Use of Flexible Funds for Respite Services in a Managed Care Wraparound program

Jennifer Taub Ph.D., UMass Medical School Joseph O'Garr, B.S., UMass Medical School Jack Simons, Ph.D., Coordinated Family Focused Care, Lawrence, MA Kim Smith, M.A. UMass Medical School

Presented as part of the symposium: Financing Issues in Systems of Care for Children's Mental Health At the18th Annual Research Conference: A System of Care: Expanding the Research Base March 6-9, 2005



University of South Florida, Tampa, FL

Please direct any inquiries to the first author: jennifer.taub@umassmed.edu
Center for Mental Health Services Research
University of Massachusetts Medical School
305 Bellmont St., Room 96-29
Worcester, MA 01604



Coordinated Family-Focused Care

Research Questions

There are many unanswered questions about the use of flexible funds to support community based services for children with serious emotional disturbance (SED).

This presentation focuses on the use of flexible funds to support respite services for this population.

Study Questions:

- What types of respite programs are accessed with flexible funds (in-home vs. out of home)?
- What are the costs associated with these services on the program and individual client levels?
- 3. What is the relationship between child functioning and use of respite services?
- 4. What is the relationship between child factors and use of respite services?

Respite Care - Some background

- The majority of research focuses on the developmentally disabled population and the effect of respite on caregiver stress.
- Respite care has been defined as "temporary care given to a disabled individual for the purpose of providing an interval of relief to the individual's primary caregiver(s)." (Cohen, 1982, p.8)
- Respite can occur as
 - □ Crisis vs. planned
 - □ In-home vs. out-of-home or overnight

Respite and Developmental Disabilities

- In general, families prefer in-home respite care (Cohen, 1982; Boothroyd, 1998)
- Some new data shows parents prefer out-of-home respite and demonstrates a discrepancy between family and caseworker preferences (MacDonald & Callery, 2004)
- Evidence suggests there are no significant demographic differences between groups of respite users and nonusers (Wherry et al, 1995)
- In-home and out-of-home respite is effective in reducing caregiver stress in families of children with developmental disabilities (Rimmerman, 1989; Mullins et al, 2002; Chan and Sigafoos, 2001)

Respite and Serious Emotional Disturbance

- Respite care is described as an important social service often needed by families of children with SED (Stroul & Friedman,1986).
- Case-workers of children with SED estimate that approximately 7% of families in their caseloads require respite care services (Trupin, 1991).
- Children of parents who utilized respite care tend to be younger and have a higher number of functional impairments (Boothroyd et al, 1998).
- Respite care users reported less availability of social supports and more difficulty managing their child's behavior (Boothroyd et al, 1998).
- In a wait-list controlled longitudinal study involving both in-home and out-of-home respite, respite care resulted in:
 - reduction of caregiver personal strain
- fewer incidents of out-of-home placement
- dose effect with increased use resulting in reduced out-of-home placement and increased family optimism (Bruns & Burchard, 2000)

Flexible Funds: What we know

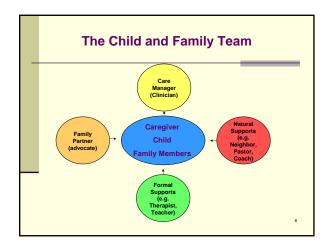
- One published study has described the use of flexible funding dollars in providing supports for children with SED. These dollars are used for services such as respite care as part of a wraparound service program (Dollard et al, 1994)
- Only one other study has looked at child factors and flexible funds spending. It demonstrated that:
 - □ Higher CAFAS scores predict higher Medicaid reimbursements
 - The only factor predictive of case management hours and flexible fund spending was a previous history of psychiatric hospitalization (Jenson et al, 2002)

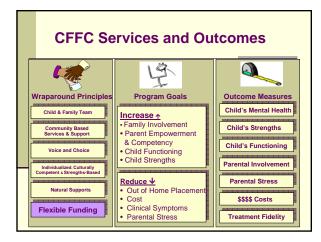
Coordinated Family Focused Care (CFFC)

What is CFFC? It's a five site wraparound services program for children with Severe Emotional Disturbance (SED) at risk for out-of-home placement in Massachusetts

How are children eligible for CFFC?

