What Tribal Communities Can Do To Sustain Family-Driven Care

According to the National Federation of Families for Children’s Mental Health (NFFCMH) and the Substance Abuse and Mental Health Services Administration (SAMHSA), “Family-driven means families have a primary decision-making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation. This includes:

• Choosing supports, services, and providers;
• Setting goals;
• Designing and implementing programs;
• Monitoring outcomes; and
• Determining the effectiveness of all efforts to promote the mental health of children and youth.”

How the guiding principles of family-driven care are implemented varies from community to community. Despite differences, both tribal and non-tribal systems of care encounter the same challenge of sustaining family-driven practices over time. What is clear is that, as tribal communities adopt family-driven care principles into their work, they have adopted some system of care best practices favored by non-tribal communities and adapted others to fit the unique challenges faced by Indian Country.

“Why Are You Asking Us?”: Introducing Family-Driven Care to Communities

For family members who seek behavioral health care for their children, navigating across multiple systems can be a daunting and intimidating process.

Guiding Principles of Family-Driven Care

• Families and youth are given accurate, understandable, and complete information necessary to make choices for improved planning for individual children and their families.
• Families and youth are organized to collectively use their knowledge and skills as a force for systems transformation.
• Families and youth embrace the concept of sharing decision-making and responsibility for outcomes with providers.
• Providers embrace the concept of sharing decision-making authority and responsibility for outcomes with families and youth.
• Providers take the initiative to change practice from provider-driven to family-driven.
• Administrators allocate staff, training, and support resources to make family-driven practice work at the point where services and supports are delivered to children, youth, and families.
• Families and family-run organizations engage in peer support activities to reduce isolation and strengthen the family voice.
• Community attitude change efforts focus on removing barriers created by stigma.
• Communities embrace and value the diverse cultures of their children, youth, and families.
• Everyone who connects with children, youth, and families continually advance their cultural and linguistic responsiveness as the population served changes.

2. Ibid.
Longtime system of care trainer and family advocate Shannon Crossbear (Ojibwe/Fort William First Nation) explains, “As family members, lots of times we’re involved with multiple systems. A couple of years ago, there was a [survey] of 371 family members with adolescents who had been involved in substance abuse treatment asking how many systems they were involved in. It was amazing. The average number was 3.5. That creates problems when one system is asking you to do one thing and the other system is asking you to do something different.”

Elevating families to a prominent role in child-serving systems creates opportunities for them to address the confusion caused by conflicting messages and to cut down on redundancy in services and requirements. By adopting a family-driven approach, systems of care aim to lessen the burden by moving families from more traditionally accepted family involvement and family engagement roles, to empowered, primary decision-makers in their children’s care. (See diagram.)

“Family-driven care is the most important part of our program,” says Dr. Carrie Johnson (Dakota Sioux), director of United American Indian Involvement’s (UAII) Seven Generations Child and Family Behavioral Health Program in Los Angeles. “It is really important for families to be involved in the services and in setting the goals for their family.”

Still, Johnson acknowledges how difficult it can be to begin this work. Despite family-driven-centered practices that thrive today, she states, “It was a challenge at first. When you don’t have family-driven involvement it’s difficult to figure out exactly what means and how you do that. We struggled with that too. We would send out invitations to a family meeting and they wouldn’t come! We had to continually ask ‘Why? What’s going on? Why aren’t they coming and most importantly, what do we have to do differently?’”

The solution, Johnson explains, was in changing their outreach approach to focus on one-on-one personal outreach to each family. With telephone calls and eventual face-to-face individual meetings, Johnson’s staff asked families what they would like to see in Seven Generations’ services.

This shift, intended to change practice from provider driven to family driven, can prove difficult, particularly for families unaccustomed to system of care principles. As Johnson explains, “I think that families are often not used to being asked what services they want. They’re usually just given a list of services for them. So it’s a new thing for them. Sometimes they’re not sure [why they are being asked] and say, ‘You’re the ones providing the services, why are you asking us?’”

Yet in answering such questions from families, Johnson and her staff have been successful in orienting participants to principles of family-driven care. She explains, “You have to educate and tell [family members and youth], ‘These services are for you. We want to provide the services that are best going to benefit you, so we need your input. That’s why we’re doing this.’ Once they see that you are listening to them and you want to hear from them, they become more and more involved.”

