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# Family Care and IRIS Ombudsman Program

For Enrollees Age 18-59

# Year 4 Annual Report:

July 1, 2011 - June 30, 2012

Report Date:
October 1, 2012

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## Family Care and IRIS Ombudsman Program Overview

The Family Care and IRIS Ombudsman Program (FCIOP) provides advocacy services to enrolled and potential recipients (or to their families or guardians) of the IRIS and Family Care/Family Care Partnership (FC/FCP) programs who are aged 18-59. The ombudsman program is state funded and contracted with Disability Rights Wisconsin (DRW) through the Wisconsin Department of Health Services (DHS). It is authorized and funded by the 2011-2013 biennial budget, Wisconsin Statute Sec. 46.281(1n)(e). The legislation sets as a goal one advocate for every 2,500 adults under age 60 who are enrolled in IRIS or FC/FCP.

> *I firmly believe that having [the ombudsman's] support and guidance was the absolute in the positive outcome of [the member's] state fair hearing. She was always available to answer any questions we had or to guide us in a direction that was in the best interest of [the member]…He and his family will be forever grateful for [the ombudsman's] support, legal guidance, empathy and compassion.*
>
> *Relative of FC member*

### FCIOP Program

The program operates as a division within Disability Rights Wisconsin. It is comprised of six ombudsmen, supported by a program attorney and a program manager. Services are available across the state. Ombudsmen are located in DRW's 3 offices—Milwaukee (3 ombudsmen), Rice Lake (1), and Madison (2). The Milwaukee office services the counties of Kenosha, Milwaukee, Ozaukee, Racine, Sheboygan, Washington and Waukesha. The Rice Lake office covers the counties of Ashland, Barron, Bayfield, Burnett, Chippewa, Dunn, Eau Claire, Iron, Pepin, Pierce, Polk, Price, Rusk, Sawyer, St. Croix and Washburn. The Madison office covers all other counties. Advocacy services are provided at no cost.

**Number of Individuals Assisted through FCIOP Grows Steadily Each Year**

| | Year 1[1] | Year 2[2] | Year 3[2] | Year 4[2] |
|---|---|---|---|---|
| Developmental Disabilities | 19 | 64 | 158 | 166 |
| Physical Disabilities | 63 | 213 | 255 | 318 |
| DD & PD | 9 | 107 | 79 | 93 |
| New Info & Referral | 26 | 79 | 141 | 157 |
| New Cases | 65 | 305 | 370 | 434 |
| Cases continued from previous year | | 44 | 78 | 101 |
| Cases closed this year | | 345 | 492 | 569 |
| **Total number of people assisted this year[3]** | **94** | **381** | **534** | **577** |
| **Total number of service requests this year[3]** | **98** | **426** | **606** | **696** |

*[1]November 1, 2008 - June 30, 2009 for year 1* *[2]July 1- June 30 for each subsequent year*
*[3]NOTE: Number of service requests is higher than number of people assisted because one person could make more than one request for assistance.*

### Case Handling

Ombudsmen respond to a wide variety of requests with a range of complexity. Some requests are very simple and require only information or referral. Most requests are more involved. As a general rule, ombudsmen attempt to resolve issues informally before exploring formal means. To do this,

they rely on building positive working relationships with a variety of entities involved with managing and providing services for adults with disabilities. These include managed care organizations (MCOs), IRIS (Include, Respect, I Self-Direct), Aging and Disability Resource Centers (ADRCs), the Department of Health Services, county systems, mental health and specialty complexes, providers of services, advocacy associations and more. For more involved cases, ombudsmen investigate the facts and help the caller work toward solutions. This might include providing technical support and building self-advocacy skills, communicating and intervening directly with people or organizations involved to negotiate disagreements, or assisting an individual with an appeal or fair hearing. Help with appeals or fair hearings might involve preparing members, providing a letter of support, or representing members. Each case is unique and is handled individually.

While ombudsmen handled a wide variety of cases, the top six presenting issues were:

97 Service reduction
85 Service denial (denial of a new request)
83 Relocation (primarily involuntarily due to rate dispute with MCO)
66 Enrollment/Eligibility Problems
48 Service Termination (existing services terminated)
45 Disenrollment Issues

For more detail on these and other issues handled by FCIOP, see Appendix, pages 7-9.

