing algorithms for understanding the cause of the list of complaints presented by the parents and caregivers of your patients who have developmental and other disabilities.

Complete information about the campaign is available for free download at this website: <www.disabilityandabuse.org>.

Sincerely yours,

Co-Principal Investigator of the ACE Study

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May 4, 2015

Dear Advocates for Individuals with Disabilities:

In this morning’s email, I read an article in the Sacramento Bee detailing yet another child abuse case at a school perpetrated by the special education teacher, not reported by the aides or administration to police, nor to the parents of the abused students.

As you are well aware, this is one case out of many similar cases across the nation.

Since I work in the area of abuse, I am aware that in such cases, the parents are completely unaware of what is causing the changes in their children: resistance to go to school, changes in eating patterns (won’t eat, overeats), must sleep with parents, increase in anger, frustration, changes in mood including changing from a happy or content disposition to angry, depressed, withdrawn. Onset of tearfulness or crying. Among many other changes.

The parents typically talk about what they are observing, and ask each other (and themselves) what could be the cause of all these changes? They search their souls. They think about everywhere the child is, with whom the child interacts, etc.

All of the parents I have worked with have said they had a “fleeting thought” that it could be the school, but then quickly—almost unthinkingly—dismissed the thought. They are loyal to the schools. They believe to their core that the school is a safe haven. They have been told and believe that all staff members have years of training, are credentialed and expert in their work, and are dedicated to the well-being of their special needs students. They are professionals.

This is an unshakeable belief that PREVENTS further critical thinking. All have asked the teacher and the aides who work in their child’s classroom about the changes their children exhibit, and whether or not these school staff can help the parents unravel the mystery, and all have been told there are no known problems at school, although some say they, too, have noticed changes, and some even report the parents for suspected abuse after the parent reveals their concern to these school staff. It is my impression that there is a universal pattern where the staff members protect each other. None to date has made a mandated child abuse report. Staff members are supported by administration, which sets about “managing the information” but not protecting the children.

At some point, the truth comes out. Many parents learn about the abuse when they receive a telephone call from the police. Whether it is through learning about the abuse by reading a news article, a call from the police, or learning from other parents, the relief of the parents is coupled with feelings of anger, and betrayal. They report feeling relief that they finally know the cause of the significant
changes in their child. They feel anger that their trust was betrayed, and anger with themselves for not realizing that their child’s efforts to not go to school were that child’s communication that school had become a dangerous place.

Parents have told me, “I just could not believe that the teacher would hurt my child.” Often, “in IEP meetings the teacher seemed just fine.” Others, “I felt something ‘off’ about the teacher” and “I just had a bad feeling about the teacher.” Even when children have outright said, “the teacher hit me,” parents did not believe their child. They trusted the schools. Then they learned the teachers or aides had lied to them.

There is a sense of being betrayed by their community. The parents experience an earthquake in their rock of trust in the schools.

Most often, the parents have done all they could to help their children, by taking them for evaluation by their medical providers (pediatricians, developmental physicians, neurologists, psychiatrists) and mental health providers (psychologists, social workers, counselors). They describe the changes in their children to this practitioner who, most often, has known the child and the family for many years. Not one of these practitioners has brought up the possibility of abuse as the proximate cause of the constellation of symptoms that mirror the list of symptoms in any publication on child abuse. Of course the list is the same for abuse victims who have reached the age of majority.

From this reality grew the “Rule Out Abuse Campaign.” It is an informational campaign to alert medical and mental health providers to the fact that abuse plays a large part in the lives of children and adults with disabilities. The Campaign simply asks these practitioners to add “abuse” into the list of possible contributors to the changes reported by the parents. Had any of them done so, the abuse may have been detected earlier. Having identified that the constellation of symptoms has no other cause, the possibility of abuse must be explored. This is not the purview of the practitioner, but the responsibility to cause an investigation is not only in their purview but is their responsibility to file a suspected child (or dependent adult) report to the authorities.

That is all that is asked for within the Rule Out Abuse Campaign. We are asking for all those who care about accelerating the identification for the cause of changes in children and adults with disabilities that mirror those of abuse victims, to join us in this campaign.

As Ambassadors of the Rule Out Abuse Campaign, you are asked simply to download the documents available at the www.disabilityandabuse.org homepage, print them out and speak about this in your local community’s medical and mental health provider agencies. You can forward them by email to all agencies in your community (local and state) who serve children and adults with developmental disabilities. You can include this letter as an introduction.

