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ABSTRACT

These guidelines are intended to assist states and local communities in developing quality respite services that meet the diverse needs of families and children with disabilities, with chronic and terminal illnesses, or at risk of abuse or neglect. The guidelines support the philosophy that all families can benefit from temporary intervals of rest and relief (respite) from caregiving responsibilities. Respite reduces family stress, helps preserve the family unit, supports family stability, and prevents possible abuse situations. The guidelines address the following broad areas: (1) family involvement; (2) care needs of the child; (3) care providers; (4) community involvement; (5) service delivery; (6) administration; and (7) evaluation. (DB)

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ACCESS TO RESPITE CARE AND HELP

NATIONAL RESPITE GUIDELINES

Respite Services for Families of Children with Disabilities
Chronic and Terminal Illnesses
and
Children At Risk of Abuse or Neglect

Developed by

ARCH National Resource Center
for Respite and Crisis Care Services

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NATIONAL RESPITE GUIDELINES

Respite Services for Families of Children with Disabilities, Chronic and Terminal Illnesses, and Children At Risk of Abuse or Neglect

Introduction

Background

Respite care programs emerged in the late 1960's as a result of the deinstitutionalization movement with the belief that the best place to care for a child with disabilities was in the child's home and the community. Respite became an essential component in the overall support services that families needed to care for their child at home.

In the 1970's another type of respite emerged in the form of crisis nurseries. These nurseries were designed to provide temporary child care for young children at risk of abuse and neglect, and to offer an array of support services to the families and caregivers of these children.

Recognizing the effectiveness of respite and crisis nursery services, in 1986, Congress passed the Temporary Child Care for Children with Disabilities and Crisis Nurseries Act (as amended). This act established federal funding for respite and crisis nursery demonstration projects. Administered through the U.S. Department of Health and Human Services, Administration for Children and Families, Administration on Children, Youth and Families, Children's Bureau, competitive grants have been awarded to states since 1988 to assist public and private agencies in developing model temporary care services across the nation.

As more and more respite services are being developed, and interest from local communities is on the rise, some confusion has arisen concerning the definitions of respite and crisis nursery services. Because the differences between these two types of temporary care are negligible, and the goals of each are family support, family preservation, and prevention, professionals and families who use the services prefer a more generic definition that reflects the philosophy behind the intent of the services.

Respite, temporary relief for families and caregivers, is a service in which care is provided to children with disabilities, chronic or terminal illnesses, and to children at risk of abuse and neglect. Respite can occur in the child's home or in a variety of out-of-home settings, and can occur for any length of time depending on the needs of the family and available resources. As a vital part of the continuum of services for families, respite reduces family stress and thereby helps preserve the family unit, supports family stability, and prevents lengthy and costly out-of-home placements and possible abuse and neglect situations.

Access to Respite Care and Help (ARCH)

ARCH is a National Network and Resource Center designed to create a nationwide system of respite options that provide temporary relief and support to families and caregivers. In order to meet the needs of this nationwide system, ARCH provides information, training, technical assistance, evaluation, and research activities to service providers, families, and states in developing and maintaining respite services. This work affords ARCH an opportunity to view a range of respite models and programs which subsequently brings knowledge of quality of respite services. With the large numbers of new programs springing up across the nation, ARCH believes it is important to establish some guiding principles for respite programs to follow.

The National Guidelines

Because of ARCH's commitment to strengthening and preserving family stability by developing flexible, affordable respite options that address individual family choice and need, these National Guidelines have been prepared to assist service providers in developing quality services, and to help families have some means of discerning the quality of their options.

The guidelines support the philosophy that all families can benefit from temporary intervals of rest and relief from caregiving responsibilities and that respite should be available to all families who need it. The guidelines are intended to reflect a family-centered philosophy that recognizes and draws upon family strengths.

The guidelines are not attempting to set standards or requirements, but merely to establish some guidelines to assist states and local communities in developing quality respite services that meet the diverse needs of families. Programs must consult with state, county, and/or local licensing agencies to make sure they are in compliance with licensing or certification rules that apply to the type and location of the services.