*[The ombudsman] offered superb assistance and her presence added much to the effectiveness of our meetings with [MCO] staff.*
*Parent of FCP Member*

Of 79 satisfaction surveys returned during the program year, 61 or 77% indicated that the ombudsman was "very important" in solving the problem. Sixty-three or 80% were "very satisfied" with the overall results of assistance received. Sixty-eight or 86% would call an ombudsman again, and 71 or 90% would recommend the ombudsman service to a friend.

## 2011-2012 Impacts on IRIS and Family Care/Family Care Partnership

### Family Care Audit

On April 27, 2011, the Legislative Audit Bureau (LAB) published its audit of Family Care (found at http://legis.wisconsin.gov/lab/reports/11-5full.pdf). The result was a mixture of positive findings and recommendations for improvements or consideration. Department of Health Services officials worked to address identified concerns within the timeframe required. The Department's initial responses, as requested by the LAB, were released on September 1, 2011 (found at http://www.dhs.wisconsin.gov/ltcare/Reports/PDF/dhsresponselabrpt090111.pdf).

*Thank you! Found excellent information and positive results—without your help problems would not have been resolved.*
*FC Member*

### Enrollment Cap

On July 1, 2011, the Wisconsin legislature placed a cap on enrollment for new applicants of publicly funded long term care programs for adults with disabilities and the elderly. The cap was lifted on April 3, 2012, with 2011 Act 127. During the eight months the cap was in place, counties that still had waiting lists while still transitioning to Family Care watched them increase again. Counties that had eliminated their waiting lists (were at full entitlement) initiated them again. Advocacy groups expressed varying opinions about the impacts of the cap on people being served, or waiting to be served, by the state's long term care programs for adults. There was disagreement as to the adequacy of services and supports people on waiting lists received. The Department of Health Services published a report describing its perspective of the impact of the enrollment cap (found at http://www.dhs.wisconsin.gov/ltcare/update-041712.pdf).

### Sustainability Measures

Because the enrollment cap was put in place in part as a cost saving measure, the Department of Health Services proposed a number of measures that would find future cost savings. These can be found at http://www.dhs.wisconsin.gov/ltcreform. Links to the specific papers can be found at the bottom of the page. The measures are focused on seven topical areas:

- Employment Supports
- Family Care Administration and Program Efficiencies
- Family Care Benefits
- IRIS and Self Directed Supports
- Living Well at Home and in the Community
- Residential Services
- Youth in Transition

The measures will be studied and implemented throughout the next few years.

> *Very, very satisfied and this absolutely improved my situation. [The ombudsman] was fabulous! Thank God for this service!*
>
> *IRIS Participant*

## Patterns and Trends Affecting Multiple Individuals

Because the Family Care and IRIS Ombudsman Program receives calls from around the state and across long term care programs, it has a unique vantage point from which to identify some of the patterns and trends that affect multiple individuals. With this information, FCIOP staff are able to work with the Department of Health Services or other organizations to develop solutions.

It is important to note a few things about what we see:

- People only call us when they are having a problem. We do not receive calls from people who are satisfied with their service plans or treatment by an MCO or IRIS. The listed issues identify the problems, not the positive experiences people have.
- Very often people who call FCIOP are completely frustrated. We seldom see problems in their early developing stages where they might have less impact and be more easily resolved. Therefore, FCIOP staff may get the perception that issues we see rise to a higher level of immediacy or that they affected more individuals than they did. It is necessary to take a close look at these situations to ensure information and anticipated effects are accurate.

- We do not see local advocacy efforts and are not able to identify trends at that level. For example, a local advocacy group might be working on transportation (such as lack of adequate transportation providers) long before we start receiving calls about this issue. We would not be able to say that transportation provider adequacy isn't a problem. We would only be able to say that we don't receive many such reports.

With these caveats in mind, the ombudsman program can be a place where trends "collect" and the program can therefore identify matters that develop. The following list illustrates the issues that most prominently rose to the surface during the fiscal year of 7/1/11-6/30/12.

### Residential Moves Due to Rate Disputes

In the previous fiscal year (7/1/10-6/30/11) approximately 20-30 individuals had been given discharge notices by their residential providers due to rate disputes with managed care organizations. This usually occurs when a provider concludes that it cannot adequately serve a member (or members) at the rate that is being offered by a MCO. While this was considered quite serious, a new roll-out of discharges was about to take place. At the end of the year covered by this report, at least 84 individuals dealt with this situation. Though many of the cases eventually do resolve, this is an extremely anxiety producing event for the members and their families. Their rights lie in the MCO's adherence to the process that is supposed to follow the notice—the care teams are directed to take specific steps to find new residential locations that meet the needs of the affected members.