I am also asking the Arc of the US and every chapter to forward this letter and Rule Out Abuse documents to any and all medical and mental health practitioners in their communities. Please send to your local UCEDDs and other organizations with a responsibility to provide information about people with disabilities to the greater community. Finally, I am asking you to make this available to parents, who may be able to more quickly pinpoint the source of their child’s distress.

Sincerely,

[Nora J. Baladerian, Ph.D.]

[Signature]
Recognition of a Pattern, Call for a Response: A “Rule Out Abuse Campaign” for Physicians (Part 1)

by Nora J. Baladerian, Ph.D.

Over the past 20+ years working with children and adults with intellectual and developmental disabilities who have been victims of abuse, I have noticed a consistent and clear problem: the parents are confused by and concerned with the onset of a constellation of new moods, behaviors, regression or loss of language skills completely different from their child’s prior psychological and developmental presentation. Prior state of well-being is absent. There is no identifiable cause. Part II includes statistics showing high rates of disability-abuse. (Click here)

They may take their concerns to their physician (pediatrician, neurologist, psychiatrist). The practitioner, focused on the disability, does not rule out or identify abuse as a possible cause. Yet, the signs and symptoms presented by the parents are those included in lists of “typical signs of abuse.” I believe these practitioners, so focused on the disability “forget” that children are vulnerable to child abuse, and adults are vulnerable to dependent adult abuse.

I propose a “RULE OUT ABUSE CAMPAIGN” to urge practitioners to put abuse (back) on their list of possible causes to rule out when asked to examine children or adults with intellectual and developmental disabilities when significant changes occur.

PROBLEM TO BE SOLVED: failure to recognize signs of abuse

Typically a distinct change has occurred in the individual including new fears, regression in previously achieved developmental milestones, new difficulties in communication and mood changes, such as tearfulness/crying and/or anger and aggression and loss of interest in activities previously enjoyed. They live in distress rather than the prior state of well-being.

The parents inform their health care practitioner that they have asked the teachers and aides at the program (school, day program) their child attends, where they are assured that all is well. The parents have not been warned or prepared to know that such persons may be lying to them (for their own self-preservation). Further, in the cases in which I have been involved, the administration of the school/program has made efforts to keep the abuse a secret and conspire to protect their staff rather than the students or participants of their programs. It could be a camp, church, or other place frequented by the child. The individual with a disability may be a child or an adult. If an adult, the same pattern described above may emerge while the adult is attending a day program, working, participating in a social experience or residing in a licensed residential program or facility.

The parents, confused and frightened, take the child/adult to their physician at the local Children’s Hospital, HMO or private practice. In addition they may seek help from a mental health specialist such as a psychiatrist, psychologist or social worker.

In my experience with dozens of families, none of these practitioners, although specializing in working with individuals with intellectual and developmental disabilities, has identified abuse as a possible cause of the symptoms pattern that, frankly, screams abuse. It appears that abuse is not on their list of contributors or conditions to rule out. Why not? Or better, how can it be quickly added?

PROPOSED SOLUTION: Health Care Professionals

(1) The major organizations for licensed health care professionals serving children and adults with intellectual and developmental disabilities should issue a bulletin that describes the current knowledge on the incidence and prevalence of abuse of children and adults with disabilities. The bulletin should include a list of typical changes in abuse victims, including how these may manifest in children/adolescents with I/DD and other disabilities. The bulletin should encourage practitioners to include in their assessments of presenting problems, the practice to rule out abuse as a possible cause of the changes, and comply with the laws in their state for mandated reporting of suspected abuse.

(2) Physicians should advise the parents of signs of abuse and mandatory reporting laws. For example, California law states: "Any mandated reporter who has knowledge of or who reasonably suspects that a child is suffering serious emotional damage or is at a substantial risk of suffering serious emotional damage, evidenced by states of being or behavior, including, but not limited to, severe anxiety, depression, withdrawal, or untoward aggressive behavior toward self or others, may make a report to an agency specified in Section 11165.9. (Cal. Penal Code § 11166.05)

(3) The health practitioner should also recommend or authorize a two-week release from school/day program to check for any reduction in symptoms during this holiday from school (like a medical holiday). This allows time for the law enforcement agency to conduct its investigation, and time for the child/adult to be free from a possible source of trauma/abuse.

