

Members

Rep. Wes Culver, Chairperson
Rep. Sheila Klinker
Sen. Patricia Miller
Sen. Jean Breaux
Sally Lowery
Suda Hopkins
Betty Williams
Christopher Durcholz
Susan Ferverda Hoback
Bettye Dunham
Scott Sefton
Sharon Kooi



COMMISSION ON DEVELOPMENTAL DISABILITIES

Legislative Services Agency
200 West Washington Street, Suite 301
Indianapolis, Indiana 46204-2789
Tel: (317) 233-0696 Fax: (317) 232-2554

LSA Staff:

Susan Kennell, Attorney for the Commission
Bill Brumbach, Fiscal Analyst for the Commission

Authority: IC 2-5-27.2

MEETING MINUTES¹

Meeting Date: October 9, 2012
Meeting Time: 10:00 A.M.
Meeting Place: State House, 200 W. Washington
St., Room 404
Meeting City: Indianapolis, Indiana
Meeting Number: 3

Members Present: Rep. Wes Culver, Chairperson; Rep. Sheila Klinker; Sen. Patricia Miller; Sen. Jean Breaux; Sally Lowery; Betty Williams; Christopher Durcholz; Bettye Dunham.

Members Absent: Suda Hopkins; Susan Ferverda Hoback; Scott Sefton; Sharon Kooi.

I. Call to Order

Representative Wes Culver, Chairperson, called the meeting to order at 10:00 A.M. Chairperson Culver explained that the purpose of the meeting was to receive input from individuals receiving services from the Division on Disabilities and Rehabilitative Services (DDRS), as well as parents, guardians, and advocates of individuals receiving services. Because of time constraints, each individual presenter was given four minutes.

¹ These minutes, exhibits, and other materials referenced in the minutes can be viewed electronically at <http://www.in.gov/legislative>. Hard copies can be obtained in the Legislative Information Center in Room 230 of the State House in Indianapolis, Indiana. Requests for hard copies may be mailed to the Legislative Information Center, Legislative Services Agency, West Washington Street, Indianapolis, IN 46204-2789. A fee of \$0.15 per page and mailing costs will be charged for hard copies.

II. Testimony

A. Ms. Andra Cockran discussed issues her family faces with her 25 year old autistic son. (Exhibit 1) Ms. Cockran expressed concern that benefits under the Family Support Waiver (FSW) are insufficient to meet the needs of her son.

B. Mr. Bob Guzzo discussed issues his family has with the DDRS policy of limiting the amount of time family members can be paid for providing services to a family member with a developmental disability to 40 hours a week. (Exhibit 2) There was discussion of the policy, including the difficulty of finding service providers in rural areas on one side of the issue and the potential for abuse when paying family members and lack of supervision for the services being provided on the other side of the issue.

C. Mr. Jeff Huffman discussed issues with waiver services for his son who has Down Syndrome. Mr. Huffman told the Commission that his son was recently targeted for the waiver. The family had difficulty scheduling meetings with DDRS to determine what his son's needs were and what services were needed. Mr. Huffman believes that the emphasis was on what could be spent and not on what his son needed. He believes that there should be a way to defer waiver services until a later date if the individual does not need the services now but is eligible for the waiver now. At the later date when the individual needs services, the services would be automatically available. Currently, if the individual refuses service because the individual does not need the service now, the individual is placed at the end of the waiting list.

D. Ms. Kris Reese has a 22 year old daughter with autism. Ms. Reese testified that the services available to her daughter do not meet the actual needs of her daughter.

E. Mr. Joe Meares told the Commission that the budget for providing services to his 14 year old daughter does not reflect the actual needs of his daughter. The budget has been increased, but the available services do not meet her needs. In order to keep the money from the waiver, Mr. Meares believes he is forced to use the money in ways that are not the most beneficial.

F. Ms. Kerry Fletcher told the Commission that two of her three children have genetic disorders. The family is receiving money from the Family Support Waiver for services that their 10 and 12 year old children do not need. They would like to waive the children's waiver eligibility until the children graduate from school and will need the waiver services.

G. Mr. Steve Dick discussed his issues with food stamp consideration in eligibility determinations. (Exhibit 3) Mr. Dick has a court case pending against the state on the issue.

H. Mr. Shawn Rector discussed several issues he has with the waivers. He believes the waiver system needs to be more flexible. He receives more services than he needs. He would rather have more services through medical waivers. Medicaid does not pay for his specially made shoes or for both of his hearing aids. He needs to limit his working hours at a shelter so that he does not earn too much money to remain eligible for services.

I. Ms. Betty Williams emphasized the importance of employment for individuals with developmental disabilities. She would like to see changes to the system that would allow individuals with developmental disabilities to earn and save more money without losing eligibility for services.

J. Ms. Holly Paauwe discussed the issues faced by families with children who have dual medical and developmental disability diagnoses. (Exhibit 4) She indicated that families of children with dual diagnoses need to be included in waiver discussions.

K. Ms. Laura Fife discussed issues related to dual diagnoses. She believes that the system is fragmented and that money could be better spent if there was more coordination with state programs. (Exhibit 5)

L. Mr. Fred Jackson discussed issues receiving services for his son with Prader Willi Syndrome. (Exhibit 6) Mr. Jackson's son has been receiving services at a specialized facility in Wisconsin. He believes that FSSA arbitrarily said that his son could no longer receive services out of state and has not provided viable alternatives in Indiana.

III. Other Business

Mr. Shane Spotts, Director DDRS, responded to some of the comments made during the meeting. Mr. Spotts indicated that the comments that people now have too much money for services is a difference from when people did not have enough money. He said the budgets were previously based on how much an individual spent in a year. Because of that, people tried to spend as much money as possible. Under the new plan, the case workers try to determine how much money an individual needs. That amount then becomes the base. If less money is spent in a year, the base does not decrease for that individual. So the need to spend every cent every year has hopefully been eliminated. Mr. Spotts said that there needs to be a partnership between case managers and families to budget properly. Mr. Spotts was not sure how much money DDRS reverted at the end of the fiscal year but agreed to obtain that figure for the Commission.

Mr. John Dickerson, Executive Director of the ARC of Indiana, thanked the Commission for listening to members of the public at the meeting.

IV. Adjournment

Representative Culver adjourned the meeting at 12:00 P.M.

DD Commission
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10-9-12

Exh.b.t 1

Comments for the Commission for
Intellectual and Developmental
Disabilities

Andra Cochran
October 9, 2012

Thank you for this opportunity to speak before this commission. My name is Andra Cochran. My husband and I are the parents of a 25 year old adult with autism who, among other things is non-verbal and has serious communication deficits with resulting behavior issues. He is 6'4", 380lbs, with size 16 feet, and a 7 foot wing span. Although he would not stand out in the Colts locker room., he stands out everywhere else. He lives at home with us.

My Goals for Today

- Ensure understanding
- Demonstrate that FSW funding is insufficient for all but a very few
- Express hope that we can engage in further dialogue
- Call for ways to lower actual costs and still improve outcomes

10/9/2012

Andra Cochran

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•First to make sure we all have the same understanding of what we face. And by “we” I mean those who joined the waiver waiting list after May 1999.

•Demonstrate that the funding we will receive under the FSW is woefully insufficient to cover the needs of all but a very few, and will place a significant, if not impossible burden on many families, which will almost certainly result in many needs going unmet.

• Express hope that we can engage in further dialog regarding the ways to reduce the gap in funding inherent in this model and still increase the number of participants served.

And perhaps more importantly

•Call for us to redirect some creative effort to finding ways to lower the actual costs of care and services regardless of who pays for it and at the same time strive to achieve better outcomes .

Results

- More participants will be brought into services on the FSW
- Participants will stay on the FSW long into the future

Caveats

- Needs of existing and new participants in the FSW are not significantly different from those currently served
- Actual costs of care and services will not go down

Consequences

- Costs will be born by families, or
- Needs will be unmet

10/9/2012

Andra Cochran

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The goals and rules for implementation have been made quite clear in the information posted on the DDRS website, including the Waiver Amendments themselves, the Section 144 report, the FAQs and Manuals. In the interest of time I will say only that the critical element of this change is that the CIH waiver is now exclusively needs based and no longer has a waiting list. This severely limits access to this waiver. Only 116 “new” participants – meaning those who are not transitioning from other funding sources – will move onto the waiver per year and those individuals must meet one of the three emergency criteria.

Clearly the results are positive in the short run for many new participants. By limiting the number of future participants on the CIH, many more new participants can be funded, although at the much lower funding levels of the FSW. The flip side however is that participants who are currently or will be receiving the FSW will remain on the FSW long into the future – specifically until one of the emergency criteria is met - parents turn 80, parents die, or the participant is subject to extraordinary health and safety risks.

There are also caveats and consequences

The needs of new and existing FSW participants are not significantly different from those individuals currently being served. And this program does nothing to reduce the actual costs of serving these individuals. This means simply that the cost of servicing these individuals will be shifted back to the family. Indeed, according to the Section 144 Report, this initiative has been packaged within the context of more adults living at home as a “national trend” and keeping the family unit together.

If the family can’t or won’t cover the difference between the cost of serving the needs and the funds available from the FSW, the needs will remain unmet.

So what are these costs?

Distribution and Average Per Capita Costs

Total Current Population							
ALGO Level	0	1	2	3	4	5	Total
# Beneficiaries	274	124	932	2,352	2,526	618	6,826
% Distribution Mix	4	2	14	34	37	9	100
Average Cost (\$) Per Capita	4,145	30,366	43,138	64,691	81,036	116,580	69,844

ALGO Levels 0 to 6

OBA Budgets range from \$12,000 to \$180,000

10/9/2012

Andra Cochran

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Objective Based Allocations for these individuals are based in part upon ALGO ratings which measure levels of disability. Possible budgets range from approximately \$12,000 to \$180,000.

What you're seeing is a Distribution by ALGO level of Individuals currently served by waivers and the average per capita cost for each category:

Two things are clear.

The majority - 71% - of the current population being served are rated Algo 3 or Algo 4.

The only individuals with costs under the FSW cap of 16,250 are those with the least needs, Algo level 0.

For purposes of this next illustration I am assuming an individual with certain characteristics th

Description – ALGO 4

Requires full-time supervision (24/7 frequent and regular staff interaction, requires line of sight) for medical and/or behavioral needs. Needs are moderately intense, but can still generally be provided in a shared setting.

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The description you see is that of an individual who meets the criteria for ALGO 4, which again accounts for about 37%.

There is nothing in this description that indicates that this individual would meet the new stringent requirements for a CIH waiver,

So for the purposes of this discussion we will assume that this individual would not qualify for CIH unless his/her parents were very old, dead or there were extraordinary health and safety risks facing this individual.

Funding Levels

	At Home	Alone	W/1 Room mate	W/2 Room mates	w/3 Room mates	Overall Average Per capita
School w/o waiver IDEA/add'l funds	13,000					
School w/ FSW	27,750					
Average per capita w/CIH	46,584	76,923	84,822	81,592	77,004	69,873
OBL for ALGO 4 w/CIH (pre 5/99)	60,775	101,722	96,735	90,322	85,335	
FSW Participant w/ALGO 4 characteristics (post 5/99)	14,750	14,750	14,750	14,750	14,750	

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Andra Cochran

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Now let's look at the funding levels available for this type of individual under different circumstances.

Whether or not a child receives the FSW while attending school, the level of support drops significantly after leaving school. After the school years, the FSW may cover some day services and some respite or a few hours per month of behavior therapy. Most will find that these services are less consistent and far less intensive than those received in school settings.

Even if an individual continues to live at home, which is the lowest cost alternative for the state, the difference between the average per capita cost and the FSW is almost 32,000. If your child has the characteristics of an ALGO 4, then the difference is 56,000. **This creates a huge financial gap that will be difficult if not impossible for many families to fill.** And this is just the financial gap.....This does not even begin to address the commitment of time, transportation and loss of wages that at least one care giver in the family must make.

