

Disability Issues formerly Together

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a publication of the *Information Center*

Disability Information: A Vision

by Nancy C. Schock

FFor many years, my consuming interest, second only to my family and home, has been searching for information about disabilities. The information includes facts and ideas on how to prevail, and how to find sources of help. My goal has been to create a store of knowledge that can be used by individuals living with disability, and other concerned people, in developing their lives.

The search began in the 1950s when we discovered that our 4-year-old daughter had a severe hearing loss. It increased greatly when our fourth child, a son, was diagnosed with Duchenne Muscular Dystrophy. While seeking information on how to help our daughter, son and other three children flourish, I learned that there appeared to be no single collection of information that could provide us with answers nor even start us on our search for solutions. Whatever pockets of information existed were elusive, and an appropriate language and system for describing and organizing information had not been developed. As the years went by, and after locating resources such as *Accent Magazine* and the *Rehabilitation Gazette*—which led to other resources—I made some progress with my search.

Finding ways for people with disability to expand and enrich

their lives has been a most challenging and exciting task. From the beginning, I saved tidbits of information unrelated to our specific needs. I believed that information on any disability and for any age might benefit someone and was too precious to let go. Although I did not publicize my growing files, neighbors and friends increasingly referred people dealing with disabilities to me for help because of our personal experiences. In time, it was clear that trying to collect, evaluate, and disseminate all this information was too much for one person. It was then that I began defining my dream, which led to my vision.

My dream was that life could be richer for people living under circumstances different from their neighbors or associates. It could be richer if they had access to resources or guidelines about their particular situation that would lead them into the mainstream of life. My vision has been, and continues to be, the creation and maintenance of a comprehensive source of information that persons living with disability, and others seeking to help, could access directly and receive a response that will enhance their lives. The access could be through any means: person-to-person, by telephone, by attending a meeting, or by printed material in either paper

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Fay Honored

Information Center board member and independent living pioneer, Dr. Frederick A. Fay was recently recognized with the 1997 Henry B. Betts Award. The Betts Award is funded by the Prince Charitable Trusts and is named for the chairman of the Rehabilitation Institute of Chicago. It is presented to recognize leaders who effect meaningful change that enhances the quality of life experienced by people with disabilities.

Dr. Fay was introduced to the ceremony at the Library of Congress, via the wonders of modern telecommunications, by Justin Dart, Jr. who chaired the committee which selected him for the honor. The event was attended by the Center's president, Nancy Schock.

Fred Fay, working entirely from his home in Concord, Massachusetts, has been for years the unparalleled advocate, organizer, leader, political activist, thinker, and lobbyist for rights

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INSIDE

FROM THE CENTER
RESOURCES
EDUCATION
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QUESTION & ANSWER

January/March 1998

Center Sets Goals for the Future

The Information Center has completed the first step of a Needs Assessment/Strategic Planning process.

From our two hundred survey forms printed in the last edition of *Disability Issues*, and meetings with social service organizations, analysis of telephone records (we still receive 400-500 calls per month), discussions with business, community, and government leaders, the Board learned a great deal about the needs of our constituents. The Center thanks you for your interest and the time you took to answer our survey.

The results were overwhelming and clear. Respondents to the survey are interested in seeing the Information Center resume full operations.

Executive Director Matt LaBarre explains that feedback indicates a dramatic need for timely information in the areas of housing, early intervention, equipment/technology, access, and transportation. Individuals living with disability are also in need of responses to their questions about counseling, support, travel, recreation, and education. "Even more overwhelming" according to LaBarre, "was the consistent expression of the need for a personalized and interactive dialogue around individuals' requests for assistance."

After reviewing the needs assessment data, the board committed to a two phase Strategic Plan. Highlights of the plan include:

- Building a mostly all-volunteer organization that will include regional steering committees to acquire information and referral data and assist in education, outreach, advocacy, and fundraising. Eventually, the organization's office will be staffed by volunteers coordinated by an Operations Manager.
- Developing a broad-based fundraising program — building on "investments" from individuals, fraternal organizations, businesses, and foundations, as well as occasionally pursuing some state grants. We need to develop and rely on broad and varied support to insure a secure future for the organization.
- Conducting a Public Information Program to let more people, potential users of our services as well as donors, know about the Information Center.

