

**Family Care and IRIS
Ombudsman Program
for Enrollees Age 18-59**

**Annual Report
Year 2:
July 1, 2009 - June 30, 2010**

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Protection and advocacy for people with disabilities.

Overview

In its 2007-2009 biennial budget, and as amended in the 2009-2011 biennial budget, the Wisconsin legislature enacted sec. 46.281(1n)(e), Wis. Stats. This provision requires the Wisconsin Department of Health Services (DHS) to contract with an entity to provide advocacy services to actual or potential recipients of the Family Care and IRIS programs who are under age 60 or to their families or guardians. The legislation sets as a goal one advocate for every 2,500 individuals under age 60 who receive the Family Care benefit. DHS selected Disability Rights Wisconsin (DRW) as the provider and entered into a contract with DRW that became effective October 1, 2008 and was renewed in July 1, 2009.

This second year of operation continued to be extremely productive and successful for Disability Rights Wisconsin's Family Care and IRIS Ombudsman Program (FCIOP). The program continued to refine its administrative infrastructure, hired and trained two new ombudsmen, engaged in vast amounts of outreach and provided assistance to members in Family Care, Partnership and IRIS. During the second year, the program hired a second full-time ombudsmen in DRW's Milwaukee office and one full-time ombudsman in DRW's Rice Lake office. They joined the one full-time ombudsman in DRW's Madison office, with the hiring process begun for a second ombudsman in the Madison office.

This past year, staff finalized FCIOP Policies and Procedures, continued to refine client intake and standardized materials and reconfigured its electronic case data system to accurately capture Family Care and IRIS Ombudsman case data, outreach activities and other related projects.

Outreach

FCIOP organized and implemented an intensive outreach strategy during this second year. It updated program brochures in English, Spanish and Hmong and printed and distributed them throughout the state. The program continued to distribute newsletter articles and program announcements to ADRCs, other disability organizations, parent groups, DRW staff and Board and other avenues. We also continued to add consumer education and outreach materials to DRW's Family Care and IRIS Ombudsman Program website.

Staff organized and conducted significant outreach activities. Staff met with representatives of ADRCs, parent organizations, advocacy groups, Independent Living Centers, social service agencies and others. Outreach activities were conducted in the counties throughout the state, with an emphasis on counties that were newer to Family Care and IRIS and/or with a new ombudsman. In addition, in coordination with the Milwaukee County DRC, staff conducted seven consumer trainings for Milwaukee County held in August 2009 for nearly 300 consumers, their representatives, family members and advocates. Another set of Milwaukee County area trainings was conducted in November-December 2009 and still another in late spring 2010. In preparation, staff put together and continually updated a Consumer Information Packet about Family Care, Family Care Partnership, PACE and IRIS.

In addition to DRW-organized outreach activities, staff have made presentations about consumer rights and Family Care & IRIS at many conferences, in-services, and other venues. These

have included presentations for staff of independent living centers, self-determination conferences, brain-injury groups, Governor's Councils on Physical Disabilities and Developmental Disabilities, and others.

Program staff continued developing positive working relationships with managed care organizations (MCOs) by organizing individual meetings with each MCO in the state, exchanging ideas about working together, outreach and advocacy. Staff also attended numerous DHS-sponsored meetings with the MCOs and began participating in the regular DHS-organized Member Rights Work Group.

Websites

To facilitate sharing of documents and information, FCIOP staff has created an internal website for FCIOP staff that contains DHS resources, templates for client letters and advocacy materials, indexed hearing decisions, MCO and ADRC contracts and relevant law.

In addition, staff continue to place valuable consumer materials on DRW's public website, including outreach materials, consumer education materials and links to external resources. <http://www.disabilityrightswi.org/programs/family-care-ombudsman-program/>

Individual Requests¹

Consumer requests for assistance from the Family Care and IRIS Ombudsman Program increased significantly in the second year. The program provided Information and Assistance to 79 individuals and case assistance to 349 individuals for a total of 428 requests. Of the 384 new FCIOP clients served over the course of the year, 213 were people with developmental disabilities, 64 were people with physical disabilities, and 107 were people with both physical and developmental disabilities.

