

Family Care Ombudsman Program for Family Care and Partnership Enrollees Age 18-59

Annual Report Year 1: November 1, 2008 - June 30, 2009

**Report Date:
October 1, 2009**

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Protection and advocacy for people with disabilities.

Overview

In its 2007-2009 biennial budget, the Wisconsin legislature included 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 benefit 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.¹

Upon passage of the budget, Wisconsin DHS set out to develop its Request for Proposal and the process of selecting the provider of advocacy services, known as the “Family Care Ombudsman Program.” After a competitive process, DHS selected Disability Rights Wisconsin (DRW) as the provider and entered into a contract with DRW that became effective October 1, 2008.

Disability Rights Wisconsin’s Family Care Ombudsman Program (FCOP) had a busy, productive and highly successful first nine months. The program developed its administrative infrastructure, hired and trained new staff, engaged in vast amounts of outreach and provided assistance to members in Family Care and Partnership. In the upcoming year, the program will be increasing staff in all three DRW offices and is expanding the scope of the program to include the “Include, Respect, I Self-Direct” (IRIS) participants.

The program began with the hiring of Program Manager Betsy Abramson. A long-time advocate for the elderly and people with disabilities in Wisconsin, specifically in the areas of long-term care and adult protective services, Abramson jumped right in to develop the program at DRW. Within a few months, DRW hired three additional staff: Milwaukee DRW office ombudsman Jamie Miller; Madison DRW office ombudsman Teresa Clark; and FCOP attorney, Sarah Pitsoulakis. All ombudsman staff have experience in individual casework and advocacy on behalf of people with disabilities.

Both FCOP and other DRW staff working on Family Care issues participated in an intensive 3-day training in March 2009, organized by Abramson and Pitsoulakis. Trainers included both internal DRW staff and representatives from DHS and the University of Wisconsin. Staff put together two volume binders with resource materials and created internal websites for the manual’s contents and other shared documents and ombudsman materials. Staff developed draft FCOP Policies and Procedures, client intake and client evaluation forms and reconfigured its electronic case data system to accurately capture Family Care Ombudsman case data, outreach activities and other related projects. Staff developed Memoranda of Understanding with the Board on Aging and Long-Term Care’s Ombudsman for Family Care enrollees age 60+ and the Disability Benefit Specialist Program.

Outreach

FCOP implemented an intensive outreach strategy during this first partial year. It developed program brochures in English, Spanish and Hmong and printed and distributed over 10,000 copies.

¹ This provision was retained in the 2009-2011 state budget, and expanded to include advocacy services for those who participate in IRIS (Include, Respect, I Self-Direct), the self-directed services option, which is also operated under a federal Medicaid waiver.

The program wrote newsletter articles and a program announcement and distributed them to Survival Coalition members, Independent Living Centers, other disability advocacy organizations, parent groups, the Board on Aging and Long-Term Care, Aging and Disability Resource Centers, DRW staff and Board and other avenues. DRW also created a Family Care Ombudsman Program section of its website, and uploaded consumer education and outreach materials to it.

Staff also 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 following counties: Ashland, Barron, Columbia, Dane, Douglas, Dunn, Eau Claire, Fond du Lac, Green, Kenosha, Racine, LaCrosse, Outagamie, Marathon, Milwaukee, Portage, Sauk, Washington, Waukesha. In addition, they began planning for a series of seven consumer trainings for Milwaukee County, which were held in August 2009 for nearly 300 consumers, their representatives, family members and advocates. In preparation, staff put together a Consumer Information Packet about Family Care, Family Care Partnership, PACE and IRIS.

Sample presentation materials, newsletter articles, the brochures and other outreach materials have been placed on DRW's website.

Program staff continued developing relationships with managed care organizations (MCO)s 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 to continue to build connections.

Case Rounds

To provide program guidance, share strategies, and engage in group problem-solving, FCOP determined that staff from DRW's three offices would benefit most from monthly case rounds. Accordingly, staff has convened a monthly conference call, during which staff from the three offices present cases, discuss experiences, consult on strategies and share policies, procedures, training opportunities and other information. Regular in-person in-services are also being planned.

Websites

To facilitate sharing of documents and information, FCOP staff has created an internal website for FCOP 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 Requests²

Consumer requests for assistance from the Family Care Ombudsman Program have increased throughout the year. During this first partial year ending June 30, 2009, (eight service months) the program provided Information and Assistance to 26 individuals and case assistance to 65 individuals for a total of 91 requests. More than two-thirds (63) of FCOP clients were people with physical disabilities, 19 were people with developmental disabilities and nine were people with both physical and developmental disabilities. The largest referral sources were: Family Members, Friends, Guardians; the individual with disabilities him/herself, the Aging and Disability Resource Center; and the Managed Care Organization. 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 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
- 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
- MCO failure to follow the Resource Allocation Decision (RAD) method

Staff has assisted members with all levels of assistance. 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 disputes. Some have involved assisting members in filing and pursuing MCO grievances and seven 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 the great majority of clients indicating they were "very satisfied."

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.

² This report includes data only on DRW casework funded by the Family Care Ombudsman Program. DRW staff funded by other sources also provide advocacy assistance to Family Care enrollees. This assistance is not reflected in this report's data.

