NCOR

National Center on Outcomes Resources

Community and Quality: A Guide to Incident Management and Quality of Life Outcomes

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The National Center on Outcomes Resources (NCOR) is the research division of The Council on Quality and Leadership in Supports for People with Disabilities and provides leadership in outcomes research, analysis and dissemination. NCOR is a clearinghouse and information resource on outcomes data on all aspects pertaining to people with disabilities.

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- Provide consultation, education, and other learning tools to build individual and organizational capacity;
- Conduct research and promote the availability of data for decision making and policy development; and
- Provide access to the latest information, developments, trends and best practices to consumers, their families, support and service organizations, and governmental organizations.

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ISBN 1-930660-09-X

On June 22, 1999 the U.S. Supreme Court ruled in the Olmstead Case that states are required to provide community-based supports and services for people with mental disabilities if treatment professionals determine it appropriate and if the individual does not object to such placement.[1]

The Olmstead decision highlights the dramatic changes in the provision of services and supports for people with developmental disabilities:

- The number of people with developmental disabilities in public institutions has declined from 149,892 in 1977 to 51,485 in 1999.[2]
- During the period from 1993-1998, the number of people in residential services increased from 362,440 to 416,717, an increase of 15%. This expansion has been fueled by a 60% increase in people living in settings for six or fewer people.[3]
- An equal number of people (416,441) in 1998 received state services and supports while living with families, in foster care, or in their own homes.[4]

Introduction

Despite the decrease in institutional care and the increase in community services at the beginning of the new century, there is a great variation in fiscal efforts among the states. The demand for community-based services has outpaced the rate of state development of community services. State waiting lists attest to the need for unavailable community supports and services. The National Conference of State Legislatures estimates that there is a need for an approximate 18% growth in residential services to meet the needs of people on the waiting lists.[5]

The growth of community supports and services has been dramatic. But, recent media attention to the community service system raises questions about the quality of services and supports. From the controversial discussion of mortality rates in community services across the country, the media attention is calling into question two decades of community development.

NCOR is concerned about these recent developments for two reasons:

- We know from our national accreditation, training, and quality improvement consultation that there are indeed instances of poor service and support. We have witnessed instances of abuse and neglect. We recognize these limitations in the service system and continue to act on our mission and vision.
- We are concerned that the media attention is moving beyond specific situations and leading the general public and some policy makers to conclude that the community service system has failed.

The continued growth of community services and supports of high quality will demand that we both guarantee the basic protections in the areas of health, safety, and continuity as well as promote the attainment of person-centered outcomes and self determination. Paradoxically, strong protections in health, safety, and continuity result in the possibility for greater innovation and personal planning and self determination. The general public and state and local officials will tolerate new approaches to services and supports when they are assured that people remain safe and healthy and that there is a continuity in staffing, services and supports in people's lives.

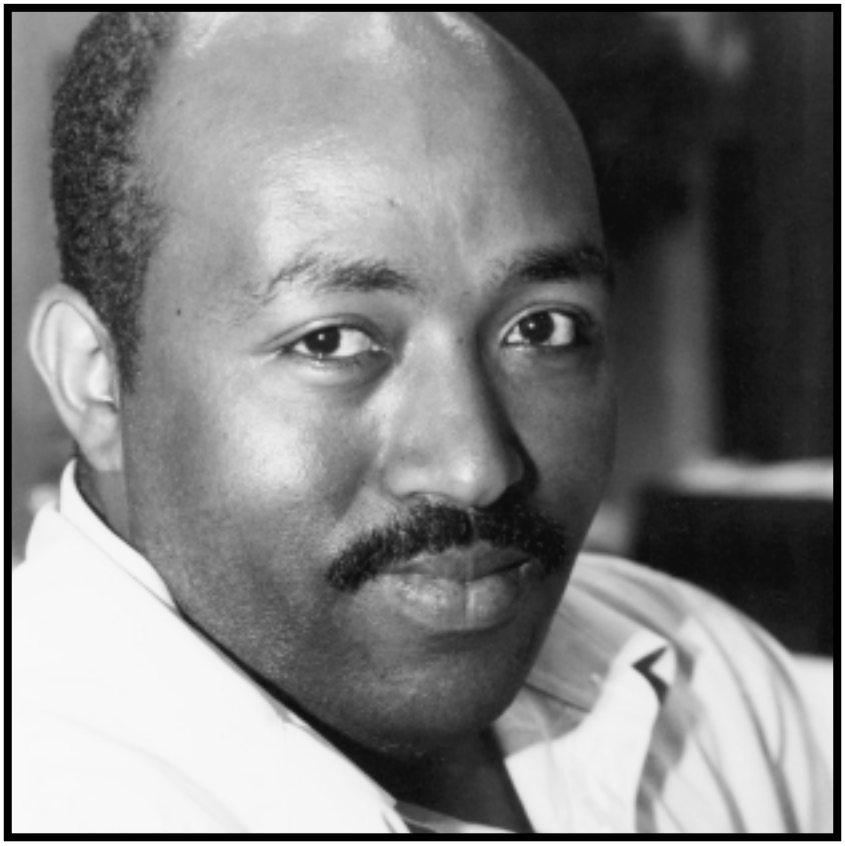
A Responsibility for All Employees

Providers of service and support, whether formal or informal, are responsible for guaranteeing the health, safety, and continuity of people supported by the organization. This includes the Board of Directors, management, service and support staff, volunteers, and people receiving services and supports and their families. Incident management is part of that responsibility. Incident management takes on particular importance in community-based, decentralized systems because the direction, control, and reporting for congregate care settings don't work in the community. In the community, incident management is every employee's responsibility.

Incident management refers to organizational efforts to prevent, identify, investigate, and review allegations and incidents of abuse and neglect. Generally, one person with a title such as Quality Improvement Coordinator, Quality Assurance Director, or Risk Manager assumes primary responsibility for incident management. But, the prevention of abuse and neglect is only as strong as the competence and commitment of the least competent and least committed staff person.