The largest referral sources were: family members, guardians or friends; Family Care information; the individual with disabilities him/herself; Aging and Disability Resource Centers; and the MCOs. The first contact was primarily by telephone. Cases included issues related to eligibility, coverage and terminations/reductions.

See APPENDIX for client and case breakdown details. Examples of Family Care and IRIS issues include:

- termination of eligibility based on the functional screen;
- reduction in service hours;
- denial of choice of providers;
- denial or terminations of services;
- denial of medical equipment;

¹ This report includes data only on DRW casework funded by the Family Care and IRIS Ombudsman Program. DRW staff funded by other sources also provide advocacy assistance to Family Care and IRIS enrollees. This assistance is not reflected in this report's data.

- denial or termination of certain medications or therapies (physical therapies, daily living skills, acupuncture, massage therapy, mental health counseling);
- reduction or termination of family-provided care;
- inaccurate computation of cost-share;
- defective Notices of Action by the MCO; and
- MCO failure to follow the Resource Allocation Decision (RAD) method
- complications and delays in instituting self-directed supports
- complications and delays in converting from Family Care to IRIS or from IRIS to Family Care
- lower-than-needed IRIS individual budget allocations
- lack of Medicaid due process protections in IRIS policies

Staff has assisted members with all levels of advocacy. Some cases have primarily consisted of explaining choices and benefits to members. Most have involved contacting MCOs' Member Rights Specialists and Interdisciplinary Teams to negotiate disagreements. Thirteen involved assisting members in filing and pursuing MCO grievances and only nine required representing clients at administrative hearings, post-hearing memos and implementation of administrative law judges' decisions.

Client satisfaction surveys indicated consistently positive evaluations of DRW's Ombudsman work, with 78% of clients responding to surveys (80 responses to 348 surveys sent) indicating that the ombudsman was important in solving their problem, 80% very satisfied or satisfied with the assistance received, 85% very satisfied or satisfied with the explanations received and 82% very satisfied or satisfied with follow-through. Nearly 90% said they would call the ombudsman again and 91% said they would recommend the ombudsman services to a friend.

Work Groups

DHS staff have participated in numerous time-limited and on-going work groups related to Family Care and IRIS including those focused on the Family Care Notice of Action, several groups related to the functional screen, the full IRIS Committee, the IRIS Quality Sub-Committee, the IRIS Individualized Services and Supports Sub-Committee, the Member Rights Work Group and the Quarterly Ombudsman Meetings. In the coming year, staff will join the Care Management Work Group as well.

Patterns and Problems Affecting Multiple Individuals

Staff has also worked diligently in responding to problems identified as affecting multiple individuals and/or MCOs. These include the following:

Reductions in Service Hours at Transitions from Waivers: Cases from around the state have involved significant reductions in supportive home care and personal care hours, particularly for individuals first transitioning from the COP and CIP to Family Care. In many cases, the reductions appear arbitrary, not based on comprehensive assessments and are resulting in critical loss of assistance to members.

Reductions in Hours Provided by Family Members or Respite for Family Members: A subset of the above issue is the reduction of hours approved to be paid to family members providing care to Family Care members. Many cases involve family members who have provided care to adult family members for numerous years and at the onset of Family Care are receiving notices of severe reductions in approved service hours provided by family members. In other cases, respite hours for family members are also being cut from hours approved during the years their loved ones were COP and CIP clients.

Notices of Action: During its first year of operation FCIOP staff identified inconsistencies and deficiencies in various MCOs' Notices of Action. In other cases, MCOs have conveyed denials and reductions orally instead of in written notices, as required. A work group of staff from DRW, BOALTC, DHS staff and the Department of Administration's Division of Hearings and Appeals was created. FCIOP and BOALTC then worked with DHS's Member Rights Work Group to successfully develop a standardized Notice of Action for reductions, terminations and denials of supports or services that contains all of the statutorily-required items and is more consumer-friendly. Final implementation will begin Fall 2010.

