Executive Summary

At the direction of Governor Frank O'Bannon, the Indiana Family and Social Services Administration has aggressively pursued reform for all of the at-risk populations for which it provides services. Despite this level of effort, Indiana continues to lag behind the rest of the country in providing a comprehensive array of long-term care services that includes not only the traditional healthcare service settings, but also affordable housing and sufficient in-home and community-based service options. This array of services is critical for facilitating consumer choice and independence, and promoting quality of care and quality of life for Hoosiers who are at risk for, or already in need of, long-term care services.

Persons who utilize long-term care services (regardless of funding source) include: the frail elderly; adults and children with physical disabilities; adults and children with developmental disabilities; adults and children with mental illness; and children and their families who are at risk of involvement in the child protective system, the juvenile justice system, or through academic failure in the education system.

There continues to exist a number of significant obstacles that make reform of Indiana's long-term care service delivery system in Indiana difficult to accomplish. Namely, affordable housing and community care services are extremely limited, making true consumer choice generally unavailable. Similarly, services and funding opportunities for children who are seriously emotionally disturbed or who are considered to be at risk of abuse, neglect, delinquency, developmental delay, developmental disability, or academic failure in Indiana are either not available, or are not managed consistently throughout each of Indiana's 92 counties.

To increase the momentum for expanding community capacity and consumer choice, the Indiana Family and Social Services Administration, in an unprecedented effort, teamed up with the U.S. Department of Health and Human Services to pursue innovation and to firmly establish lasting change. Three Federal grants, created in response to the landmark disability decision, *Olmstead v. L.C.*, were sought and subsequently awarded, to assist Indiana in once-and-for-all overcoming the long-standing barriers that have made reform so elusive in the past.

The three grants are as follows:

- *Real Systems Change Grant.* The purpose of this grant is to: establish a Commission that will provide a constant forum for interaction with consumers of long-term care services and their advocates; identify best practices and barriers to community integration and consumer control; provide oversight and monitoring; assist in the implementation of a series of mini-grants to local communities; and make further recommendations for policy and funding actions.

- *Nursing Home Transitions Grant.* The purpose of this grant is to: develop models for the diversion of persons from nursing home care and for the transition of nursing home residents back into the community; provide training, education, and outreach; collaborate with nursing home associations, housing partners, assisted living facilities, and community stakeholders; develop a team to design and facilitate the transition process; identify and select candidates to be transitioned and/or diverted; and evaluate and prepare reports.

- *Community Personal Assistance Services and Supports (CPASS) Grant.* The purpose of this grant is to: provide outreach and information about consumer-directed care services; develop a consumer-directed personal assistance services model and the supporting infrastructure; establish a fiscal intermediary structure for the attendant care workers; provide enhanced training; develop quality assurance, conflict resolution, and emergency assistance protocols; and develop a system for outcomes-based reporting.

At the lead in this effort, was the appointment by Governor O'Bannon of a bi-partisan, broad-based Commission, representing experts in fields that have never before been convened, to direct and coordinate the elements of long-term care in Indiana that have long been disconnected or altogether absent.

The Commission was funded primarily by the Real Systems Change Grant, but also receives funds from the Nursing Home Transitions and Community Personal Assistance Services and Supports grants for its role in coordinating all three initiatives; it used no state funds.

The Commission's primary purpose was to develop short- and long-term strategies to create or expand community options for persons at risk of being institutionalized, or for those currently in a nursing home or other institutional setting within Indiana's long-term care service delivery system. Its specific functions included: identification of the policy issues surrounding institutionalization; compilation of key statistics and other resource materials; identification of successful and innovative programs that break traditional housing and service barriers; solicitation of consumer perspective; and development of funding and policy strategies. Its work was intended to complement, and not duplicate, the valuable work already accomplished by so many others. The Commission met at least monthly since August 2002. It has produced an Interim Report presented to Governor O'Bannon in December 2002, and now this June 2003 report. The Commission will meet one last time in December 2003 to examine and evaluate progress made on both the short- and long-term recommendations presented in both reports, and to evaluate the progress made on systems change through the mini-grants and the impact that Senate Bill 493 (2003) has had on Indiana's home and community-based services system.