(4) Referral for mental health trauma treatment for the patient should be made. A similar referral for the parents and other family members is also recommended. (Some reviewers of this document suggested that I include Munchausen's or Munchausen's by proxy. While such conditions do exist, they are tiny in number, and this may be a good recommendation. However, most Munchausen's patients (abusers) would not, with their family members, demonstrate the same depression, anxiety, secondary trauma in the way the parents of the victims I have served have done. The parents with whom I have worked are open, and any record, any inquiry is welcomed.)

These recommendations apply to all professionals to whom parents turn for support and intervention for children with disabilities.

(5) I also recommend that the listed professionals (and others) change their curricula to add a course of training on abuse of individuals with I/DD for those currently completing their education to become qualified to practice in their field; a course for those who are in preparation for becoming licensed, and those who are already licensed and will be renewing that license.

This should be made mandatory. While I realize that making anything mandatory may require changes in legislation and policy both by the state and the regulatory agencies, as well as among the University and other entities, it should be done.

Too many people are suffering for too long while the perpetrators continue to abuse and/or protect the abusers. And those to whom the parents turn may be unaware, or are seemingly unaware, that abuse is a likely contributor and certainly one that matches, in whole or in part, the list of symptoms cited to them by the parents and guardians.

Part 2 contains details on symptoms and other scientific information. Part 2 is found online: http://disabilityandabuse.org/rule-out-abuse-physicians-2.pdf

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Rule Out Abuse Campaign Part 2

Specific suggestions for addressing the reason for the Rule Out Campaign are grounded in the research on abuse of children and adults with intellectual and developmental disabilities. Part 2 includes citations to the research. Part 2 was designed to include a “quick look” at signs and symptoms for health practitioners, and provide a quick look at contributing factors such as trauma and the ACE Study.

This second part also allows for a brief comment responding to questions that have arisen regarding suspecting the parents of child abuse. While it is true that a large percentage of abusers are family members, it is also true that an apparently growing number of abuse cases occur without the knowledge of the parents while their children are attending school, supportive therapy sessions, on the school bus, or for older children or adults, attending state-supported day or work programs, or participating in Independent Living Skills programs or residences. The Rule Out Abuse Campaign began with a focus on these cases, where the parents are blindsided by the changes in their children, and are at a loss to discern the reason for the signs and symptoms listed herein. And, when consulting with their physicians, found that they were baffled as well, and none suggested abuse as a possible contributor.

1. Statistics On Abuse Of Children And Adults With Disabilities

a. Children with disabilities are abused more than generic kids.

Research shows that children with disabilities are more vulnerable to abuse than their generic counterparts by a factor of 1.7 (Westat, 1991) or 3.4 (Sullivan et al 2000). Here are the numbers when you “Do the math.”

<table>
<thead>
<tr>
<th>All types of Child Abuse</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Girls 1 in 4</td>
<td></td>
</tr>
<tr>
<td>Sexual abuse</td>
<td></td>
</tr>
<tr>
<td>Girls: 1 in 4</td>
<td></td>
</tr>
<tr>
<td>(sexual abuse)</td>
<td>(25%)</td>
</tr>
<tr>
<td>Boys 1 in 4</td>
<td></td>
</tr>
<tr>
<td>Boys: 1 in 6</td>
<td>(17%)</td>
</tr>
</tbody>
</table>

\[ x \ 1.7 = 43\% \]
\[ x \ 3.4 = 85\% \]

Sources:
2. 1.7 DHHS/NCCAN (Westat Inc., 1991)
3. 3.4 Boystown Research Hospital (Sullivan & Knutson, 2000)

According to American Humane Associates:

One million children abused annually. 50.7% girls, 47.3% boys.
8% of these are children with disabilities, who are abused at twice the rate of generic children.

2 x 50.7 = 101.4%  
2 x 47.3 = 94.6%  
b. Abuse of adults with disabilities:

➤ Annually abuse is reported among vulnerable adults, elders and children:
  ➤ 5 million vulnerable adults
  ➤ 2 million elders
  ➤ 1 million children
  ➤ 2 million + 1 million = 3 million children/elders abused compared to 5 million adults with disabilities who are abused
  ➤ From this data, we can see that adults with disabilities are abused more than children and elders combined.

(Petersilia, 2000)
(NCPEA, 2013)
(NACC, n.d.)

2. Signs And Symptoms Of Abuse Among Children And Adults With I/DD

Signs vary among abuse victims. Here is a list of common signs. The essential sign is a change in the person.

Abuse that is not sexual in nature:
There has been a change in mood, conduct, and/or communication.

DEVELOPMENTAL
Regression from skills already mastered
New disabilities: psychiatric, physical, sensory, communication or other.