- Ages 3-18
- Reside in one of the 5 cities where it is offered
- Child and Adolescent Functional Assessment Score of 100 or greater
- Presence of Severe Emotional Disturbance (SED)
- Caregiver willing to participate in team process
- Child and family have tried other, less intensive, services





Flexible Funding in CFFC

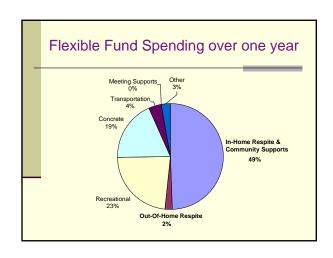
- The CFFC case rate is \$62.22/child per day (based on a 365 day year); \$1892 per child per month.
- Programs are expected to use approximately 20% of the case rate for services that are deemed necessary by the team and cannot be paid through other funding mechanisms.
- These "Flexible Funds" can be used to support client-level services and supports (e.g. summer camp) as well as program-level services and supports (e.g. dinners for weekly "Family Nights" for all families in the program).
- Programs may distribute funds across caseload as determined by clinical needs. They do not need to spend a set amount on each child, but the CFFC provider must guarantee that there are adequate funds to meet the needs of every child in the program.
- These "Flexible Funds" are subdivided into seven categories.

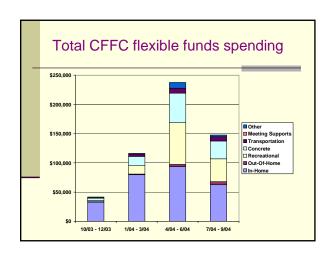
Flexible Funding Categories in CFFC

- <u>Recreational</u>: Recreational activities, after school and summer programs. Activities that enhance social skills and peer interactions. This also includes activities that strengthen famlly interactions.
- Concrete supports: Purchases that support the family's ability to provided food, shelter, utilities, and related essentials that address short-term emergency needs.
- In-home and community supports: Includes any 1:1, specialing or sitter services in the child's home or a community setting
- Out of home respite/placement: Respite, either crisis or planned, that occurs out of the home in a foster home, group home, or residential program, which is not otherwise paid for by insurance.
- Non-Medically-Necessary Transportation: Taxi vouchers, gas cards or other arrangements to assist with transportation to school meetings, care plan meetings or program activities.
- Meeting attendance: Supports attendance by payment to formal and informal supports who would not otherwise be compensated to attend care planning Team meetings or Local Committee meetings.
- Other: Any other service or purchase for a specific child and their family, or for the CFFC program in general. Examples include food, gifts, transportation not covered by above category.

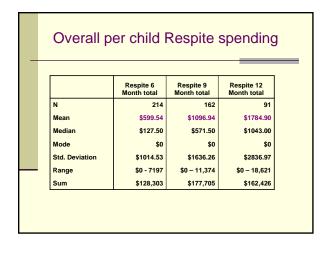
What types of respite programs are accessed with flexible funds (in-home vs. out of home)?

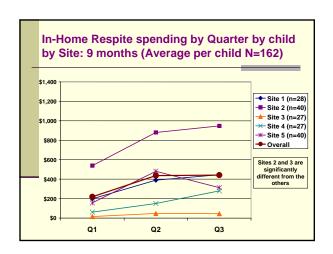
- Respite care used in each community reflect the available services and supports in that community
- Services change and develop over time as relationships are developed with community providers, and as community resources are accessed and developed
- A variety of programs and services are utilized
 - $\hfill \square$ In-home respite: Specialized babysitting, mentoring
 - Out-of-home respite: Planned stays at crisis units, other established community programs; respite foster care for short term planned stays
- Programs face challenges in helping families access respite resources