The FSSA has said that individuals receiving the FSW are free to live independently outside the family home and should find roommates in order to do so. It is difficult to imagine how an individual with an FSW could fit in or "carry his/her weight" living with 2 or 3 other roommates with CIH funding. It is also hard to imagine how 2 or 3 ALGO 4's receiving only 14,750 each could pull this off without significant additional resources.

It is also hard to imagine how one could earn enough to significantly offset the cost. Family contributions to make up the short fall may also be problematic if one were trying to preserve SSI benefits.

Consequences

- Most of the FSW participants will face a huge gap in funding versus needs
- Undue burden beyond the means of many
 - Many needs will not be met
- Does nothing to decrease actual costs or improve outcomes

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Andra Cochran

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We have shown that most of the FSW participants will face huge gaps in funding versus needs.

Realizing the size of these gaps we must acknowledge that this places an undue burden beyond the means of many families.

However, of greater concern to me – as both a parent who will bear these costs directly and as a taxpayer who will bear them indirectly -- is the fact that nothing in this new plan does anything to decrease the actual costs of serving these individuals or improve our outcomes.....These should be among our first priorities and are not impossible goals.

Hope

Further Dialogue

- Address the chasm between the two Waivers
- Address ways to achieve better outcomes while lowering actual costs of care -
 - REGARDLESS OF WHO PAYS FOR IT

10/9/2012

Andra Cochran

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As a society we have made so much progress in our attitudes about what it means to be “Intellectually or Developmentally Disabled”. With the advances that have been made under the IDEA and the implementation of current and ongoing research and evidence based practices, the potential to live life more fully, enjoy liberty more completely and pursue his or her own happiness is greater than ever. It would be a shame to turn the clock back by severely underfunding genuine need. The inability to serve individuals with I/DD whether due to lack of funds or lack of knowledge is what led to the institutionalization of so many in the past. The cost of undoing that has been and continues to be great. However, just as we are completing the push to de institutionalize, we seem possibly on the brink of creating a new wave of institutionalization of a different sort.

Surely there is room for further dialog to address the chasm between these two waivers so that individuals, especially adults, with I/DD really can get what they need to live more productive and meaningful lives.

But even more importantly, there is a screaming need to address ways to achieve better outcomes with lower actual costs regardless of who pays for it. This is where we should be directing our creative energy.

Thank you.

Slides deleted from original
presentation

New Reality

- Changes Effective September 1, 2012
 - Supports Services Waiver \$13,500 – Family Support Waiver \$16,250
 - Less \$1,500 case management fee = \$14,750
 - Net gain of \$1,250
 - CIH combines the old DD and AU waivers
 - Eliminates old waitlist
- CIH “needs-based” only
 - New Participants must meet one of 9 Reserve Capacity Priority criteria.
- Affects primarily those who joined waitlist after May 1999

New CIH Waiver Participant Qualifications and Slots

Reserve Capacity Priority Criteria	Actual and Projected Slots				
	YR 1	YR 2	YR 3	YR 4	YR 5
transitioning to the community from NFs, ESN home, and SOFs	48	163	45	45	45
no longer need/receive active treatment in SGL	2	20	2	2	2
transitioning from the Terminated Autism Waiver			584	16	0
transitioning from 100% state funded services	60	89	10	10	10
aging out of DOE, DCS, or SGL	37	122	37	37	37
requesting to leave a Large Private ICF/IDD	2	2	2	2	2
Total Non Emergency Slots	149	396	680	96	96
Death of a Primary Caregiver where there is no other caregiver available	50	73			
Caregiver over 80 years of age where there is no other caregiver available	64	86			
Extraordinary health and safety risk for participant	4	10			
All Emergency Slots	118	169	116	116	116
All Reserve Capacity Slots	267	565	796	212	212
Unduplicated # of participants	7370	7688	8025	8776	9111
Year to year change		318	337	751	335

10/7/2012

Andra Cochran

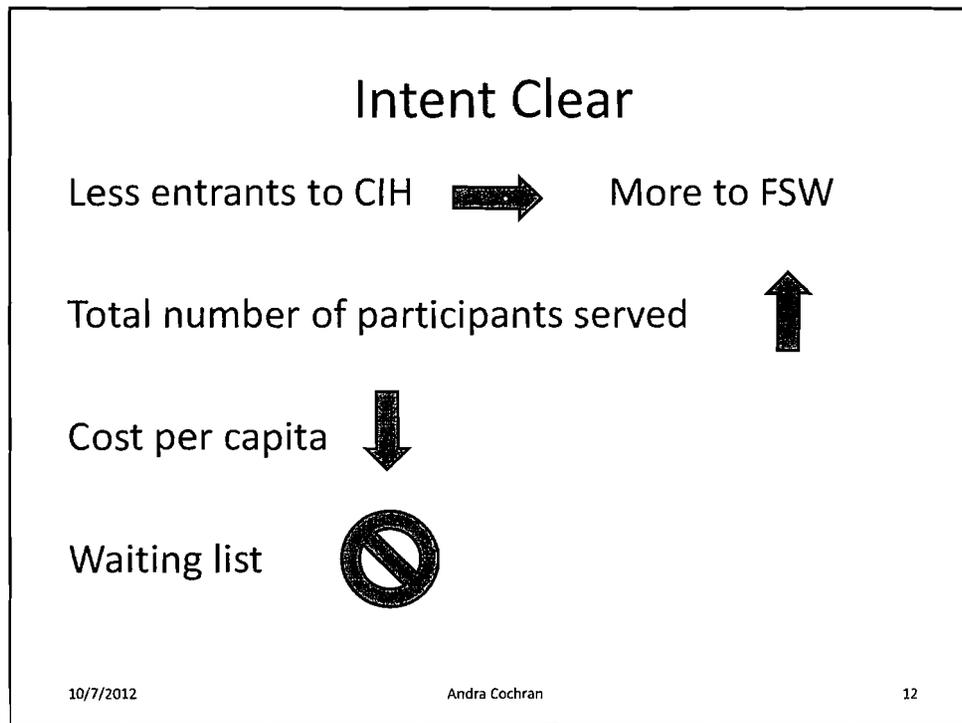
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This chart was compiled from data in the Amendment to the Waiver Document. What you see here is a summary of the descriptions of priority categories and the number of slots allocated for each.

Those shown in blue are transition slots dedicated to individuals who are currently being served in some other way and accounts for 96 participants in each of Waiver years 4 and 5.

Those in red are slots that will be available to “new participants.” These account for 112 slots in each of years 4 and 5. This significantly fewer number of total slots filled than in previous years.

There have always been “reserve capacity slots” for this waiver. However restricting new participants to only those available reserve capacity slots is new. Prior to this change there were others taken from the waiting list who received waivers as well.



By significantly narrowing the criteria for the CIH or “large” waiver, there will be fewer new individuals receiving the CIH waiver and the funds that would have been used to serve them will be diverted to those who are waiting for the FSW. This means that more people will receive services but will be served by the FSW waiver at much lower funding levels than those already receiving the CIH. This is of course the goal – along with greatly reducing if not eliminating entirely the waiting list for the Family Support Waiver.

While in the long run these changes will have a negative impact on individuals who joined the waitlist after May 1999, they are viewed by many as necessary and positive. It is hard to argue in the short run that it is not better to have more individuals receive some help rather than no help.

Comments of Bob & Paula Guzzo to the Indiana Commission on Developmental Disabilities
Public Forum about changes to DD waiver system, October 9, 2012, Indianapolis, IN

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Thank you for providing this opportunity for Medicaid Waiver participants to speak to you about their experiences. There are many issues regarding implementation of the Medicaid Waivers that deserve the attention of the Developmental Disabilities Commission.

We are Bob & Paula Guzzo, parents of Scott Guzzo. Our comments today regard a recently introduced DDRS policy change that you may not be aware of. DDRS has "40-hour policy" that basically says relatives cannot collectively provide more than 40 total residential habilitation & support (RHS) hours of paid service per week. It is not a promulgated rule yet it can adversely affect a Waiver Participant's right to choose his/her personal care attendants.

This policy restricts an adult Waiver participant's right to have his/her relatives provide residential service. The modification to the policy (announced in the January 2012 DDRS Quarterly Update and effective 3/1/12) expands limits on parents, step-parents and legal guardians to also include spouses, brothers/sisters, children, grandparents, grandchildren, aunts/uncles and first cousins. This includes natural, step, half, adopted and in-law relatives.

In order to stay under four minutes, just a few of our concerns with this policy are provided today, but we can share more in-depth information separately from this meeting.

This policy, both before and after it was modified, appears to violate the federal Medicaid Act Statute that says a Medicaid beneficiary can choose his/her direct care staff. FSSA's own web site says "An individual has the following responsibilities when receiving waiver services: To choose your providers for your services." and the DDRS Waiver Manual includes individuals in its definition of providers. Yet the 40-hour policy can force Waiver participants to select individuals as their caregivers other than the related ones they would otherwise choose.

Here's an odd effect of this policy: while the policy puts limits on traditional families, there is no limit on unrelated people living together! For example, a participant with a 100 hour per week RHS budget can have a participant's mother provide 40 RHS hours a week, a live-in boyfriend another 40, and the boyfriend's cousin the last 20 hours! If the mother and boyfriend marry, however, the policy would immediately restrict the mother, new step-father and new step-cousin to 40 total hours! Get divorced, and these very same people could once again provide 100 hours.

For a short while after the modified policy went into effect, DDRS theoretically allowed exceptions in emergency situations, but that is no longer the case. So if a Waiver participant suddenly lost the services of a non-related caregiver and the only quick remedy was to hire a fully trained and capable relative, that participant would just be 'out of luck.'

Comments of Bob & Paula Guzzo to the Indiana Commission on Developmental Disabilities
Public Forum about changes to DD waiver system, October 9, 2012, Indianapolis, IN

Perhaps most interesting, there is no cost differential to the State whether a Waiver participant chooses relatives or non-relatives. This suggests the policy is not in place to resolve a cost issue, but is designed only to limit employment of immediate and extended family even if they are the best people to provide the participant's needed Waiver-funded residential care.

In conclusion, we present this out of concern for the basic rights of all of Indiana's Medicaid Waiver participants. As long as this policy stands, the State of Indiana is denying basic human rights and conveying an image of not fully supporting family units. We contend that all qualified caregivers employed by an approved provider agency should be eligible to provide services to Waiver participants, related or not, where "qualified" basically means that caregiver is fully trained, capable, willing and caring, and is wanted by the participant.

For full disclosure, you should know that we have an appeal on this issue that is still awaiting an ALJ's decision. Again, we can provide more background on this issue. Thank you for your attention.

Bob & Paula Guzzo
9915 Darmstadt Rd.
Evansville, IN 47710
(812) 867-6871

APR 11 2012
11:41 AM

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10-9-12
Exhibit 3

PREPARED STATEMENT TO THE
COMMISSION ON DEVELOPMENTAL DISABILITIES

October 9, 2012

Ladies and gentlemen of the Commission, I thank you in advance for the opportunity to address this body on the status of individuals with severe developmental disabilities. I am the guardian for a 28 year old adult who is severely developmentally disabled; who does not read, write, or even talk; and functions on about a 6-7 year-old level. He and many others like him are under the Medicaid Waiver program. The mantra of the Waiver program is that it is in place to allow these individuals "to live and participate in the community" in the least restrictive environment.

Indiana voluntarily joined the Federal Medicaid Waiver program to bring some \$5.6 billion last year alone into this state to support these individuals in community settings and to avoid the need for institutional placements. As part of this joint venture, Indiana agreed to co-sponsor part of the costs and to provide elements of the support needed by these individuals; and toward that end this legislature has been appropriating some \$2.9 billion dollars per year for Family and Social Services Administration (FSSA) to provide those benefits to Waiver recipients.

