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Advocacy for Affected Children: An Interview with Sis Wenger

William L. White

Introduction

Effective policy advocacy requires many critical traits: intelligence; organization; skills in listening, speaking and writing; trustworthiness; and stamina, to name a few. For nearly four decades, Sis Wenger has been at the forefront of advocacy for the needs of children and adults affected by parental addiction and she has exhibited the full spectrum of such traits. Ever-present in addiction-related policy forums, hers is always the voice calling attention to the needs of affected children. In the spring of 2014, I had the opportunity to interview Sis Wenger, President and CEO of the National Association for Children of Alcoholics, about her life and her work.

Please join us in this most interesting conversation.

Early Advocacy Career

Bill White: Sis, you have been one of the most visible and effective advocates for children of alcoholics. How did such activism begin?

Sis Wenger: I was a volunteer in the Junior League of Birmingham, Michigan, running a Child Advocacy Project in the late '70s. I was responsible for managing child advocacy programs, including a juvenile delinquency prevention project, a project addressing the needs of new mothers who had minimal capacities to nurture their children, and a third project to link agencies involved in child abuse and neglect into an effective state system so that affected children would not keep "falling between the cracks." As reports on these projects continued to roll in, I kept hearing about drinking in the families of the impacted child clients. Finally, I asked about forty women across the projects to review their caseloads and tell me about the role alcohol played in problems within these families. They began to realize that the vast majority of the problems they were working to address were either created by parental drinking or exacerbated by it.

I knew nothing about young or adult children of alcoholics and, in fact, didn't even know the term "children of alcoholics" at that time. We looked closely at the program for young mothers and found that these young mothers were all adult children of alcoholics who had had terrible childhoods. That was my first full awareness that growing up in these families could create problems in adults -- not just in the children. So, about ten of us went back to the Junior League leadership and said, "We think we're still using a Band-Aid approach." And we asked the Junior League to pay for us to get some training on alcoholism. We went as a team to a conference in San Diego and listened to people like Father Martin and Jerry Moe. It was called

"Fam Con"—a conference on addictions in the family. Then we went to NCA conferences and a couple medical conferences, and it just became increasingly clear to us that people who are addressing the needs of highly troubled children were failing to address the impact of parental alcoholism on these children. We decided that the Junior League should educate decision-makers in the systems that impact children and families about the developmental and familial effects of alcoholism. So, that's how I got started. I had been blessed with growing up in a healthy family without any drinking problems (although alcoholism did touch my family later as is so often the case with Irish families). That's how I became involved. I was very angry that such critical understanding (so obvious to us volunteers) was being missed in the systems that were, in fact, often compounding the pain and impacting the lives of children who really needed help but, instead, were getting punished or shunted around or put in foster care. It wasn't right, and the Junior League went to work to dispel the ignorance and denial of adults in systems making pivotal decisions about children in trouble and troubled children and it supported the development of training projects for those decision makers -- in the schools, the courts, the social service agencies, and addiction treatment programs. I still get angry at the resistance to providing the help that is known to make a difference for the children who are the first hurt by addiction in the family and the last helped, especially in light of what is known about the lifetime consequences of chronic emotional stress on young developing children in both their personal lives and in health and economic costs.

NACoA

Bill White: This growing awareness around the country set the stage for the birth of the National Association for Children of Alcoholics (NACoA). Could you describe the birth and early history of NACoA?

Sis Wenger: In the late 1970s and early '80s, there were others who were beginning to give voice to what they had experienced as children and were then beginning to address in their professional lives. I met some of them at the conferences we attended, including Claudia Black, who was describing what we had surmised. And we brought these early leaders to Michigan to train our volunteers and introduced them to the major schools systems with whom we were working. So, nationally, this was also an emerging time, a tipping point that was occurring. A number of young professionals from across the country, predominantly educated in the fields of psychiatry, psychology, and social work were utilizing the strength of their own experiences of having been raised with alcoholism's cloud over their families to help validate the experiences of their clients. There were so many firsts that were occurring. I remember reading about Claudia Black in a full page article in Newsweek Magazine that acknowledged the phenomena of both young and adult children. And then there were national television programs, including one with Claudia and five young children who talked about their experiences. Never before had there been such discussions in the national media. Books directed toward the young and the adult child were being written by these young professionals, and they became required reading for my volunteer classes, along with Father Martin's "Chalk Talk" and Johnson Institute's "I'll Quit Tomorrow." A language was being developed, a framework was being offered that helped people raised in such families begin to speak out and not remain in emotional isolation with the shame, fear, and loneliness that was so pervasive in their lives. That language empowered those of us who were

advocates and educators. It gave us common sense language for interpreting the slowly emerging study of children of alcoholics by NIAAA scientists.