Respite can be provided in a variety of settings and these guidelines are intended to cover general principles that apply to all of them. Respite may be offered in the child's home, a provider's home, a child care center, family day care home, group home, or foster home, via community recreation programs or summer camps, in hospitals, shelters, residential facilities, or facilities designed specifically for the provision of respite care.

Contributions to these guidelines have been made by families, respite providers, administrative personnel, licensors, nurses, social workers, educators, government agency personnel, and a host of others. The common thread among the contributors is the philosophy that all families can benefit from temporary relief from caregiving without fear of endangering their child or the relationship with their child, and that all children should receive quality care from competent, caring providers.

I. Family Involvement

Note: *Within this document, "family" has been used to designate the child's parent or primary caregiver. This could include biological, adoptive, foster, and extended families.*

- 1.1 Respite programs should involve families in service design and implementation.
 - 1.1.1 Programs should solicit family input regarding service delivery on an ongoing basis (e.g. needs assessments, service satisfaction surveys, advisory boards).
 - 1.1.2 Programs and families should work together to clearly define family roles and responsibilities within the services being provided.
- 1.2 Respite services should be developed so that they are family-centered.
 - 1.2.1 Programs should build on the strengths and resources of families.
 - 1.2.2 Programs should assist families in identifying their particular need(s) for services.
 - 1.2.3 Families should receive appropriate emotional support and reassurance about having their child in care.
 - 1.2.4 Family preferences for service entry, location, hours, activities and delivery should be respected and accommodated to the greatest extent possible.
 - 1.2.5 Families should have access to their children while they are in care.
- 1.3 Each family's unique characteristics should be respected in the provision of respite services.
 - 1.3.1 Each family's cultural heritage should be acknowledged and respected. Every effort should be made to incorporate the family's cultural needs into the respite services.
 - 1.3.2 Diversity in family composition should be acknowledged and supported in the provision of respite services.
 - 1.3.3 Each family's spiritual beliefs should be acknowledged and respected.
- 1.4 Family privacy and confidentiality should be respected at all times by program staff and volunteers.
 - 1.4.1 Programs should only request information that is necessary for the provision and evaluation of services.
 - 1.4.2 All written records and oral interactions (for example, phone conversations, meetings) should be kept confidential.
- 1.5 If specific ancillary services are not available to families within the respite program, families should be referred to other community agencies that can meet their services needs.
 - 1.5.1 Programs should identify and maintain current information on other community services that families may find helpful.
 - 1.5.2 Programs should facilitate referral to other services, when requested.

II. Care Needs of Child

- 2.1 Each child receiving respite services should be treated as an individual, with his or her unique strengths and needs acknowledged and planned for accordingly.
- 2.1.1 Children should not be grouped or labeled based on their disability and/or presenting diagnosis.
- 2.1.2 The care provider assigned to the child should have appropriate skills and sufficient information about the child to be sensitive in meeting the child's needs.
- 2.1.3 Family/child routines and preferences should be respected and maintained whenever possible.
- 2.1.4 If requested and appropriate, families should be able to receive respite services for all of their children. If respite is offered outside the family's home, siblings should remain together or have access to one another.
- 2.2 Respite services should be designed to respect each child's privacy and possessions.
- 2.2.1 When children are receiving respite care in out-of-home settings, they should be permitted to bring with them some special personal possessions in addition to their clothes.
- 2.2.2 A child's need for privacy should be respected without compromising the child's safety.
- 2.3 Children need to be cared for in ways that support their physical, emotional, cultural, spiritual, and social well-being.
- 2.3.1 Children should be encouraged to perform physical activities which they have an interest in, which they are capable of, which they are learning, and which do not compromise their safety.
- 2.3.2 Children should be encouraged to express their fears, anxieties, frustrations, anger, sadness, and/or joy with adult support, and without compromising the safety of the child, other children, or the care provider(s).
- 2.3.3 Each child's cultural heritage should be acknowledged and respected. Every effort should be made to incorporate the child's cultural needs into the respite setting.
- 2.3.4 Each child's spiritual beliefs and practices should be acknowledged and respected. Individual religious practices should only be encouraged if they are at the request of the child and/or family.
- 2.3.5 Respite services should support a child's social development with respect to the child's

cultural and social history. Children should be provided ample opportunity to engage in social activities with other children and adults. Such activities should be developmentally appropriate and should not compromise the child's safety.