Our ability to reach our goal of resuming all our programs and services, as well as potential new programs, is predicated on our ability to raise at least \$90,000 in the next 3-6 months. **Your help is important to our success.**

"We are blessed with a number of new volunteers who have indicated an interest in active program participation through the surveys. However, to be successful, we need more volunteers right in your own community. And, of course, we need your continued financial support" LaBarre continues.

Anyone interested in participating in this exciting effort in a voluntary, advisory, or financial capacity should call Matt LaBarre at (508) 898-9360.

911 and Us

Enhanced 911 service has come to Massachusetts and offers significant benefits for people with certain disabilities. If it has not yet come to your state, it will soon.

E911 Silent Call Feature assures equal access to the emergency telephone network for callers who, for whatever reason, can not speak aloud. You can now call 911 and communicate your emergency needs by pressing specific keys. A 1 tells the operator that you need police, 2 means fire, and 3 indicates you require medical assistance.

If you need help and can not speak because of disability or the situation your in, such as home invasion or abuse, you can still call 911. The telecom-municator who receives a silent call will ask the caller a series of questions about their situation. You will be able to answer by use of the touch-tone keypad. For example the number 4 means yes and 5 means no.

With enhanced 911 the operator sees the address you are calling from on the screen before them and your "silent" answers determine the specific emergency response to be dispatched.

If you need more information on enhanced 911 you may call the Statewide Emergency Telecommunications Board at (617) 944-9113.

Toys

With thousands of toys on the market, it is often hard for parents of children with disabilities to know which are a good choice for their children. You want toys that will be fun not frustrating and developmentally appropriate. Now there is help to

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Learning Disabilities: Inclusion and Exclusion

by Frank Garfunkel - Boston University

Recently the president of Boston University fired a warning missile over the bow of the ship of learning disability (LD) in higher education. Like many others involved in this growing debate, he questioned the entire process of giving students special dispensations if they have learning disabilities. He rejected the practice of giving waivers from mathematics and foreign language courses to some students with learning disabilities; that is, students who have documented histories of having learning disabilities, as had been done. He called for more frequent evaluations of students with learning disabilities. Every three years each student in the University's LD program would be reevaluated. He stated that evaluations would only be accepted if they were done by qualified physicians and psychologists, and only if there was a clear neurological basis for the learning disability.

These are not, by themselves, unreasonable positions. The field of learning disabilities does not rest on a firm foundation. Indeed, there is serious disagreement about whether it **is** a field. There is also considerable disagreement about the definition of LD, about what to do with students who are said to have LD and about who should be teaching LD students. There are at least 20 different definitions or formulas for identifying students with learning disabilities. Many of these formulas will identify different students as having LD. Consequently, when current practices are critiqued, such as those being used at BU,

it is difficult to defend them.

What is unreasonable is the position that there is to be little or no individualization or reasonable accommodation for students with learning disabilities at Boston University, and that such accommodations should not exist because students would be "getting out" of certain requirements. Talented students at Boston University and at other universities often pursue alternative curricula. At Boston University there is a University Professors Program which makes it possible for selected students to take alternative programs. If some students have this option because of their "special needs", it would follow that there are other students whose "special needs" should also be given options. Therefore, the president's position is invidious; it leads to an unequal protection dilemma by implying that students with disabilities are not entitled to alternative curricula, while students who have not been identified as having LD's are entitled to curricular alternatives. Or perhaps there is a distinction between getting out of something as opposed to

getting into something. This implies that there is a discernible difference between the two; that the different intentions of students can be measured. While we trust non-LD students to make choices, we cannot trust students with LD, or psychologists who have testified to the legitimacy or the inappropriateness of certain courses for them, to do so.

The problem for higher education is, with so many symptoms of LD and so little agreement about how to classify students with those symptoms, (where to place and what to do for those students), how are institutions of higher education to respond? It should be clear that there is no simple response to such a complex question that must consider not only students with disabilities but all students. There are questions specifically about learning disability issues: Should there be special dispensations for students who are classified as learning disabled? Should there be concern for students who are faking a learning disability? Given that the construct "learning disability" is so amorphous, should it be abandoned?

