

# THE CORE REPORT

Volume 3 Issue 1

March 10, 2004

## **Data Brief: Self-Determination and Consumer Outcomes**

This is the first in a series of data briefs highlighting interesting trends in the Consumer Survey data collected as part of the National Core Indicators ([www.hsri.org/nci](http://www.hsri.org/nci)). These briefs will not represent in-depth analyses (given limited resources) but will showcase provocative and/or unexpected findings. We leave the conclusions regarding what these data suggest for policy-making primarily to the reader in the interest of stimulating discussion.

The first data snapshot explores differences in the outcomes of individuals who are reported as having “individually-negotiated budgets” (and a small subset of those who have “a relationship with a fiscal intermediary”) and those who do not. An initial examination of the NCI Consumer Survey data collected in 2002-2003 (N=8313) suggests that states may use different criteria to define the presence of these elements of self-determination, as evidenced by the high proportion of respondents said to have individually-negotiated budgets (50.7%) and the fact that the proportions varied widely from state to state. To reduce this potential source of error, individuals living in institutional or non-specified residential settings (e.g., specialized DD facility, nursing home) were excluded from the analysis, based on the fairly safe assumption that individuals living in these types of settings do not have the option of individually-negotiated budgets.

Realizing that states may define this term differently and that it certainly isn’t a perfect reflection of self-determination, we also present results for the small subset of people who reportedly use fiscal intermediaries in addition to having individually-negotiated budgets. This subgroup may more accurately represent people exercising self-determination, although the number is very small (N=135) in comparison to the rest of the sample.

Keeping in mind the caveats presented above, the results do reveal significant differences in outcomes between those with and those without individually-negotiated budgets. For some outcomes (most notably the choice and decision-making measures), the differences are even more striking for the subset of people who use fiscal intermediaries. For the purposes of this brief report, we will use the abbreviation “IB” to indicate “individually-negotiated budget” and “FI” for “fiscal intermediary.” Unless otherwise noted, all figures reported here are derived from the NCI Consumer Survey 2002-2003 data collection.

The results presented below are especially timely given the interest nationally in moving systems to more person driven models as well as the interests of CMS in Independence Plus approaches to Home and Community Based Waivers.

## How Many People Have Individually-negotiated Budgets and Fiscal Intermediaries?

After excluding individuals living in institutional settings, the sample was reduced to N=6992. As noted above, the proportions varied widely from state to state and the judgment as to whether or not individuals have IBs or FIs may be somewhat idiosyncratic depending on who is filling out the information. Results for the entire sample show 50.4% with IBs and an additional 1.9% with both IBs and FIs (see Figure 1).

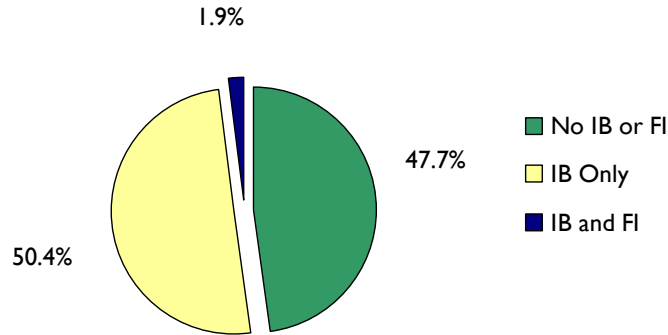


Figure 1. Percent of People in Non-Institutional Settings with Individually-negotiated Budgets and Fiscal Intermediaries

## Where Do People With Individually-negotiated Budgets Live?

For the sample as a whole, the distribution of types of non-institutional residential settings is shown in Figure 2. A little over one third (35%) of individuals in the sample live with a parent or relative, another 30% live in a group home settings, 21% live in independent homes or apartments, and the remaining 14% are split almost evenly between provider-operated apartment programs and foster/host homes.