I provide this preface as I also am the person who two years ago was forced by FSSA to file a class action lawsuit against them to enjoin them from violating Federal food stamp laws by directly offsetting dollar-for-dollar all food stamps received against the \$200 per month grocery allowance allowed to Waiver recipients under the Residential Living Allowance (RLA) program. This practice and this allowance (without any COLA adjustments) had been in place for at least a decade until FSSA got caught. FSSA spokespersons called the lawsuit totally frivolous until legal experts from across the country and the Federal government announced that the practice was totally prohibited. Then their tune changed to that there was "some ambiguity in their policy" and that they were rewriting it to clarify the matter.

The result was a new 10 page RLA Policy which very clearly stated that EBT/SNAP food stamps benefits would no longer be considered income or benefit within a Waiver recipient's computation of RLA living expenses. Thus, FSSA was no longer directly violating Federal food stamp law. However, in doing so, and in my words in retaliation for getting caught, FSSA in a very calculated method, completely avoided using the words "room and board, food, groceries, or grocery allowance" anywhere within this Policy Statement, despite 40% of the 10 page Policy Statement being dedicated to allowed and non-allowed living expenses. Then, very quietly, they informed all Waiver care providers that not only were food stamps no longer to be included within RLA budget computations, but also Waiver recipients could no longer include any allowance for food or groceries within their RLA budget requests. When this elimination of a grocery allowance, which had been in place for at least a decade, became public, FSSA's spokesperson publically stated: "Receiving a benefit reduces their need. If your need has been reduced then you should reduce the supplemental program."

This un-promulgated “silent” Policy Statement change is wrongful towards these seriously disabled consumers on numerous levels. FSSA, in its very calculated manner, has sought to achieve indirectly what they were prohibited from doing directly, i.e. **“no participating State or political subdivision thereof shall decrease any assistance otherwise provided an individual or individuals because of the receipt of [Food Stamp] benefits”** again in direct violation of the very same Federal food stamp law. See 7 U.S.C. §2017(b).

Secondly, the Policy Statement further violates the very definition of what an RLA budget is to provide to cover under state law **“funds authorized ... to cover the actual costs of room and board ...”**. See 460 IAC 6-3-47. Although “room and board” is not statutorily defined in the Indiana Code or IAC, the term is used interchangeably in many other provisions for lodging and food expenses. It is further almost black letter law defined as lodging and food expenses; so much so that in a 3rd Circuit Court of Appeals opinion where the State of Pennsylvania sued the U.S. Dept of HHS questioning what was or was not included within “room and board”, the Court traced the term back to circa 1403 and defined it to clearly include all incidents of lodging and food in the form of daily meals. However, FSSA has taken the position that they have absolute discretion to define what is or is not included within this definition.

Further, even the very computational method of determining the food stamp benefits this state provides to consumers, contains a presumption that the individual will contribute 30% of their net income towards their monthly food expenses. However, FSSA denies even this allowance, very strictly providing that all sources of income (usually just Social Security benefits for these individuals) must be used for FSSA’s allowed list of living expenses, and no portion may be reserved for food or groceries. Although there may be significant fraud in the food stamp program it is not being perpetrated by these severely handicapped individuals.

The result is that after 2 years of fighting my way up through the administrative appeals process, I have just recently filed a second class action suit against FSSA for violations of Federal and state law. A copy of that suit which goes into far more detail is attached to my text.

The result of the RLA Policy Statement (which again is totally silent on its face) and FSSA’s interpretations imposed upon Medicaid Waiver recipients and their care providers, is that these severely disabled persons are being forced to subsist at a sub-poverty level and rely on about \$5.69 per day in food stamps as their sole source of food and nutrition. As the second attachment to this text illustrates, FSSA is forcing these individuals to subsist at nutritional level lower than any comparable measure; so much so that it is barely 25% of what Indiana state employees are provided in food per diem. I expect most of you here today will spend more than \$5.69 on lunch alone while these disabled recipients are forced to live the entire day on that amount.

In conclusion, you will hear often that FSSA is forced to live within their means and must make choices on which programs to fund; but I will point out that is a red herring rebuttal. In a public statement, the House Budget Fiscal Analyst stated that it would cost approximately

\$900,000 per year to provide a grocery allowance to these Waiver recipients. In the last 3 fiscal year end reversions (2010 – 2012), FSSA has reverted over \$463.6 million of its appropriations back to the general fund. Less than 90 days ago, FSSA reverted over \$47.6 million, which all by itself could have funded grocery allowances for more than a generation. This state boasts of having the largest cash reserves in history while some of its most defenseless citizens under its care live in sub-poverty conditions.

I am not trying to argue that these severely disabled adults have an absolute right to anything. But this state chose to join the Medicaid Waiver program because it would save billions of dollars over institutionalizing these people. However, despite the defined benefits and appropriations given to FSSA to accomplish their mission, they have chosen to force these people into a take-it or leave it sub-poverty existence. These consumers don't vote and have no political or economic voice; most do not even read or write; but the state chose this role and it is an embarrassment in how FSSA is treating the very people it was chartered to assist.

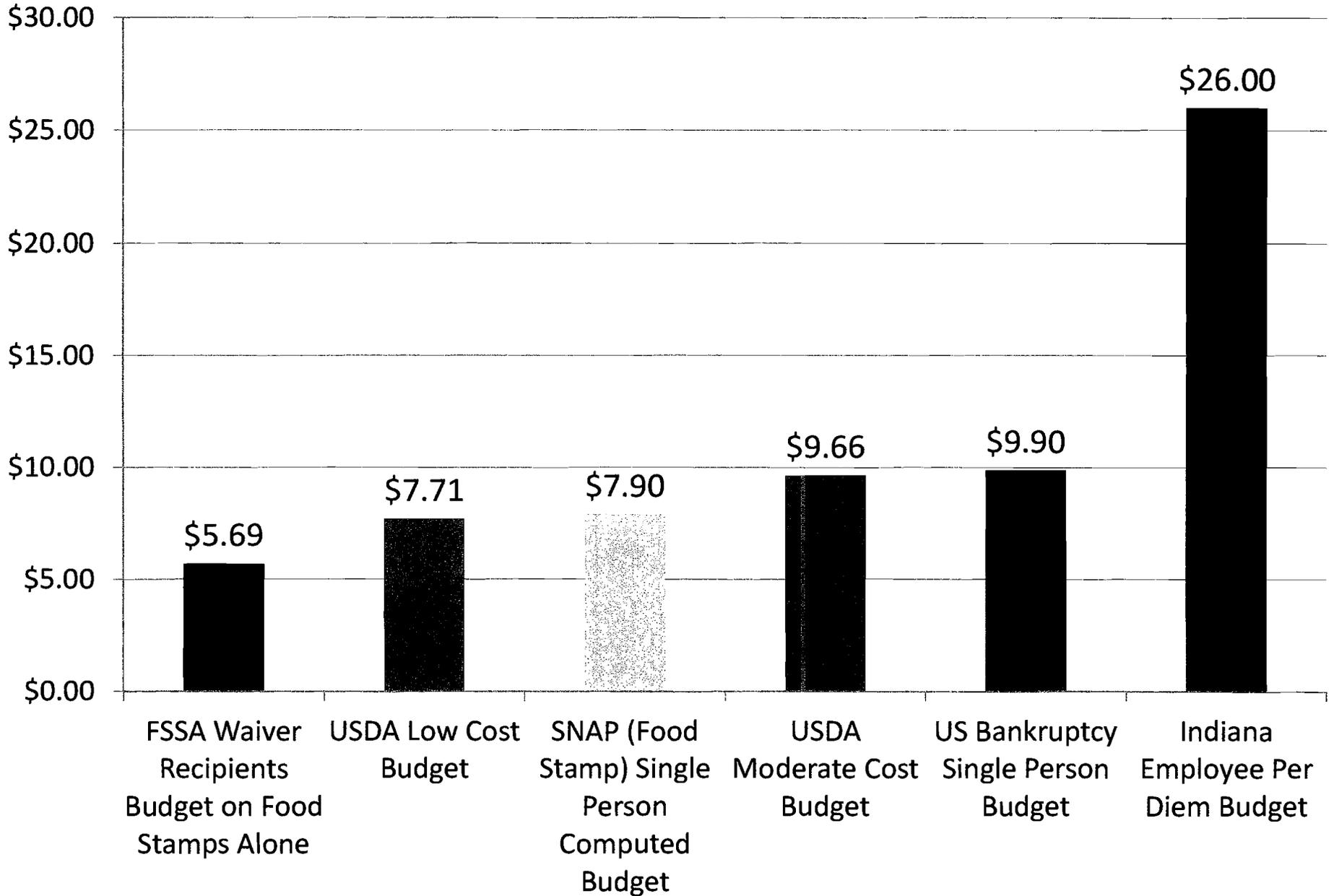
Thank you again, and I am willing to answer any questions now or later as my contact information is included within the attachment.

Respectfully,

A handwritten signature in black ink, appearing to read "Steven K. Dick". The signature is fluid and cursive, with the first name "Steven" being the most prominent part.

Steven K. Dick

Table of Comparative Per Diem Food Budgets



Date Sources:

1. \$173/month in food stamps times 12 months divided by 365 days equals \$5.69 per day
2. Official USDA Food Plans, June 2012, can be accessed at www.cnpp.usda.gov , low-cost, male, age 19-50
3. SNAP Guide to Food Stamp computations can be accessed at Center on Budget and Policy Priorities, www.cbpp.org which details that SNAP computes the food stamp benefits on the presumed basis that the recipient will be contributing 30% of their net household income towards food.
4. Official USDA Food Plans, June 2012, can be accessed at www.cnpp.usda.gov , moderate-cost, male, age 19-50
5. US Bankruptcy food allowance can be accessed at www.justice.gov/ust/eo/bapcpa for National expense standards
6. Indiana employee per diem food allowance can be accessed at www.indianahotels.org/informationcenter for per diem rate information

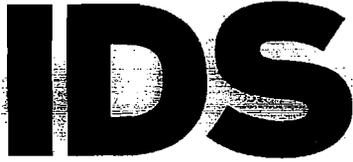


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CITY & STATE

440 developmentally disabled Hoosiers lose funding

By RACHEL STARK | IDS
POSTED AT 12:37 AM ON NOV. 4, 2010 (UPDATED AT 12:37 AM ON NOV. 4, 2010)

Nancy Smith was checking budgets when she noticed a policy change that would affect the way hundreds of developmentally disabled Hoosiers receive food.

Smith, the associate director for Supportive Living at Stone Belt Arc in Bloomington, had not received notification of a policy change ending a grocery benefit formerly paid to Indiana residents with autism, Asperger's syndrome and other developmental disabilities who receive a Residential Living Allowance.

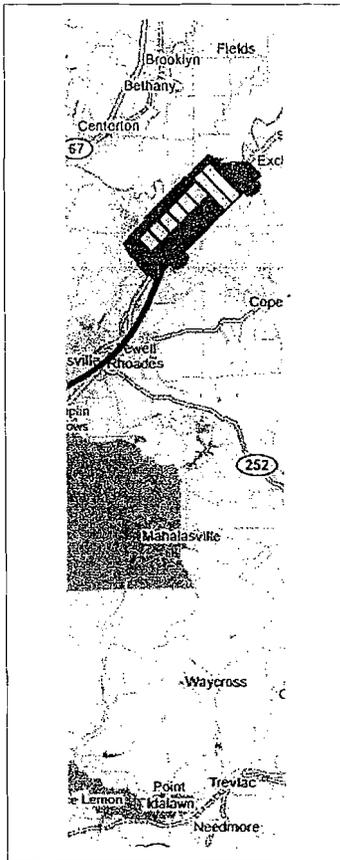
Confused and surprised, Smith, who works for one of the largest service providers for the developmentally disabled in south central Indiana, picked up the phone and called a service provider in a neighboring county. She wanted to know if they had noticed the changes too.