But, in order to answer questions about LD it is first necessary to deal with basic university issues. Who are to be educated in universities? Should higher education be responsible for quality control? (Are there ab-

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Editor: J. Archer O'Reilly III

From Our Readers

Museum of Fine Arts Truly Welcomes All

by Joyce Cohen

Thousands of visitors enjoyed the Boston Museum of Fine Arts' recent exhibition, **Picasso: The Early Years, 1892-1906**. From September to early January many attended in wheel chairs while others took advantage of special sign language interpreted tours, free recorded tours for the blind or print handicapped, and special large print gallery guides explaining these amazing paintings from Picasso's first years as an artist in Spain and later in Paris. Few dispute the quality of the permanent collection or the Museum's special exhibitions, but not everyone is aware that the MFA is one of the nation's outstanding facilities when it comes to accessibility and sensitivity to the needs of diverse visitors.

Eleanor Rubin, Coordinator of Access for Audiences with Disabilities has worked in the museum's education department since 1978. Everything about Rubin is colored by a keen awareness of the special needs of individuals living with a disability. Her business card is printed in Braille along with regular text. Her communications invite you to talk with her through her e-mail address (erubin@mfa.org) and let her know what you require and, after your visit, how it went. She can be reached at TTY (617) 267-9703 by hard-of-hearing or deaf individuals who require information. The website at <http://www.mfa.org> gives you extensive information about access, exhibitions, facilities, and programs. The regular telephone number is (617) 369-3302.

If you are planning a visit to the museum this winter or spring to see **A Grand Design: The Art of the Victoria and Albert Museum** or **Julia Margaret Cameron: Victorian Photographer**, the new galleries of art from Africa, Oceania, and the Ancient Americas, or to simply enjoy your favorite works among the permanent collection, you can call ahead to Rubin at (617) 369-3302 and inform her about any special requirement you may have. It is important to know in advance that both the parking lot and the garage have accessible parking spaces. The Museum's floor plan now has universal access features; restrooms and elevators are wheelchair accessible. The beautiful new Fraser Garden Court has a lift which can be used with help from readily available service staff.

Accessible pay phones and a TTY for the deaf or hard-of-hearing are located in the West Wing lobby of the museum. Assistive Listening Devices are a free service in the Remis Auditorium and available in the Louise Riley Seminar Room and Galleries upon prior request. Both lecture spaces are accessible to wheelchairs.

Throughout the year special programs are offered which are of particular interest to audiences with disabilities. **A Feeling for Form** is designed for visually impaired museum visitors and provides a special tactile introduction to objects in the collection. **Meeting Museum Masterpieces** is a program for senior and inter-generational groups which combines slide presentations and gallery events. **Artful Adventures** feature gallery tours and hands-on art activities designed for children and teenagers including those in alternative classrooms and with special

needs.

In recent years the Boston Museum of Fine Arts has been recognized by the American Association of Museums for its efforts to broaden the audiences attending the museums' programs and make this cultural resource truly accessible. By working with the Massachusetts Commission for the Deaf and Hard of Hearing, Very Special Arts Massachusetts, and National Braille Press, Rubin has made a remarkable resource available to individuals living with a disability.

Joyce Cohen teaches in the Art and Music Department at Simmons College.

Host a Party for the Information Center

Matt's General Store, representing outstanding products including **Avon**, **Tupperware**, **Fuller Brush**, and **Watkins**, will donate between 10% and 40% of all sales from *One Hour Home Parties* or *Nineteen Minute Office Parties* to the Information Center. Parties are simple to organize and enjoyable to attend. The Center can also be benefited by your purchases from one or more of the above vendor's catalogs.

Participate in an easy, fun, and worthwhile fund-raising project for a worthy cause, continuing and expanding the services of the Information Center.

Call Matt LaBarre at (508) 898-9360 for additional information or a catalog.