A strong incident management program requires the continuous sharing of information and values throughout the work experience of employees. Incident management principles and practices should be a natural part of the employee's work life. For this reason, incident management is closely tied to the quality of life of people receiving services and supports and to the quality of work life of the people providing the services and supports. A focus on the quality of life of people receiving services and supports enables organizations to organize resources to facilitate personal outcomes rather than to meet program goals. Personal outcomes replace program goals. A focus on the quality of work life demonstrates that the organizational values and principles pertain to employees. Organizations demonstrate respect for employees, provide opportunities for personal and professional growth, and recognize that all employees can contribute to both personal outcomes and organizational success.

Organizational quality improvement plans provide an opportunity to integrate elements of quality of life, quality of work life, and incident management. The plan may identify strategies for facilitating personal outcomes and organizational efforts to enhance employees' morale and professional development. The plan would also include policies, procedures and plans to protect individuals from abuse and neglect. These policies, procedures, and plans should be very specific. The quality improvement plan should identify people responsible for specific actions. For example, support staff may invite a family member to stop in unannounced for lunch or dinner once a month to be sure the food is wholesome and tasty and to conduct a consumer satisfaction survey. Frequent interaction with family, friends, and neighbors decreases incidents of abuse and neglect. Isolation and lack of involvement provide opportunities to foster abuse and neglect.



Despite our best efforts at preventing abuse and neglect, allegations of these violations will require investigation. The tasks associated with incident management include: identification, investigation, and review. We have included the identification of corrective and preventive measures and follow-up to ensure they are meeting their purpose under the review section.

Identifying Abuse and Neglect

Any incident management system depends on the ability and willingness of people connected with the program to identify abuse and neglect when they see it and raise questions when they suspect it. Organizations must pay attention to incident management in policies and training materials. The definitions of abuse and neglect must be consistent with those used in law and regulation by the licensing agency. Materials should be in language and format that is understandable to the people using them and should be widely distributed—not just to staff but to consumers, their families and others who are part of an individual's inner circle.

The questions which follow may help improve the drafting, revision or dissemination of an abuse and neglect policy and training materials.

Incident Management

Looking at the Policy

- Does the incident or abuse/neglect policy express your agency's values regarding how people with disabilities should be treated and supported?
- Has the policy regarding abuse and neglect been developed with input from consumers, their families and advocates, and staff of the program? Is the document written in language and formatted to enhance its accessibility and readability for the people who need to use it?
- Is the policy consistent with relevant laws and regulations? Is the policy clear about whether the intent to harm is a necessary condition for abuse/neglect, i.e. does the policy require that, in addition to a breach of duty, a staff person must have the intent to harm a person receiving services in order for an action to be considered abuse and neglect?
- Does the policy identify who can perpetrate abuse/neglect—employees of the organization only, volunteers, members of the community, family members,

other recipients of service? If abuse and neglect are defined as violations committed by a staff member, does the policy provide guidance on how to handle incidents in which consumers are harmed by those other than staff?

- Does the policy address verbal, psychological, financial and sexual abuse, as well as physical abuse? As more persons with disabilities take paying jobs, organizations need to be attentive to the possibility of financial exploitation.
- Does the policy explicitly state that the first duty of any person witnessing or discovering abuse or neglect is to ensure the health and safety of the individual?
- Does the policy address the responsibility of all staff (regardless of rank or title) to report suspected abuse/neglect? Is it clear who writes the incident report; is it the staff person who discovered/witnessed the abuse/neglect or the supervisor to whom it is reported? Does the policy address the responsibility of staff to cooperate with an investigation?
- Does the policy identify who is responsible for advising guardians and family members of an incident? Does it identify reporting responsibilities to external agencies, including licensing, oversight, child and adult protective agencies and law enforcement?
- Are time frames for reporting to external parties and for the completion of investigations and the review of incidents included in the policy?
- Finally, does the policy address the investigation of deaths of individuals in care? The death of each individual should be screened to identify areas where further inquiry may be necessary. Many times, agency policy only requires the review of unusual or unnatural deaths. While only these deaths may constitute "incidents," broadening the review to all deaths provides the opportunity to look at the adequacy of medical care, comfort measures, involvement of family and other loved ones, the effect of the death on people the individual lived, worked and played with and any other issues that come to the fore.

The investigation of some deaths will require the investigator to have dealings with specialists not frequently encountered, e.g. coroners, medical examiners, EMS and ambulance teams. Organizations need to ensure that the investigator has guidance in the performance of these duties as required.

Disseminating the Policy

Organizations need to keep the incident policy in the hands of all staff, consultants, and volunteers. Additionally, it needs to be given to family members, advocates and recipients of service as appropriate. The vigor and frequency with which the contents are discussed will indicate the centrality of the document to the organization's resolve to protect individuals in care.

Programs should consider these questions in determining whether their policies are getting the attention they deserve.

- Are abuse and neglect periodically discussed with consumers? Are examples provided? Would role playing help consumers understand? Do consumers know whom to tell if they believe they or someone else is being abused?
- Are copies of the policy shared and discussed with parents/guardians and others when planning for and with an individual?
- Does the orientation training contain a module on abuse/neglect? Could the module be strengthened by the addition of consumers and family members expressing their perspective? Is there an objective assessment of the candidate's understanding of the material at the close of the training?
- Is there an expectation that staff will be given incident training periodically (at a minimum annually)? In addition to the basics, does the training provide adequate explanation to staff about what will follow once an allegation/incident is reported, including discussion of the investigation and review process, identification of corrective measures (including, but not limited to, possible disciplinary and counseling measures) and follow-up to assess the efficacy of corrective measures?
- Do supervisors engage in frequent discussions with staff about abuse and neglect, particularly about more subtle forms of these violations, giving examples particularly relevant to their work site? Examples might include the use of intrusive procedures not in a behavior plan in the absence of an emergency which endangers a human being; failure to provide necessary personal care which leaves an individual dirty, wet or uncomfortable; rushing through feeding, placing someone in danger of choking or aspiration; leaving a vulnerable person unattended in a bathtub; and, coaxing a disabled person to pick up the check for lunch for himself and his service coordinator.