The repeated and increased residential discharge activity, again concentrated primarily in the northwest part of the state, but spreading through the central region, raises concerns about rate setting practices. It is difficult for members to remain the focus when a rate dispute starts rolling. Some of this could be avoided by a statewide standardized residential rate setting tool. A project to develop just that was tabled in 2011. In its stead, each MCO developed and implemented its own tool. There is no approval process in place to assure that rate setting tools accurately take member health and safety needs into account and appropriately apply them to an adequate rate.

> *I was very happy to know [the ombudsman] was on the conference all with [the MCO] and myself to help me understand the appeal and changes (for the good)… Thanks again for all your help.*
> *Guardian of FC Member*

In addition to a rate setting methodology approval process, it would be helpful if further consideration were to take place about how members are notified of moves. Since in the end a majority do not actually move, it would make sense to save them the stress of thinking they will. A process wherein the MCO and residential provider must do everything possible to find a solution before the member is discharged would cause far less upset.

### Long Term Care Functional Screen Issues

The Long Term Care Functional Screen (LTCFS) is a tool developed by the state for the purpose of determining functional eligibility for publicly funded long term care services. Basically, it is a yes or a no—are you eligible or not? Since its inception it has taken on roles that require far more nuanced information. One of the newer roles is to provide an IRIS allocation. This is the initial "estimate" or "ceiling" upon which an individual's budget is based. Another role for which the LTCFS is being increasingly used is to provide information about acuity (level of need) of members. It is being integrated in many of the tools used by some managed care organizations to set rates or service hours.

Since both of these newer uses has a direct bearing on the level of services available to members, it is increasingly important that the screens are accurate. The Department of Health Services is working on a system for greater accountability among screeners, which includes designation of lead screeners; higher standards and retesting for screeners; and inter-rater reliability audits.

LTCFSs are to be redone only if there is a change in the member's condition. Though process improvements have been put into place, there still must be an allowance for the possibility that screener errors produced a faulty result. Such a result could not only impact level of service, as noted, but it could also cause a person to lose eligibility.

A related issue is the question of whether LTCFS adequately captures certain types of needs. It is now widely acknowledged that the need for supervision caused by behavioral problems, seizure disorders, brain injuries, some mental health disorders, and personal safety issues is not integrated into the tool. Because supervision needs can involve a significant amount of time, the absence of the information can have serious consequences in correctly identifying a person's level of need for services or supports. There needs to be either a way to integrate these types of information into the existing LTCFS or there needs to be a supplemental tool that does so.

### Mental Health Issues

In general, this is an area that has seen some improvement. Care teams of managed care organizations now have access to mental health expertise. While teams vary in their willingness to draw on this expertise, the fact that it is there has resulted in some improvement to access to mental health services. IRIS has also increased its capacity to address mental health issues by designating staff with this knowledge.

> *[The ombudsman] did a very good job of educating me so I can advocate for my son. I feel Family Care will be more willing to listen and get my son what he needs because…I contacted the ombudsman…Thank you!*
> *Guardian of FC member*

While we applaud these efforts, there is still more to be done, particularly for people with highly complex mental health needs. This issue is related to the next point—relocations from institutional settings.

### Relocations from Institutional Settings

Individuals can become essentially stuck in institutional settings if their needs are highly complex or expensive. Care management organizations have demonstrated a reluctance to develop supportive residential settings for those caught in this type of situation. The result is that people who are ready to leave any variety of congregate setting—nursing home, mental health institute or behavioral health department, correctional setting, and other places—cannot do so because there is no place for them to go. Once out of those settings, the costs to MCOs can be high. Some MCOs work diligently to try to set up appropriate placements but seem to struggle to achieve them. Others don't appear to try very hard. Using Money Follows the Person funds, the Department of Health Services is working on placing community placement specialists around the state to move this process forward. In addition, a DHS initiative is intended to work toward collaboration to improve crisis intervention and stabilization of individuals in this type of situation. We look forward to the potentially positive results these efforts will bring.

## Year Five Plans for FCIOP

The Family Care and IRIS Ombudsman Program will continue to work toward the goals of assisting individuals with challenges in receiving adequate services and supports within the publicly funded long term care system and watching for trends that affect these individuals.

### Sustainability Measures—Development and Implementation

As specific plans are made to roll out the Department of Health Services sustainability measures, FCIOP will monitor the efforts to find cost savings and will provide feedback and recommendations to ensure that due process rights are protected and programmatic changes have few consequences.