The Indiana Family and Social Services Administration enacted this Residential Living Allowance policy change in September.

The allowance is a state-funded program with the goal of enabling individuals to live on their own rather than in assisted living.

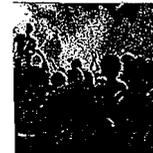
The 10-page policy outlines a list of expenses included in the allowance — such as rent, utilities and telephone — and two pages of expenses not included. However, groceries are never mentioned in the allowance.

On Oct. 25, a legislative Select Joint Commission on Medicaid Oversight had a meeting in Indianapolis to discuss the issue.



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DIGITAL POLL

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- Yes, they live there.
- Maybe, if they are not from Indiana
- No, they should vote in their home towns.
- They don't need to vote.

VOTE VIEW RESULTS

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Before the FSSA policy was enacted in September, The American Civil Liberties Union and Steven Dick, an Indianapolis attorney, brought a lawsuit against the FSSA regarding decreases in the grocery allowance.

FSSA spokesman Marcus Barlow said the changes were made in response to misuse of the grocery allowance. He said 70 percent of the individuals misstated their income.

"We reduced the scope of the program," Barlow said. "We felt that the individuals who are receiving RLA could also survive off of federal benefits, so we focused that money more on things the federal government doesn't pay for."

Twelve Indiana House and Senate members make up the Select Joint Commission on Medicaid Oversight that met last week.

One of these members is State Senator Vi Simpson, D-Bloomington, who expressed concern not only for the termination of the grocery benefit, but also for the general lack of information provided for legislators.

She said she wants specific information from the state administration on budget cuts.

"This is very secretive," Simpson said. "(The state) will not tell us things we've been requesting for a year. It's important we have these meetings because we get information from the public."

While budget cuts are expected during these times, Simpson argued that this one went too far.

"Everyone is interested in cutting budgets, but the vulnerable populations have been extraordinarily impacted by these budget cuts," she said.

"You judge a society by how it cares for its most vulnerable citizens. I would say we're getting a failing grade."

Dick said he feels a close tie to the population Simpson referred to.

His son, Michael, is autistic. At 26, he functions as a nonverbal 6- or 7-year-old, Dick said. Michael lives in a rental house and receives help from 24/7 care providers.

Previously, his son was given \$200 a month for groceries. Now he receives \$181 a month in food stamps or about \$6 a day.

"These people don't have the ability to go to food banks — they're dependent on service providers or relatives to care for them," Dick said. "They have no voice."

Despite public outcry and concern from the Medicaid Oversight Committee, the FSSA is not obligated to change the new policy.

Erik Gonzalez, fiscal analyst for the House Democrats Ways and Means Office, said the committee's concern was included in the meeting's final report. The report, a reflection of points covered in the meeting, is sent to the Indiana Legislative Council.

The FSSA estimated that 440 Indiana residents receive the RLA and will be affected by the change. At least 11 of the people live in Bloomington and use Stone Belt as their service provider, Smith said.

With the higher rents in town because of college housing, the budget cuts



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Indiana Daily Student

could be a bigger blow to the locals. But Smith said she is optimistic about the wealth of Bloomington resources that can ease the burden.

“I think agencies are working really hard to be proactive to help make sure people are signed up for every benefit they can get, find the right roommates for people and do the things the state is asking us to do,” Smith said. “We’re trying to do the best we can.”

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3 COMMENTS

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veronica

Total Score : 0

Posted at 11:18 PM on Nov 04, 2010

Although this cut may not be severe, funding for many services for individuals who are developmentally disabled has been cut left and right in several states. The housing options may not be ideal. Agencies like Stone Belt cannot pay their employees enough, resulting in high turnover rates and possibly less than desirable employees who have the responsibility for another human's life. In many cities, individuals with developmental disabilities may not have access to job coaching or day centers that can teach them skills and help them earn a paycheck. So while this cut itself may not seem to be a big deal, if you look at it in the bigger picture you may understand why it would initially cause alarm. Even if it turns out to not be a problem, I think a lot of people are simply tired of the system.

Report Abuse



Luke

Total Score : 0

Posted at 03:29 PM on Nov 04, 2010

If I am reading this correctly, the cut was 19 dollars a month and it switched to food stamps instead of cash. Also, if SEVENTY PERCENT of the people receiving the money were misstating their income, something needed to be done. Instead of attacking the state, attack the people who were cheating the system.

Report Abuse



IB Forum

Total Score : 0

Posted at 03:24 PM on Nov 04, 2010

If I were one of the those complaining about Our Man Mitch's minions.....I would be careful.....they might just do the thing those types do.....blame the weakest of all of for making harder on them. Most of the concerned citizens should be able to remember back when the Hero/God of the Republican party the Great Ronny came down with those big pangs of sorrow and decided that the right thing for him to do for those poor unfortunates was to kick them out of their homes and turn them onto the street so guys like Our Man Mitch and his budget cutters can blame those evil 400 autistic citizens for wrecking the state budget....I mean come on....those poor unfortunates should really be ashamed of the way they have ruined our fiscal budget.....maybe Mitch should kick em out again....if it was good enough for Ronny why not Mitchie....after all he is gonna try for that big ole white house, right?

Report Abuse

[Top](#)

CAMPUS	REGION	ARTS	OPINION	SPORTS	SPECIALS	DIRECTORY
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STATE OF INDIANA)
) ss
COUNTY OF MARION)

IN THE MARION COUNTY SUPERIOR COURT
CAUSE NO.:

49D02 12 09 PL 036552

MICHAEL DICK, by his guardian and next)
friend Steven K. Dick, on his own behalf)
and on behalf of a class of those similarly)
situated,)

Plaintiffs,)

v.)

INDIANA FAMILY & SOCIAL SERVS.)
ADMINISTRATION, BUREAU OF)
DEVELOPMENTAL DISABILITIES)
SERVS. OF THE INDIANA FAMILY &)
SOCIAL SERVS. ADMINISTRATION,)
MICHAEL A. GARGANO, in his official)
capacity as Secretary of the Indiana Family)
and Social Services Administration, and)
SHANE SPOTTS, in his official capacity)
as Director of the Division of Disability and)
Rehabilitative Services of the Indiana)
Family and Social Services Administration,)

Defendants.)

FILED



SEP 18 2012

Elizabeth J. White
CLERK OF THE MARION COUNTY COURT

**VERIFIED CLASS ACTION COMPLAINT FOR DECLARATORY
AND INJUNCTIVE RELIEF, AND VERIFIED INDIVIDUAL PETITION
FOR JUDICIAL REVIEW OF FINAL AGENCY ACTION**

COMES NOW Plaintiff/Petitioner Michael Dick, by his guardian and next friend Steven

K. Dick and by Counsel, and being duly sworn upon his oath states as follows:

Introductory Statement:

1. This action challenges the practice or policy of the Indiana Family and Social Services Administration whereby a monetary grocery allowance allowed to individuals enrolled in the Indiana Medicaid Waiver Program has been decreased or eliminated because such individuals are receiving Federal Food Stamps. Following a similar class action lawsuit

in July 2010 wherein the Plaintiff proved that Indiana Family & Social Services (FSSA) was routinely violating 7 U.S.C. §2017(b) by directly offsetting Waiver recipient's receipt of Food Stamps dollar for dollar against their Residential Living Allowance (RLA). In acknowledgement of the violations, FSSA re-wrote their RLA Policy to expressly eliminate the inclusion of Food Stamps as "income or resources" within the computation of their Individual Community Living Budget (ICLB) used to compute the appropriate RLA. However, in re-writing said 10 page Policy Statement, FSSA deliberately and with intent to indirectly do what they were caught directly doing, drafted the Policy Statement without ever once mentioning the words "board, food, groceries, or grocery allowance" despite four (4) full pages of specifically enumerated permissible and non-permissible budget expenses.

Then immediately upon the Policy Statement becoming effective, the Bureau of Developmental Disabilities Services (BDDS) of the FSSA announced to Waiver recipient care providers that since "board, food, groceries, or grocery allowance" were not an enumerated permissible expense, they were a non-permissible expense despite not being so stated. Said calculated maneuver was to do indirectly what they had wrongfully been doing directly, ie, reducing any food expense allowance to Medicaid Waiver recipients by reason of their receipt of Food Stamps; which is in direct violation of the second clause of 7 U.S.C. §2017(b), prohibiting the decrease of any assistance otherwise provided by reason of receipt of Food Stamps.

Accordingly, the Plaintiff's Verified Class Action Complaint for Declaratory and Injunctive Relief is brought pursuant to 42 U.S.C. §1983, as well as under the Supremacy Clause of the United States Constitution, and under Indiana law.

2. The Plaintiff/Petitioner also brings this action as a Verified Individual Petition for Judicial Review of Final Agency Action pursuant to Indiana Code §4-21-5.5-1, *et. seq.*, seeking judicial review of the final agency action of Indiana Family and Social Services Administration wherein the appeal of his RLA budgets was denied. This decision was premised on the legality of the Defendant's practices or policies concerning the disallowance of any grocery allowance and related issues, and insofar as those practices or policies violate State and Federal Law, the Agency decision must be set aside.

Parties

3. Michael Dick is an adult resident of Marion County, Indiana. He brings this action by his guardian and next friend, Steven K. Dick, and on behalf of both himself and a class of those similarly situated.
4. The Indiana Family and Social Services Administration is the state agency responsible for the operation of the Medicaid program in Indiana, including the Medicaid Waiver Program and the Developmental Disabilities Waiver Program (DD Waiver) thereunder.
5. The Bureau of Developmental Disabilities Services (BDDS) of the Indiana FSSA is the division of the Indiana FSSA responsible for the operation of the Developmental Disabilities Waiver Program in Indiana.
6. Michael A. Gargano is the duly appointed Secretary of the Indiana FSSA, and is sued in his official capacity.
7. Shane Spotts is the duly appointed Director of the Division of Disability and Rehabilitative Services of the Indiana FSSA, and is sued in his official capacity.

Class Action Allegations

8. The Plaintiff brings this action on his own behalf and on behalf of a class of those similarly situated pursuant to Rule 23(A) and (B)(2) of the Indiana Rules of Trial Procedure.
9. The class is defined as:

Any and all persons in Indiana enrolled in the Developmental Disabilities Medicaid Waiver Program, or who will be enrolled in the Medicaid Waiver Program, who received a residential living allowance prior to RLA Policy Statement (Policy Number: BDDS 460 0901 001) and thereafter had their RLA grocery expenses reduced or denied; or thereafter applied for and were denied a RLA containing any allowance for grocery expenses; and who were also enrolled or will be enrolled in the Federal Food Stamp Program.
10. As defined, the class meets all requirements of Rule 23(a) of the Indiana Rules of Trial Procedure. Specifically:
 - a. The class is so numerous that the joinder of all members is impracticable. While the precise number of class-members is presently unknown, it is believed to number well into the hundreds, if not thousands. The number of individuals enrolled in the Medical Waiver Program is at least in the thousands, and because both the Medicaid Waiver program and the Food Stamp program are income-based, a significant number of persons enrolled in the Medicaid Waiver program are also enrolled in the Food Stamp program. In the 2010 class action, FSSA ultimately issued class notices to some 1500 members.
 - b. There are questions of law and fact common to the class, specifically:

Whether the Defendants' practices or policies concerning the denial of any residential living allowance for "board, food, groceries, or grocery allowance" for individuals enrolled in the Medicaid Waiver Program or Developmental Disabilities Waiver Program violates Federal or state law?

- c. The claims of the representative party are typical of those of the class.
 - d. The representative party has satisfied all administrative appeal requirements and will fairly and adequately represent the interests of the class.
11. The further requirements of Rule 23(b)(2) are met in this case as they relate to the class inasmuch as the parties opposing the class have acted or have refused to act on grounds generally applicable to the class, thereby making appropriate final injunctive and corresponding declaratory relief with respect to the class as a whole.