Investigating an Allegation of Abuse/Neglect

Good organizations understand the importance of the investigation of serious incidents, and recognize that competent investigations protect consumers, innocent staff, and the agency. They employ trained investigators whose job is to respond to the scene of a serious incident as soon as possible and carry the investigation through to closure, and they avoid assigning incident investigation to the clinician least busy at the moment or to a rotation of staff, all of whom have other responsibilities. They expect that their investigator will not only find out "who did it," but will identify underlying causes and contributing factors by addressing such issues as policies and procedures, training, the culture of a program, supervision styles, scheduling, as well as circumstances unique to the incident.

The qualities of a good investigator might be summed up in eight characteristics: 1. high ethical standards; 2. an experiential as well as textbook knowledge of the field of developmental disabilities; 3. excellent communication skills, both verbal and written; 4. versatile interviewing techniques; 5. good judgement about when to call for the assistance of experts; 6. an understanding of external reporting responsibilities and due process; 7. curiosity; and, 8. the bent of personality that does not suffer too enormously from not being the most popular member of the organization.

High Ethical Standards: Trust. The effective investigator must engender the trust of consumers, staff, family members, advocates and others. These people must believe that the investigator will be objective and fair. Without this kind of trust, witnesses and other parties to an incident will convince themselves that their primary duty is to protect themselves from an encroaching injustice and will respond with either a conspired version of what happened or silence.

Comprehensive Knowledge of Developmental Disabilities: In interactions with consumers and external parties and in the review of clinical material, the investigator should demonstrate a comprehensive understanding of developmental disabilities. The investigator must be knowledgeable about specific developmental disabilities and the limitations they can impose on an individual's ability to tell his story. She must be able to help the individual diminish the impact of these obstacles to the degree possible.

Additionally, an investigator needs to be able to critically read the records relevant to an investigation. This means she must be able not only to understand and assess what is there, but also be able to recognize pertinent gaps in the record, to realize that something is missing which should have been addressed. Finally, the investigator needs to appreciate the "real-world" of a care system where demands are high and resources often scarce. It is particularly necessary that she appreciate the challenges facing the direct support staff member, if she is to identify factors contributing to an incident.

Excellent Communication Skills: Often when there is an allegation of serious abuse or neglect, people are so outraged or in such denial that they lose perspective. The good investigator helps people focus. She may be talking to medical personnel, to the licensing agency and perhaps to law enforcement. She will be keeping families and guardians informed, and will be responding to questions from concerned staff. The ability to determine what can and should be shared, and with whom it can be shared is essential, as is its clear communication. When the investigation is complete, the clarity of the written investigation summary will directly effect the administration's, the incident review committee's (and other relevant parties') weighing of the evidence supporting the investigator's conclusions regarding what happened and why. Presenting all relevant facts and omitting extraneous information in an investigation summary is essential. Absent these efforts, reports invite cursory reading and misinterpretation.

Versatile Interviewing Techniques: In many allegations of abuse and neglect, much of the information that an investigator compiles will come from interviews. While this booklet is not a special investigations manual and cannot cover the subject of interviewing in depth, we can offer some guidelines for good interviewing:

- The investigator needs to determine who will be interviewed and in what order. It helps to visualize potential interviewees as occupying different points on concentric circles, with the investigation starting at the outer edges, moving closer to the alleged perpetrator on the innermost ring who is usually interviewed last.

- A good interviewer has her introduction and list of essential points to cover prepared in advance. She makes an attempt to put the interviewee at ease and generally begins with broad questions, e.g., "Tell me what you know about ____" and moves to more focused questions later.
- She is prepared to meet challenging interviewees, e.g. the reluctant witness, the witness who loves the limelight, the frightened victim or witness, the hyperbolic witness who sees sinister intent in every ominous event.
- She avoids making promises she cannot keep. This is particularly true concerning promises of confidentiality. For example, she will not promise that "whatever you say is just between you and me."
- She secures a written statement summarizing the interview which is signed and dated by the interviewee attesting to its accuracy.
- She conducts second interviews when necessary to address discrepancies between interviewees or inconsistencies within a statement.

Calling for Expert Help: Investigators will sometimes need the assistance of persons with particular expertise. Investigators generally need medical experts to interpret autopsy results, x-rays and other information to determine whether the event as described could have caused the injury/harm presented, and to review hospital and other medical records to assess whether care provided to an individual meets current practice standards. Occasionally, investigators need other kinds of expertise, e.g. a plumber may be needed to check water-mixing valves during an investigation of a burn or the assistance of a rape counselor may be needed in interviewing a rape victim. An agency needs to facilitate arrangements for these services.

Understanding External Reporting Responsibilities and Due Process: In those instances where a crime may have been committed, it is essential that the investigator ensure that the police have been informed and that she follow their instructions, even if it means that the agency investigation may be delayed. Failure to follow police instructions can result in the contamination or inadmissability of evidence in a criminal proceeding. Investigators must also ensure compliance with regulations addressing notification to other external parties, such as licensing, oversight, and child and adult protective agencies.

Under certain circumstances, persons suspected of abuse and neglect have contractual rights. It is particularly important that the investigator know and respect these rights. Failure to adhere to contractual rights, such as legal or union representation during an interrogation, cannot only jeopardize disciplinary action in the matter at hand, but can destroy staff's trust that investigations will be even-handed and thus can negatively impact future investigations.

Curiosity: Organizations will want to employ an investigator whose curiosity will lead her to formulate different theories of the case and set out to find the truth. Curiosity is an essential attribute when investigators are expected to look beyond the obvious and uncover contributing causes. For example, rather than simply conclude that the individual who fell out of a Hoyer lift was improperly secured by the staff assisting him, the investigator may need to talk to the manufacturer and/or get into (or have a colleague get into) the lift and try to tip it in the same fashion that it was claimed it was tipped by the individual who fell out.