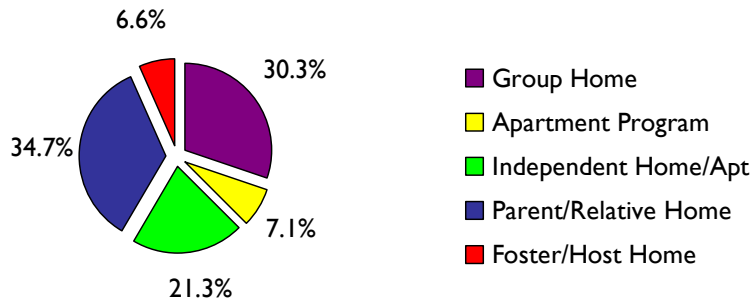


Figure 2. Type of Residence (Non-Institutional) of People in NCI Sample

Figure 3 takes each type of residential setting and shows the distribution of people in that setting who report having IBs and FIs. These results suggest that in the NCI sample, people with IBs are more likely to live in independent homes, apartments, and group homes than individuals who do not have IBs. Those without IBs are more likely to live with their families or in foster/host homes.

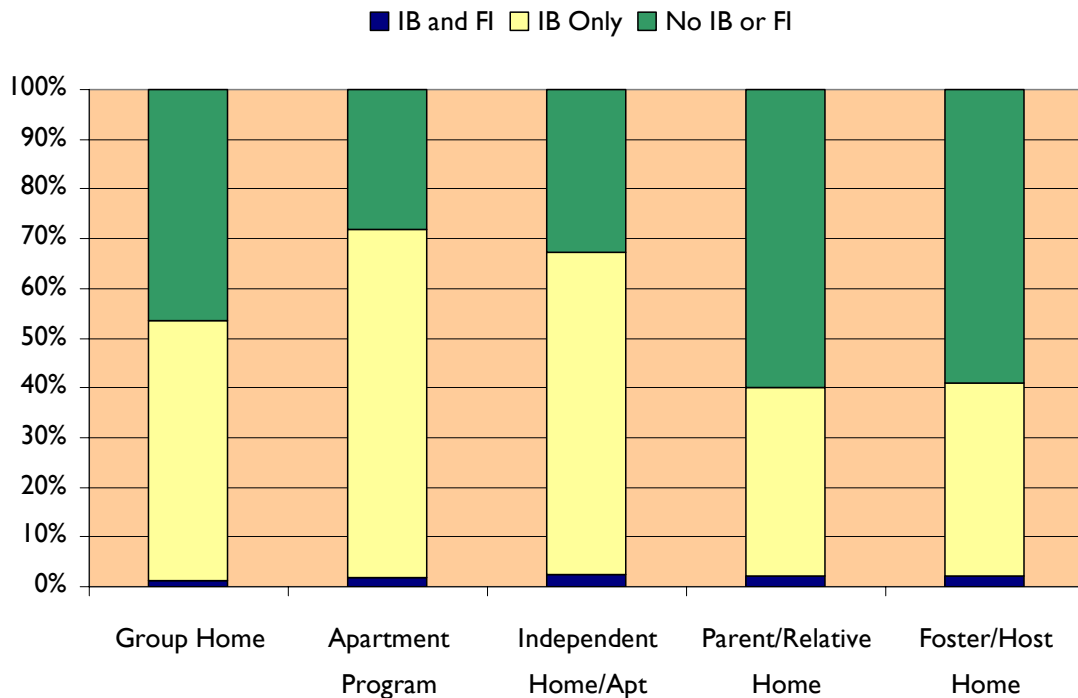


Figure 3. Distribution of People with Individually-negotiated Budgets and Fiscal Intermediaries, by Type of Residence

### **Do People with Individually-negotiated Budgets and Fiscal Intermediaries Have More Control Over Their Lives?**

For each choice item, there are three possible response options, generally worded as follows: 0=someone else made the choice, 1=the person had some input, 2=the person made the choice. Interviewers are instructed to code “2” only if they are convinced that the person truly made a choice. It is important to note that for the purposes of this analysis, we only report the percentage of people who scored a “2” response, whereas in the general NCI summary reports we combine the “1” and “2” codes and report the percentage who either made their own decision or had some input. Using the higher standard was deemed more appropriate for the purpose of this analysis and in fact produced much more discriminating results than the combined method.