BEHAVIOR
Eating, sleeping, dressing skills/preferences
Does not want to go to x location or with x person
Re-enacting/acting out what was done to him/her (replicating the assaultive act upon self or others)
Self-harm or mutilation
Self-injury

PHYSICAL
Clothes are changed, soiled or torn
Change in monthly menstruation
Diarrhea or constipation; enuresis or encopresis
Change in appetite, change in food preferences (food, texture)
Gain or loss of weight
Change in energy
New ailments: headaches, stomach ache, back ache, difficulty hearing, seeing, walking, etc. Include chest pain, heartburn, increased use of OTC’s.
Bruising, petechiae, swelling or lack of use of an extremity, welts, burns, marks of objects, bite marks
Sweating, anxiety, dizziness, sense of panic

PSYCHOLOGICAL
Onset of new fears such as social anxiety, generalized anxiety, specific phobias
Depression and sadness, tearful, crying, inconsolable
Irritability, anger, easily frustrated
Withdrawal
Trouble thinking, concentrating, remembering
Somatization
Change in normal behavior & personality
Sleep disturbances
Needing to sleep with parents
Change in interest in normal activities
Difficulty learning
Angry, irritable, easily frustrated
Wanting to stay home
New phobias, terror of leaving the house or going to usual location (school, day program, church, work, etc.)
Episodes of lack of control, tantrums longer and inability of parents to communicate during tantrum w/ child

COMMUNICATION
Change in communication including selective mutism (when a previously verbal child stops talking after a trauma.)

Sexual Abuse:

BEHAVIOR:
A change in modesty, ranging from becoming overly concerned about their body to engaging in inappropriate sexual behaviors; Onset of increased sexualized conduct; Self-molestation (replicating assaultive act upon oneself)

PHYSICAL:
Genital pain, itching, discharge and bleeding; stomachaches, headaches and other physical complaints;
Indications of a sexually transmitted disease (STD) – itching, burning, pain with urination/defecation; Change in monthly menstruation

PSYCHOLOGICAL:
Sleep disturbances, bed-wetting, new fears, and refusal to go to certain places or be with certain people.
School problems, difficulties with peers, excessive crying, depression, clingingness, aggression or secretiveness. Other psychological changes include running away, drug or alcohol use, excessive day dreaming, isolating themselves.

COMMUNICATION:
New questions related to sex, the body, pregnancy, touching the body, photos or pornography. New problems are emerging regarding texting, being asked to take and send photos.

NO CHANGE:
Some may not demonstrate any type of change. Some offenders are able to groom children for abuse in a manner that makes the child feel comfortable, close to and even protective of the offender, while remaining unable to report or evade the abuse.

3. Signs Of Post-Traumatic Stress Disorder (PTSD) In DSM-5

Health practitioners should be aware of the changes in DSM-5 developed by Michael Scheeringa, M.D.
A challenge for the Diagnostic and Statistical Manual (DSM) taxonomy has always been to consider developmental differences in the expressions of disorders in different age groups. Research has suggested that individuals of different ages may express features of the same criteria somewhat differently. The Fifth Edition of the DSM (DSM-5) includes a new developmental subtype of PTSD called Post-traumatic Stress Disorder in preschool children. Since an alternative diagnostic set of criteria was initially proposed by Michael Scheeringa and Charles Zeanah (2), the criteria have been refined empirically (3,4), and endorsed by a task force of experts on early childhood mental health (5). Because young children have emerging abstract cognitive and verbal expression capacities, research has shown that the criteria need to be more behaviorally anchored and developmentally sensitive to detect PTSD in preschool children (2,13). The criterion that the children's reactions at the time of the traumatic events showed extreme distress has been deleted. The change to the re-experiencing symptoms is a relatively minor change in wording to increase face validity and, thereby, lower the symptom detection threshold. The major change was to require only one symptom in either the avoidance symptoms or negative alterations in cognitions and mood. The symptoms of "sense of a foreshortened future" and "inability to recall an important aspect of the event" were deleted. The wording of two symptoms was modified to enhance face validity and symptom detection. Diminished interest in significant activities may manifest as constricted play. Feelings of detachment or estrangement may be manifest more behaviorally as social withdrawal. The symptoms "irritability or outbursts of anger" was modified to include "extreme temper tantrums" to enhance face validity.


4. Trauma-Informed Medicine

According to Substance Abuse and Mental Health Services Administration (SAMHSA), individual trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being.