The Popularity Penalty: An investigator asks hard questions of friends on the job, of supervisors, and of consumers, and she evaluates their performance within the context of the incident under investigation. This makes even good staff wary. To varying degrees, the investigator is an outsider. When she is particularly ill at ease with this separateness, the investigator will be torn between the responsibilities of her job and the competing need to be liked—an uncomfortable state that can effect both her personal and professional life.

Reviewing Incidents and Taking Preventive/Corrective Measures

Once an incident has been thoroughly investigated and the summary completed, the work of the Incident Review Committee begins. Generally, an agency will appoint several standing members and a chairperson who will meet regularly. Often the members will represent different specialties, job titles or programs within the agency. Family members and advocates commonly sit on the committee, and other people from outside the agency who have an interest or expertise may be invited to join. These non-staff members help broaden the committee's perspective and encourage more objective discussions of personnel matters. The committee may request the presence of others whose expertise would be helpful during a particular deliberation. For example, on occasion the committee may need the expertise of a speech, occupational or physical therapist.

Duties of the Review Committee

The duties of the Incident Review Committee should be clearly described in the incident reporting and review policy. These duties might include:

- Ascertaining that incidents were reported, investigated and managed in compliance with regulations and agency policy.
- Assessing the adequacy of investigations under deliberation. Usually the investigator is available to the committee to answer questions or clarify points in her report. If the committee is not satisfied with the investigation and/or has questions which are not answered, it will send the investigation back for further work.
- Determining appropriate corrective and preventive actions. Often agencies request that the investigator make recommendations for corrective actions. The committee will review these recommendations and make any additions, deletions or modifications. The committee will determine how and when it will assess the efficacy of the corrective actions and who will "close the loop" and report this information back to the committee.
- Requesting and analyzing trend, pattern and benchmarking data and responding appropriately. This might include requesting follow-up studies or making recommendations to improve performance.
- Periodically disseminating the outcomes of the review process (with names changed or omitted) to all staff as a way of informing them of the positive effect that the reporting and investigation of incidents is having on addressing issues which impact them.

The director of incident management should be able to provide the review committee with trend data and with data related to patterns in incidents. Trend data can be particularly helpful as one measure in assessing the effectiveness of corrective actions. Pattern data will identify persons and circumstances which occur frequently in incidents. This would include people who are vulnerable and appear often as victims and those whose behaviors result in incidents, as well as information about location, time, activities and other variables.

In some very sophisticated incident management systems, an agency can compare the frequency of specific types of incidents within its program with the data from similarly situated programs. This benchmarking capability will become more commonly available as states and regions sort aggregate data using agreed upon criteria and make these aggregate numbers available.

Other Considerations

The incident management policy should cite circumstances under which a particular committee member should not participate in the review of an incident, such as when he or a member of his family has been directly involved in an incident. The policy should also speak to the confidentiality rules related to the information that comes before the committee and related to its deliberations. Organizations would be wise to consult the licensing agency or an attorney to learn what information and under what circumstances the incident review proceedings are protected from public disclosure. Failure to understand the rules governing legal confidentiality could result in the IRC inadvertently losing the privilege guaranteed them in some state statutes.

The committee chairperson will ensure that minutes of the proceedings are kept and that incidents which the committee determined need further investigation are

tagged for timely follow-up. Completed investigations, including corrective actions, are forwarded to the agency's head and others as identified in the incident management policy. The agency head is kept informed about the progress and effectiveness of corrective and preventive actions.

Agencies which support many individuals and have a large volume of incidents may divide the work of incident review to subcommittees. For example, the agency may have a review subcommittee for work and recreational programs and one for residential programs, or it may have one review subcommittee for minor incidents and one for serious incidents. The committees must review trend and pattern data across these divisions to gain an agency-wide perspective and to identify all consumers and staff who need attention.

A Closing Note

Sometimes, with all the attention to the reporting, investigation and review of incidents, employees forget that an event that results in an allegation of abuse or neglect is an interaction between human beings. Allegations can result from a variety of causes—from abusive and neglectful behavior, from misunderstanding or misinterpretation of benign behavior, from false accusations, accidents, and harmful, but nonetheless unintended, mistakes. In all appropriate instances, program administrators will want to facilitate a dialogue among the parties where feelings are shared, explanations offered, apologies made and accepted, and work toward reconciliation is begun.

Mistreatment of individuals is only occasionally the result of conscious actions by malevolent service providers; most commonly it is the by-product of a service system where both the individuals served and the staff have insufficient resources and supports. Environments which are pleasant, reflect the preferences and meet the needs of the people who use them, where staff have a genuine concern for the individuals they care for and support are essential to prevent abuse and neglect. Enriching the living and work environments of individuals with disabilities has the added benefit of fostering the development of self-advocacy skills and strengthening community protections for vulnerable individuals.

Creating Desirable Homes and Programs

Some organizations craft very individualized environments and forget basic protection from harm issues; others create safe and structured environments which are depersonalized and lack spontaneity. Exemplary programs have found a way to avoid the hazards and tap the best of both styles.

The characteristics of a quality life are individualized: the young man who considers his weekday lunch at a fast food restaurant a highlight of his day would not share a common definition of ideal living with the retiree who delights in spending the day sitting on his front porch snoozing and watching people pass by. Nonetheless, there are some considerations that are universal and supercede specific preferences. These include physical and emotional environment issues, activities, community supports, strategies for handling problematic behaviors and physical and mental health care.

The Physical Environment

An organization serious about preventing abuse and neglect will ensure that individuals live and engage in daily activities in pleasant environments. Listening to and closely watching an individual's expression of his wants and needs are essential to helping him construct environments that are pleasing to him. This checklist may be helpful in looking at existing programs and in thinking about ways to use space:

- Is the physical environment adequate in terms of space and function? Is lighting, ventilation, and temperature adequate?