The birth of NACoA was facilitated by Joan Kroc, a very strong supporter of Al-Anon and Alateen for affected family members and who had already become active in trying to educate physicians in alcoholism through the program she funded called Operation Cork. She invited these young professionals to her ranch in southern California in November 1982 through Cathleen Brooks, who had written a booklet called *The Secret Everyone Knows* about growing up with alcoholic parents and then her own early alcoholism. Mrs. Kroc surmised that there had to be many more people trying to do what Cathleen was doing in programs for young children in San Diego, and she was right; there were. The birth of NACoA, which began at that first meeting at the Kroc Ranch and culminated at a second meeting there in February, 1983, was a moment when those who had come together knew intuitively that they could do far more collectively than individually. Yet few had the experience of knowing how to build or run a non-profit organization. As Robert Ackerman said at a reunion gathering during NACoA's 30th anniversary celebration conference, "We were often called missionaries, but more realistically we were "passionaries". They weren't willing to sit in fear about what they did not know, but were mobilized with the trust and faith that the truth of the experiences of the lives impacted by addiction was more powerful than the shame of the disease. In many cases, they blindly just moved forward, and the truth of their messages was realized by all who heard.

The stories of that first November weekend all note how overpowering and emotional it was for these young professionals to find each other. It was a weekend of sharing. Joan Kroc wanted something more concrete, and invited the group back in February to plan for appropriate action. NACoA was officially created as a national membership organization on Valentine's Day, 1983, and that's why we have Children of Alcoholics Awareness Week each year during the week of Valentine's Day. A part of NACoA's early mission was about education, and for several years it offered conferences throughout the country. At the time, there were few skilled clinicians to work with this population and in many cases these conferences were moments of great validation and healing. They would also become the initial training ground for clinicians.

Bill White: Could you share with our readers a bit about your history, the history of your involvement with NACoA?

Sis Wenger: I became involved with NACoA because I became connected to many of its founders whom I had met and engaged to help train our community education volunteers in the years before there was a NACoA. They helped immeasurably with the education of our volunteers in the Junior League partnership with Henry Ford Health System's newly developed residential and outpatient addiction treatment center at Maplegrove. This program, Maplegrove Community Education, which is still offering community training thirty-five years later, at one point, had over 200 volunteers, and helped nurture the development of hundreds of Student Assistance Programs across five counties of southeastern Michigan

After working with many of the NACoA founders for years to feed the work I was doing in Michigan, and after one of my key volunteers, Mary Carol Melton, had joined the early NACoA board and was by the late 1980s the NACoA Board Chair, I was asked to join the board with the understanding that I would only serve a two-year term and my only responsibility would be to help the board members to become systems change advocates. Eighteen months later, Mary Carol had to suddenly resign due to a family medical crisis, and I was asked and agreed to take

over the Board Chair position for the remaining six months of my term. (And it has been a long "six months.")

My first action was to help the board assess what NACoA's true status was and its strengths and potential and to determine where we should be located and how we should be structured and where our energies should be focused to address our mission effectively. Within three months, we closed the office in Southern California and moved to Washington in February 1992. I remained in the Board President position for the next three years traveling between home and Washington while we found financial resources and new board talent to make moving forward possible. We moved away from what had been a strong state chapter system but had become a failing chapter system, to an affiliate system, bringing NACoA diverse local organizational partners across the country and now internationally.

Bill White: When you look over those years, could you highlight some of the major activities that NACoA was involved in that you feel particularly good about?

Sis Wenger: I think the most important thing we did was during a board retreat in the early 1990s, not long after we moved to Washington. It was a serious effort to review our mission, review whether or not we had the capacity to fulfill that mission, and, if not, what we should do to correct that situation. We concluded that we had enormous power in the great talent of our still active founders and our strong advisory board and our board of scientific advisers. In addition, our Board comprised some of the top expert talent in the field. Our greatest deficit was that we were beginning anew in Washington with no money. However, that was easier to surmount because of the dedicated talent available for any desired program initiative. The retreat discussions focused on our need to influence four systems that impact children's lives: social work, education, clergy, and primary care. Board members divided up to take on these various systems, forming small subcommittees.