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Johnson has seen Seven Generations evolve from a Circles of Care grantee (2001-2004) to a Systems of Care grant program (2005-2011) graduate. Along the way, family-driven care has similarly evolved. She says, “Family-driven care’ doesn’t just mean that you have a family member at your meeting. It is much more than that.”

Today, Seven Generations involves families in individual monthly meetings to assess whether families are getting the services they need. Families provide leadership in governance of Seven Generations through an advisory board. Also, at the conclusion of the System of Care grant in 2011, families were asked to evaluate Seven Generations’ progress and to give direction about future goals and programs. “They assist us with our overall program development,” Johnson says.

Sustaining Family-Driven Care
Once families have embraced their role in family-driven care, sustaining this work becomes the next significant challenge. For many systems of care, creating a separate non-profit 501(c)3 family organization provides the structure around which families can organize and seek funding. As Crossbear explains, “The thing that the 501(c)3 [structure] allows organizations outside of tribal communities to do is contract. It allows them to be able to go for funds in order to sustain themselves and the work.” The NFFCMH, a system of care technical assistance and training provider, notes on its website that it links more than 120 chapters and state organizations focused on the issues of children and youth with emotional, behavioral, or mental health needs and their families. Many of these family-run non-profit organizations were created through the support of System of Care grant funding.

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While such a model of sustainability works for many systems of care, very few tribal families have opted to create a separate non-profit organization. Crossbear has many explanations for this. She says, “First, there are lots of cultural differences. In tribal communities, the level of challenge for us is so much higher than in non-tribal communities. Our families are so overwhelmed with so many issues and so much. If you’re 30 miles from anything, if everyone lives in different districts and no one has any gas money, then where are you going to have a support meeting? These are very practical things that just are not in that dominant culture experience.”

Further, Crossbear says that 501(c)3 organizations “operate differently. There are all these regulations and hoops to jump through. [Native] families just don’t want to do it. They don’t want to organize in that way. In non-tribal communities, there is a very distinct line between professional and parent. But in tribal communities, we’re all family. We’re all related. So we see it differently.”

Crossbear describes one tribal community’s process of considering whether or not to organize as a local chapter of the NFFCMH. Ultimately, they decided against it citing the overlapping of issues experienced by families and their desire for a holistic approach to finding solutions. Crossbear explains, “Even when we asked if we should separate families experiencing substance abuse [from] families experiencing mental health issues, they said, ‘We’re all in one big room. We experience it all. How can we separate?’ That’s very different from dominant culture.”

So what is working for tribal communities? First, Crossbear explains, “[Successful sustainability] is about developing different models. The important thing is the organizing itself, not the model of organization. What has not appeared to work is pushing [Native] families to organize under a 501(c)3. What appears to be more successful is allowing families to develop whatever they want. For example, if they want to form a network, then they have to find out ways to do pieces of work that will help them sustain themselves going forward. There are places where it really is working.”

Tribal communities have indeed formed networks like those Crossbear describes. According to its mission statement, the Society of TRUTH (Tribal Families Rural and Urban Together Healing) was created “to provide a coalition of organizations and grassroots community members that is inclusive of all youth, family, service recipients, and elders to share information, resources and most effective practices that support intergenerational healing while sustaining the health of our communities.”

Creating an active Facebook page allows Society of TRUTH members to stay in contact with one another. The result has been a sustained exchange of information between tribal families across the country. As Crossbear states, “It’s a network of families who have been involved in systems of care or other initiatives that are still [asking each other], ‘What are you doing and where are you at now?’”

The National Family Dialogue for Youth with Substance Use Disorders, whose mission is “to enable the experience-based knowledge of the family voice to strengthen, improve, and sustain the treatment and recovery system for youth with substance use disorders and create the true change necessary to make the vision a reality,” has also allowed tribal families to participate in supportive networking.

3. See www.facebook.com/groups/societyoftruth

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It, too, manages an active Facebook following, as well as hosting regular conference calls for its members.