- Are living and activity spaces clean?
- Are they well maintained and free of safety hazards? Are appropriate safety devices in working order, e.g., smoke detectors, fire extinguishers and mixing valves? Failure to pay adequate attention to safety measures can result in accidents and/or incidents. These lead to allegations of neglect against direct support staff present at the time of the occurrence and against administrators and supervisors for failing to exercise due diligence in maintaining a safe environment.
- Are there accommodations for quiet space? This is particularly important for people with communication difficulties, lest staff wait for behavioral cues, which sometimes are recognized too late. For example, at home, can people get away from the television and CD player, without having to go lie on their beds? At work can someone easily get to a space where he is away from others and from noise? If space is limited, even a small area protected by book cases with a rocking chair or recliner can be very helpful. Creating an attractive quiet space outdoors might also be an option.
- Have the privacy needs of individuals been respected? Are bedrooms and bathrooms private areas? Do employees promote telephone, mail, and visiting privacy?
- Do people choose decorations and accessories which express their personality or interests? Objects which have meaning to a person mark his space as his own and are more likely to be valued and handled carefully.
- Have specialists carefully assessed each individual's need for adaptive and augmentative devices and ensured that these are available as needed?
- Persons with communication difficulties have other communication systems and/or augmentative communication devices and are trained in their use. An inability to communicate pain and simple needs and wants may lead to problematic behaviors which, if not handled well by staff, can result in confrontations and physical interventions.

The Psychological Environment

Verbal and non-verbal communication both reflect and shape the psychological environment. Efforts to enhance the communication skills of persons with disabilities have a positive effect on the psychological environment, as well as on the individual. Additionally, they are often an essential first step in teaching individuals self-advocacy skills which empower them to recognize mistreatment and report it.

Self-advocates have identified good staff as the single most important factor is creating a quality home and work environment. Creating a supportive environment requires managers to ensure that there is a good fit between the staff and the individuals receiving services and or supports. This requires observing and listening to staff and to the individuals being supported. Self-advocates describe the impact of direct-service staff on their lives most clearly (Impact 1998):

> **To us it is really simple—if agencies have good staff, we have good lives. If agencies have bad staff who aren't trained, don't understand our disabilities or have attitude problems, we suffer the effects.**

The self-advocates indicated that good staff:

- Are supportive and try hard to understand our problems;
- Have creative ideas to help us resolve our anger and control our own behavior;
- Know our disabilities and know the things that are out of our control;
- Try to understand where we are coming from;
- Don't hold grudges;
- Are there for us when we need them;
- Are loyal, honest, trustworthy and respectful;
- Go out of their way for us.

The advocates were equally articulate in describing "bad" staff who:

- Don't show up for work when they are supposed to;
- Yell and threaten; hit us and put us in seclusion;
- Have bad attitudes;
- Steal and are disrespectful;
- Sit around all day just waiting until it is time to leave.

Ensuring a good fit between the staff and the people in the program means more than finding efficient personnel; it means finding staff who take their work seriously and form relationships with the people they care for. Without this bonding, an essential deterrent to abuse and neglect is lost. Every person receiving services or supports should get to spend some time each day with someone who is important to him. This special time helps fulfill a basic need for nurture and ensures a compassionate response to the hurt, pain and joy that are part of every life. It further provides the person with a safe place to talk about situations that cause him concern and where he feels protected if he makes a disclosure about abuse and neglect he has experienced or witnessed.

Caring relationships promote physical and psychological health, but everyday administrative considerations shape the emotional climate of services and supports as well. Staff need to be attentive to such issues as the real-time demands of taking care of an individual's personal care needs and the timing of meals, work, and leisure on a person's performance and behavior. Since periods of transition between activities and among employees are times when incidents often occur, sufficient time and staff should be provided to cover these periods.

Organizations need to clarify that discussions about providing quiet time and space to reduce the likelihood of stress-induced behavioral incidents do not sanction unimaginative, do-nothing programs. The objective is to enable individuals to be comfortable and peaceful, not sleep-inducing boredom. Exploring with employees the link between poor, unimaginative and unfulfilling activities and the discontent and behavior problems which ensue helps clarify the intent of these considerations.

Maintaining and Monitoring Quality Environments

Physical and emotional environments are fragile. Staff must ensure that they remain supportive and enriching. Employees can implement quality assurance plans which identify specific quality indicators, solicit the opinions and suggestions of the people served and establish monitoring and reporting procedures. In designing evaluation strategies, organizations need to support the cultural, ethnic and religious diversity of the service recipients and staff. Appreciation of this diversity should be evident in the assessment tools and in the training provided to staff who use them.

While objective measures of quality are often useful and necessary, they do not replace interpersonal interactions. Objective quality data is good, but the "grandmother" test (Would I want my grandmother to live/work/play here?) is the litmus test.

Activities

Testimony from persons with mental disabilities about the importance of meaningful work and activities to their sense of self-worth is convincing, and government, public agencies, and private providers have taken measures to remove obstacles which hinder persons with disabilities from reaching their work goals. The efforts that staff expend in finding work and activities that are fulfilling and enjoyable for participants are rewarded with positive and reinforcing interactions and fewer occasions of problematic behavior. Consequently, there are fewer instances where staff are intervening and unpleasant physical contact is likely — a situation frequently resulting in either abusive actions or actions interpreted as abusive.

Finding enjoyable and fulfilling activities for persons who are disabled and have had limited experiences means trying new undertakings in different environments. This will sometimes end in failure. Yet without the introduction of new experiences, what was once enjoyable becomes drudgery; what was once skill-building becomes mind-numbing. Activities which contribute to the happiness of others teach skills which enable individuals with disabilities to exercise control over aspects of their lives while they affirm our mutual interdependence. Finding enjoyable activities which enable persons with developmental disabilities to contribute to the common good, to be the "giver" and not always the "receiver" has become a priority for some exemplary programs. An old Jewish tale makes the point:

> **A young woman once asked a very old woman,**
> **"What is life's heaviest burden?"**
> **The old woman replied,**
> **"To have nothing to carry."**

Below is a short list of activities that have been successful. Programs might consider adapting these to meet their own requirements or they might spark new ideas.