Legal Background

Background to the Medicaid Waiver Program

12. Medicaid is a Federal program of medical assistance for the poor and disabled established by Title XIX of the Social Security Act and funded by Federal government and participating states. *See* 42 U.S.C. §1396, *et. seq.*
13. Federal Medicaid appropriations to the states are designated to enable states to furnish medical assistance to those whose income and resources are insufficient to meet the costs of necessary medical services. *See* 42 U.S.C. §1396.
14. Eligibility for Medicaid is limited to low-income people who fall into one of several categories or groups specified in Federal law, which includes disabled persons. *See* 42 U.S.C. §1396a(a)(10)(A).

15. State participation in the Medicaid program is voluntary. However, states that chose to participate in the Medicaid program must submit plans to the United States Department of Health and Human Services in order to qualify for the Federal matching funds, and those plans contain the requirements that a state must meet to receive Federal approval. *See* 42 U.S.C. §1396a(a).
16. Indiana participates in the Federal Medicaid program and is bound by all of its requirements. *See* Ind. Code §12-15-1-1, *et. seq.*
17. The U.S. Department of Health and Human services may waive certain requirements of the Medicaid program for states that include as “medical assistance” under their State plan, certain home and community-based services that are provided to an individual who, but for such services, would require the level of care provided in a hospital, nursing facility, or intermediate care facility for the mentally retarded. *See* 42 U.S.C. §1396n(c)(1).
18. In order for a waiver to be approved by the U.S. Department of Health and Human Services, the requesting state must provide assurances that:

the average per capita expenditure estimated by the State in any fiscal year for medical assistance provided with respect to such individual [enrolled in the Waiver program] does not exceed [one hundred] percent of the average per capita expenditure that the State reasonably estimates would have been made in that fiscal year for expenditures under the State plan for such individuals if the waiver had not been granted. *See* 42 U.S.C. §1396n(c)(2)(D).

Background to the Federal Food Stamp Program

19. The Food Stamp program is a Federal program of assistance (now known as Supplemental Nutrition Assistance Program – SNAP) for the poor that is designed to safeguard the nation’s health and well-being by raising the levels of nutrition among lower-income households, and is funded by the Federal government and participating states. *See* 7 U.S.C. §2011, *et. seq.*; 7 C.F.R. §271.1, *et. seq.*
20. Eligibility for the Food Stamp program is limited to households who fall under the stringent income thresholds specified by Federal law. *See* 7 U.S.C. §2014; 7 C.F.R. §273.9-10.
21. SNAP’s computation of Food Stamp benefits includes an “Expected Contribution Towards Food” by the individual of 30% of the individual’s net income; which FSSA/BDDS does not permit under its practices and policies.
22. States that participate in the Food Stamp program are required to enter into an Agreement with the United States Department of Agriculture in which the participating state must agree to administer the Food Stamp program in accordance with the Food Stamp Act of 1977, implementing regulations, and a State Plan of Operation approved by the Food and Nutrition Service. *See* 7 C.F.R. §272.2(b)(1),
23. One such requirement of Federal law is that:

[t]he value of [Food Stamp] benefits ... shall not be considered income or resources for any purpose under any Federal, State, or local laws, including, but not limited to, laws relating to taxation, welfare, and public assistance programs, and **no participating State or political subdivision thereof shall decrease any assistance otherwise provided an individual or individuals because of the receipt of [Food**

Stamp} benefits 7 U.S.C. §2017(b); *see also* 7 C.F.R. §272.1(a) (emphasis added).

Background as to State Medicaid Waiver Program

24. The BDDS is established within FSSA to plan, coordinate, and administer the provision of individualized, integrated community based services for individuals with a developmental disability and their families, within the limits of available resources. *See* Ind. Code §12-11-1.1-1.
25. The Indiana Administrative Code, Article 460, provides the statutory guidelines for the services and expenses to be provided to Medicaid Waiver recipients.
26. 460 IAC §6-3-29.5 defines: “Independence assistance services” means services that an individual needs to maintain independence to live successfully in his or her own home.
27. 460 IAC §6-3-31 defines: “Individual community living budget” or “ICLB” means the format used by the BDDS to:
 - (1) uniformly account for all: . . . (B) living expenses;
28. 460 IAC §6-3-47 defines: “Residential living allowance” means funds authorized by the BDDS services under IC 12-11-1.1-2(c) to cover the **actual costs of room and board expenses** as authorized in the individual’s ICLB. (emphasis added).
29. 460 IAC §6-30-1 defines RLA documentation required to include: (2) Receipts for all expenditures made from the individual’s financial resources and food stamps, including receipts for rent, utilities, groceries, clothing, household goods, and other expenditures.

Factual Allegations

30. The Indiana FSSA operates five (5) Medicaid Waiver programs that have been approved by the Federal government pursuant to 42 U.S.C. §1396n(c).

31. FSSA operates three (3) of these waiver programs, including the Developmental Disabilities Waiver Program (DD Waiver Program), through its Division of Disability and Rehabilitative Services.
32. The DD Waiver Program provides services and other forms of assistance to enrolled individuals that are not available through traditional Medicaid programs – which are known as “prior authorization” services – and that are offered to permit a person with developmental disabilities to live and receive services in the community rather than in an institutional setting.
33. One form of assistance available to eligible Waiver recipients is a residential living allowance (RLA), which is intended to address the basic needs of the individual to enable him or her to live and participate in the community, by computing all of the “actual room and board” expenses for rent, utilities, personal necessities, groceries, telephone, and similar living expenses, less the individual’s available income or assistance such as social security disability or employment income, if any.
34. Prior to Plaintiff’s class action lawsuit in July 2010, BDDS provided for at least a decade a grocery allowance within the RLA budget computation of \$200 per month, with higher adjustments allowed for medical, health, or safety justifications; but offset from that allowance all Food Stamps received by the individual (in violation of Federal law).
35. As a direct result of said lawsuit, FSSA re-wrote their RLA Policy Statement to the present Policy Number: BDDS 460 0901 001, which expressly states that “EBT/SNAP Food Stamp benefits are not to be included in the calculation for Monthly Income and Benefits;” thereby satisfying the prior injunction against offsetting requested. A true and

correct copy of the BDDS Residential Living Allowance Policy Statement is attached and incorporated herein as Exhibit 1.

36. However, in rewriting said 10 page Policy Statement, FSSA deliberately and with intent to indirectly do what they were caught directly doing, drafted the Policy Statement without ever once mentioning the words “board, food, groceries, or grocery allowance” despite four (4) full pages of specifically enumerated permissible and non-permissible budget expenses.
37. Then immediately upon the Policy Statement becoming effective, BDDS announced to Waiver recipient care providers that since “board, food, groceries, or grocery allowance” were not an enumerated permissible expense, they were a non-permissible expense despite not being so stated.
38. Said calculated maneuver was to do indirectly what they had wrongfully been doing directly, ie, reducing any food expense allowance to Medicaid Waiver recipients by reason of their receipt of Food Stamps; which is in direct violation of the second clause of 7 U.S.C. §2017(b) prohibiting the decrease of any assistance otherwise provided by reason of the receipt of Food Stamps.
39. Said intent is further supported by the public statements of FSSA’s public spokesperson who stated: “Receiving a benefit reduces their needs. If your need has been reduced, then you should reduce the supplemental program.”
40. Said Policy Statement further violates the statutory requirement that a RLA budget provide for all the “actual costs of room and board” under 460 IAC §6-3-47. FSSA is, by omission within its Policy Statement, trying to substantively modify the governing statute by ignoring “board” as a RLA living expense, when it is universally understood that the

“costs of room and board” means the costs of lodging and meals. Interpretations contained in agency policy statements lack the force of law and do not warrant judicial deference in cases involving Medicaid.

41. The Indiana legislature has funded the mission of FSSA and BDDS to provide RLA assistance to seriously disabled adults through the Medicaid Waiver program by appropriating over \$2.9 billion per year over fiscal years ending 2010, 2011, and 2012.
42. However, FSSA has reverted over \$463.6 million of its appropriations back to the general fund in that same time period and during the period this Policy Statement has been in effect.
43. The Financial Analyst for the House Ways and Means Committee has publicly stated that: “Reinstating the food allowance would cost the agency an estimated \$900,000 at a time when the state is running a \$2 billion surplus, much of which comes from money returned by agencies to the state’s general fund. For a small amount of money, these people can be appropriately served.”

Allegations Concerning the Petitioner/Plaintiff

44. Michael Dick is a twenty-eight-year-old resident of Marion County, Indiana. He is severely autistic, non-verbal, cognitively impaired, and has been enrolled in the Developmental Disabilities Waiver program operated by FSSA/BDDS since 2005.
45. Mr. Dick is also enrolled in the Federal Food Stamp program, and has been since 2006, when he was required by FSSA/BDDS to apply for Food Stamps as a condition of receiving a RLA through the DD Waiver program.
46. Since this appeal was filed on December 1, 2011, Mr. Dick has been denied the right to include within his RLA budget any allowance for food, groceries or board expenses;

because of the BDDS Policy Statement and the FSSA/BDDS interpretation that all such need is being met by Food Stamps.

47. Prior to the new Policy Statement, Mr. Dick was allowed to claim a \$200 per month grocery budget, albeit offset by whatever Food Stamps were being received.
48. After denial of his RLA budgets, Mr. Dick is being restricted to surviving on \$173.00 per month, or \$5.69 per day, Food Stamp only grocery budget, which is far below any reasonable costs for such living expenses.
49. FSSA/BDDS further requires that Waiver recipients submit 100% of all other income or benefits to their defined permissible living expenses to minimize any possible RLA. In Mr. Dick's case that means that all \$698 of SSDI received must be applied to FSSA/BDDS' permissible living expenses without any reservation of part of those funds to assist in the provision of adequate grocery expenses.
50. This policy further violates the SNAP Food Stamp computation process which presumes that an individual contributes 30% of their net income toward their food budget.
51. Although the RLA Policy Statement provides that an individual's monthly residential living expenses should not be more than 150% of the poverty level for a single individual as published in the Congressional Federal Register (CFR poverty level for 2012 is \$11,170 per year so 150% would equal \$1,396.25 per month), FSSA/BDDS is requiring these seriously handicapped Waiver recipients to subsist on 50% of that amount per month with no RLA assistance; well below the poverty level.
52. The decrease in Mr. Dick's grocery allowance occurred solely because of the prior lawsuit and revised RLA Policy Statement and did not occur because of any other

changes in Mr. Dick's income or in the cost of living, or as a result of any other uniform budgetary adjustment by the Agency unrelated to the prior lawsuit.

53. Mr. Dick timely and properly appealed the Agency's decision to disallow any grocery allowance but his claim was denied by an administrative law judge in an Order dated August 10, 2012. A true and correct copy of the Administrative Order granting Motion to Dismiss is attached and incorporated herein as Exhibit 2.
54. Mr. Dick timely and properly requested the Agency Director's review of the administrative law judge's decision but was denied on August 20, 2012. A true and correct copy of this denial letter is attached and incorporated herein as Exhibit 3.
55. Mr. Dick has timely and properly exhausted the administrative appeals process to the extent that such exhaustion is necessary for him to pursue judicial review of the final agency action against him.

Concluding Allegations

56. As a result of the practices or policies of the Defendants, the Plaintiff and the putative class members are suffering irreparable harm for which there is no adequate remedy at law.
57. The Defendants have at all relevant time acted under the color of law.
58. The actions of FSSA/BDDS in the present case are retaliatory, arbitrary, capricious, an abuse of discretion, and/or contrary to law; contrary to constitutional right, power, privilege, and/or immunity; in excess of statutory jurisdiction or authority, or short of statutory right; without observance of procedure required by law; and/or unsupported by substantial evidence.