The Commission accomplished its work with the assistance of five special task forces that were assigned specific policy issues and a Consumer Advisory Committee that was specifically convened to research and evaluate the relevant policy issues, advise the Commission, and increase the scope and substance of Hoosier participation in formulating the solutions needed to break new ground in Indiana.

The Commission also worked with the Indiana Family and Social Services Administration to develop and award a number of mini-grants funded through the Real Systems Change Grant. These mini-grants were designed to create community partnerships, provide incentives for public/private partnerships, and serve to encourage innovation at the community level between community stakeholders.

There were two rounds of mini-grant solicitations: the first round of mini-grants was awarded in February to twelve different communities and totaled more than $430,000; and the second round of grants was awarded in May to eleven different communities and totaled more than $320,000. The grants were rated by a committee of staff of the Indiana Family and Social Services Administration and consumers from the Commission's Consumer Advisory Committee. Grants were considered if they fostered collaboration among community partnerships and totaled not more than $40,000 per grant. Innovation was favored over traditional, as was the development of

new capacity over simply expanding existing capacity. The focus was on maximizing and leveraging the funds by working to match other funding sources in the local communities.

The Commission determined in one of its early meetings that the original assignments and time-lines established for both the Commission and its task forces were not responsive enough to the urgency of many of the system problems and the opportunities presented by the upcoming legislative session. As a result, the Commission decided to deviate from its original workplan and instead refocus the task forces on identifying the most significant of the long-term care service delivery barriers and to develop comprehensive recommendations in response. Sixteen (16) individual recommendations were developed and presented in an Interim Report to the Governor in December 2002. The current status of each recommendation is included within this Report.

Since the publication of the Interim Report, the Governor's Commission on Home and Community-Based Services, its Task Forces, and the Consumer Advisory Committee have focused on the development and evaluation of a number of additional, but generally much more far-reaching actions. A number of new actions have been developed, all of which are absolutely essential to create the basic infrastructure, improve processes, and/or provide the services and supports needed to deliver quality services cost-effectively, while significantly enriching the lives of frail seniors, persons with mental illness and disabilities, and children and their families who are at risk.

The Commission recognizes that state resources (both in terms of funding and staff) are extremely limited, and that some actions are dependent upon the successful completion of others. Nevertheless, it believes strongly that now is the time to make significant and lasting change. The Commission therefore presents twenty-eight (28) new actions to serve as a blueprint for reform in Indiana. The actions are organized into four (4) categories: rebalancing the long-term care system; removal of barriers; community capacity; and children at-risk.

- Rebalancing the Long-Term Care System – This category includes ten (10) actions that are specifically targeted to those changes which will provide or build upon the community service infrastructure needed to support a large and ever-growing consumer population.

- Removal of Barriers – This category includes eight (8) actions that specifically focus on removal of key obstacles to expanding or improving community-based care.

- Community Capacity – This category includes eight (8) actions that specifically focus on opportunities to build upon or improve the services and supports that must be in place for consumers to live safely and successfully in a community-based setting.

- Children at-Risk – This category includes two (2) actions that are specifically targeted to improve and/or expand upon the service delivery system for children who are at risk and their families.

A master list and brief description of all twenty-eight (28) actions are attached at the end of this Executive Summary. They are sorted according to the categories identified above and include a brief description of the actions to be taken, identification of the agency or office responsible for taking the lead, and indication, if applicable, of legislative action that is required.

As the specific actions were developed, it became apparent that there were many issues that either fell outside the charge of the Commission, outside the charge of the individual task forces, or

required resources beyond the scope of this project and process. These issues, are, nevertheless substantive and must be addressed for meaningful systems changes to occur. They include: quality assurance; training and outreach; service access; interagency coordination; consumer choice; affordable and accessible housing; provider capacity; and Federal barriers.

In addition to the recommendations in the Interim Report and the actions in the June 2003 Report, there are a number of other steps that can be identified for action in the future. These steps or actions are not as easily defined, and cannot necessarily be assigned realistic timeframes and evaluation criteria because they depend on a set of unknowns. The unknowns include: the role of the Regional Planning Councils; quality assurance systems; Federal barrier changes; on-going evaluation through benchmarks and a Report Card; consumer participation; additional efforts through the New Freedom Initiatives; lessons learned from Best Practices; and structural support for Interagency coordination.