- The cooking possibilities are limitless. In one town, individuals learning kitchen skills cut up salad greens and put them in plastic bags. They packed the bags into a box and placed the box on the lap of a classmate who used a wheel chair. Then the four pushed the wheel chair to a soup kitchen in a church down the street where they mixed the greens to make an attractive salad for the guests eating lunch. In another area, a church outreach worker asked for volunteers who would make soup for her to bring to people who had just been released from the hospital. A community residence signed up and makes a delicious chicken soup when their turn comes around.
- People interested in gardening adopted a plot of community land and were responsible for planting flowers and taking care of them. In one instance, this was a visual treat for everyone who used the public library.
- Individuals read stories to children in a nursing home. People who could not communicate well verbally wrote

their stories on their communication devices and shared them to the delight of the children and the staff.

- An entire day program agreed to support a community dinner to benefit a counseling center. Some people shaped the hundreds of meatballs that were needed, others made placemats to put under the flowers on each table, still others rolled a knife, fork and spoon in a napkin for place settings, others were greeters and ticket takers.
- Instead of simply going to the market to get supplies for their own residence, one home also does the grocery shopping for an elderly woman each week. Instead of one cart, the residents push two, and they deliver the groceries to the very grateful "grandmother" who often invites them in.
- Staff framed some of the artwork produced by people with disabilities, and it was placed in the hallways of several local banks and stores.

The positive reinforcement cycle which operates in these situations is powerful. The work itself is satisfying and provides practice in self-control. The praise and appreciation from those who receive the benefits act as an incentive to continue.

Community Supports

A fair measure of a disabled person's vulnerability is his degree of isolation. The suggestions for meaningful and enjoyable activities bring people with developmental disabilities into regular contact with the local community. As a result, they can make a contribution and become part of the community. These activities foster the development of relationships between people with disabilities and others. These relationships provide one of the surest defenses against undetected and unreported abuse and neglect.

The more people who know the person receiving supports, see him regularly and take an interest in him, the more likely it is that they will take action when something is wrong. For example, if the produce manager who knows the men and women who every week buy salad greens for the soup kitchen should see one of the men limping, wouldn't he ask what was wrong? In contrast, people who have little or no family contact and live in segregated settings, attend self-contained day programs and are seen by an advocate or service coordinator only a few times a year are particularly at risk.

Collegial relationships with others in the community are an important deterrent to abuse and neglect, but a close relationship with someone willing to enter into the life of a person with a disability, give good advice, and speak bravely and articulately on his behalf when necessary is the strongest defense against mistreatment. Family members traditionally play this role. In the absence of family, it is often difficult to find people who are comfortable in this role, and so service systems appoint paid advocates. While this is a positive measure, it should never be a rationale for slowing the search for someone who has a genuine, unpaid interest in the disabled individual. Finding such people requires that organizations publicize the need, provide the necessary supports to encourage the development of the relationship, and report the successes to the community at large.

Handling Difficult Behaviors

Seriously problematic behaviors of persons with disabilities are closely linked with abuse and neglect. Aggression, seriously self-injurious behavior, behaviors which repeatedly bring staff into contact with bodily fluids, and insulting and denigrating verbal assaults all require staff to demonstrate considerable self-restraint. Direct support staff are particularly effected by problematic behaviors because they deal with them most frequently and often in situations and at times when clinical staff and administrators are not available. An organization should maintain clinical staff during morning and evening routines which are times of close interaction and high stress.

Organizations need to assist some persons with developmental disabilities to enhance communication skills. Undifferentiated responses, such as yelling or head-banging, are inefficient methods to communicate the need for pain relief for a headache, for example. But if they are the only tools the individual has, he will use them to communicate. The nurturing of close relationships with people who can read the person's body language and other cues can provide a soothing response and reduce problems. Group and individual instruction related to anger management, relaxation techniques, and impulse control are useful not only for individuals who have problems in these areas, but also for others who live and work with them.

Staff who develop and implement treatment and behavior plans for persons with problematic behaviors might also want to consider two other techniques which can be visualized as bookends supporting the successful resolution of behavioral

incidents: the use of advance directives and de-briefing.

- When a person with a disability is able to talk about his problematic behavior and recognizes the need for staff to take action to protect him or others, establishing an advance directive may be useful. In this process, the individual (with a family member or advocate, if the person wishes), and the relevant staff meet and discuss how the individual would like staff to respond to the target behavior. He supplies important information about what he believes would help him curtail the behavior and those staff actions which would merely inflame the situation. Together, the group formulates an action plan which meets the objectives of each party. This plan is written out and signed by the participants. Each time the problem behavior is observed, staff remind the individual of the actions they will be taking and that he agreed to these because he believed they would be helpful to him. This technique is most useful with persons who have good communication skills and some insight into their behavioral difficulties. Persons with a dual diagnosis of developmental disability and mental illness can often use this technique profitably.
- When a behavioral incident is over and the individual has regained self-control and is willing to talk about it (or listen to staff talk), de-briefing can bring positive closure. Together the staff member and the individual determine what prompted the behavior and identify and perhaps rehearse preferable responses. They also review the staff's response to ensure that it is consistent with the advance directive and assess whether any changes are needed.

Physical and Mental Health Care

In instances where staff have the duty to provide physical and mental health care, failure to provide competent and timely care is neglect. The duty to establish, compassionately implement and ensure that people receive the medical and mental health care they need places considerable responsibility on staff at all levels. This checklist identifies some essential tasks:

HEALTH CARE COORDINATOR

- Has she secured a complete medical history of the individual?
- Has she secured a primary physician for the individual? Is she aware of all of the practitioners providing services to this individual? Does she communicate with these practitioners as necessary?
- Has she developed consultation forms and procedures which ensure that specialists are provided all of the information they need to treat the individual?
- Has she developed, with direct support staff, procedures to ensure timely medical follow-up recommended by a practitioner?
- Does she have access to a listing of all the medications an individual is taking? Are there procedures in place to ensure that medications are received from the pharmacy on time?
- Has she assured that staff caring for an individual understand his medical/mental health status? Has she alerted staff to signs and symptoms related to a specific condition or medication?
- Has she defined those common situations which call for consultation with a physician, e.g., temperature over 101 F, diarrhea for more than 24 hours, etc.?
- Has she established written protocols for responding to medical emergencies?
- Has she established written protocols for collecting essential medical data, such as seizure time, duration and characteristics, taking and recording vital signs when requested?