Tribal families may not be creating 501(c)3 non-profit family-run organizations, but they are nonetheless organizing. Whether it be through their engagement in national networks, community gatherings, charter organizations, or via their leadership in the governance structures of organizations like UAII’s Seven Generations Program, tribal families have been asserting a significant role in all aspects of child-serving systems.

The Importance of Embracing and Facilitating Family-Driven Care

According to Crossbear, the principles of family-driven care are quickly gaining widespread acceptance. She states, “Family involvement is emerging in all the different systems, whether it be child welfare, juvenile justice, or mental health. It’s important enough that federal grants coming out of the Department of Justice, SAMHSA, and the Department of Education are all including this component.”

Many tribal Systems of Care grant communities are leading efforts to embrace family-driven care, which bodes well for their capacity to find diverse funding streams for sustained work.

Beyond addressing the fiscal considerations of sustaining family-driven care, successful tribal systems of care communities recognize the importance of constantly re-assessing whether and how family-driven principles guide their work. (For a practical checklist to help in such an assessment, see “Questions to Assess Family Involvement in System Design and Development.”)

UAII’s Carrie Johnson explains, “We need to educate our providers on the importance of family-driven care and be prepared to explain what it is to our families. Then, it’s making sure you’re providing activities they’ll feel comfortable with. We always look at our work as their program. It’s not ours. It’s theirs.” This approach helps emphasize the sense of family “ownership” of the services and programs.

Crossbear agrees that asking families to provide leadership and direction is essential to making sure efforts address true need. She says, “We can change people’s perceptions and reduce stigma, but most importantly, when people seek help, it has to be good help [that we provide].”

Sustaining the “good help” Crossbear mentions is a matter of committing to continued dialogue with families. Johnson explains, “How we continue to keep them engaged is by really listening to what they want. Then they start to feel more comfortable and trusting of us, knowing that their input is something we take very seriously and integrate into our program.”

According to Crossbear, once such momentum is established, supporting and sustaining family-driven principles becomes second nature. She says, “What contributes to success? [It happens when] people fully embrace the idea of families as partners. If they can sustain that idea—if they can sustain system of care principles and thinking—then they will find ways to sustain the activities.”

Questions to Assess Family Involvement in System Design and Development

- What is your group currently doing to encourage family involvement?
- Is it working?
- Does your group have a family recruitment plan?
- Is there a role for families that have survived their children’s mental health problems and are ready to support other families through their crisis?
- Is the family participation and involvement valued and supported through financial incentives?
- Does the group accommodate flexible meeting times to encourage family participation?
- Are locations for meetings chosen where families feel comfortable?
- Are meetings held when family partners can attend?
- Are there numerous ways for families to participate?
- Are families sitting on boards and policy making committees?
- Are families participating on internal quality assurance committees?
- Are family members participating in system trainings?
- Are parents/and or caregivers supported as co-trainers whenever possible?
- Have family members been trained as system evaluators?
- Are youth invited to participate along with their families?
- Does your organization believe that families and youth have within them the resources to change their lives?

4. See www.facebook.com/groups/165531130167937/.
5. Developed by Libby Jones and Pat Solomon. Adapted from www.ncdhhs.gov/mhdsas/services/serviceschildfamily/Toolbox/partnering/partnering.htm
A Conversation with Shannon Crossbear

Shannon Crossbear (Ojibwe/Fort William First Nation) is an independent consultant who has offered training and technical assistance with the National Federation of Families for Children’s Mental Health for over 10 years, consulted with Georgetown University, Garret Lee Smith Suicide Prevention Programs, the National Child Traumatic Stress Networks, and the Aboriginal Healing Strategy. In addition, she has consulted extensively with NICWA, including lending her expertise to tribal system of care grantees. Having played a leadership role with the First Nations Behavioral Health Association, the Society of TRUTH, and the National Family Dialogue for Youth with Substance Abuse, NICWA staff recently spoke with Crossbear about sustaining family-driven work over time, and the challenges unique to Indian Country in doing so.

You have a very unique and compelling point of view when it comes to family involvement in children’s mental health services. Can you describe how you got into this work?