Learning Disabilities

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solute levels of quality?) Should all students be judged by a single standard of competence? Does a college degree mean that a graduate is competent? How is competence measured? Is there a relationship between academic performance and vocational success? If students with LD are to be functionally excluded, then other students who can not be judged competent should also be excluded. One reason universities need to make exceptions for students with LD, is that to not make exceptions would likely eliminate many students who are not recognized as having LD.

When the subject of waivers comes up the administrative response is often, if exceptions are made for some students, exceptions will have to be made for all students. If students with LD can get waivers of particular courses for reasons that are suspect, why shouldn't all students have the right to ask for and receive waivers? In what direction should we be moving? Should we be narrowing the field for LD students? Or should we be broadening the academic horizon for all students? The principle that is being addressed is the need for educational institutions to adapt to students, rather than students having to adapt to institutions. Admittedly, there is always some movement in both directions. There are a few higher education institutions that have been founded on principles of institutional adaptation to students (Hampshire, Reed, Evergreen); however most colleges and universities (and secondary schools) expect students to adapt to institutional expectations.

Clearly, the contribution of

special education has been to promote the concept of adaptation (or reasonable accommodation), but only for students with disabilities. If we accept the imperative of inclusion (that most students with disabilities will be educated in regular schools and classes), and if the basic assumption of inclusion is adaptation, inclusion will work only if adaptation applies to all students, with and without disabilities. If only students in special education are getting adaptive education, it will contradict the basic assumption of inclusion that these students should not have entitlements that further isolate them from their peers. However, the extension of beneficial practices should not be curtailed because either group does not have them. If individual program planning is beneficial to special education, it should be available in regular education.

There is one practice that is inimical to inclusion, homogeneous ability grouping. The application of such grouping too often means placing children with disabilities in the lowest ability groups. There are conflicting principals at work; homogeneous grouping is exclusive, heterogeneous grouping is inclusive. Inclusion has made greater progress in primary and middle schools than in high school or college because secondary curricula leads to classes where subject and ability level are intertwined. An advanced mathematics course, or a remedial one, is, by definition, a homogeneously grouped class. However, as long as schools are homogeneously grouped, adaptability will be minimal. There are students in universities who have a disability and yet, with reasonable accommodation, can matriculate in advanced courses. Such inclusion, and such suc-

cess, will be hampered by adhering to practices that inhibit accommodation.

That is the challenge for inclusion. Can it continue and expand in exclusive environments? Can reasonable accommodations be one way the educational institution adapts to all students rather than being seen to grant a privilege to one identified group? This is another example of the need to consider the broader context if we are to change the relationships between individuals with and without disabilities. In the broad context, we seek a community where our perceptions of individuals with disabilities are perceptions of individuals, where disability, racial, religious, ethnic and gender differences are eclipsed by individual differences. We need to learn to honor, value, and adapt to all differences.

Frank Garfinkle is Professor Emeritus at Boston University. He is an expert in special education and an advocate for the educational rights of students with disabilities.

Share Your Information

As Nancy Schock has taught us, the exchange of life-enhancing information is a two-way street. In order for the Center to share with others, you must share with us.

If you have products, services, or information of interest to anyone with disability, or if you have recently uncovered resources that are new or hard to find -- Please share them by sending this information to the Center.

Thank you from all those you will be assisting.

Vision

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or electronic format. Ideally, the response would provide timely, accurate, and useful information—the hope and expectation being that this information will lead to specific services, opportunities, ideas, knowledgeable individuals, literature, and/or agencies that can help in addressing issues or problems.

The dream and vision are the start. Bringing the resource to life and keeping it alive has been and still is the challenge. As many of you know, an information center as described above opened in May 1977 in Boston and was generously housed and supported by the Massachusetts Rehabilitation Commission for 19 years. During that time, other government agencies, private organizations, and individual donors provided additional funding by contract, grant, or contribution.

Scores of individuals affected directly or indirectly by disability contributed their insights, experience, resources, and labor to building an effective service organization. The Center was, as I believe the vision requires, a cooperative effort by all of those involved.

At the beginning, the staff, board, volunteers, and users of our service – working together – decided on an appropriate name. At a time when common reference was to a “handicapped person,” the friends at the center chose the name “Information Center for Individuals with Disabilities,” a clear statement by all involved that a disability is only one aspect of a person and does not define his or her worth or quality of life.