"In the U.S., 61% of men and 51% of women report exposure to at least one lifetime traumatic event, and in public behavioral health settings, 90% of clients have experienced trauma. Data suggests that ... ignoring trauma can hinder recovery. All care — in all health settings — must address trauma in a safe and sensitive way in order to ensure the best possible health outcomes.”

Providing care in a trauma informed manner will promote positive health outcomes. A trauma informed approach is defined by SAMHSA as “a program, organization, or system that is trauma-informed realizes the widespread impact of trauma and understands potential paths for recovery; recognizes the signs and symptoms of trauma in clients, families, staff, and others involved with the system; and responds by fully integrating knowledge about trauma into policies, procedures, and practices, and seeks to actively resist re-traumatization.” Reference: http://www.integration.samhsa.gov/clinical-practice/trauma
5. ACE: Adverse Childhood Experiences Study

Adverse Childhood Experiences Study, completed in 1999, demonstrated that such events contribute to later significant physical maladies. Thus it is essential when identifying childhood abuse to be vigilant to prevention efforts. The ACE study information can be found online at: http://www.cdc.gov/violenceprevention/acestudy.

The ACE Study is one of the largest investigations ever conducted to assess associations between childhood maltreatment and later-life health and well-being. The study is a collaboration between the Centers for Disease Control and Prevention and Kaiser Permanente's Health Appraisal Clinic in San Diego.

More than 17,000 Health Maintenance Organization (HMO) members undergoing a comprehensive physical examination chose to provide detailed information about their childhood experience of abuse, neglect, and family dysfunction. To date, more than 50 scientific articles have been published and more than 100 conference and workshop presentations have been made.

The ACE Study findings suggest that certain experiences are major risk factors for the leading causes of illness and death as well as poor quality of life in the United States. It is critical to understand how some of the worst health and social problems in our nation can arise as a consequence of adverse childhood experiences. Realizing these connections is likely to improve efforts towards prevention and recovery. It is essential to include children with disabilities into an awareness of the impact of adverse child experiences on them.

6. References To Articles On Abuse Of Children And Adults With I/DD


2. Child Abuse & Neglect, Vol. 24, No. 10, pp. 1257–1273, 2000 Copyright © 2000 Elsevier Science Ltd. Printed in the USA. All rights reserved 0145-2134/00/$–see front matter; PII S0145-2134(00)00190-3, Maltreatment and Disabilities: A Population- Based Epidemiological Study; Patricia M. Sullivan Boys Town National Research Hospital, Omaha, NE, USA; John F. Knudson

3. Summaries from four reports Save the Children, Sexual abuse of children with disabilities. Docs-.22867-v1-sexual_abuse_of_disabled_children_summaries_from_three_reports1_0.pdf


For additional information on abuse and those with intellectual and developmental disabilities, visit disabilityandabuse.org

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Guide on Responding to Suspected Abuse of People with Developmental Disabilities

Ten Tips for Parents or Family Members whose Loved One Receives Educational, Residential, Transportation, Day Program Services

1. Know and believe that abuse can happen to your loved one

2. Become familiar with the signs of abuse. Any signs of injury, changes in behavior, mood, communication, sleep or eating patterns are included.

3. When you suspect something is wrong honor your feeling & act immediately. See #4.

4. When you suspect abuse, call a Child or Adult Protective Services agency and the police.

5. Do not discuss your suspicions with anyone at the program where you believe abuse is occurring, as they may deny any problem, punish your loved one, and attempt to destroy any evidence that may exist.

6. Remove your loved one from the program immediately.

7. If there are injuries or physical conditions, take your loved one to a physician, not only to diagnose and treat the condition, but create documentation of your visit and the findings. Take your loved one to a mental health practitioner who can document the changes in his or her behavior and mood and who can document what your loved one’s memories are of the abuse.

8. Create a document in which you write all of your activities. Begin with when you first suspected abuse or neglect. What were the signs or signals you noticed? Write the dates of these, and if there were injuries, detail what they were, their appearance, and where on the body you saw them. If staff gave an explanation, record this in your file. Write down when you called the police or protective services agency, the name of the representative, time and date of the call and what was said. If a staff member discussed this with you, write down what they said and their name and the date and time of the discussion.

9. Notify the Regional Center representative of your findings, suspicions and actions or your disability program in your state.

10. Get a police report. Contact the Victims of Crime program in your area and seek their support for reimbursement of costs and therapy for the family.

Prepared by The Disability and Abuse Project of Spectrum Institute, disabilityandabuse.org