The Commission would be remiss if it failed to mention how much work remains to be done. Despite the activity and the level of progress that has been made by the Indiana Family and Social Services Administration and other state and local agencies over the past few years, Indiana continues to remain significantly behind most other states in re-focusing its scarce resources on more desirable, less costly community-based service delivery options. Spending priorities in Indiana continue to focus on institutional care, and progress in resolving many of the more complex service delivery problems such as caregiver support, eliminating process and system barriers, understanding the needs and desires of consumers, and shortage of caregivers, for example, has been frustratingly slow. Furthermore, the common framework for healthcare that is provided in traditional institutional settings and that favors medically cautious modes of care over care that relies upon consumer independence and freedom of choice continues to be extremely difficult to change.

The Commission accepts this current reality but commits itself to being part of the solution. It strongly advises the Governor, State Agencies, and the Indiana General Assembly to pursue each action aggressively and at the earliest opportunity possible. Each is critical in achieving the long-term care reform that has long been envisioned by the Governor, Indiana Hoosiers, and by so many others.

Master List of All 28 Actions Grouped by Category

Category: Rebalancing the Long-Term Care System

Lead Agency: Office of the Governor

Action: The Governor must direct the Indiana Family and Social Services Administration and other state agencies to pursue all grant opportunities made available through the President's New Freedom Initiative and all other grants that support Olmstead and the shift of the long-term care service delivery system.

Description of Action: The Governor will direct the State Agencies with aggressively pursuing the new Federal grant initiatives that provide states with the funds (at least $417 million in 2004 and another $1.68 billion for the next four years), expertise, and technical support to make significant and enduring reforms in the administrative infrastructure and delivery of housing and services to persons who depend upon public assistance. The grants are specifically targeted to expand community care options and to assist states in shifting the balance of care away from non-essential institutional care.

Action: The Governor should create a cross-disability consumer advisory council to advise him, the Indiana Family and Social Services Administration, and other state agencies on issues that facilitate continuing progress on *Olmstead* plan implementation and the movement of services toward home and community-based care. The Governor should strongly consider reappointing the members of the Commission's Consumer Advisory Committee, since they represent all target populations and have demonstrated strong understanding of the issues and the ability to collaborate well together.

Description of Action: The formal establishment of a cross-disability consumer advisory council will create a mechanism for consumer input that does not currently exist. Policies that directly and indirectly affect consumers are currently made with little or no consumer input, resulting in policies and process issues that may not address the needs, values, and priorities of consumers.

Lead Agency: Indiana Family and Social Services Administration

Action: Raise the monthly income eligibility standard for the Medicaid Aged and Disabled Waiver (and all other applicable waivers) to the federally-allowed limit of 300% (i.e., $1,656) of the Supplemental Security Income amount. This change will allow an individual to keep more of his/her income and still be eligible for Medicaid Waiver services. This Action is further supported by a similar provision included in Senate Bill 493 (2003).

Description of Action: The Indiana Family and Social Services Administration will revise eligibility criteria for the Medicaid Aged and Disabled Waiver to allow an individual to keep a greater portion of his/her income and still be eligible for the Waiver Program. This change will assist in eliminating the bias toward traditional nursing home care by making community-based services a true option for qualifying consumers.

Action: A targeted Medicaid Home and Community-Based Services Waiver for Adult Foster Care must be developed and implemented. This should be a new, separately-funded Medicaid Waiver Program that is specifically targeted to build capacity in this service area.

Description of Action: Foster care is essential for persons who are elderly and persons with disabilities who need a combination of residential care and services. Indiana does not currently offer this type of service, as a result, many individuals who can no longer remain at home, but who could thrive in an alternative setting, are forced to "choose" costly nursing home care.

Action: Adult day services should become a targeted service within Indiana's long-term care service delivery system, not only for consumers who receive public assistance, but also for consumers who are able to pay privately.

Description of Action: Adult day services are significantly under-utilized in Indiana and are not available in many parts of the State. This must be corrected, since adult day services fill an important place in the long-term care service delivery system. Namely, they provide a real non-institutional and cost-effective alternative for elderly and disabled persons whose primary caregivers are in need of respite or work outside the home.

Action: State and/or contractor staff must be integrated into the nursing home discharge process to ensure that consumers who are able to remain in their own homes/community setting can receive necessary services and/or support and monitor consumers who are placed in nursing homes for temporary care to ensure that they are successfully transitioned back into their own home or alternative community setting of their choice.