### Expansion of Family Care/IRIS

There are a number of counties that remain on the legacy waiver program (the county-based system for long term care services). These counties generally hold lengthy waiting lists. Some counties have been planning to roll into Family Care/IRIS in the coming year. When the enrollment cap was lifted, however, the decision to expand Family Care/IRIS into new counties became a less nimble process. At this writing it is not known whether expansion will happen in the coming year. If it does, it may affect the staffing patterns of FCIOP.

### Program Goals

Many changes, large and small, are on the horizon for the structure and delivery of Family Care and IRIS. Ombudsmen will continue to work with individuals to help them resolve their challenges. We will also continue to work with the entities involved to ensure adequate services and supports are provided for individuals with disabilities.

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Family Care and IRIS Ombudsman Program Manager
October 1, 2012

# Appendix
## Report of Cases—July 1, 2011 - June 30, 2012

| | |
|---|---|
| **Number of FC cases in this reporting period** | |
| New I&A | 157 |
| New this reporting period - opened as case | 434 |
| Number of cases continuing from previous report | 101 |
| Number closed this reporting period | 569 |
| | |
| **Target Population*** | |
| Developmental Disability | 166 |
| Physical Disability | 318 |
| Developmental Disability & Physical Disability | 93 |
| | |
| **Contact/Referral Source*** | |
| 211 Help Line | 1 |
| ADRC | 1 |
| Adult Family Home | 42 |
| Advocacy Group | 3 |
| Attorney | 5 |
| BOALTC | 1 |
| County CSP | 1 |
| DHS | 6 |
| DQA | 1 |
| DRW client previously | 1 |
| DVR | 1 |
| Family Care Program | 3 |
| Friend/Family Member | 151 |
| Guardian | 2 |
| ILC | 51 |
| Internet | 48 |
| IRIS program | 76 |
| Legal Aid Society/Legal Action | 9 |
| MCO | 2 |
| Metastar | 13 |
| Phone Book | 1 |
| Provider | 2 |
| Self | 26 |
| Social Worker - non-FCIOP | 6 |
| State | 2 |
| Training/outreach by DRW | 10 |
| Transit Agency | 1 |
| WI Dept of Public Health | 80 |
| Not Selected | 22 |
| | |
| **Method of First Contact*** | |
| Telephone | 563 |
| E-mail | 7 |
| Mail | 1 |
| Face to face | 6 |