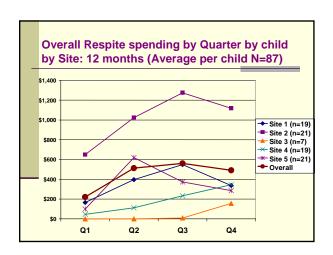


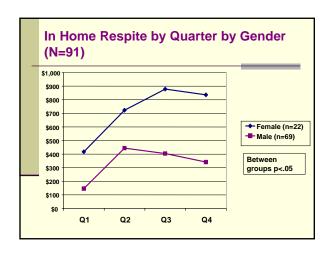


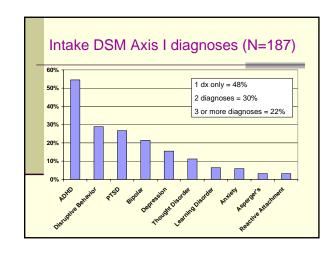
Percent of Children Utilizing Respite After 3 months in the program, 37% of children had received some form of respite By 6 months, 60% had received respite By 9 months, 70% had received respite By 12 months, 78% had received respite

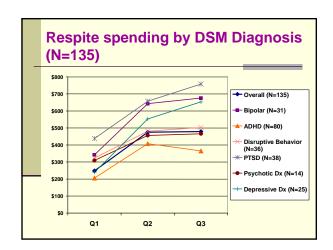


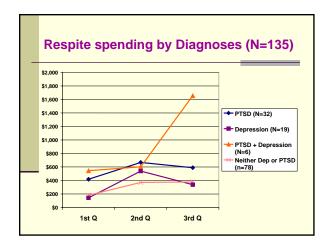












Child Functional Impairment: Child and Adolescent Functional Assessment (CAFAS)

Hodges, K. (2003)

The CAFAS is a clinician rated assessment of impairment in youth with emotional, behavioral, or substance abuse problems. It has 8 subscales which are each rated to assess the level of impairment in each individual area. Each scale is rated No impairment, Mild, Moderate, or Severe. Total CAFAS Scores can range from 0 - 240. The subscales are:

- 1.School/Work Performance: assesses ability to function in a group
- 2.Home Role Performance: assesses youth's ability to follow reasonable rules and perform age appropriate tasks
- 3.Community Role Performance: assesses the respect for the rights of others and their property and conformity to laws
- 4.Behavior Toward Others: assesses youth's daily behavior toward others 5.Self Harmful Behavior: assesses the extent to which the youth can cope without resorting to self harmful behavior
- 6.Moods/Emotions: assesses the youth's control over his or her emotions
- 7.Substance Use: Youth's substance use and the extent to which it is maladaptive or disruptive to normal functioning
- 8. Thinking: assesses the youth's ability to use rational though processes

Child's Mental Health Status: Youth Outcome Questionnaire (YOQ)

Burlingame, G. M., Wells, M.G. & Lambert, M. J. (1996)

- A Standardized, reliable and valid parent-completed symptom checklist. Contains 64 items completed on a 1-5 Likert scale (Never to Frequently) over previous 7 days. Contains 6 subscales:
- Intrapersonal Distress (ID): Anxiety, depression, fearfulness, hopelessness and self-harm.
- 3. Interpersonal Relations (IR): Communication and interaction with friends, cooperativeness, aggressiveness, arguing, and
- Social Problems (SP): Delinquent or aggressive behaviors; includes substance abuse.
- 5. Behavioral Dysfunction (BD): Organization, concentration, hyperactivity, impulsivity.
- Critical Items (CI): Describes features of children and adolescents often found in inpatient services where short-term stabilization is the primary change sought. Includes paranoid ideation, obsessive-compulsive behaviors, hallucinations, delusions, suicidal feelings, mania, and eating disorder issues.

Correlations between Respite \$ and child

-									_
			Respite	Respite	Respite	Respite	Total \$	Total \$	Total \$
			\$ Q1	\$ Q2	\$ Q3	\$ Q4	Respite	Respite	Respite
							6	9	12
							months	months	months
	Somatic Score	Pearson Correlation	.203(**)	.243(**)	.196(*)	.362(**)	.261(**)	.254(**)	.425(**)
	(YOQ)	Sig. (2-tailed)	0.002	0.001	0.016	0.001	0	0.002	0
		N	237	195	151	82	195	151	82
	PTSD (DSM DX)	Pearson Correlation	.180(*)	0.15	.224(**)	.359(**)	.189(*)	.236(**)	.386(**)
	(Bolli Bit)	Sig. (2-tailed)	0.015	0.058	0.009	0.001	0.016	0.006	0
		N	180	161	135	86	161	135	86
	CAFAS Self harm	Pearson Correlation	0.113	0.081	.185(*)	0.162	0.125	.156(*)	0.202
		Sig. (2-tailed)	0.066	0.241	0.018	0.124	0.069	0.047	0.055
		N	265	212	162	91	212	162	91