Description of Action: By integrating state/contracted staff into the nursing home discharge process, the State can ensure that consumers who can remain in their own homes/community setting can receive necessary services and/or support, and can monitor consumers who are placed in nursing homes for temporary care to ensure that they are successfully transitioned back into their own home or alternative community setting of their choice.

Action: Funding for public assistance programs should be transparent to the consumer and should follow the consumer to the service setting of his/her choice. This principle has been embodied within Senate Enrolled Act 493 (2003 Indiana General Assembly).

Description of Action: By allowing public funds to follow the client, the State will remove the long-standing bias that forces consumers to "choose" institutional service simply because there are no other funds available. This change will provide the financial and administrative means to consumers to apply a set amount of funding toward approved services that they need but in the setting (community or institutional) of their choice (This Action is already embodied in Senate Enrolled Act 493).

Action: The Indiana Family and Social Services Administration must dedicate and charge staff to fully and immediately develop the Medicaid Home and Community-Based Services Waiver for Assisted Living. Efforts must focus on recruiting and enrolling assisted living providers and developing a compatible consumer base.

Description of Action: There has been a lack of dedicated state staff to date to develop the assisted living program that has been in place since July 1, 2001. By refocusing on this priority program, the State will develop an essential residential care and services option for persons who can no longer live on their own but who do not need the intensive and costly level of care provided in a nursing home.

Action: The Indiana Family and Social Services Administration should establish a centralized Medicaid financial eligibility determination unit that is dedicated to Medicaid Waiver Program applicants. The purpose of this administrative change is to expedite the approval process for Medicaid Waiver applicants so that undesired institutionalizations may be avoided, and consumers are given the opportunity to receive services in their own homes and/or other community setting and to age in place for as long as possible.

Description of Action: The Medicaid Waiver application is so cumbersome and time-consuming that many persons who are elderly and physically disabled are institutionalized because they can no longer wait to receive the necessary services. By centralizing the financial eligibility determination process, approval time should be substantially reduced.

Action: Adult foster care should be added as a service component to Indiana's Medicaid Home and Community-Based Services Waiver for the Aged and Disabled.

Description of Action: In order to allow the Medicaid Aged and Disabled Waiver to have the most flexibility in serving consumers in all types of settings, the Waiver should be amended to include the opportunity for consumers to receive services in an adult foster care setting. This Action differs from the Action that requires the establishment of an Adult Foster Care Waiver because this waiver primarily serves persons who reside in their own homes, so the number of persons on the Aged and Disabled Waiver who will subsequently choose adult foster care services will be small.

Category: Removal of Barriers

Lead Agency: Indiana Family and Social Services Administration

Action: The Indiana Family and Social Services Administration should immediately evaluate and implement administrative process changes that will streamline and significantly reduce the time involved in determining Medicaid Waiver Program eligibility (focusing on development and approval of the individual plan of care/cost comparison budget and the level of care entry) and initiating services to no more than 20 days. The Agency should also implement a pilot program with the Medicaid Aged and Disabled Waiver that will transfer the daily management (other than the negotiation of rates and payment of vendors) of the program to the local level in order to reduce processing time.

Description of Action: The Medicaid Waiver application and approval process is extremely cumbersome and time-consuming. Therefore, it is necessary for the Indiana Family and Social Services Administration to immediately evaluate and modify the administrative process so that consumers receive approvals much more timely and services can be more quickly initiated. Additionally, a pilot program should be developed that allows as much

decision-making as possible to be performed at the local level to further reduce processing time and improve the eligibility decision-making process, and the quality of services.

Action: The Medicaid Waiver approval process should be modified to allow the cost comparison budget that is developed locally and early on in the approval process to serve as the initial waiver plan of care.

Description of Action: The Medicaid Waiver application and approval process is extremely cumbersome and time-consuming. By allowing the cost comparison budget to serve as the initial waiver plan of care, consumer services may be authorized and begun more quickly.

Action: State eligibility policy and/or administrative process for Medicaid and Social Security benefits should be modified to ensure that there is no lapse in coverage when a consumer transitions from an institution into the community or when a child ages out of foster care. There should also be developed an expedited process for persons who were not on Medicaid and/or who did not receive Social Security benefits at the time of admission to the state hospital to apply for and become approved for Medicaid and Social Security (when all eligibility requirements are met) prior to discharge in order to ensure that both Medicaid and Social Security benefits are available to the individual immediately upon discharge.