Functional Screen: Cases throughout the state have identified problems in MCOs' application of DHS's functional screen, which determines both eligibility and DHS's capitation rate to MCOs for each member. Problems identified have included: screeners not permitting or gathering collateral information and sources; screeners not breaking down tasks; conducting screens without guardians or other key individuals involved; screeners not asking about members' "worst days"; screeners making conclusions about members' ability levels without observing members actually engaging in the activities. In addition, a change in the functional screen instructions this year resulted in large numbers of individuals losing eligibility and consequent increased requests for assistance from FCIOP staff.

Residential Moves: As a result of residential rate reductions instituted by some MCOs, large numbers of individuals in certain areas of the state faced the possibility of moves from long-time residences. FCIOP was involved in many of these cases to prevent moves where a member's outcomes could not be supported in a different location or to assist members in selecting an appropriate alternative residence, where appropriate. FCIOP staff also worked with DHS to develop a Technical Assistance memo to MCOs to fully describe required protocols and ensure resident's rights were honored.

Mental Health: While consumers with mental health diagnoses are not a primary target population for Family Care, state-collected data indicates that over 60% of Family Care members have co-occurring mental illnesses, ranging from depressions and anxieties to serious and persistent mental illnesses. Members in several MCO areas report concerns about the adequacy of MCO's mental health provider network, confusion about coordination with county mental health systems and the availability of quality mental health services.

Guardianship and Protective Services: Transitions from county-based systems to Family Care has resulted in some confusion about the role of the county adult-at-risk agencies and MCOs regarding such issues as: the impact of court orders under Ch. 51 (mental health) and Ch. 55 (protective services), reporting and investigation of suspected abuse, neglect, financial exploitation

and self-neglect. Similarly, there is a lack of clarity about responsibility for ensuring that appropriate legally-authorized decision-makers are involved in developing and agreeing to member-centered plans where members/participants are not capable of doing so.

Employment: While making progress, Wisconsin DHS has recognized that the state lags behind other midwestern states on employment issues for adults with disabilities. DRW has received requests for assistance from individuals in sheltered workshops who are interested in exploring supported and integrated employment.

Transition from Schools: Young adults with disabilities in the Wisconsin public school system have come to expect and rely on public service systems. While Family Care and IRIS hold great promise for transitioning youth who previously languished on waiting lists, new concerns have arisen about their functional eligibility for the adult programs, how to find needed services while waiting for Family Care to begin or complete transition in their respective counties, how to work with managed care under Family Care, and meaningful day activities.

Year Three Plans

In its third year of operation, DRW's Family Care and IRIS Ombudsman Program will expand its efforts in numerous ways.

First, it will continue to increase capacity by hiring a second full-time Family Care Ombudsman in its Madison office and begin plans for additional ombudsmen as enrollment continues to increase.

Second, FCIOP will continue to assist individual Family Care and IRIS enrollees and their representatives with individual case concerns. Ombudsmen will continue to provide information, assistance, negotiation and representation, as appropriate, to Wisconsin's rapidly expanding number of adults with disabilities in publicly-funded long-term care programs.

Third, FCIOP staff will continue its ambitious outreach for the entire state, both to educate consumers about their rights under Family Care and IRIS, explain the availability of the ombudsman services and to hold listening sessions about experiences with Family Care and IRIS to date. Similarly, staff will continue to develop consumer education materials and make them available through DRW's Family Care and IRIS Ombudsman Program website.

In addition to individual casework, FCIOP staff will be tackling Family Care and IRIS-related issues that appear to be affecting numerous clients and/or emanate from many areas in Wisconsin. DRW is eager to continue to partner with consumers, family members, other advocates for people with disabilities, advocates for the elderly, school staff, providers, MCOs and state staff to help Family Care and IRIS achieve their goals of real long-term care reform in Wisconsin.

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