We started with the doctors. The model we used was to recruit the presidents of the top primary care organizations that focused on care of families, adolescents, and children. We invited them to Johns Hopkins for a one-day meeting and they all came. We basically said to them, "These are the children that we're worried about. These are their burning issues. They come through the offices of the doctors that you represent every day. The doctors and the nurses don't see their real problems so cannot help them in the ways they most need it. These children are being impacted emotionally and physically and the trajectory of their lives is being impacted because no caring adult is giving them the opportunity to surface the truth about their lives so that they can get the help they need. We don't know what you should do about it but we'd like to know how we can help you do it." They went to work, and they told us what we had to do: 1) commission research papers covering key topics they identified that would address needed physician competencies in this area; 2) develop those competencies at the standard levels of competency accepted in the medical profession, and 3) get both the competencies and the research papers published in a highly respected medical journal. It was a long process, but all three steps were accomplished and a White House meeting with the presidents of all the major medical organizations endorsing the identified Core Competencies for the Involvement of Health Care Providers in the Care of Children and Adolescents in Families Affected by Substance Abuse.

Then, NACoA moved from primary care to education and early childhood professionals to clergy and to social work. We have done each core competency development initiative differently in collaboration with the leaders in professional education in each field. Because of the common sense approach, engaging leaders in the fields where we would like a change in education and in systems functioning to address the needs of "our kids," we have been able to fund these efforts, and we have worked with top talent in each system who have volunteered in our efforts because they see the value to their own professions of our core competency development approach as a first step in effecting change. That changed everything because it made us focus on the people that can do something every day for children when no national organization can have that daily personal opportunity, and it has given us the means to create education and program products and the related training to support the work of professionals in these systems.

Bill White: How is NACoA currently financed?

Sis Wenger: We are currently funded by personal donations, by contracts for program work, by training programs for clergy and for working with children, as well as the sale of our evidencebased whole family recovery program - Celebrating Families! TM and training to implement it. We are also funded by SAMHSA to provide a webinar series, Understanding Addiction and Supporting Recovery and for an upgrade of the Children's Program Kit that we created several years ago, with over 150,000 of them distributed to date to help children of addicted parents in schools, treatment centers, church youth programs, and youth recreational programs. We are hopeful that a new website will also bring awareness of the critical nature of our work and motivate some of the one in four adults in this country who are children of alcoholics to support us to help the children coming along not to suffer as much as they may have suffered. We continue to maintain that if you provide preventive interventions for young children who live in these volatile families, you will prevent an enormous amount of mental health costs in adolescence, early adulthood, midlife, and later life. That's why our founders came together all those years ago. They were treating people with mental health problems that were rooted in their childhoods; and they believed working to prevent these problems made the most sense. Today, with the dramatic results of the Adverse Childhood Experiences (ACE) Study continuing to pour out the evidence of what our founders saw and knew in 1983, I hope this concept of helping the children NOW -- not later -- will move up the list of federal, treatment, and personal priorities, and thus save lives, families, and countless millions of dollars in health, mental health, and prison costs in the future.

Reflections on Codependency

Bill White: There is a particular period in this history that I'm interested in. In the 1980s, there was a peaking of cultural interest in COA and ACOA issues and the concept of codependency, with the latter creating a subsequent cultural backlash. How do you now view that period?

Sis Wenger: The codependency concept emerged out of the first NACoA conference. It was talked about right from the beginning. Tim Cermak wrote his two volume treatise on treating codependency and it was widely appreciated in the clinical world. For many, codependency was