As noted in Figure 4, individuals with IBs and FIs were much more likely to exercise control in all areas of their lives. Although the subgroup of people using FIs is much smaller than the other two groups, the findings suggest that the more strictly defined self-determination model is associated with higher levels of choice and control. With the exception of choosing support staff at work, all choice items revealed statistically significant differences between the three groups at the  $p < .01$  level.

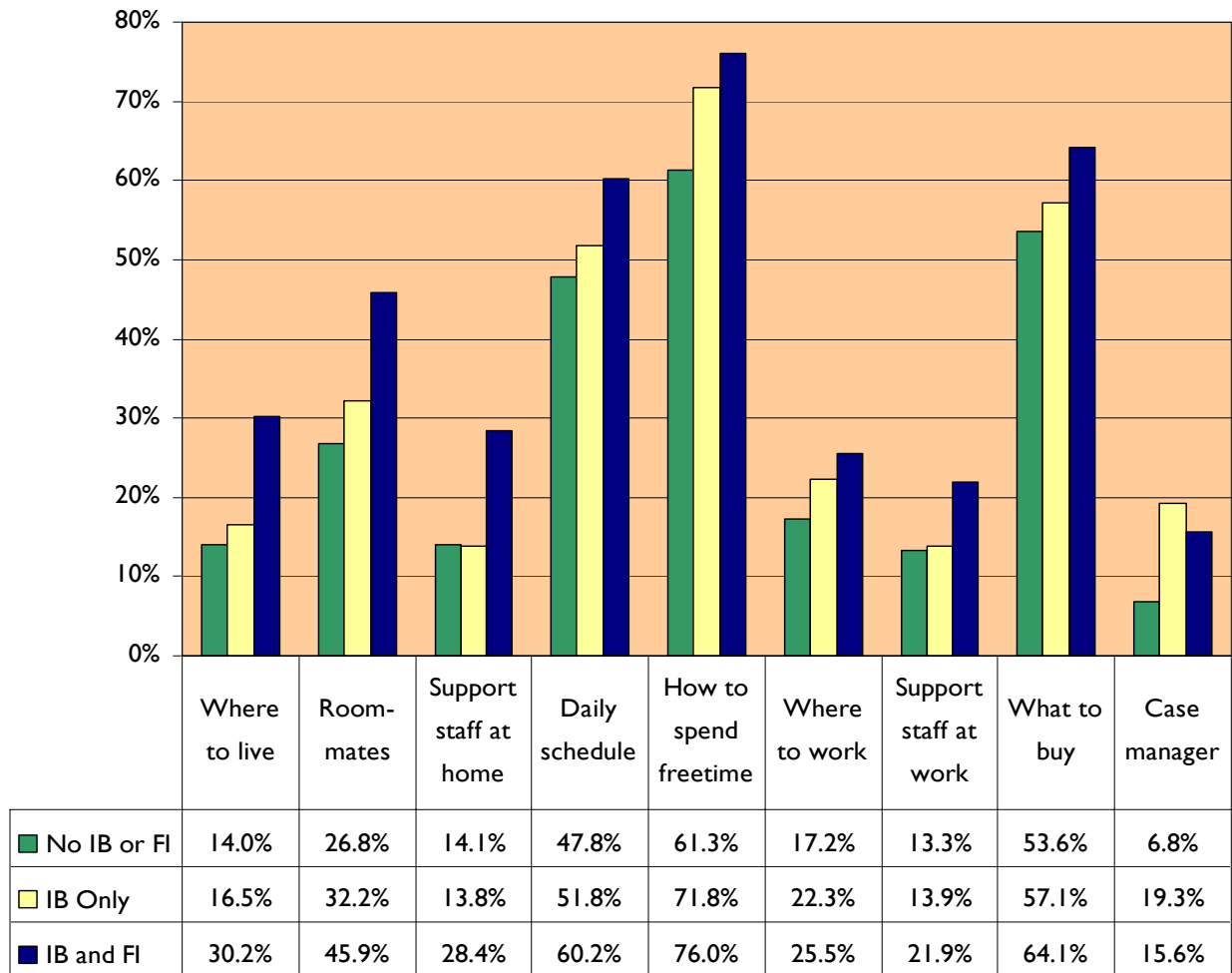


Figure 4. Choice and Decision-making Outcomes for People With and Without Individually-negotiated Budgets and Fiscal Intermediaries

## To What Extent Are Individuals with Individually-negotiated Budgets and Fiscal Intermediaries Included in Their Communities?