I. COUNT ONE: CLASS ACTION COMPLAINT FOR DECLARATORY AND INJUNCTIVE RELIEF

59. Paragraphs 1 through 56, inclusive, are incorporated and re-alleged as if set forth fully herein.
60. The FSSA/BDDS's practice or policy of denying any RLA allowance for "board, food, groceries, or grocery allowance" for individuals enrolled in the Medicaid Waiver Program or DD Waiver program, written in direct response to the prior class action suit for improperly offsetting Food Stamps, violates Federal Food Stamp law (7 U.S.C. §2017(b) and 7 C.F.R. §272.1(a)) as a decrease in assistance otherwise provided an individual by reason of the receipt of Food Stamps benefits; and therefore must be considered a suspect policy.
61. The FSSA/BDDS's RLA Policy Statement and their actions of elimination of "board, food, groceries, or grocery allowance", by silent omission, further violates the statutory requirement that an RLA budget provide for all the "actual costs of room and board" under 460 IAC §6-3-47; and is an attempt by FSSA to substantively modify the governing statute by ignoring "board" as a RLA living expense in a Policy Statement which lacks the force of law; and therefore must be considered a suspect policy.

II. COUNT TWO: INDIVIDUAL PETITION FOR JUDICIAL REVIEW OF FINAL AGENCY ACTION

62. Paragraphs 1 through 59, inclusive, are incorporated and re-alleged as if set forth fully herein.
63. The Petitioner in this cause is Michael Dick, who resides at 2807 Westleigh Dr., Indianapolis, IN 46268.

64. The Agency whose actions are at issue in this cause is the Indiana Family and Social Services Administration (which is located at 402 W. Washington St., Room W-461, Indianapolis, IN 46204) and/or the Bureau of Developmental Disabilities Services of the Indiana FSSA (which is located at the same address, Room W-453).
65. Mr. Dick has standing to pursue judicial review in this cause pursuant to Indiana Code §4-21-5.5-3, for the agency action at issue was specifically directed at him and he was the party to the administrative proceeding that led to the agency decision.
66. Mr. Dick has exhausted all administrative remedies available within the Indiana FSSA, and received the Notice of Final Agency Action on August 21, 2012.

Request for Relief

WHEREFORE, the Plaintiff/Petitioner respectfully requests that this Court:

1. Set aside the decision of the state agency in the present case, thereby setting aside the budget denials of the agency and the decision of the administrative law judge dismissing appeal of those denials.
2. Certify this cause as a class action, with the class as defined hereinabove.
3. Declare that the Defendants have violated the rights of the Plaintiff and the class for the reasons specified above.
4. Issue a permanent injunction enjoining the Defendants from indirectly counting an individual's Food Stamps as a benefit and thereby reducing assistance otherwise provided an individual by reason of the receipt of Food Stamps.
5. Invalidate the RLA Policy Statement at issue, and its application by the Defendants for violating the statutory requirement that an RLA budget provide for all of the "actual costs of room and board" under 460 IAC §6-3-47; and as an attempt by FSSA to substantively

modify the governing statute by denying "board" as a RLA living expense in its Policy Statement, which lacks the force of law.

6. Award the Plaintiff and the class their costs and reasonable attorneys' fees pursuant to 42 U.S.C. §1988.
7. Award the Petitioner damages, costs and reasonable attorneys' fees under his individual cause of action.
8. Award all other relief just and proper under the premises.

Respectfully submitted,



/s/ Steven K. Dick
Steven K. Dick (#22613-49)
SK DICK & ASSOCIATES LLC
225 N. Delaware St.
Indianapolis, IN 46204
T) 317-269-3422
F) 317-269-3428
Steven@skdicklaw.com

Attorney for the Plaintiff/Petitioner and
the putative class

VERIFICATION

I hereby verify, under penalties for perjury, that the foregoing statements are true and correct to the best of my information and belief.

Date: _____



/s/ Steven K. Dick

Guardian and next Friend of Michael Dick

DD Commission
Meeting 3
10-9-12
Exhibit 4

Thank you for the opportunity to speak today.

I am here on behalf of my daughter, Hailey. Hailey has a rare chromosome deletion. Her syndrome is nameless and her health concerns are many. She has profound cognitive disability, various anatomical deformities, and a MACE ostomy. She has sensory issues; toileting, feeding, sleeping and auditory challenges. She exhibits pica and a lack of awareness of possible dangers.

Currently, Hailey receives support on the Aged and Disabled – or A&D - waiver. We use our budget to provide roughly 2-3 nights of sleep because of Hailey's problematic sleep patterns in spite of various medicines trialed. We are fortunate to have these supports. Hailey is a person that I would call "dually eligible" because her health, safety, and behavioral assessments would meet both nursing level of care and institutional level of care. As such, my testimony will focus heavily on the dually eligible -- people with both cognitive disability and healthcare needs. Since Hailey's needs make her a dually eligible, we applied for the A&D waiver in addition to the FSW and CIH waivers that are administered by BDDS. During my and my husband's work hours, Hailey is supported by Medicaid-PA home health services to assist with her medical needs. This is funded by Medicaid and not the waiver.

Indiana's waivers are administered by 2 different administrative entities. The A&D and TBI waivers are administered by the Dept of Aging while the FSW and CIH waivers are administered by BDDS. As such, these waivers have differing services available to recipients and guidelines. For the dually eligible that meet both levels of care, this is challenging. As the cognitively disabled become an aging population as well, it would be worthwhile for the service offerings to mirror one another to better fit the client's individual needs. It is here that I think the state needs to look at opportunities to better serve the clients. **Administrative functions that require duplication of time, effort and funding should be simplified.**

To better assist the dually-eligible, the people with cognitive disabilities and significant health issues, I would suggest:

- (1) **The state must do better at educating their staff at the DFR about Medicaid spend-down so that families who require these supports can access them.** Families on any waiver waiting list who is eligible could then use this service to support them in retaining employment. The new structure for BDDS waivers puts an increased reliance on family support. Medicaid PA for persons with healthcare needs to support them while their caregivers work is a necessity and access to this service is essential.
- (2) **Coordination of waiver supports and PA supports can be very challenging --efforts to better coordinate these efforts is needed.** Home health agencies

(5) **We need to look at other inequities between the waivers that are administered by the department of aging and BDDS.** One of the reasons that we still hope that Hailey will eventually be served by the CIH waiver is because the BDDS waivers allow for staff to assist Hailey with medication administration. The A&D does not allow for that – and her independence would require this support to be in place. Additionally, she would need support to assist her with her financial management to secure her independence, and the Aging waivers do not allow for providers to support clients in this capacity. Another recent change to the Aging waivers is that they removed a cap on care because the courts of Indiana found it to be unlawful. The caps and spending restrictions in place on the BDDS waivers may also be similarly problematic.

In conclusion, I hope that you will look at opportunities to better spend taxpayer money where administrative function can be condensed, service menus simplified, and services left uncompromised. I also challenge you to better orchestrate the waiver programs so that they better respect the families and natural supports with whom you are relying to partner with in the care of individuals. I also ask that you initiate assistance in better coordinating care across funding streams – Medicaid-PA funding and waiver funding should be seamless to the user and more easily understandable to all. And because Medicaid-PA is available to eligible persons both on waiver and still awaiting the waiver via Medicaid-D and possible spend-down guidelines and because it is essential to ensuring that the caregiver can remain employed, staff at the DFR need to be better educated in assisting families to access these services within the spend-down guidelines. If you have any concerns or questions about my testimony, I am glad to speak with you further or answer any questions.

DD Commission
Meeting 3
10-9-12
Exhib. #5

Good morning. I want to thank the Commission for the opportunity to share my family's story, as well as our concerns about recent changes to the waiver programs in our state. While I will try hard to bring to light the complexities and needs of my child and family, and the impact of waiver changes within the framework of a complex disability system, all while limited to 4 minutes, please know that I am also available to continue the conversation in more detail at any time after this.

I am here today for my daughter, Avery, and the other children like her. I have a concern that families like mine have largely been left out of the discussions and preparations of our waiver systems and that, as a result, worry that the needs of our families will continue to go unmet under recent waiver changes. I understand rules and regulations and budgets are important, but this affects my child and countless other real children, and that's very important to me.

Avery is 7 yrs old. She was born with a brain malformation that affected her left cerebral cortex and which causes her to have complex special health and developmental needs. This malformation is her primary medical diagnosis, but it's responsible for a host of other medical and developmental diagnoses and issues that she deals with, including epilepsy (once catastrophic and for which she underwent 4 different brain surgeries to gain some relief from), right-sided hemi paresis (weakness of the entire right side of her body); right homonymous hemianopsia (loss of the right field of vision in each eye); gastroparesis (slow gut motility); feeding aversion and dysfunction; left optic nerve damage; cortical vision impairment; incontinence; and an inability to talk, walk, sit-up or even hold her head up, unsupported, for periods longer than a minute. She has significant global developmental delays, impacting her gross and fine motor skills, as well as her speech. Aside from a blink reflex, she has almost no ability to protect herself from harm or to sense danger. She requires total assistance for all ADLs (dressing, grooming, bathing, personal care, eating, toileting, etc.) and she certainly has some level of intellectual disability as a result of the brain malformation itself. She cannot tell us if she's hurting or if she feels bad; we rely primarily on physical cues that could be missed by an unskilled observer.

We signed Avery up for the Medicaid waiver programs at 15 mo. old, applying for the A&D waiver, and the former DD waiver and the SS waivers. It took about a year for Avery to reach the top of the A&D wait-list. She was assessed and found eligible, meaning that she met eligibility screening criteria for nursing LOC. Our family was fortunate, as Avery was only 2 ½ years old at the time. Because of the waiver, Avery was granted access to Medicaid disability insurance¹ with a disregard of parental income and resources. As result, I was able to reenter the work force and know that Avery's needs would still be met, thanks primarily to Medicaid State plan PA approval for

nursing hours which provide for Avery's care while her father and I work. Medicaid disability only became our secondary policy; we've always paid for and carried primary insurance on Avery through her father's employer. Access to Medicaid disability, however, meant that we could finally receive the therapy services Avery needed, but that our private insurer limited or denied. It meant we could finally get an adaptive bath seat for her but which our private insurance specifically excluded. It meant no longer being on the cusp of total financial peril for health care co-pays and uncovered services that we couldn't afford. I cannot express the importance of this safety net for our daughter and our family with enough emphasis.

The respite care also afforded to us through the A&D waiver was a God send. We finally had the means to take a break and know that our daughter's medical needs would be met while we did. It couldn't have been a more impactful and needed support in our lives then, and it continues to be that today. It gives us the time to have a date night, to reconnect as partners, to address other areas of our home and life that otherwise would be ignored, and it gives us a means to devote some more concerted time to our son, whose is 4 years older than his sister, without compromising her needs at the same time. It's not simply parents that are making sacrifices for their child with significant needs; it is absolutely the siblings too. For the first time this past spring, our 11 year old son finally had his first opportunity to play a team sport. Up until then, life had been too unstable to commit to anything outside of our basic routine for more than a couple of weeks. We still know that anything can change for our daughter on any day and we have to be prepared to change course in an instant.

There are other children like Avery. I call these children and my daughter, "dually eligibles". Avery truly lives each day in the world of special health/medical needs and the world of ID/DD, meeting both Nursing LOC and Institutional (ICF/MR) LOC, at the same time. It would be erroneous to say that she always lives and operates in one of these worlds more than the other. The totality of her needs extend at great depth into both worlds. She's not alone in this respect, but it's a problem area that our current waiver system does not address well.