- 2.4 Each child receiving respite care should be provided with interesting, creative and developmentally appropriate activities.
 - 2.4.1 All infants and children should be given stimulation and encouragement to explore their environment.
 - 2.4.2 Television viewing should be minimized for all age groups. If television is viewed, programming should be developmentally appropriate, and the care provider should interact with the child and provide companion activities to enhance the experience.
 - 2.4.3 While in respite care, infants and children should have a structured schedule to help them feel secure. Periodic free play sessions with options and choices for children should be part of the daily schedule.
 - 2.4.4 Care should be given to see that children cared for in mixed age groupings do not become bored with activities above or below their developmental level. Every child needs to experience competencies and challenges that enhance self-esteem.
- 2.5 Each child receiving respite care is entitled to good nutrition.
 - 2.5.1 Family/child food preferences should be respected in planning and providing for each child's nutritional needs.
 - 2.5.2 USDA nutritional guidelines should be followed for all age groups.
 - 2.5.3 Meals should be attractively presented, occur regularly and frequently, and should never be limited in quantity (unless under physician's orders), withheld, or forced.
 - 2.5.4 Meals should provide a socially pleasant environment and care providers should eat with children.
 - 2.5.5 Children should be encouraged to feed themselves as independently as possible.
 - 2.5.6 Infants should always be held for bottle feedings and spoken to while being fed.
- 2.6 Children receiving respite care are entitled to experience good hygiene and any needed health care.
 - 2.6.1 Children should be bathed and dressed in clean, appropriate clothing and should be shown respect in the process.
 - 2.6.2 Children should have daily dental hygiene.
 - 2.6.3 Children's hair should be clean and free of lice, and should be brushed and combed as well. A child's hair should never be cut or hair style altered without parental permission. Special hair and skin care should be available for children who need it.
 - 2.6.4 Pertinent medical information should be solicited and kept by the service agency and/or respite provider.

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- 2.6.5 The service agency and/or respite provider should have information on contacting the family in the event of an emergency. When an emergency occurs, the family should be contacted immediately.
 - 2.6.6 A signed consent by the family (primary caregiver; legal guardian) should allow for immediate medical emergency treatment in the event of an accident or illness while the child is in care.
 - 2.6.7 Prescription medication that needs to be administered to the child by the provider should be administered only with the written consent of a parent or guardian and under applicable state laws. If the child receives medical attention while in care, written permission to administer medications in accordance with the prescription should be obtained from the physician prescribing medications. Documentation should include date, time, dose, and name of the person who administered the medication. A copy of the medication documentation should be given to the parent/guardian when the child leaves care.
 - 2.6.8 Families should be assisted in accessing any needed health care for their child, if appropriate.
- 2.7 The respite care setting should be clean, safe, and free of hazards for children.
- 2.7.1 Children should be free to explore an environment that is free of safety hazards. (For example, a toddler should not be exposed to a play area that includes tiny toy pieces that could end up being choked on or swallowed.)
 - 2.7.2 Children should be supervised by an adult at all times while in care.
 - 2.7.3 Children should be protected from physical, sexual, and emotional abuse by other children and care providers.

III. Care Providers

Note: *The information presented in this section and the sections that follow is pertinent for providers working within a formal respite program which is administered by an agency. Some of the information included may also be appropriate for providers who provide respite services as independent contractors or as part of a generic community service (i.e. parks and recreation program), or who provide respite more informally (i.e. volunteer program, parent co-op). In situations where cash assistance is provided for family members to locate, train, and hire their own provider, then the family may want to directly address some of the guidelines in this section.*

- 3.1 Recruitment campaigns for providers should be carefully planned to encourage potential providers to respond to the need for respite.
 - 3.1.1 Families should be encouraged to identify providers whenever appropriate.
 - 3.1.2 Efforts should be made to recruit providers from ethnic and cultural groups similar to the families being served.