On most items related to community inclusion, analyses tend to show little differentiation. This result is partly due to the fact that most people across the board have very high rates of participation in community activities (e.g., shopping, going on errands, eating out), and the small variations are quite difficult to analyze statistically. However, there were a few items that revealed some differentiation: participating in integrated sports/exercise, going to clubs or community meetings, and attending self-advocacy activities (see Figure 5). The results for these three items were statistically significant at the  $p < .05$  level.

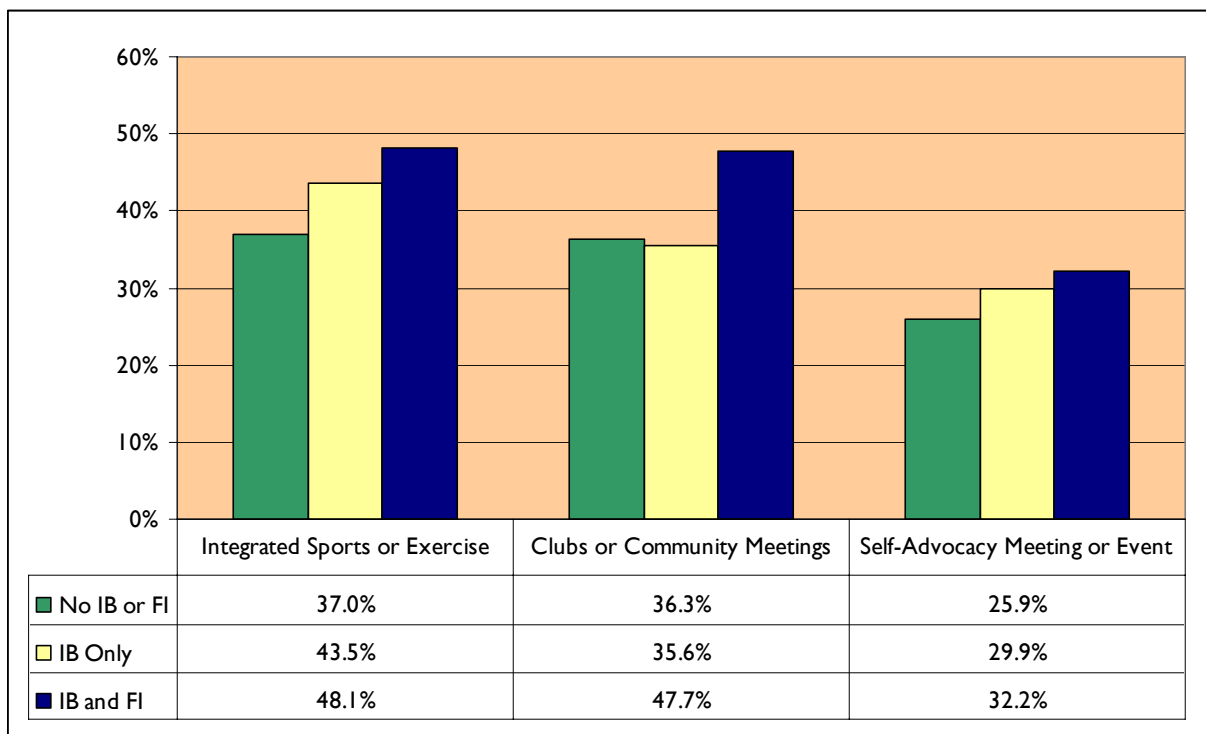


Figure 5. Selected Community Inclusion Outcomes for People With and Without Individually-negotiated Budgets and Fiscal Intermediaries

## What is the Relationship of People with Individually-negotiated Budgets to Their Case Managers?

Finally, we take a look at differences between people with and without individually-negotiated budgets with respect to their relationships to their case managers. People with IBs are more likely to report knowing their case managers. Likewise, a higher percentage of people with IBs report that their case managers get what they need and ask them what is important. These differences were all found to be significant at the  $p < .001$  level. This finding may be a reflection of the more person-focused planning approach used in supporting people with individually-negotiated budgets.