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: DRW staff early identified inconsistencies and deficiencies in various MCOs' Notices of Action. In other cases, MCOs have conveyed denials and reductions orally, instead of as required, in written notices. A workgroup of staff from DRW, the Board on Aging and Long Term Care, DHS staff and the Department of Administration's Division of Hearings and Appeals was created and is developing a standardized Notice of Action that contains all of the statutorily-required items and is more consumer-friendly.

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 members' with abilities that fluctuate about their "bad days"; screeners making conclusions about members' ability levels without observing members actually engaging in the activities.

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 most 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.

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.

Employment: 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.

Waiting List Management: This past year resulted in the state legislature extending waiting list phase-in from 24 to 36 months in counties that are currently in the process of or slated for transition to Family Care and IRIS. This has increased the confusion about timing and the number of emergency situations. A particularly difficult situation arose in Douglas County where 53 individuals who had been receiving services funded only by the county, were notified that their services would

drop by 50% in April 2009 and be eliminated entirely by the end of 2009. A scramble to determine eligibility for the wait list ensued, but still, some consumers are or will be without services they relied on in the past.

Transition from Schools: Young adults with disabilities in the Wisconsin public school system have come to expect and rely on public service systems. Upon exiting from high school, many of these individuals have languished on county waiting lists for many years. New concerns have arisen about their functional eligibility for Family Care and IRIS, how to find needed services while waiting for Family Care to begin or complete transition in their respective counties, and how to work with managed care under Family Care for those eligible to engage in meaningful day activities.

Year Two Plans

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

First, it will increase capacity by hiring a full-time Family Care Ombudsman in its Rice Lake office, adding an additional full-time ombudsman in its Milwaukee office and beginning plans for an additional ombudsman for its Madison office.

Second, FCOP 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, FCOP staff will be implementing an ambitious outreach plan 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 participate in 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.

Fourth, FCOP statewide and Milwaukee staff recognize the large challenge of Milwaukee County's transition to Family Care, Partnership, PACE and IRIS. With over 2,500 current COP and CIP participants set to transition beginning November 1, 2009 and additional hundreds of individuals on waiting lists, FCOP is preparing to assist participants and their families during this critical transition year.

FCOP 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 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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Family Care and IRIS Ombudsman Program Manager
October 1, 2009

Family Care Ombudsman Program -- Disability Rights Wisconsin November, 2008 - June 30, 2009 Year 1 Totals (Only 8 months in Year 1)*										
Number of FC cases										
New I&A	26									
New this reporting period - opened as case	65									
TOTAL	91									
Target Population										
Developmental Disability	19									
Physical Disability	63									
Developmental Disability & Physical Disability	9									
Contact/Referral Source										
ADRC	10									
Advocacy Group	3									
BOALTC	1									
County DHS	1									
DD Council										
DRW advocate (non-FC)	1									
Estate Recovery letter	2									
Family Care written information	8									
Friend/Family Member/Guardian	20									
ILC	4									
Legal Aid Society										
MCO or CMU	9									
Metastar	6									
Nursing Home										
Self	11									
Training by DRW	2									
Social Worker - non-Family Care	1									
WI Dept. of Public Health										
Not Selected	3									
Method of First Contact										
Telephone	77									
E-mail	1									
Mail										
Face to face	4									
Issue and MCO involved	WWC	CCO	Care WI	SWFCA	CHP	CCI	CCCW	Milw DoA	NoBr	TOTAL
Abuse/Neglect			1		1					2
Assistance with MCO's grievance procedure			2							2
Assistance with state fair hearing										0
Choice of Provider					1				1	2
Cost Share			1		1	1				3
Denial of prescription medication			2							2
Denial of visitors										0
Discharge planning			2							2
Disenrollment			7		1				1	9
Enrollment/Eligibility			2		1	3	1			7
Equipment Denial										
Estate Recovery			1		2					3
Home modification (accessibility)			1			1				2
MCO terminates provider relationship					1					1
Medical treatment	3				1					4
Provider Quality	2		1							3
Relocation	3		5		1	2	1		1	13
Safety					1	1				2
Self-directed supports					1		1			2
Service delay							1			1
Service denial (additional service[s] or hours)	1	1	3		2	2	2			11
Service denial (specific service)		1	7		2	1	3			14
Service reduction			3		3	9	1			16
Service termination	2		5		1	4		1		13
Other										0
Total by MCO	11	2	43	0	20	24	10	1	3	114**

Family Care Ombudsman Program -- Disability Rights Wisconsin November, 2008 - June 30, 2009 Year 1 Totals (Only 8 months in Year 1)*										
Result / Outcome for Closed Cases during this Reporting Period										
Full Satisfaction	10									
Partial Satisfaction	10									
Issue Expired (Client withdrew issue, client died)	5									
Unknown - provided advice only										
Referral to ABC for Health	1									
Referral to ADRC	5									
Referral to Elderly Benefit Specialist	1									
Referral to county Adult Protection worker	1									
Referral to BOALTC	6									
Referred to DQA	1									
Referral to ILC	3									
Referral to MCO Member Advocate	2									
Resolution requires gov't policy change/legislative action	1									
Not resolved to client's satisfaction	4									
*This report, which covers only the first 8 months of the program's operation, includes data only about casework funded by the Wisconsin Department of Health and Family Services for DRW's Family Care Ombudsman Program. Other advocacy assistance provided by DRW staff to Family Care enrollees is not included in the above data.										
**Some cases involved more than one issue.										