Indiana's waiver programs are administered by two different entities, with one being focused on Medical based needs and the administration of the associated medical model waivers while the other is focused on ID/DD needs and the administration of the associated developmental model waivers. This has been the case for as long as our family has been involved in the system and continues to be the case despite the recent changes to waiver services. Each model attempts to address the needs of its eligible clients and the services under each waiver reflect, to large degree, the "model" that it falls into. This means that the A&D and TBI waivers provide home and community based services largely meant to address the medical needs and complexities of the client that would otherwise qualify for Nursing home placement without HCBS; while the CIH

and FS waivers (formerly Autism/DD waivers and SS waiver, respectively) provide home and community based services meant to address client needs resulting from ID/DD disabilities that would otherwise be eligible for placement in a ICF/MR. For children that fall into both worlds, the “other” needs seem go unrecognized under one side or the other. Even though Avery and our family benefits from the A&D waiver at this time, we are keenly aware that her ID/DD needs are not met under the waiver. She does not have access to services such as music therapy, community habilitation services, etc. For that reason, we also have her on the wait list for ID/DD model waivers. At the time that we signed up for those waivers, our hope and desire was that she would eventually qualify for the Developmental Disabilities waiver itself, now absorbed into the CIH waiver, and thus be able to access the myriad of DD type services she would also most certainly also need as she reaches adulthood. Yet, it’s always been on our minds that neither waiver meets her totality of needs, and as such, we’ve always struggled with how the waiver system would be able to meet her needs in the future, especially as she approaches adulthood.

With legislation that was passed in 2010, the developmental model system of waivers came under review. As a result, changes were recommended and adopted such that we now have only 2 waivers under the DD model. A lot of advocacy and effort from many parties went into this review and consideration of changes and I am thankful to all those involved for having some of the tough conversations and for making some of the tough decisions that were required. While there are some significant pros (for families and clients in general) to be recognized in the changes that were made on the DD side, it also seems that any opportunity to fully consider and address the needs of our families like ours was missed.

This is a crucial point, because of what was happening at the Dept. of Aging with respect to the A&D waiver at nearly the same time. The Dept. of Aging rescinded a 2006 policy that allowed children with significant ADL needs (at various ages) due to a DD diagnosis, qualify for the A&D waiver. They also began to apply a harder interpretation of the “skilled need” criteria within the eligibility screening tool. All this was done, to my knowledge at least, without a call for stakeholder input, and, according to recent discussion at a DDRS Powerful Parents meeting, also without any notice to or coordination with BDDS. I worry that those decisions may very well prove to be a failure of due care for our families.

The net effect of this change in A&D policy seems to be:

- *Children, who once qualified under a ‘skilled need’ as interpreted prior to the current policy change, are no longer eligible under the ‘skilled need’ eligibility screen unless the need stems from a medical condition that is **unstable and complex**. It appears that this determination is ultimately up to supervisors in*

the Dept. of Aging, based on policy materials I have been able to find. It's unclear what role a child's primary or treating physicians are allowed to play in that determination, but I would argue that it should not be solely left up to the discretion of non-physician staff of the Dept. of Aging.

- *Children, who qualified for A&D waiver under the 2006 policy, **may no longer qualify at their annual assessment.*** This is the case as I am being told with regards to my daughter. Even though she has a skilled need (though not considered unstable and complex per their interpretation and application to my daughter) **and** meets the ADL eligibility screening criteria, she will no longer be eligible for A&D services because she has a DD diagnosis as well. I am told that only ADLs due to medical diagnoses can count for eligibility under the new policy. It appears that, in cases where children have both medical and DD needs, the Dept of Aging is making a decision that DD needs trump the medical needs in determining which waiver system a child belongs in. As such, per our own CICOA case manager, they are now required to track (for existing clients on the waiver that have a DD diagnosis) that the client has signed up for the DD side waiting list. The intention being that the client will be allowed to continue with A&D waiver services only until a DD slot opens for the child.
- *More children will need to be served under the DD waiver model system as a result.* Is the new DD waiver model system prepared to handle the medical needs of these children? . It seems as though it would be difficult, at best, with the funding cap of the FS waiver and the limited and strict emergency criteria now being imposed for access to the more intensive services under the CIH waiver. This is a huge concern for our family, because it's unclear if the more basic needs of my daughter can be met under the current waiver structure AND because BDDS does not seem to have been aware of the Aging policy change and its impact on their side of the waiver system.

As a result of the changes made to both sides, there is added complexity to a system that already had difficulty in meeting the needs of children with both medical needs and ID/DD. The changes did little to address the concurring needs issue, but instead complicated it further. The scenario for our child, as well as others, now seems to be this one:

A child with significant disabilities that has medical and DD needs can't qualify for the A&D waiver unless his/her medical needs are complex and unstable, because DD needs trump medical needs and ADLs not due purely to a medical diagnosis cannot be used to meet eligibility screening. Such a child, with significant disabilities, both medical and developmental in nature, is left to apply for the DD side waivers for their HCBS services. However, barring emergency

criteria defined in the new CIH waiver, or barring a rare exception, this child can only qualify for the FS waiver.

CONCLUSION?

The limited funding level and limitation of services under the FS waiver, compared to the child's level of care (recognized by the State Medicaid plan –through PA nursing authorization) seem unlikely to be able to meet the child's and family's basic HCBS service needs, especially for the years it will take many of these children to qualify for the CIH waiver, if ever.

I understand that there are limits to resources; but there are surely better solutions for children and families like mine. It's important to continue the work of exploring, finding and making available the supports and services that have the most impact for children and families while also being good stewards of our tax dollars. I have been told that DDRS intends to keep looking at our waiver programs and making adjustments and changes as funding allows and where warranted. I hope that is a promise that our families can count on. I kindly implore our policy-makers, advocacy groups and all those involved in creating and using these waiver systems to take the opportunity now, and in the future, to address this critical group of children and the need gap that continues to exist, more significantly than it did before these changes were made. I respectfully ask that BDDS and the Dept. of Aging find a way to work together to make sure our two waiver systems do not leave out groups of families in the future. I also ask that families stop being effectively penalized for providing good care for their child in absence of waiver services. I offer a few brief suggestions that may assist in closing this gap between the needs of my child and the services offered under our waiver systems.

- **Allow for appropriate care providers (service classifications) based on a child's needs (up to nursing level when appropriate) across the waiver programs so that medical needs can be met on every waiver.** This is simple a tool for protecting the child medical and health care needs, regardless of the waiver they are served under.
- **Do not force families to use service levels that they do not need for the goal of the service.** (e.g., do not require nursing care for a skilled need when the skilled need will not be present or necessary during the time of service).
- **Remove the cap for waiver services that are medically necessary or that penalize families of children with more complex/medical needs.** (e.g., families receive less services hours of respite as nursing level need under a cap than respite as attendant care level of need for the same budget dollars due to differences in billed unit rates)

- **Allow access to both medical and ID/DD types of waiver services based on needs of the child across the waiver programs.** This could allow for a reduction in administration and duplication of efforts across the waiver managing entities, while also allowing providers to serve both sides more easily and efficiently, impacting their service delivery and easing staffing issues for the client across their service needs.

Finally, in the future, families **representing the entire spectrum of families of children with disabilities** should be invited to the table for these crucial discussions. Some current events and historical evidence suggest this has not always been the case. How else do we begin to really understand the variable needs of these families, the totality of difficulties that different families face in meeting their child's needs, and what these families may be able to offer or propose as ideas for cost-saving options given their perspective of what works, what doesn't and the lessons they've already been forced to learn about stretching limited resources within their families. It seems likely that this is the clearest path to practical but impactful solutions for families such as mine, that both honors the limited nature of our tax dollars and the duty we all have to make sure they are spent wisely and only when and where needed.

In the world of parents, we are not so different than any others. We want for our daughter the same things we want for our son. We want them both to be happy and to reach their full potential, whatever that potential may be. Does helping our daughter reach her potential call for greater work, efforts, supports and services? Yes it does. Is it worth it? We believe it is. Can we do it all on our own? No - even in spite of wishing and desiring that we could.

Thank you for your time.

¹Avery would likely have been eligible even before that point, but no one told us about Medicaid disability at the time, and my husband earned too much for HHW-A, and Avery's couldn't get HHW-C because we had access to private insurance.

Carlie Jackson Summary

October 1, 2012

OD Commission
Meeting 3
10-9-12
Exhibit 6

Summary of Issue:

Carlie Jackson can receive the best services available to meet her unique needs associated with Prader Willi Syndrome (PWS) at less cost of federal and state money at her current home in Wisconsin. As legal guardians of Carlie Jackson we want the best services and care for her, which ensures her safety, health, and well being while maximizing her quality of life. We strongly believe her current home at Prader Willi Homes of Oconomowoc (PWHO), in Wisconsin, is the most appropriate placement to achieve this. PWHO has demonstrated, time and time again, their superior services throughout the 8+ years Carlie has lived there. Carlie's State Line Item funding ended 8/1/12 (even though there is an active appeal filed May 25, 2012 with no hearing date scheduled). Her legal guardians are privately paying to continue services at PWHO. FSSA has committed to funding services for Carlie under a CIH Medicaid Waiver in order to maximize federal dollars. We believe the CIH Waiver funding can be used to provide services to Carlie at PWHO in Wisconsin and the total cost of care will be up to 100% less than available care in Indiana. This equates to a savings of nearly \$2,000,000 for the State of Indiana and more than \$3,000,000 for the Federal Government over Carlie's projected lifetime. We also believe Indiana does not have a provider with the knowledge, experience, and reputation for care of Carlie, with her very unique needs, comparable to PWHO. As a matter of note, several other states currently fund residents at PWHO with Medicaid waiver dollars.

Objective: Best services available for the safety, health, and quality of life for Carlie Jackson with the most effective and efficient use of available funding.

Pending Legal Action: Appeal to State Terminating Funding (funding ended 8/1/12) filed 5/21/12 based on arbitrary date of termination without appropriate transition plan in place.

State Attorney, Scott Newton, filed Motion to Dismiss.

Carlie Jackson filed Defense to Motion to Dismiss 7/11/12.

Waiting on ALJ, Kevin Wild, to rule on Motion to Dismiss.

No hearing date set.

Background

Carlie has Prader Willi Syndrome (PWS). This rare condition is characterized by an insatiable hunger, low metabolism, and variety of mental and emotional challenges. Carlie is 31 years old however, developmental in the 5-7 year old range. In 2000, Carlie was placed in a group home operated by ResCare through the Indiana Bureau of Developmental Disabilities Service (BDDS). This placement put Carlie at risk in a number of aspects; physical health, emotional health, and safety.

Physical Health: The Provider did not possess the necessary knowledge of her condition allowing unattended access to food. She gained weight and could have overeaten to the point of serious health issues, and potentially death.

Emotional Health: The Provider allowed Carlie to be alone overnight with an emergency placement. This emergency placement described, in detail, previous traumatic experiences. This person also told Carlie she was the "devil" which absolutely devastated Carlie emotionally.

Safety: On a first visit to a sheltered workshop with the Provider staff, Carlie was sexually molested in the workshop bathroom as a workshop employee reportedly observed.

As parents and legal guardians we removed Carlie from the ResCare home after approximately 4 months. She then lived at home with minimal state assistance through a Medicaid Support Services Waiver. Several emotional and physical issues developed after the time in the group home. Through research, interviews, and site visits we found Prader Willi Homes of Oconomowoc (PWHO), a provider specializing in Wisconsin in Carlie's condition. After demonstrating no Indiana provider could meet Carlie's needs and with Carlie in a medically fragile state due to her morbid obesity, BBDS agreed to fund Carlie's placement at PWHO (through State Line Item funds). Carlie has lived at PWHO, an employee owned company, since January 2004. It is her home with long time friends, housemates, a boyfriend of 6 years, an amazing staff, and proven program specifically for her condition. Her weight decreased from 219 lbs at the time of placement to a current weight of approximately 122 lbs (4' 6" tall). BBDS has been invited to participate in all case conferences but chose to not participate in any.