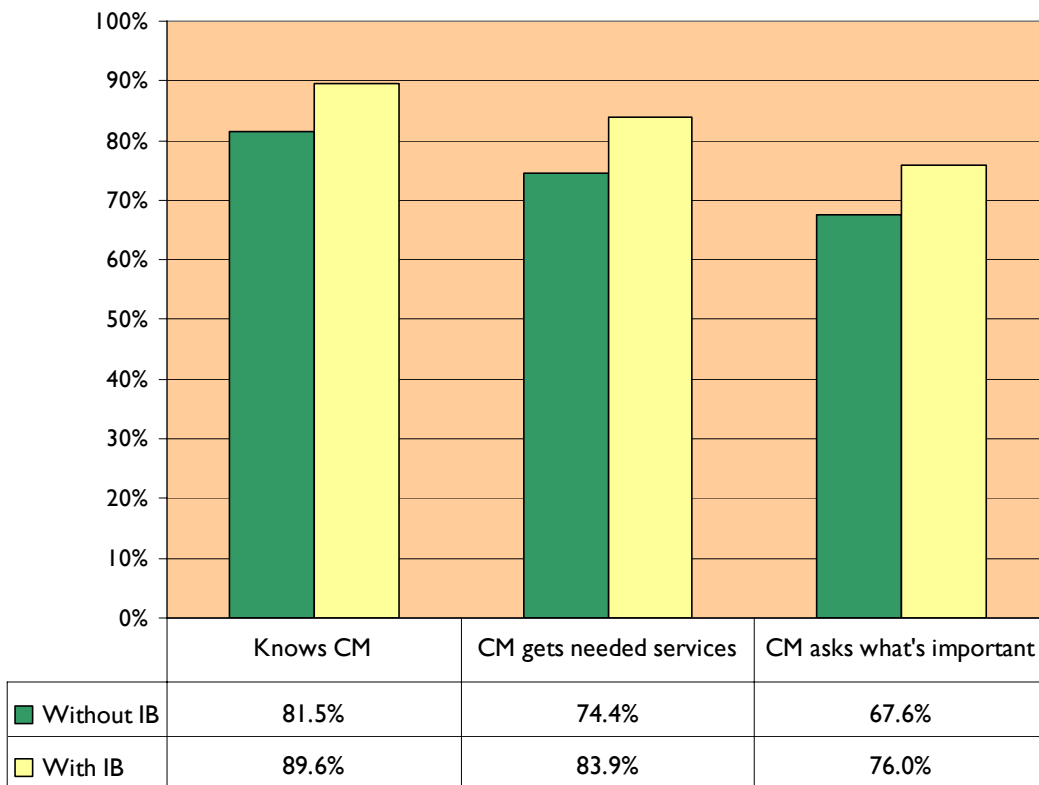


Figure 6. Case Management Outcomes for People with and Without Individually-negotiated Budgets (Includes People with Both IB and FI)

## Summary

As noted in the introduction, this highlight of selected findings is meant to be suggestive rather than definitive. The results presented here certainly do suggest (albeit with some caution regarding variation in data collection) that the “individually-negotiated budget” variable, and perhaps the “fiscal intermediary” variable to a greater extent, may be associated with higher outcomes in terms of people having greater control over their environments, making more choices, living somewhat more independently and having improved relationships with their case managers.

## In the Next Issue

The next Data Brief in this series will examine Consumer Outcomes by Type of Residence.

For more information visit the NCI website at [www.hsri.org/nci](http://www.hsri.org/nci) or contact:

Valerie Bradley or Sarah Taub  
Human Services Research Institute  
2336 Massachusetts Avenue  
Cambridge, MA 02140  
(617) 876-0426