seen and understood as how the adult child was impacted, and it expanded to include people from non-addicted but highly dysfunctional homes. I think the codependency movement was a great gift at the time. In time, it was so generalized (and bastardized) that it lost its meaning. I can remember times when I was simply being thoughtful or helpful and then being accused of being "codependent." as though I needed therapy for just being kind. But I believe that phase has passed. Television programs initially helped to bring clarity about the concept and then later help with sensationalizing it and too many charismatic public speakers, who may not have been good clinicians, took part in this. At least, that was my perception of it at the time, and it led to great misunderstanding of the work being done by competent clinicians. There was a wave, a monumental wave that rolled across this country for adult children of alcoholics who felt like someone had finally opened the window and let the pain out. They couldn't get enough of it. They went to meetings, and they went to clinicians and the clinicians couldn't get enough of it either. So many mental health clinicians and other counselors came to the NACoA conferences to learn about their clients and, while they were there, they were often learning about themselves. The founders were brilliant in understanding the need to help people process what they were learning - both those impacted and those treating them. And the press, including the Washington Post, jumped on all of this in a big way which helped move the awareness and discussions across the country.

While Al-Anon had begun to sponsor specific ACOA Al-Anon meetings at this time in California and a few other states, a group of people felt drawn to the codependence movement as more in tune with their own life experience wanted something more. They came together and created Adult Children of Alcoholics, ACA. And now, there's an ACA World Services organization and an ACA Big Book and a continuation of meetings - mostly in the western part of the country, but spreading.

That was a very interesting time. NIAAA's director, Dr. Enoch Gordis, and some of the scientific people in Washington were very disdainful of codependency because of its lack of scientific and clinical foundation in their view. Some in the scientific community didn't find NACoA and its messages to be credible. However, little by little NIAAA's and others research provided evidence of the deleterious impact of parental alcoholism on children and respect grew. Today, the meaning given to codependence is how one is impacted when growing up with addiction and this is what much of the current trauma-informed treatment is about - developmental trauma. With the breakthroughs in science, including what we continue to learn from the ACE Study and neuroscience, the early work of NACoA's founders is validated repeatedly. In addition, it was the early work that created the foundation for the codependency field and developmental trauma work today, as well as the wave of adult child awareness, treatment, and recovery that empowered the masses. I believe that, today, there is no community in the nation that does not have at least one clinician schooled in adult child work, and that is an ongoing gift from NACoA to the country and to thousands of marriages

History of NANACOA

Bill White: Could you describe the history of NANACOA?

Sis Wenger: Yes, in fact, this spring in Denver, there was a celebration of the 25th anniversary of the founding of NANACOA during White Bison's Wellbriety Conference.

NACoA was officially incorporated in early 1983. At our national conference in 1987, a group of about twenty-five Native American leaders came to the NACoA Conference. Following that conference, there was a considerable amount of interaction, primarily spearheaded by Cathleen Brooks, who was the person who helped to bring the NACoA founder group together five years earlier. In 1988, at our conference in New Orleans, a hundred Native leaders from multiple tribes came together at the conference, created the Circle of a Hundred and decided then to create the National Association of Native American Children of Alcoholics (NANACOA), not as a NACoA affiliate, but as a colleague organization. NANACOA really thrived for almost ten years. The organization did a tremendous amount of training on reservations and with city folk, but they never had an effective plan for financial sustainability after the first wave of federal funding disappeared. White Bison felt that NANACOA shouldn't get lost and they partnered with those who were left in NANACOA to revive it. Some of the original NANACOA leaders had a merging ceremony at one of the White Bison Conferences a few years ago where they blended the robe (NANACOA) and the hoop (White Bison). And this is the base for the Wellbriety Movement hosted and sponsored by White Bison. During the conference, Cathleen Brooks was officially installed as a member of the Wellbriety Movement Council of Elders.

A collaboration between NACoA and the Wellbriety Movement was announced at the Denver conference. Wellbriety/*Celebrating Families!*TM, will be the family education and support program component of the Wellbriety Movement's comprehensive community trainings. *Celebrating Families!*TM is NACoA's evidence-based, 16-week, whole family recovery support program; it has been enhanced with culturally specific learnings by the Wellbriety Movement and added to each of the lessons.

State of the Movement

Bill White: Could you summarize the state of the movement today to address the needs of children of alcoholics?

Sis Wenger: What has happened for adult children of alcoholics is not yet true for children of parents with substance use disorders (alcoholism or drug addiction). Services for children have dropped off, partly tied to the Department of Education's reduction in funding for things like student assistance programs. Our preventive efforts have been severely harmed by policies that are not based on what is needed -- again -- by troubled children and children in trouble. We have moved back in many systems to where we were 35-40 years ago - especially in our schools where, for example, ill-advised and costly staffing meetings and disciplinary actions have supplemented the early intervention programs of help that existed in the context of the proven effective student assistance programs in earlier years.