I came to this work as a parent, as a family member. There were both mental health and substance abuse challenges in my family. My middle son died by suicide after he self-admitted for suicidal ideation. He was actually in a hospital on suicide watch when he died. There is something wrong with that picture. My youngest son had trauma issues as the result of the loss of his brother; he ended up going down a path where substance abuse was an issue. There were questions that I didn’t know enough to ask of the hospital. At the time, families were often blamed for the situations that they found themselves in. That wasn’t helpful. I was working [from the perspective], “We are living with these challenges day in and day out. We need assistance and often the assistance offered doesn’t meet the need.” So I began to advocate for that family voice to be present.

So [now] I do a lot of advocacy to address how families get the help they need. [I ask], “What for us as tribal people has sustained us?” [I advocate] for some of our traditional practices which have proven very helpful in our process toward recovery and wellness. [My advocacy] was about, “How do we hold systems accountable?”

I’m now working with Project LAUNCH¹. I am also co-director of the National Family Dialogue for Adolescent Substance Abuse. There are all these pockets of excellence and family groups and organizations throughout the country, but there’s no unifying voice at the national level around families and adolescent substance abuse. I’m working to help create the networks to connect the dots.

What roles should families play in system of care service provision?

Systems can’t know [what the true needs are] unless there are families who are at the table when decisions are being made about treatment plans, courses of action, and determining when something is working or is not working. Families need to have input into that process. Is that happening? I would say currently that this is a very basic principle of systems of care and if it’s not happening, then they’re not doing a system of care.

Our constituents consistently want to know what other communities are doing to sustain family involvement in Indian Country? Do you have examples of when this has worked well? To what do you attribute this?

One tribal community had a very strong family component during their system of care [grant period]. Then their system of care initiative graduated. Their families couldn’t organize into a 501(c)3 because there were tribal regulations around

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¹ Project LAUNCH (Linking Actions for Unmet Needs in Children’s Health) is the SAMHSA Center for Mental Health Services program that promotes the health and well-being of children from birth to age 8. Visit www.samhsa.gov/samhsanewsletter/Volume_18_Number_3/PromotingWellness.aspx to learn more about Project LAUNCH.
The Blanket Weavers: An Urban Indigenous Family Group Influences Systems Change

The Blanket Weavers, a group composed of indigenous family members who have children in youth services or the mental health system, operates under the umbrella of the Native American Health Center (NAHC). The Blanket Weavers grew out of a community planning process for what would later become Urban Trails San Francisco. As part of the planning process, the NAHC invited San Francisco area community members to a series of focus groups. The purpose of the focus groups was to listen to indigenous people talk about their families’ experiences with child-serving systems. The focus groups provided community members with a series of opportunities to express their opinions on how Urban Trails San Francisco should be developed to best support their children.

The name “Blanket Weavers” was created by families during community meetings. They said the name was a way to describe how they wanted to create a “blanket system of care.” In other words, the name “Blanket Weavers” was a symbol of how they wanted to wrap around, with other agencies, to find provide support for their children. The concept also calls to mind a place that feels purposeful and safe, a place where their voices would be heard.

Blanket Weaver Group Development

The meetings were open to anyone and invitations to attend were distributed through flyers and word of mouth. Food and childcare were always provided, not only to show respect and understanding for family needs, but to help enable full family participation.

Early discussion in the Blanket Weavers meetings focused on helping the family members understand what a system of care is all about. Families did not understand what a system of care was, or how a system of care approach to services would be different. The federal “family-friendly” language used to describe a system of care was still foreign to the indigenous community. Instead, the words and phrases used by conventional social marketing were translated into the community’s way of talking and with community examples. Community members shared their examples of what systems could do to better help their children. The Blanket Weavers group also took time to help community members understand how, and why, Urban Trails San Francisco would work with other system partners. For myriad reasons, many indigenous families had a healthy mistrust of mainstream child welfare and other child service systems.1

Although the system of care family advocacy and cultural staff attended the early Blanket Weavers meetings, over time, the Blanket Weavers became “family member-only” meetings. By keeping to family only, families felt that the meetings were more welcoming. It was easier for family members to speak openly when surrounded by peers. A meeting of family peers made it easier for people to shed any self-consciousness about expressing their opinions.

Urban Trails San Francisco was able to provide incentives to encourage family participation in the early days. All of the incentives supported the day-to-day sustainability of the family. For example, some of the incentives included grocery debit cards for $10, and student backpacks during back-to-school time.