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- 3.1.3 Efforts should be made to recruit providers representing both male and female role models for children.
 - 3.1.4 Efforts should be made to recruit providers who live in areas easily accessible to families.
 - 3.2 Because providers are the key to successful programs, it is important to thoroughly assess their qualifications and character.
 - 3.2.1 Providers should be of good moral character and have no record of committing crimes against children.
 - 3.2.2 Providers should be knowledgeable about child development and developmentally appropriate activities.
 - 3.2.3 Providers should have experience working with the population of families and children they are serving (i.e. families of children with disabilities, chronic or terminal illnesses; families in crisis) and demonstrate compassion and understanding.
 - 3.3 Paid staff should be paid a worthy wage for their work.
 - 3.3.1 Respite programs should make every effort to pay providers wages appropriate to their level of experience and the type of care they give.
 - 3.3.2 Whenever appropriate and possible, providers should receive benefits such as health insurance, paid sick and vacation days, and a retirement package.
 - 3.4 Whether performing their work in the company of co-workers or in the isolation of their home or the family's home, providers should have access to peer support for the difficult and challenging work they do.
 - 3.4.1 Regular staff meetings and inservice training should be available to all providers.
 - 3.4.2 An administrative staff person should be assigned the duty of maintaining consistent and ongoing contact with providers to answer questions, listen to their grievances, and share in the joys of providing respite services.
 - 3.4.3 In case of emergencies while a child is in care, providers should have access to an administrative staff person at all times.
 - 3.5 Providers and volunteers should receive preservice training, as well as regular inservice training on topics relevant to their work.
 - 3.5.1 Family members should be involved in determining training content and in assisting in the training of providers. Training could involve formal group presentations, as well as direct training of providers by family members in the home.
 - 3.5.2 Providers should receive training which not only enhances their skills, but lets them know they are a valued member of a team, worthy of receiving information to improve the quality of their work. Whenever possible, providers should be involved in determining the training and in assisting in the presentation of training.

3.5.3 Providers should receive training prior to giving care to children. Training should be individualized to meet the needs of providers. In some situations, providers may already possess the requisite skills and background. In general, the following topics should be included in training for providers caring for children. Additional topics may need to be added in specific circumstances.

- Overview of respite services
- Confidentiality
- Policies and procedures for the respite program
- Child development
- Conditions of children which providers are likely to encounter, such as disabilities, chronic or terminal illnesses, and children at risk for abuse and neglect
- Emergency procedures (First Aid, CPR, program emergency protocols)
- General information about the spread of infectious disease, and universal precautions to be used in the care of children to avoid the spread of disease
- Behavior management; what behaviors to expect from children with disabilities and chronic or terminal illness and/or children whose family is experiencing crisis; managing children with difficult behaviors
- Effective ways to work with families of children with disabilities and chronic or terminal illnesses and/or families in crisis
- Program procedures for the administration of medication and other health-related tasks; special hair and skin care
- Cultural diversity and sensitivity
- Child abuse and neglect detection and reporting protocol
- Crisis intervention; issues in domestic violence and substance abuse
- Planning and preparing developmentally appropriate activities; maintaining appropriate routines and schedules for children

3.5.4 Providers and programs should exceed state licensing requirements, as needed, in determining the ratio of children to providers to meet the special needs of particular children.

Children in respite care frequently have additional needs for assistance and supervision. Providers can more readily respond to those needs if they have only a few children in their care. It is recommended that the adult/child care ratio be determined by the individualized needs of each child. In practice this will mean that some care will be appropriately provided in small groups, and, in some instances, care will be provided on an individual basis.