The state of the movement: The knowledge base needs to be more systematically integrated into the education of our primary health care, mental health, and addiction professionals, as well as our clergy and pastoral counseling trainings and the education of social workers and educators. Although there has been some progress, what we still lack is what we attempted to begin with the development of core competencies in each system that has regular

access to children and/or hurting families. We still have not systematically impacted programming within family service agencies and juvenile justice programs. Specific programs for helping children of addicts have been cut across the country although it is widely known how important it is to meet their needs. As a result, more kids are troubled and in trouble. They are in systems of care where the caretakers have not been educated to understand their issues and needs. More kids are becoming addicted, and more kids have mental health problems.

Children and the Addiction Treatment Industry

Bill White: One of the things that NACoA has tried to do is to call upon the addiction treatment industry to better attend to the needs of families and children. How well are those needs being addressed to date by the treatment industry?

Sis Wenger: Not well. But for a long time, the treatment industry had a place to refer children. If John Doe went to a treatment program and he had school-age children, the addiction professional could advocate for the children to get into a school educational support program. But today, many of those programs no longer exist, as mentioned earlier, and there isn't anything else filling the gap. Children do not fit into prevailing models of addiction treatment; yet we know that addicted persons have lower rates of relapse and recidivism when their family members are also offered programs of education and support for the healing they need. Too many treatment program executives think children don't belong on their campuses; I would submit that the truth is that - as in the home - children cost energy and money. I often wonder how long this attitude would last if referring clinicians and referring drug and family courts simply required such a program or no referral. Child-focused awareness and services have eroded within the addiction treatment field.

The obviously ideal program is the children's program at the Hazelden/Betty Ford Center run by Jerry Moe. There are other programs at Henry Ford Maplegrove or Brighton Hospitals in Michigan or Father Martin's Ashley in Maryland. The Maplegrove program runs a whole family recovery program in conjunction with the primary addiction client. Volunteers are often part of the presenting team. For many years that same program ran summer camps with trained and skilled volunteers for over 500 children in three counties, all free. So it is possible. Today, we probably still need "passionaries," as Bob Ackerman called the early NACoA founders. Being inventive, persistent, and a little entrepreneurial can help.

The Media and Affected Children

Bill White: What changes have you seen in how the media has covered children of alcoholics over the years?

Sis Wenger: In the early '80s, there were many reporters who were very curious about this thing called "children of alcoholics" and the issue got a lot of attention. Reporters of all types began showing up in our meetings and national and regional conferences, and they told the story they were witnessing. There was one or more reporters from the Washington Post who followed one of our conferences in the mid-1980s, took copious notes, interviewed many conference participants and major presenters. There was a considerable amount of scientific findings

reported at that conference and there was a tremendous amount of very interesting clinical evidence. The press paid attention and generally reported accurately. Through them, the attention of a number of key decision-makers also learned. The media coverage that grew from that really was tremendous. Every time we had an article about the work we were doing, it made things happen.

Bill White: But it seems much of that coverage has since disappeared, particularly in this last decade.

Sis Wenger: Right. It is not old news. But it is not as exciting to reporters as adolescent overdoses, or as children thrown over bridges or drunk mothers driving a car load of children to a soccer game. The isolation, confusion, and desperate silence of the child living in an addicted family has not changed, and it will not until we as a society begin to put a face on this child and remind all those in the "recovery movement" as well as those professionals who have the opportunity, in the decisions they make every day, to provide healing and support rather than deepen the hurt and damage.

Federal Leadership

Bill White: What grade would you give our federal leadership on the issue of children affected by parental addiction?

Sis Wenger: Well, it would depend upon the decade you're talking about. In the late 1980s, there was strong interest. Currently, they have floated away from it by name, but they are dealing with it all the time in the trauma-informed work, and interest groups, and products to support trauma. CSAP used to give considerable attention to children of addicted parents and they came to us frequently. We developed the *Children's Program Kit* for Native Americans as well as the primary one mentioned earlier. We produced a comprehensive book on Student Assistance, and after the first publication and great demand, it has not been reprinted. Early in this decade, SAMHSA/CSAT supported multiple products to assist clergy and other pastoral ministers, and they are still coveted. The Department of Education has pulled completely away from the issue in recent years. We know from the prevalence data that one in four children are impacted, and it is affecting their brain development and their social and emotional well-being as children and for life if they do not receive help. But they're invisible and don't count until they get into trouble, and that's too late for most prevention and early intervention strategies. We don't ask the preventative questions that would surface the people in trouble who aren't noticeable yet. This, too, will take training for the adult professionals who could and should help.