Later, when funding cutbacks could not support family incentives, staff wondered if the families would continue to attend if no incentives were provided. They did. Families continued to come to the Blanket Weavers meeting, and 10 core members have remained with the Blanket Weavers group for over five years. This showed that family incentives work as an effective ice breaker, but after the group bonds over their common cause of addressing their children’s futures, family members will continue to attend on their own.

1. For example, although Congress passed the Indian Child Welfare Act in 1978 in response to the alarmingly high number of Indian children being removed from their homes by both public and private agencies, the percent of indigenous children in child-serving systems continues to be disproportionately high.

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Another important factor that helped to facilitate the development of the Blanket Weavers group was the role played by family advocates. Family advocates are family members who became employees of the system of care. In the beginning, family advocates facilitated Blanket Weavers meetings, with hope that as the group members observed the family advocates in their organization and facilitation roles, new family leadership would emerge. It did.

As the Blanket Weavers group grew, more organization and structure was needed. First, the group members created a mission statement which is “to provide opportunities for awareness of our Indian culture and to help create healthy families in our communities.” A mission statement helped to maintain the group’s focus on support and advocacy for healthy tribal families. It simultaneously acknowledged the role of indigenous culture as a prerequisite for positive change. They also created group agreements for their meetings which included responsibilities for developing an agenda, being respectful of others, not allowing cell phones or side conversations, and other group rules to support efficient meetings.

The Blanket Weavers meet every month, but they also asked for family volunteers to attend other related meetings that were important to the system of care development. Family members agreed and family voice and family influence was present at the social marketing meetings, the outcome evaluation meetings, and the governing board meetings.

The Urban Trails San Francisco governing board is a broad coalition of community members, indigenous service providers, and other service providers representing state services and the city and county of San Francisco. Approximately 50 people attend the quarterly governing board meetings. The Blanket Weavers are an important part of this system of care governing body and represent the principles of family-driven care. The governing board meetings also give family members an opportunity to hear reports and to talk directly with city and county administrators about services for their children.

Blanket Weavers as Social Advocates
The Blanket Weavers became social advocates. They advocate best about what they know. From a personal perspective, they have seen and experienced how their youth are thriving with system of care services. They have seen how the system of care has worked for their children and the real, positive changes in their behavior and school attendance. They want their children to be good community members, but they say it is hard to do in the city. In this environment, the system of care approach is making a difference and helping their children.

From a family and community perspective, they have witnessed how it helps youth when everyone from the different systems are on the same page. They say it’s a beautiful thing to see the parents and caretakers become empowered and want to put their energy into positive change. More importantly, they know that when their children see their parents at the meeting tables, youth experience a sense of pride.

Blanket Weavers Concerns
The Blanket Weavers are concerned about many things that impact the wellness of their children. Today, their concerns are focused on three areas:

1. System of care financial sustainability;
2. Affordable housing; and
3. Changing state systems and their ability to continue as a viable voice for the family perspective.

The ongoing financial sustainability of the system of care initiative, especially after the federal funding cycle ends, is of huge concern to the Blanket Weavers family group as they developed over the years. Following is a list of action steps they took, in partnership with the NAHC, to improve their community and transform indigenous family members into social advocates for children’s mental health and wellness.

- Create a symbolic name for your family group
- Develop a mission statement
- Conduct family-only meetings for family comfort
- Encourage family participation by providing incentives in the formative years
- Create group meeting rules
- Explain everything using the community’s language and community examples
- Develop ways to improve meeting organization and structure
- Encourage and nurture family leadership
- Create multiple opportunities for family participation in meetings and advocacy
- Serve on community coalitions
- Realize that parent/caretaker presence at the meeting table will boost children’s pride
- Identify allies in child-serving systems and build relationships
- Participate in other system of care-related meetings (e.g., social marketing, outcome evaluation, and governing board)
- Study the issue
- Do your homework and develop advocacy strategies
- Create succinct but powerful advocacy messages
- Speak (advocate) about what you know
- Increase peer advocacy training opportunities
- Advocate for peer intern positions to help families move from volunteer to employee status

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2. Indigenous youth were part of the original Blanket Weavers group, and then created their own group called Youth Reach.
Weavers. The Blanket Weavers hold the system partners responsible and ask, “What are you as partners doing to help with sustainability?” In another example, the Blanket Weavers expressed concern for Native staff during discussion of potential cutbacks. They attested to the value of the recruitment and hire of Native, credentialed, mental health staff to their families. They advocated for minimal disruption to this investment made by the NAHC.