IV. Community Involvement

- 4.1 Respite service options should be developed and provided within the context of the family's community and its unique characteristics. When planning and providing respite services, programs should conduct a survey of community resources and needs. This process serves to gather information, educate the community about respite service options, and foster collaborative relationships.
- 4.1.1 Programs should conduct outreach activities through phone calls, mailings, and meetings to determine what services are currently available within the community and what gaps and needs exist. A broad array of community agencies should be contacted.
- Examples of organizations that might be included are: human service agencies, parent groups, disability organizations, schools, health agencies, child care centers, family day care providers, recreation programs, summer camps, group homes, residential programs, local government, hospitals, clinics, shelters, substance abuse treatment programs, crisis intervention agencies, business, religious and community service organizations.
- 4.1.2 Generic community programs should be contacted to determine if they are currently providing services to families of children with disabilities and chronic or terminal illnesses and/or families in crisis. When necessary, generic programs should be educated about the Americans with Disabilities Act (ADA) and families in crisis, and provided with resource information and technical support.
- 4.1.3 Agencies already known to provide respite services to these populations should be contacted for updates and consultation regarding new programs.
- 4.2 Once it is clear what community services are available and what gaps exist, then respite programs should plan their service development to meet specific needs. Community service coordination and collaboration should be built into program development and service delivery plans. Communities should plan an array of respite service options to meet the changing and diverse needs of families.
- 4.2.1 Information should be maintained on all agencies providing respite services.
- 4.2.2 Information should be solicited and maintained on all agencies providing additional services to families of children with disabilities and chronic or terminal illnesses and/or families in crisis.
- 4.2.3 Each respite program should provide other community agencies with relevant information about their program, such as the population served, program description, and referral procedures.
- 4.3 When planning and providing services, respite programs should collaborate with other agencies and parent/family organizations to enhance service provision.
- 4.3.1 Service options should be developed which meet the needs of families who are unserved or underserved and which interface effectively with existing service systems, programs, and existing natural supports.

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- 4.3.2 Programs should engage in interagency collaboration to enhance the array of respite services, thus providing families with appropriate choices and options.
 - 4.3.3 Respite programs should consider collaboration on training, funding, sharing technical expertise and support, and the development of multiple community service options.
 - 4.4 Programs should develop plans to include marketing and fundraising goals. The ability of an organization to continually adjust its services to meet consumer needs is key to its survival.
 - 4.4.1 Programs should develop a mission statement.
 - 4.4.2 Goals, objectives, and action plans should be established to determine the program's role in the community.
 - 4.4.3 The respective needs of primary and secondary consumers should be analyzed continually and adjustments should be made accordingly.
 - 4.4.4 Programs should have a well developed promotional campaign as a result of their marketing efforts.

V. Service Delivery

- 5.1 Respite services should be "family friendly" and easy to access. It should be clear to families what they need to do to receive services (e.g. who to call, paperwork, eligibility).
 - 5.1.1 Programs should have one point of entry for families to access services (e.g. help line, referral agency, case management).
 - 5.1.2 Programs should make the entry process clear to families and simple to follow.
 - 5.1.3 Programs should have guidelines for eligibility, selection, and priority for services.
 - 5.1.4 If necessary, programs should maintain a waiting list and provide respite services to those families as soon as possible.
- 5.2 Respite services should be planned and developed so that a variety of family needs can be met. Service options need to be flexible and responsive to the changing needs of families.
 - 5.2.1 Services should be available during the day, for overnight care, and for longer periods of time, if necessary.
 - 5.2.2 Services should be made available in generic community settings where families receive other services, whenever possible.
 - 5.2.3 Services should be made available on a planned or immediate basis, to be responsive to family needs. Families should have a choice of provider and should be able to request a change in provider.
- 5.3 In order to offer families a range of service options which will meet their current and future needs, communities and programs should provide service options that address the needs of families. Respite services could include the following:

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- An in-home program, where services are provided in the family's home or a care provider's home
 - A center-based program, where families bring their child to a facility in their community to receive respite care
 - A child care setting, such as a child care center or a family day care home, which is designed to provide respite care in addition to their regular child care services
 - Recreational programs provided through parks and recreation departments and YMCA agencies, which provide recreational programs that offer families respite breaks
 - Generic community programs where children receiving respite services are integrated into programs provided for all children
 - Summer camps that provide day time or overnight options
 - Residential and group home programs
 - Licensed foster homes for children
 - Emergency shelters for children and shelters for the homeless
 - Hospital-based programs
 - Cash assistance or parent subsidies so families can pay for and access respite care options of their choice
 - Registries that list providers so families can make their own decisions on choice of providers

5.4 In addition to respite care, many programs provide additional related services to enhance the respite experience and to meet other needs that families may have. Agencies should facilitate each family's awareness of, and access to, additional services within the agency, and from other agencies or sources. These services could include:

- Transportation
- Parent education
- Parent, sibling, and family support groups
- Counseling and therapy services
- Case management or service coordination
- Early intervention services

VI. Administration

6.1 An advisory committee or board should be established to provide oversight for respite programs. Representation should include family members, community members, and professionals involved in human services. Depending on program needs, it may be helpful to include an attorney, accountant, health care professional, child care provider, psychologist, or other relevant community mem-

bers. Whenever possible, it is desirable to have a board member with professional expertise and experience in marketing. If an advisory committee or board is already in place, a representative or subcommittee should be assigned to address relevant program issues.