DIRECT SUPPORT STAFF

- Overall, have the policies and procedures developed by the health care coordinator been taught to direct support staff sufficiently well that they can be held accountable for implementing them?
- If they are administering medications, are direct support staff sufficiently trained and is their understanding and technique evaluated periodically? Do they understand the purpose of the medications they are giving?
- Do they know the medical and mental health status of the persons they care for? Do they know the signs and symptoms of common illness and also of the specific conditions of the people for whom they are caring?
- Do they know when to contact medical personnel and what to do if they cannot reach that person?
- Do direct support staff ensure that when an individual is taken to a medical appointment, he is accompanied by a knowledgeable staff member with whom he is comfortable?

Organizations can minimize abuse and neglect by paying attention to work life issues, particularly for staff in direct support roles. Organizations must protect individuals with developmental disabilities from persons who are likely to harm them. This requires the consistent application of recruitment strategies, screening and interviewing procedures.

The Role of the State

States have set up various systems for identifying people who have abused dependent persons or engaged in behavior which, if repeated, would place vulnerable individuals at extreme risk. The kind of information available and limitations on access are defined by law. In some situations, organizations may be able to obtain a criminal history check of a potential employee or match a job candidate against a sex-offender registry. In other instances, the state may keep a data base of persons who have abused dependent individuals.

The laws authorizing the collection of this information may place an affirmative obligation on an agency to follow specific procedures to clear candidates for employment and to report people whose actions might warrant their inclusion in the data base. For example, a state-wide data base might identify those adults who have been found to have abused or neglected children in the past. Programs which serve children in residential settings may be required to submit the names of new employees for screening. They may also be required to report allegations of child abuse and neglect, so that an independent investigation can determine culpability. The perpetrator's name would be added to the data base, if the investigation corroborated the allegation.

Since there are no universal rules governing information access, organizations need to be aware of the relevant laws, so that they can avail themselves of all information to which they are entitled and to ensure that they are in compliance with screening and reporting requirements.

Program Measures

Beyond using centralized information systems to screen candidates, organizations need to check references and contact a candidate's former employers. While it may be that former employers will merely confirm a person's term of employment, it is nonetheless important to make the

call, since it provides evidence that the agency took reasonable steps to screen employees, should a serious incident call the hiring practices of the agency into question. Additionally, when the human resource staffs of local agencies trust each other, they may signal through their reserved response to an inquiry that something is not right when a problematic person is under consideration.

Beyond avoiding hiring unsuitable staff, organizations face other difficulties finding good staff in a tight labor market. Organizations should identify and use the recruitment strategies that work best for them. For example, candidates who hear about a position from an existing staff member may have a more realistic idea of what the job entails and are more likely to be successful. This leads to the common practice of offering bonuses to staff for recruiting new hires. For those people who do not have an insider's description of what the job of direct support entails, organizations should present an accurate (not romanticized) picture of the job during interviews and visits to the program.

Organizations will want to consider how to structure the interview process so that it distinguishes between good and poor candidates. Some considerations might include:

- Group interviews and individual interviews;
- The inclusion of colleagues as well as supervisors and employees from another part of the organization in the interview process;
- The inclusion of persons with disabilities or their family members on the interview panel;
- The use of personality and/or work style assessments;
- The use of standard questions and theoretical situations to compare the responses of candidates;
- The merits of conducting the interview at the site where the person would be working;
- The advisability of having the candidate come for a visit and interact with the people with whom he would be working before a final choice is made.

Keeping Good Employees

Use of the Probationary Period

Every organization should use a probationary period of six months to a year during which it focuses attention on the performance of the novice staff member. During this time, the organization can determine whether the individual is performing adequately and terminate employment without having to build a case with lengthy, progressive discipline. But this is also the time for the organization to determine whether it is providing the guidance and feed-back the staff member needs to succeed. Monthly or semi-monthly face-to-face sessions with the supervisor, followed by a short written synopsis of the major points discussed keep each party aware of progress (or lack thereof) and the commitments for action made during the session. These short reports should provide the new employee, the supervisor, and other administrators a good sense of whether this employment relationship is working out.

Beyond looking at specific skills and time and attendance issues, the probationary period should be used to determine if the new staff member has built the kinds of relationships with the people he supports and cares for which enhance the quality of their lives. If someone cannot build these relationships during the period of time when he is getting sustained support, mentoring, training and attention, then he will not likely do it when these supports are less frequent and less intense.

Training and Mentoring

Acute staff shortages may force programs to hire individuals who do not have what at other times would be considered basic skills and qualifications. Thus, training and mentoring become particularly essential, if new staff are to be successful and if programs are to avoid the toll that repeated terminations take on morale and on the people being supported and cared for. Initial and refresher training for all staff should include a module on abuse and neglect — what it is, how to respond to it, and how the agency will respond, including a review of the investigation and review sequence and due process protections. Clear job descriptions and performance expectations also protect both the program and the staff. On-the-job mentoring by a senior staff person for a period of time determined by the needs of the trainee provides new staff with timely information and immediate opportunities for skill development, making it easier to retain and apply new knowledge. It simultaneously provides support, encouragement and immediate feed-back about performance.

Failure to ensure that novice employees get the initial training and support they need can cause potentially excellent staff to leave human services work. Consider the following examples:

- A young staff member was asked to assist Joseph, a non-verbal man with autism, to bathe and get ready for bed. He helped Joseph undress and adjusted the shower

water. He put his hand on Joe's shoulder to guide him into the shower. Joseph threw himself into the shower door and hit his head on the casing, causing a laceration which required ten sutures to close. An incident report was written alleging that Joseph had been abused, since he was being made to take a shower which terrified him (he normally took a bath). The investigation found that no one had explained Joseph's bathing routine to the new staff member and consequently found no substantiation of the abuse allegation. By this time, however, the young staff member had been terminated for "poor judgement," and he refused reinstatement when it was offered.