Future of COA and ACOA Movement

Bill White: What do you see as the future of the COA/ACOA movement?

Sis Wenger: That assumes that there will be a movement. Movements don't always live forever. Sometimes, they spread across the consciousness of all people and their intent is integrated into the society's Common Knowledge and common sense of responsibility. If teachers, neighbors, faith leaders, pediatricians, and family doctors, social workers and court personnel, addiction treatment professionals, and other clinicians took actions that their job descriptions imply are

their responsibilities, no COA or ACOA movement will be needed. It will be common knowledge that as long as there are parents who suffer from substance use disorders or mental illness, their children have an intrinsic right - in a civilized society - to their own recovery and to protection from the hurt addiction causes.

As for my personal vision, I would love it if there were no need for such an organization as NACoA. that would be the ultimate success. But that can only happen with the leadership of people who have the opportunity to address the problems of children and families every day. Until then, we're always going to need advocates to get this issue on the table and keep it there long enough for that common knowledge to grip the nation and create that systemic change. Our society is still not focused on breaking the generational cycle. We're still primarily focused on the addicted individual, no matter that person's age or stage of life. My own belief is that the mission of NACoA - "to eliminate the adverse impact of alcohol and drug use on children and families" - will not be fulfilled because of actions by people in the addiction field. It will happen because of the people who work in our education systems, our child welfare systems, and our faith communities who will gain the empowering knowledge they need to act where they are and say "ENOUGH!"

Career Reflections to Date

Bill White: When you look back over your years of service to this movement, what do you feel best about?

Sis Wenger: I probably feel best about what I did in Michigan because my work there saved so many more children and families and helped so many professionals be more effective in their work. We opened the doors to treatment for hundreds through our training, and we created more student assistance programs in southeast Michigan than existed in the rest of the country at that time. We changed court procedures and changed sentences to treatment and recovery support. We provided summer camp experiences for several thousand children over ten years and changed the lives of those we trained to run them. It is easier to be accepted as credible in a local community or even across a state, than it is nationally where so many other voices are demanding attention to their own issues. However, I think you have to have an entity like NACoA with the brain trust provided by outstanding experts who can create solutions and tools that can be replicated and adapted by local organizations throughout the country. I have worked on systems change through NACoA for over twenty years. We have defined the core competencies needed by clergy, physicians, child care professionals, and educators, and we have facilitated the creation of tools that facilitate the competencies needed across those professions. That has been important and meaningful work, and it continues to bear fruit and create effective training. We brought the co-principal investigator for the ACE Study, the CDC's Dr. Robert Anda, to Washington and to public policy people there and introduced the data that has precipitated the trauma -informed work across federal agencies. Here at NACoA, that is something about which we have felt very gratified.

Bill White: What advice would you offer others who will follow in your footsteps to carry this work forward?

Sis Wenger: I think I would ask them to remember the core facts that answer the question, Why NACoA? One out of every four children in this country lives with a person who is suffering

from, if not addiction, a serious enough alcohol or other drug problem to create havoc in the family that is developmentally damaging to the children. No matter what helping role you are in within the community, the problems you are addressing cannot be fully resolved until these more hidden problems are brought to light and addressed. Remember to work to create a climate in local communities where children and families can tell the truth about their experience—no matter what service or support system they are in. Remember that if these children cannot be seen, they feel invisible and helpless. You must speak in such a way that they will feel safe enough to find their own voice. Remember to help meaningful adults to reach out and touch these children and families and offer them a way to break the silence. Doing nothing is never neutral; not acting increases the pain and deepens the problem. What I would tell everyone is to be part of the solution rather than an inadvertent part of the problem.

Bill White: Sis, Thank you for taking this time to talk about your life's work and thank you for all you do for children and families.

Sis Wenger: Thank you, Bill. It's been a pleasure.

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