6.2 Each respite program should develop policies and procedures which address the specific needs of their program. Policies and procedures should be developed on the following topics, when appropriate for the program model:

- Program mission and philosophy statement
- Types of services available
- Standards of care for children receiving services
- General emergency procedures (e.g. medical, home or facility)
- Family and child rights and responsibilities
- Family confidentiality
- Program entry and departure procedures
- Record keeping
- Medication administration and other health-related tasks
- Transporting children
- Staff behavior and expectations
- Staff communication
- Staffing ratios
- Staff job descriptions
- Other program-specific topics

6.3 Respite programs should develop a risk management plan to address quality of care and liability issues.

6.3.1 Programs should develop policies and procedures which describe all program services, staff responsibilities, and operating procedures as outlined in the previous section.

6.3.2 Programs should develop a risk management plan, to include the following steps:

- Identify the risks for providing services through the program.
- Analyze and evaluate the risks.
- Control or reduce the risks.
- Protect the agency and the consumers of its services.
- Address any risk management failures to avoid future problems.

6.3.3 Programs should consult with an attorney to review all policies and procedures, as well as the risk management plan.

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- 6.4 Respite includes a broad array of service options, some of which are licensed and/or regulated. Many respite programs are currently licensed and/or regulated through other program categories, such as child care, residential care, emergency shelter care, home health care or foster care. Respite programs have a responsibility to be aware of and to be in compliance with the specific state licensing requirements that *may* govern their activities.
- 6.4.1 Programs should contact their state and local agencies which license family child care, center child care, residential care, emergency shelter care, home health care and/or foster care to determine if any of their program services require licensing.
- 6.4.2 Home- and center-based programs should ascertain whether the health department and fire department need to inspect the premises on a regular basis.
- 6.4.3 The child's family should be made aware of whether or not the service provided falls under state licensing requirements.
- 6.5 Many respite services are provided through interagency efforts. In some instances a particular agency employs the care provider. Other times the care provider may be an independent contractor (i.e. self-employed) *or the family may choose and employ the provider.*
- 6.5.1 Respite programs which contract with providers to care for children in their homes or the family's home, should inform them that as independent contractors they must comply with IRS code requirements for the self-employed. All federal, state, and local taxes must be paid by the independent contractor.
- 6.5.2 When family members directly hire their own care provider, they act as an employer, and provide payment for services. Agencies involved in providing funds and/or training providers should make families aware of the requirements of IRS Publication 926 - Employment Taxes for Household Employers.

VII. Evaluation

- 7.1 Program evaluation serves as a useful tool to monitor the success of the program in relation to its mission and goals, and can be used to provide "objective" detailed explanation of accomplishments which is useful for attracting consumers, furthering collaboration and obtaining funding. Evaluation should start when services begin and continue throughout the duration of the program, as it is useful in improving services and service delivery. Evaluation information is also critical to the funding source, and should be carefully planned to answer key questions.
- 7.2 Respite programs should systematically conduct evaluations of their service delivery.
- 7.2.1 Minimally, the following data should be collected and evaluated on a regular basis:
- Consumer satisfaction with services
 - Units of service (numbers of children and families served; hours/days of care)
 - Ethnicity of families

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- Requests for service and waiting lists
 - Costs of services

7.2.2 Ideally, programs should evaluate the following:

- Reasons families are seeking services
- Impact of services on family stress and quality of life
- Family requests for service changes, expansion, and new service development
- Family involvement in services
- Staff satisfaction
- Program cost-effectiveness
- Impact of the services on the community
- Special activities (public awareness; fundraising)



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