As we brought the vision to reality and began talking to more

and more individuals seeking information, we learned that the center's goals were not achievable by questions and answers alone, but also by dialogue. Some questions require simple answers, for example, “How can I get license plates for my car that show that I have a disability?” Other questions are more complex, such as, “My husband is elderly and needs a wheelchair. What shall I do?” In this situation, the people involved have to discuss the need with someone who can draw on information, resources, and *experience* to deliver effective assistance. At times, the person providing the information may need to go beyond the Center's usual resources. The assistance may require dialogue with experts and with the person needing answers.

A dialogue is also essential for informing the provider about what information is needed, how to impart it effectively to the user, and how best to reach those people needing information. We learned very quickly that to be useful, information must be based on input from users. The information provider will do well to respect the primary role of the user in the process.

In addition to learning how to interact with users, the Center needed to develop an informed and comprehensive system for organizing disability information. Unable to find a precedent, staff at the Center took on the task of developing a disability taxonomy, an organized list of related categories and subjects for grouping all types of relevant information. When completed, the taxonomy allowed the Center to establish and maintain an efficient, orderly system for storing its extensive collection of information. In addition, it identified organizations and agencies

that provide additional resources related to the different categories. Our knowledge and resources evolved and expanded over the years, but from the beginning we set out to learn about existing information resources so that, instead of duplicating the services, we could refer users to those resources. We provided clear instructions on what the organizations offer and how to ask for what is needed, and asked users to call, or come, back if they required more information or if the information we gave them did not prove helpful. We also worked to improve service and efficiency by recording inquiries. As certain questions or situations came up again and again, we streamlined our response by developing concise “Fact Sheets” that provided fast complete answers to frequently asked questions. In line with the vision of the Center, the fact sheets were produced in direct response to questions from the public.

In conclusion, there has been and continues to be great need and demand for disability-related information. The most important factors in creating and operating an effective information organization are:

1. A comprehensive store of easily retrievable current and usable information.
2. Active outreach to and meaningful dialogue with the people being served.

In the final analysis, the dream, the vision, and the challenge all hinge on listening to individuals, understanding their concerns, finding answers, and connecting individuals to information that provides solutions and enriches their lives.

Nancy Schock is the founder and president of the Information Center for Individuals with Disabilities.

Question & Answer

Q: My wife requires dialysis but we would like to take the entire family on a cruise. Do you know if and how this is possible?

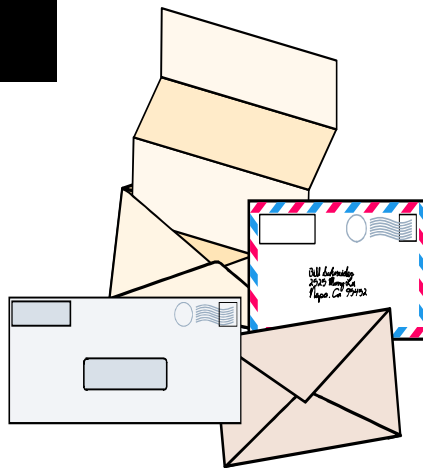
Tom, Braintree, MA

A: Yes Tom, a company in Indian Rocks Beach, Florida called Dialysis at Sea Cruises could be just what your looking for. They offer a wide range of cruises throughout the years with full dialysis service on-board. They welcome the whole family and have 20 years of experience in this specialized service. All cruises have a certified nephrologist and experienced dialysis nurses to handle all your needs. You can get more information, or a 1998 Cruise Calendar, by calling (800) 544-7604.

Q: I remember reading in *Disability Issues* several years ago about a program for free medications for those who can't afford them. I have lost the information. Can you repeat it?

Bob, Boston, MA

A: Your memory is good. We last wrote about this in July of 1994 but the program is still available. A specific list of



prescription drugs, 270 at last count, are available at no cost through the "indigent patient program" offered by more than 50 drug companies. Low-income Massachusetts residents of all ages who do not have prescription-drug coverage through and insurance policy may apply for this benefit. Applications are made through your doctor. The definition of low-income varies from one drug company to the next. Some let the doctor decide, other set an annual income limit of \$25,000 per individual and \$40,000 per couple. Individuals on Medicaid are not eligible. For an application send a self-addressed envelope to Massachusetts Home Care, 24 Third Avenue, Burlington, MA 01803. For more information call (800)

243-4636/MA. For those of you in other states, check with your state public health agency to see if there is a similar program in your state.