On April 24, 2012 I received a call from BBDS informing me Carlie's funding will terminate on August 1, 2012. They also offered a DD waiver slot to transition her to Indiana saying they would continue to pay for Medicaid services. A few days later a letter was sent to Carlie (I had it intercepted by PWHO staff). I received basically the same letter May 10 from Shane Spotts, Director of DRS (attached).

End of State Line Item(SLI) Funding

Initial meetings with BBDS included a statement that the August 1, 2012 date for end of SLI funding is flexible if process is moving. In early July, the FSSA attorney told Carlie's attorney that as long as we are progressing through the process the funding would continue. My case manager informed me on 7/12/12 that funding is ending 7/31/12. Carlie's attorney requested documentation in writing from state's attorney that funding will continue. State's attorney said no; funding ends 8/1/12. Carlie's attorney advised me an injunction can be filed which will most likely extend funding but the process is time consuming and costly (he estimated \$50K). We elected to private pay through provider evaluation process in lieu of an injunction.

BBDS stated the fastest eligibility and Level of Care has been completed is 30 days. Based on a meeting on May 25, 2012 with an Indiana provider suggested by BBDS the quickest a new home for clients with Carlie's condition could be established is 90 days (this is with no road blocks or obstacles). This equates to a timeline of 120 days for a transition without any time included to complete a provider evaluation. This is well beyond the 8/1/12 deadline to terminate funding.

We are progressing through the waiver process as defined by BDDS.

CIH Waiver Process

Legal guardian accepted the waiver slot for Carlie on May 9, 2012. Level of Care and Eligibility evaluations were complete on June 12, 2012 (this driven by BDDS, completed in a timely manner according to BDDS Generalist). Carlie's ALGO Level is 4 and her OBA is set at \$90,322.88. The first call from IPMG was on June 14, 2012. The Individualized Support Team (IST) has finalized the Individualized Support Plan (ISP) and Personal Priorities Document (PCD). A provider questionnaire (Request for Proposal) was sent to four Indiana providers and PWHO on September 6, 2012. The proposals were due September 28, 2012. A summary, by provider, of the response to the Request for Proposal (RFP) is shown below.

Indiana Mentor	Submitted a proposal on 9/27/12
ResCare	No response
QRL	No response
Knox County ARC	No response
PWHO	Submitted a proposal on 9/28/12.
Four Seasons	RFP not sent: The State provided this provider as a provider serving at least one Prader Willi Syndrome individual. However, a RFP was not sent to Four Seasons based on no response to email.

The list above includes all Indiana providers serving an individual with PWS according to the State and Carlie's case manager. The plan is for the IST to evaluate responses from providers, summarize data, and make a recommendation for a provider. The process is proceeding in a timely manner according to the case manager.

Current PWS Consumers on CIH Waiver In Indiana

BDDS has repeatedly stated that Indiana is serving 69-75 PWS consumers. One email from FSSA actually says "Currently, Indiana serves 69 waiver recipients suffering from Prader-Willi Syndrome who are thriving in a community integrated treatment situation". Carlie's attorney has requested a list of Indiana providers serving PWS consumers and I have requested the same list from the case management company. Both said list is not available. The State's attorney provided three provider names; ResCare, KCARC, and The Mentor Network. The case management company provided two; QRL and ResCare. A later e mail from FSSA to Rep Cheatham's office provided one additional provider, Four Seasons. To the best of my knowledge, the total number of PWS consumers from the providers given is 16 (this assumes 3 at ResCare based on information from Carlie's case manager since Res Care will not return phone messages or e mail and one at Four Seasons who also will not return e mail).

I attempted to contact each of the five providers given. Overview of this communication is summarized below.

ResCare: Messages left on 7/12/12, 7/13/12, and 7/16/12. Sent e mail 8/21/12. Sent e mail 9/28/12 to corporate address asking how many PWS individuals being served in Indiana. No response. ResCare did call on 9/18/12 about the RFP. When asked about number of PWS individuals being served in Indiana the answer was "I don't know".

QRL: One PWS consumer. Based on an abbreviated conversation with provider this consumer likely not compatible with Carlie. Currently in placement with one non-PWS consumer. Requested a visit to home of current PWS consumer, told consumer's family pursuing other roommate options. Stated on telephone willing to complete questionnaire but did not responds to RFP.

Knox County ARC (KCARC): One consumer in placement with one non-PWS consumer. Will not allow site visit to home of current PWS consumer. Stated on the telephone willing to complete questionnaire but did not respond to RFP

The Mentor Network: 9 PWS consumers. One 3 person setting, one 4 person setting, two 1 person settings. Would need to start new house. Proposed Bloomington for a location in proposal. Visited Indianapolis house with 4 PWS consumer on 8/8/12. One individual living without housemates in South Bend was moved from PWHO on 7/31/12, reportedly without appropriate transition plan (no legal guardian).

Communication with FSSA

I received an e mail from BDDS on 7/19/12 that all future communication with BDDS be through Scott Newton, the State's attorney. Since then numerous FSSA employees have refused to talk to me.

Specific issues FSSA has mentioned associated with continued placement at PWHO under a DD Waiver are listed below.

1. Budget

FSSA continues to say CIH Waiver is Federal and State money so cost of Carlie's care will be significantly less cost to Indiana than State Line Item funding. While this is true, with the total cost of care at PWHO likely less than an Indiana provider, the State portion of the CIH Waiver money will also be less. Budget was discussed with three of the five providers listed above. Two offered estimated Objective Based allocations (OBA) amounts under the likely scenario to serve Carlie. These amounts ranged from \$103K to \$140K annually. Two PWS individuals are currently living in 1 person settings (with a third individual planning to move in a 1 person setting on October 6, 2012). The cost for residential services in a 1 person setting is between \$20 -\$23/hr for 24/7 support. At \$20/hr this is \$175,200. Add a Behavior Management budget of \$7,862 and a Day Services Budget of \$10,500 and the total is \$193,562. The current total cost of care at PWHO (excepting SSI, which the OBA does also) is approximately \$94K. This means an annual total savings of \$99,562! At a 40/60 split State to Federal, the annual savings for the State of Indiana is

approximately \$40,000. As such, services by PWHO is significantly more cost effective and cost efficient than services for Carlie by an Indiana provider.

2. Waiver Dollars Leaving the State

FSSA says they do not send waiver dollars out of state. Waiver dollars are currently leaving the state for specific services. The waiver approved provider list includes out of state companies. Many approved providers of residential services are multistate companies with corporate offices outside the state of Indiana (i.e. Rescare and The Mentor Network). Carlie's first IPMG case manager had a business address in Louisville, Kentucky.

3. PWHO Not An Approved Provider

At the meeting with BDDS on May 1, 2012 I asked why Carlie cannot stay at PWHO with DD Waiver funding. In an e mail dated May 3, BDDS stated "Indiana does not fund out of state facilities on the DD waiver. Oconomowoc is not an approved provider. They do not provide waiver services in IN". The BDDS State Line Item Manual dated 7/1/12 states "Before implementing a specific service or support, all entities must ... be approved by the DDRS". BDDS Policy #460 1207 006 states "It is the policy of the Bureau of Developmental Disabilities Services (BDDS) to require an individual or entity to secure BDDS approval as a provider, prior to any provision of a BDDS administered service to an individual with intellectual and developmental disabilities". Thus, either PWHO is a BDDS/DDRS approved provider by virtue of following the State Line Item Manual and BDDS Policy 460 1207 006 or BDDS has funded unapproved services for Carlie for more than 6 years. As a matter of note, BDDS has not participated in any case conferences during Carlie's placement at PWHO. BDDS has had virtually no contact with PWHO or Carlie's legal guardians except from a financial perspective.

The parent organization of PWHO, Oconomowoc Residential Programs (ORP), owns and operates a facility in Lafayette, IN. This facility, formerly IDTC, is now TC Harris School. ORP is also in the process of converting the IDTC Indianapolis campus into a facility to serve adults. In 2004, BDDS approved PWHO as a provider (Medicaid Provider # 49-04-55-0882) and payment went directly to PWHO. Subsequently, the State decided to funnel payment through IDTC. At the time of this decision BDDS instructed PWHO that they no longer needed to maintain provider qualification. BDDS continued to pay for services for Carlie at PWHO through IDTC until 8/1/12. Thus, PWHOA has been an approved Indiana Medicaid provider.

4. Policy

Carlie's attorney asked the State's attorney why cannot use waiver dollars to fund PWHO. The State's attorney responded that there is a policy to not use DD waiver dollars for out of state placement. Carlie's attorney asked for a copy of the policy. The policy provided is titled "Waiver Policy Notification Policy Topic Provision of

Medicaid Services Outside the State of Indiana” (attached). First of all this is not a policy, it is a “Policy Notification”. Secondly, the document provided is basically an exceptions list to Title 405 of the Indiana Administrative Code Rule 5 Section 1. An additional exception added could allow residential services at PWHO under specific circumstances.

Not Approved in Waiver Document

In an e mail from the FSSA attorney to Carlie’s attorney dated 7/26/12, FSSA stated “My client is adamant that our waiver document, itself, is not approved to be used in this fashion”. Although FSSA will not specify exactly which “waiver document” it is inferred the document referenced is the Application for a 1915(c) Home and Community Based Services Waiver. No reference to out of state services is found in this document. In fact, under the first section entitled “Purpose of the HCBS Waiver Program” it states, “A state has the latitude to design a waiver program that is cost-effective and employs a variety of service delivery approaches, including participant direction of services”. A waiver amendment was approved and became effective on 9/1/12. This changed DD waiver to Community Integration and Habilitation Waiver (CIH waiver). This amendment states the following as the goals and objectives of the waiver.

“The Community Integration and Habilitation Waiver provides access to meaningful and necessary home and community-based services and supports, seeks to implement services and supports in a manner that respects the participant’s personal beliefs and customs, ensures that services are cost-effective, facilitates the participant’s involvement in the community where he/she lives and works, facilitates the participant’s development of social relationships in his/her home and work communities, and facilitates the participant’s independent living.”

The CIH amendment also states “SERVICE DELIVERY METHODS: Traditional service delivery methods are utilized while incorporating as much flexibility as possible within the delivery of services.”

There is no reference to out of state services.

Summary

The state of Indiana does not, in the legal guardian’s opinion, have services available to meet Carlie’s needs comparable to the current services at PWHO. Only one Indiana provider currently providing services to PWS individual(s) responded to a Request for Proposal to provide services to Carlie. To my knowledge, the only known CIH Waiver residential placements in Indiana for people with PWS are two 1 bed, a 2 bed, and a 4-bed setting operated by The Mentor Network and the non PWS room mate situations described above. While some of these are “working”, starting a new home in a new location, locating compatible housemates, and integrating the necessary services is extremely challenging. The likely scenario is Carlie being placed in a 1 person setting at a cost of approximately \$200,000 per year. This is approximately \$100,000 per year more than current cost at PWHO. Professionals in the field believe transitioning Carlie from her current living arrangements would be traumatic and likely be putting her at risk (letters attached from 2 doctors and the PWSA – USA). It is critical for Carlie’s health and safety to remain at PWHO, her

home. The initial letter terminating State Line Item funding indicates the State will continue to pay for Medicaid funded services. States other than Wisconsin are currently funding clients at PWHO with Medicaid Waiver money. My research of the Waiver Application and amendments, FSSA/DDRS/BDDS policies, manuals, and Indiana Code has not produced, in my mind, any defensible reason to deny Medicaid CIH Waiver placement out of state. As a matter of note, Carlie has continued on Indiana Medicaid for the duration of her placement in Wisconsin.

We strongly feel it is in the best interest of both Carlie Jackson and the State of Indiana, including Indiana taxpayers, to continue her placement at PWHO with funding provided by a Medicaid CIH waiver.

Fred and Jill (Lohrig) Jackson
Parents/Legal Guardians/Advocates
(812)866-8140
(502)609-7955 Mobile
freddeanjackson@gmail.com