Description of Action: System, not program, limitations prevent qualified Medicaid and Social Security beneficiaries from receiving essential services (to which they are entitled) immediately upon discharge from a state hospital. There is an urgent need for these limitations to be resolved so that at-risk persons are not transitioned back into the community without the basic financial and healthcare supports needed to survive and succeed in the community.

Action: The Indiana Family and Social Services Administration must develop the infrastructure for a consumer-directed care program.

Description of Action: Unlike other states, Indiana does not have in place a consumer-directed care program that allows consumers to personally select, hire, and fire their own caregivers. This action establishes the infrastructure and mechanism necessary to implement this aspect of personal care assistance.

Action: Indiana's Residential Care Assistance Program policy should be modified to allow consumers to choose how their funding is used; i.e., to either live in a room and board assistance setting, or to use up to the same amount for temporary tenant-based rental assistance. If the consumer could choose to use these state funds as temporary tenant-based rental assistance until affordable housing such as a Section 8 Housing Certificate is applied for and obtained, the opportunities to live and perhaps work in the community are enhanced. Funding should follow the client regardless of living environment.

Description of Action: Indiana's Residential Care Assistance Program is very specific about how funds can be used. As a result, consumers may obtain housing only from certain providers. This policy limitation hinders consumer choice and independence and deprives consumers of some additional housing options that may better meet their needs and better serve the State's interests.

Action: Implement a Medicaid Home and Community-Based Services Waiver for persons with mental illness that includes people who are dually diagnosed (developmental disability and mental illness and/or mental illness and substance abuse) and support a number of complementary initiatives that are currently underway to further expand the community service alternatives for persons with mental illness.

Description of Action: Mental health services provided in a community setting have proven to represent a much more cost-effective, desirable, and successful alternative to care provided in traditional institutional settings. Nevertheless, Indiana has never had available the funds necessary to develop a sufficient number of community service alternatives to meet the needs of its low-income, mentally ill, and dually diagnosed populations. A Mental Illness Waiver targeted to persons with mental illness will help to bridge that gap.

Action: Medicare and Medicaid wheelchair and equipment coverage policy must be made more flexible to allow for a better evaluation of the consumer's needs, consideration of preventive care, and better coordination of vendors.

Description of Action: Adding flexibility to both the Medicaid and Medicare programs will assist the consumers in receiving the equipment that they need and will benefit both programs by improving the request and approval process. Common processing errors that currently occur in both programs cause consumers who are dependent upon wheelchair and other equipment and technology to suffer deteriorating health status, loss of employment and/or wages, and displacement from the community.

Lead Agency: Indiana Department of Workforce Development

Action: The Indiana Department of Workforce Development should explore the option to provide benefits to increase the number of and retention of personal care workers. This evaluation should be based on the best practices of other states, as well as the recommendations that were made in the 2002 Caregiver Commission Report.

Description of Action: It is possible that the provision of benefits will help to build up the personal care attendant provider base and retain them in employment. The need for personal care assistance is especially acute in rural areas and is expected to grow even greater in the future.

Category: Community Capacity

Lead Agency: Office of the Governor

Action: The Governor should appoint a Housing Task Force to focus on the housing issues of the elderly, disabled, and mentally ill populations. Membership should include: representatives of the housing industry, especially builders and contractors who have expertise and experience in new construction; consumers; advocacy groups; legislators; representatives of public/private funding sources; and service providers.

Description of Action: Housing issues for individuals who are elderly or who have disabilities, including mental illness, have not been sufficiently addressed, resulting in limited appropriate, affordable, and accessible housing stock for these populations. Establishment of

a Housing Task Force will facilitate a much-needed collaboration among housing and community program and services administrators, providers, and consumers to explore public-private partnerships that are needed to develop more housing options for the target populations.

Action: The Governor should work with the Indiana General Assembly to establish a real estate transaction fee to be assessed in the transfer of all commercial, farm, and residential real estate. The proposed fee per transaction would be dedicated to the Indiana Low Income Housing Trust Fund. If a local, low-income housing trust fund already exists within a community, one-half of the funds collected from the fee would be transferred to the local fund and one-half would go to the Indiana Low Income Housing Trust Fund for statewide application.