Q: How do I get a Handicapped Plate for my car in Massachusetts? What are the requirements, the cost, and where do I get it?

Annika, Colrairie, MA.

A: The answers to your question are a bit longer than the space available here. However, we do have a Fact Sheet on Handicapped Plates and Placards available. It explains all the rules and entitlements connected to these benefits for people with disabilities and contains the application forms you and your doctor must fill out for the Registry of Motor Vehicles.

A Fact Sheet is on its way to you. If any other readers want the free Fact Sheet they may write to the **Information Center**.

From time to time we will answer questions of general interest in this section of the newsletter. If you have such questions, write to the Information Center. Please understand that there is no assurance that your question will be chosen for this column.

The **Information Center for Individuals with Disabilities**, as you know, is attempting to reorganize our services. To be successful, we need your participation!

If we are to meet the need - we must raise about ninety thousand dollars. We also need to organize volunteer committees around the state to acquire information, do outreach, and raise money.

We are very grateful to those of you who have already responded. We ask those we have not heard from to send a contribution and commit to an exciting opportunity today.

Yes, I want to be a part of the "Re-Birth" of the Information Center.

Please accept this donation of \$ _____. Please count on me as a volunteer. _____

Name: _____

Address: _____

City/Town: _____ State: _____ Zip: _____

Telephone: _____ (H) _____ (B)

Toys

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make play more accessible.

National Lekotek Center, in association with Toy Manufacturers of America (TMA) is providing a Toy Resource Hotline offering individualized assistance in selecting appropriate toys and play materials. The National Lekotek Center, a nonprofit group, provides professional training, toy lending libraries, and play-based programs for children and families with disabilities in 60 centers around the country.

The hotline can be reached by calling (800) 366-PLAY (v) or (800) 573-4446 (TDD), Monday through Friday between 9 a.m. and 4 p.m.

The American Foundation for the Blind, again with the TMA, has released the fifth edition of its *Guide to Toys for Children Who Are or Visually Impaired*. It features 85 new toys with an emphasis on multimedia and interactive toys. An introductory section makes it easy for adults to understand the selection criteria and how they can apply them to products not covered in the *Guide*.

Single copies and supplies of the 1997-1998 *Guide* are available free of charge, in print or audio-cassette, by contacting the American Foundation for the Blind, 11 Penn Plaza, suite 300, New York, NY 10001, (800) 232-5463.

Help Available

Every day more technology becomes available with the potential to assist individuals with disabilities. However, the more choices that are out there, the harder it is to know what to choose.

Help is available in New England from Gayle Yarnell who has been working with technology for the blind and visually impaired since 1978. Through her company, Adaptive Technology Consulting (ATC), Gayle offers demonstrations, evaluations and assistance in making technology decisions you can live and work with, now and in the future. Her services are available for blind and visually impaired individuals, counselors, teachers, and parents.

ATC is located in Amesbury, MA and can be reached at (978) 462-3817.

Fay Honored

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and opportunities for persons with disabilities. A co-founder of the Boston Center for Independent Living and first president of the American Coalition of Citizens with Disabilities, he has lobbied for equal access to public buildings, transportation, housing, education, employment, recreation, and technology. He has worked in the presidential campaigns of Jimmy Carter and Bill Clinton and shaped their disability positions. He is also a founder of Justice for All. It was largely through Fred Fay's efforts that "personal care assistant" became a Medicaid funded position bringing freedom and power to thousands.

Fred began his efforts on behalf of people with disabilities at the age of 17 by co-founding "Opening Doors", a counseling and information service in Washington, DC. The Information Center is proud of Dr. Fay's long association with the Center and his many years of groundbreaking contributions to the lives of people living with disability. For his vision, perception, persistence, and humanity Fred Fay has been justly rewarded.

Information Center

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