Affordable housing in San Francisco is a looming threat to the Urban Trails families. Housing in San Francisco has become the most costly in the nation, spurring a crisis that has pushed protesters into the street and low-income earners out of their homes. The Blanket Weavers plan to advocate with city officials for affordable housing as a critical standard of healthy life for their children.

The Blanket Weavers also worry about maintaining their family voice within changing state, county, and city systems. On the state level, the elimination of the State Department of Mental Health and creation of the new State Department of Health Care Services requires attention to maintaining old relationships, while building relationships with entities like the newly created State Office of Health Equity.

Blanket Weavers have also inspired separate, independent advocacy efforts. Tribal advocates continue to fight for recognition as a unique population with unique cultural needs in the midst of state transformation. On the local level, initiatives have ranged from holding the City and County of San Francisco accountable for its own recommendations for increased Native inclusion in mental health systems noted in its Human Rights Commission’s Discrimination by Omission Report, to contributing to the development of community vital sign indicators for the San Francisco Department of Public Health Community Health Improvement Plan that help focus community health efforts.

In addition, revenue from the California Mental Health Services Act (MHSA) tax provides increased funding for services, personnel, and other resources for county mental health programs. The MHSA was passed into law in November 2004 and generates revenue through a 1% income tax on California residents with personal income in excess of $1 million. This tax revenue generated an additional $1.5 billion in the California Governor’s Budget in FY 2012-2013 for mental health programs. The Blanket Weavers and other advocates for indigenous support can monitor the MHSA’s progress toward their statewide goals of serving children, transition-age youth, adults, older adults, and families with mental health needs.
“It’s not something you can take back. Once you empower families, they’re not going to go away.”

— Shannon Crossbear

Blanket Weavers Increase Advocacy
The Blanket Weavers want to learn how to be more effective advocates. They have increased their peer advocacy training, motivated by potential budget cuts and other system changes. They recognize that change can also bring opportunities and, now that they are more experienced and have “stronger voices,” they are setting the stage for advocacy at higher levels. They are reviewing policy documents to see if recommendations and promises of improved services to indigenous people were kept. They are asking, “Who do we talk to about our concerns?” They have identified key city officials to meet with, always spending time preparing a clear message prior to meeting. If they are not at the decision-making table, they ask, “Why not?” They want to sit at the tables with decision-makers. As one member explained, “We’re not there just for the soup.” Another agreed, saying, “We may have a lot of gripes, but we want to be prepared, do our research and have a clear message. We want to be productive, not counterproductive.”

Summary
The Blanket Weavers represent many of the cultural strengths of indigenous people. One of these cultural strengths is the belief that the tribal collective takes care of the children. The Blanket Weavers also understand that child-serving institutions that impact their children and youth are important, too, and that they can help these systems change to better serve indigenous families.

Although the Blanket Weavers initially came together as a group because of their shared concern for the future of Native children and families, they have now created a leadership group of indigenous parents and caretakers. The family members have transformed into public speakers and social advocates. The Blanket Weavers know that they can influence system change if they mobilize and increase their knowledge about the advocacy process.

The benefits that the Blanket Weavers bring to the San Francisco urban community are many. The bottom line is that the Blanket Weavers are a viable family-driven resource, with proven longevity, that can help the indigenous urban community and child-serving institutions provide improved services and supports for their children.

For more information about the Blanket Weavers, contact Michelle Antone at the Native American Health Center at michellean@nativehealth.org.

Additional Resources
National Federation of Families for Children’s Mental Health. www.fccmh.org/aboutus/history
National Family Dialogue for Youth With Substance Use Disorders. www.cmhnetwork.org/news/nfd
Technical Assistance Partnership for Child and Family Mental Health. www.tapartnership.org/content/familyInvolvement/default.php