Description of Action: Indiana needs a dedicated state funding source to develop and support safe, affordable, and accessible housing for at-risk families and persons who are low-income, elderly, disabled, and/or mentally ill. Housing options are scarce, which has a significant, negative impact on the ability to provide services in the community. This will require legislative action.

Lead Agency: Indiana Family and Social Services Administration

Action: The current Vocational Rehabilitation Services rate (for supported employment and hourly-based placement) should be adjusted by utilizing a standard rate-setting methodology that includes an annual formula for inflationary increases. This methodology could include an hourly or results-based formula.

Description of Action: There is a shortage of vocational rehabilitation providers because of low statewide hourly rates. Current rates were established more than ten years ago, and were only adjusted one time after that.

Action: The Indiana Family and Social Services Administration should develop a standardized, state-wide rate ceiling for similar services provided. This should be established across all programs and be based on (or be responsive to) the actual cost of services being provided.

Description of Action: Availability and funding for community-based services is often inconsistent between programs even though the services needed are the same. This creates perverse incentives for providers and makes services difficult to obtain for some consumers.

Lead Agency: Indiana Department of Workforce Development

Action: A Business Leadership Network should be developed in Indiana to establish and further strengthen the link between business and employment at the local and state levels. Business Leadership Networks assist employers by exploring methods to more effectively recruit, market, and hire the talents of job applicants with disabilities. Business Leadership Networks have been developed across the country as part of an initiative started by the Office of Disability Employment Policy (ODEP) and supported by the U.S. Chamber of Commerce.

Description of Action: Formation of a Business Leadership Network in Indiana will potentially expand employment opportunities for individuals with disabilities and/or mental illness. A similar effort has been successfully replicated in 38 other states.

Action: Employment standards for staff qualifications, outcomes, and provision of services should be developed to ensure a level of professionalism in the delivery of employment services to individuals who are disabled and/or mentally ill. Vocational Rehabilitation Services should modify and require that all vendor/provider contracts include language that ensures compliance with the standards as they are developed.

Description of Action: Indiana needs state-wide employment standards for staff qualifications, outcomes, and provision of services. These standards will assist in resolving inconsistent and sometimes poorly-managed employment services for low-income consumers with disabilities and/or mental illness.

Lead Agency: Indiana Department of Transportation

Action: The statute that currently limits the service area of a Public Transportation Corporation (PTC) to its taxing district should be reviewed by the Indiana Office of the Attorney General, and, if necessary, amended by the Indiana General Assembly to allow for the provision of the most efficient and effective transportation options for all Hoosiers.

Description of Action: Public Transportation Corporations are currently limited to their taxing district, significantly hindering access to essential services for at-risk populations. Removal of this limitation will provide consumers with the transportation services that they need to access medical and social service appointments, employment opportunities, and shopping centers. This requires legislative action.

Action: Funding for public mass transit should be increased so that all citizens have access to adequate, affordable, accessible public transportation.

Description of Action: There is insufficient public mass transit available in Indiana, especially in rural communities. Dedicated funds need to be committed to make more and better transportation services available to consumers, particularly those who are elderly and have disabilities. This will require legislative action.

Category: Children at-Risk

Lead Agency: Indiana Family and Social Services Administration

Action: The Family and Social Services Administration should assist each Indiana community to implement an integrated and unified system of care that is organized to respond to the needs of children who are at-risk of long-term out of home placement. A system of care is a "comprehensive spectrum of services and supports that are organized into a coordinated network to meet the multiple and changing needs of individuals and their families".

Description of Action: Indiana Family and Social Services Administration will work with local communities to develop a comprehensive spectrum of services and supports for children that include case management and care coordination, early identification, and timely transitions to eliminate disruption in services.

Lead Agency: Office of the Governor

Action: The Governor must issue a clear statement that identifies an on-going commitment by the State of Indiana to early identification and assessment of children who need services, as well as a comprehensive prevention and early intervention strategy for Hoosier children.

Description of Action: The Governor will affirm the State's commitment to early identification and assessment of children who need services, and a comprehensive prevention and early intervention strategy for all children by charging the Indiana Family and Social Services Administration with several new responsibilities.

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