| Issue and MCO[5] involved | Care WI | CCI | CCCW | CHP | iCare | IRIS | LCD | MCDFC | NB | SFCA | WWC | No MCO | TOTAL |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Abuse/Neglect | 0 | 1 | 3 | 1 | **0** | 1 | 0 | **0** | 1 | **1** | 0 | 0 | 8 |
| Assistance with MCO's grievance procedure | 4 | 1 | 2 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 8 |
| Assistance with state fair hearing | 2 | 3 | 1 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 7 |
| Choice of Provider | 8 | 1 | 8 | 4 | 0 | 7 | 1 | 3 | 1 | 0 | 0 | 2 | 35 |
| Communication probs. with MCO - IRIS staff | 1 | 1 | 1 | 0 | 0 | 3 | 0 | 0 | 0 | 2 | 1 | 2 | 11 |
| Confidentiality violation | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| Cost Share | 3 | 1 | 7 | 2 | 1 | 8 | 1 | 2 | 0 | 0 | 0 | 0 | 25 |
| Denial of visitors/social opportunities | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 0 | 2 | 4 |
| Discharge planning | 7 | 0 | 13 | 1 | 0 | 0 | 0 | 6 | 2 | 2 | 2 | 0 | 33 |
| Disenrollment | 2 | 0 | 11 | 10 | 0 | 11 | 0 | 7 | 1 | 1 | 2 | 0 | 45 |
| DVR complaints | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| Enrollment/Eligibility | 5 | 0 | 14 | 0 | 0 | 9 | 1 | 15 | 19 | 1 | 2 | 0 | 66 |
| Equipment Request/Denial | 12 | 1 | 12 | 1 | 0 | 9 | 2 | 2 | 0 | 1 | 1 | 3 | 44 |
| Functional screen dispute | 1 | 0 | 1 | 1 | 0 | 3 | 0 | 0 | 0 | 0 | 0 | 0 | 6 |
| Home modification (accessibility) | 0 | 0 | 2 | 1 | 0 | 1 | 1 | 2 | 0 | 1 | 1 | 0 | 9 |
| IRIS - Budget Amount | 0 | 0 | 0 | 0 | 0 | 41 | 1 | 1 | 0 | 0 | 0 | 0 | 43 |
| IRIS - FSA issue | 0 | 0 | 0 | 0 | 0 | 27 | 0 | 0 | 0 | 0 | 0 | 0 | 27 |
| IRIS - ICA issue | 0 | 0 | 0 | 0 | 0 | 31 | 0 | 0 | 0 | 0 | 0 | 0 | 31 |
| IRIS – quality | 0 | 0 | 0 | 0 | 0 | 39 | 0 | 0 | 0 | 0 | 0 | 0 | 39 |
| MCO terminates provider relationship | 2 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 3 |
| Medical treatment | 4 | 1 | 3 | 0 | 0 | 2 | 0 | 1 | 0 | 0 | 0 | 1 | 12 |
| Mental health care access | 1 | 1 | 3 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 4 | 10 |
| Overpayment | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 2 |
| Provider not being paid | 0 | 0 | 2 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 3 |
| Provider quality | 2 | 1 | 6 | 2 | 0 | 0 | 1 | 6 | 0 | 0 | 0 | 0 | 18 |
| Rate increase – no explanation | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 1 |
| Relocation | 7 | 1 | 33 | 9 | 2 | 3 | 3 | 13 | 4 | 3 | 4 | 1 | 83 |
| Rep payee issue | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 2 |
| Request for additional services | 2 | 2 | 6 | 3 | 1 | 2 | 0 | 0 | 0 | 1 | 1 | 1 | 19 |
| Safety | 3 | 1 | 5 | 1 | 0 | 3 | 0 | 1 | 0 | 0 | 0 | 0 | 14 |
| Self-directed supports | 2 | 0 | 5 | 0 | 0 | 4 | 1 | 2 | 0 | 0 | 0 | 0 | 14 |
| Service delay | 2 | 1 | 10 | 2 | 0 | 12 | 0 | 1 | 1 | 0 | 0 | 2 | 31 |
| Service denial (additional service[s] or hours) | 1 | 0 | 8 | 0 | 1 | 0 | 1 | 6 | 0 | 0 | 0 | 0 | 17 |
| Service denial (specific service) | 11 | 1 | 23 | 6 | 1 | 10 | 1 | 5 | 1 | 4 | 2 | 3 | 68 |
| Service reduction | 19 | 3 | 28 | 12 | 1 | 18 | 2 | 9 | 0 | 3 | 1 | 1 | 97 |
| Service termination | 6 | 2 | 19 | 8 | 0 | 8 | 0 | 1 | 0 | 3 | 0 | 1 | 48 |
| Transportation | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| Other | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 1 |
| **Total by MCO** | **107** | **26** | **227** | **66** | **7** | **254** | **19** | **85** | **30** | **25** | **17** | **24** | **887** |

| **How the case was resolved (may select more than one)** | |
|---|---|
| Informal Negotiation | 172 |
| Investigation/Monitoring | 116 |
| Work with IRIS Consultant or Financial Service Agency | 29 |
| MCO appeal/grievance or State Fair Hearing | 54 |
| Technical Assistance | 363 |

| **Referrals:** | |
|---|---|
| Referral to ADRC | 26 |
| Referral to BOALTC | 1 |
| Referral to DHS | 5 |
| Referred to DQA | 1 |
| Referral to other DRW staff (non-FCIOP) | 6 |
| Referral to Guardianship Support Center | 5 |
| Referral to ILC | 5 |
| Referral to IRIS Consultant | 2 |
| Referral to LAW | 1 |
| Referral to MCO Member Rights Specialist | 1 |
| Referral to private attorney | 1 |
| Referral to TMG | 2 |

| **Average Days to close a case** | |
|---|---|
| Cases only (does not include I&A) | 95 |

***[5] MCO Acronyms***

*Care WI* = *Care Wisconsin*
*CCI* = *Community Care, Inc.*
*CCCW* = *Community Care of Central Wisconsin*
*CHP* = *Community Health Partnerships*
*iCare* = *iCare*
*IRIS* = *Include, Respect, I Self-direct (self-directed alternative to Family Care)*
*LCD* = *Lakeland Care District*
*MCDFC* = *Milwaukee County Department of Family Care*
*NB* = *Northern Bridges*
*SFCA* = *Southwest Family Care Alliance*
*WWC* = *Western Wisconsin Cares*
*No MCO* = *Neither an MCO nor IRIS was involved*