- A new staff member took a special interest in Kimberly, a young woman in his day habilitation group. Kim had a boyfriend. At Christmas the staff member bought Kim a bracelet and matching friendship ring. During an argument several weeks later, Kim told her boyfriend that the staff member had given her the bracelet and ring because he liked the way she kissed him. The boyfriend reported the alleged sexual contact between Kim and the staff member. The ensuing investigation caused serious upheaval in everyone's life. At its conclusion, Kim acknowledged that there had been no kissing or other sexual contact. It was further determined that the policy which cautioned staff about buying gifts for consumers was not discussed as the holidays approached, contained no directive to consult with a supervisor before giving a gift, and no guidance as to what kinds of gifts were generally appropriate and under what circumstances.
- A staff member who usually worked in a day program was earning extra money working the night shift at a community residence. He was greeted by a supervisor and assured that after he read the daily log, he would feel comfortable and enjoy his shift. The supervisor then left him alone. The moonlighting staff member read the log which contained a notation that Andrea was to be NPO from midnight for tests in the morning. Andrea awoke early in the morning and, believing he was being helpful, the staff member gave Andrea her breakfast. When the error was discovered, the staff member incurred the wrath of the house supervisor and the physician, and he caused Andrea to have to repeat the pre-test procedures. The investigation of the allegation of medical neglect revealed that the agency had scheduled this staff person for medication administration training (at which time he would have learned that NPO meant "nothing by mouth") on three occasions, and for different reasons he had not attended. No one had followed-up.

Respect, Status and Support

Direct support staff determine quality because they provide the direct service or support. They are present at the "moment of truth" when the person experiences the service or support, exercise an immediate effect for good or ill on the people whom they support, and therein determine quality. They also are the repository of valuable information about individuals that sometimes only comes from being really close to someone, from being with him on holidays when everyone else is home and on lonely Sunday afternoons; from taking care of him in the night when he is sick; from studying his reaction to the Beatles and Beethoven. Yet, these most knowledgeable people are not regularly present and consulted during program planning. When their seat at the table is empty, the repercussions can be manifold.

Organizations enhance quality by treating direct support workers as professionals:

- Providing them with the clinical and other supports they need to do their job well;
- Empowering good employees to be creative and assertive in searching out those experiences which will make life more fulfilling for the people they support;
- Publicly acknowledging the good work of these employees and broadcasting their good ideas;
- Creating career ladders for direct support staff;
- Offering opportunities for professional growth through tuition vouchers and work study plans through affiliations with community colleges and universities. (A consortium of human service agencies working together may be a useful model for creating alliances with educational facilities and sharing training resources.)

Leaving direct support staff to "work problems out," to try it out, to muddle through, without sufficient assistance and support leads to mistreatment or neglect. This is most certainly the case when direct care staff are dealing with persons with aggressive behavior. One of the simplest and surest ways to create an abusive situation is to leave a single staff member to cope with an aggressive individual. The physical contact that almost invariably ensues poses the likelihood of pain and injury to both parties.

Organizations which permit physical interventions should provide three to four times more time teaching staff skills to help avoid these confrontations as they spend teaching restraining techniques. Further, they will refuse to sanction the use of one-person physical restraining interventions except in cases of imminent danger to a human being.

Fair, Proportional and Progressive Discipline

The certitude that an employee will be treated fairly when an untoward event occurs is essential to a quality work environment. Without it, a code of silence develops where employees will fail to report abuse and neglect when they see it and will give less than full cooperation to investigations. Agencies where employees have few contractually-guaranteed due process rights must be particularly diligent to ensure that they avoid using dismissal as a disciplinary option for less serious offenses and where the staff action was prompted by a systemic problem. Neglect, often caused because too few staff are working or because tired staff are working a double shift, happens every day in programs. The search for underlying causes of ominous incidents helps place staff actions in context and supports proportional and progressive discipline.

Conclusion

Effective incident management practices are integrated with a quality of life outcome orientation and a quality of work life practices for employees. Organizations function as systems, and an agency that demonstrates concern for its employees will find, more often than not, that employees effectively facilitate personal outcomes for the people receiving services and supports.

The quality of life and quality of work life principles promote the prevention, investigation, and review of allegations of abuse and neglect. The interaction among staff, people served by the organization, family, friends and community strengthens relationships between and among people. These strong individual, family, and neighborhood relationships discourage incidents of abuse and neglect. The close interactions and friendships also make it more difficult to conceal patterns of abuse and neglect.

The quality of life and quality of work life values and practices do not provide a substitute for strong management and effective incident management practices. They do, however, provide a context for maintaining a strong incident management program. The organization that implements quality of life and quality of work life principles and practices can promote an aggressive incident management program because it believes in the human values of all people — employees and people served by the organization.

1. De-Wayne Davis, Wendy Fox-Grage and Shelly Gehshan. ***Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators.*** (Washington, DC: National Conference of State Legislatures, 2000).

2. Robert Prouty and K. Charlie Lakin (eds.). ***Residential Services for Persons with Developmental Disabilities: Status and Trends through 1998.*** (Minneapolis: Institute on Community Integration, 1999).

3. David Braddock, Richard Hemp, Susan Parish and Mary C. Rizzolo. ***The State of the States in Developmental Disabilities: 2000 Study Summary.*** (Chicago: University of Illinois at Chicago, 2000).

4. Robert Prouty and K. Charlie Lakin (eds.). ***Residential Services for Persons with Developmental Disabilities: Status and Trends through 1998.*** (Minneapolis: Institute on Community Integration, 1999).

5. De-Wayne Davis, Wendy Fox-Grage and Shelly Gehshan. ***Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators.*** (Washington, DC: National Conference of State Legislatures, 2000).

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