Predictors of Respite Spending

	Months in the Program	N	R	R Square	Adjusted R Square	Std. Error of the Estimate	F	Predictors in the Model	\$
ĺ	6	125	.330	.109	.094	1119.158	7.512**	Somatic YOQ	\$58
l								PTSD	\$481
I	9	110	.421	.177	.154	1689.148	7.692***	Somatic YOQ	\$77
ı								PTSD	\$994
								CAFAS Self Harm	\$330
ĺ	12	67	.604	.365	.336	2583.735	12.276***	Somatic YOQ	\$199
ı								PTSD	\$2443
								CAFAS Self Harm	\$597

^{***} Significant at the .0001 level ** Significant at the .001 level

Summary of findings

- In-home respite is the largest category of flex fund spending, accounting for about half of all flex dollars spent in the program. Most children (over 60%) receive this service at some point during their enrollment.
- Out-of-home is not a highly utilized service paid from flexible funding. Less than 10% of enrolled children ever receive this service.
- We have discovered several predictors of utilization of respite services in our wraparound program:
 - □ A DSM diagnosis of PTSD
 - ☐ Higher level of Somatic complaints (Intake YOQ) and
 - □ CAFAS Self Harm subscale (Intake) are all predictive of respite spending.

Summary of findings

- There is a difference in respite spending on girls vs. boys (more is spent on girls) over a 12 month period (this difference is not significant at 6 or 9 months). This is not accounted for by the factors listed above.
- Although children with co-morbidity have higher overall respite costs, this factor in and of itself is not a statistically significant predictor of respite costs.
- Data also revealed some trends to watch:
 - □ Lower respite costs for children with ADHD
 - □ Much higher respite costs for children who are comorbid with Depression + PTSD

References

Boothroyd, R. A., et al. (1998). Understanding respite care use by families of children receiving short-term, inhonic psychiatric services. Journal of Child and Family Studies, 7(3), 353-376.

Bufferen receiving short-term, inhonic psychiatric services. Social Policy, Research, and Practice, 3(1), 39-61. Buffingame, G., Wells, M. G., & Lambert, M.G. (1998) American Professional Credentialing Services. Chan, J.B., & Sigaloos, J. (2001). Does respite care reduce parental stress in families with developmentally disabled children. Child & 700th Care Forum, 39(5), 252-263.

Chen, S. (1982). Supporting Families Through Respite Caire. Relabilisations Literature, 43(1-2), 7-11.

Functional Assessment Science in a sample of youths with serious emotional disturbance served by Center for Mental Health Services-Unded demonstrations. The Journal of Behavioral Health Services & Research, 1997.

Bernor, C. E. et al. (2002) Practication resource utilization by children with serious emotional disturbance and their miles. Journal of Child and Family Studies, 11(3), 361-371.

Macdonald, H. & Calleyy, P. Different meanings of respite a study of parents, nurses and social workers caring for children with Complex needs. Child. Cair. Health & Development. 30(3), 278-288.

Miller A. (1988) Provision of respite care for children with developmental disabilities. A longitudinal study. Ordifers in Services. Social Policy, Research, and Practice, 5(2), 123-138.

5(2), 123-188.
Rimmerman A, (1989). Provision of respite care for children with developmental disabilities: Changes in maternal coping and stress over time. Mental Retardation, 27(2), 96-103.
Stroug B, A F eridman, R M, (1986). A system of care for children and you with severe emotional disturbances. (Revised edition). Washington, D.C. Georgetown University Child Development Center, CASSP Technical Assistance Center.

Assistance Center. Trupin, E. W., Fortyn-Stephens, A., and Low, B.P. (1991). Service needs of severely disturbed children. American Journal of Public Health, 81, 975-980. American Journal of Public Health, 81, 975-980. American Journal of Public Health, 81, 975-980. Wherey, J.N., Shema, S.J., Baltz, T., & Kelleher, K. (1995). Factors associated with respite care use by familles with a child with disabilities. Journal of Child and Family Studies, 4(4), 419-428.