

Community Council
2008-09 Study Committee
Meeting Summary
January 27, 2009

Present: Alice Bagley, Jean Ann Mitchell, William Sanderson, Karen Wolf, Peggy Sanderson, Donald Priest, Niki Flemmer, Samantha Bowen, Kate Bobrow-Strain, Brian Gabbard, Melinda Brennan, Karen Kirkwood, Tim Meliah, Corey Muse, Eloise Phillips, Carlotta Richardson, Punkey Adams, C. Godard-Gross, Carmen Bernal, Paula Nichols, Kevin Scribner, Roger Lizut, Teri Barila, Joe Huether, Terry Heisey, Harvey Crowder, Becky Hermsen, Dorothy Knudson, Connie Taylor-Randall, Nancy Carter, Mira Gobel, Lucy Gregoire, Matt Eppelsheimer, Chris Howard, Roger Bairstow, Julie Reese.

Chairman Roger Bairstow opened the session with a note that two summaries were distributed today for the group to read. The one labeled “January 6” should be changed to January 20 (Community Support—Coleman/Kirby). The other is January 13 and Bunny Baker’s name should be corrected on page 3. A review of the group process check prompted Roger to remind the group that in the past summaries have been delayed for distribution while awaiting presenters’ responses. Since we are nearing the findings sessions, each meeting’s summary will be provided at the following session whether or not the presenter has responded.

The group adopted the January 6 summary (Parenting—Pankl) distributed last week.

The topic for the evening is *Parents’ Perspectives* and guest speakers Tammy Patrick and Paul Apositilidis shared their experiences in accessing services for their children.

Paul Apostilidis

Paul’s opening remark was that Walla Walla has tremendous educators, serious gaps in child psychiatry and no summer programs for children with mental health issues.

Paul and his wife have two children, Anna, 11½, and Nicco, 8. Nicco was adopted when he was just days old. He has experienced a variety of mental health problems his whole life. Nicco didn’t sleep through the night until he was three. He hit children and adults to get attention.

He started at the Walla Walla Community College cooperative preschool when he was 3½. The educators there were very positive and the parents in the cooperative work together and are very supportive.

Entering kindergarten at Green Park, Nicco was put on a behavior plan. He was diagnosed with Opposition Defiant Disorder (ODD). He met with a psychologist from Pasco three times weekly. He was treated with a “chart and sticker” regime—good consequences come of good behavior and bad consequences come of bad behavior. The parents, teachers, psychology staff, and Mike Lambert invested lots of time in Nicco (meeting, consultations, “team” approach with non-school providers, etc.) and worked on his social skills training. He stopped being aggressive until the end of first grade.

Summers are difficult times for children with mental health issues, especially for those whose parents work full time. There is a deficit in summer programs for kids who “can’t make it” at a Campfire or YMCA program. Nicco has tried different camp programs; it never works. There is also a need for daycare for working parents.

Much of the time he does fine, but “when he crosses the line, he *really* crosses the line.” His behavior is unpredictable. He knows that what he does is not right, but cannot help himself. After an episode he feels very bad about himself. His parents can see the onset of an episode when he is humming, going about an activity very purposefully, and seems very calm.

At the start of second grade, his aggression toward adults had escalated. When he was disciplined, he ran away from the school grounds and was consequently suspended. Because he had a long record of intervention, his parents' request for Nicco's placement in the multi-age program at Prospect Point was approved. Prospect Point has small classes and adults in the classroom in addition to the teacher (estimated 1 adult to 2 students). There is an intense focus on behavior and expectations are apparent and because of the adult-student ratio, they are enforced. Staff works closely with the students with the intention that the student can return to his regular classroom. If this setting doesn't work, another option may be entering Pendleton Academies as a day student.

Nicco's parents consulted Dr. Varnell at the County Health Department. No further diagnosis was made. The Apostilidises read about the Western Pennsylvania Child Bipolar program at the University of Pittsburg and took Nicco for a full-day evaluation. The resultant diagnoses were ADHD and emergent bipolar disorder, which they were told should be treated as if it were full-fledged. Paul said clinic employees told him that a report, written by Heather Strader at Green Park, was far and away the best report they've ever received.

Paul noted that after the diagnosis, they came home to find a psychologist. There isn't one in Walla Walla. They went to the Tri-Cities—they're not taking new patients. The Children's Hospital in Seattle told them it would be unethical to treat someone on the "other side of the state". So there is no one available to them. When something isn't working with the medication they have no one to call; often not even the prescribing doctor at the University of Pittsburg. Paul expressed the need for Walla Walla to have one or more child psychiatrists who keep up with the most current mental health research.

Dr. Henderson at the Walla Walla Clinic works with the family, but is very open with them that she has to educate herself to do so because she isn't trained in psychiatry. She has been advocating for them with a Seattle doctor, but it is a lengthy, if successful, process to be added to his caseload. They have heard that Wenatchee and the Tri-Cities hold teleconferences for parents, medical professionals with Children's Hospital staff, but he needs to learn if that is a possibility for their family. He said he had also been told about something called PAL, but doesn't know that is.

They have been working with a psychologist at Sumac Street, accessing parent training, play therapy, and sessions with child and parents together. They also have invested in counseling for Nicco's sister.

Treating mental health issues is very expensive. Nicco is covered by private insurance that pays at 50% of the cost and only for a set number of visits. Each year they use the entire year's coverage by March 14, and must then pay out of pocket for services, about \$500/month.

There are few child psychiatrists in big cities, but there is a real scarcity in every rural community in the country, according to Paul's research.

Tammy Patrick

Tammy is a single mother who lives in Milton-Freewater with four children. Her second son, Eric, has a variety of mental health issues. He is now 17. Eric was placed on an Individual Education Plan (IEP) for speech and language when he was two years old.

In the second grade he was diagnosed with ADHD and Cornelia de Lange Syndrome (manifests variously as mental retardation (IQ less than 85), missing body parts, characteristic body features, etc.) Eric has a mild case; his IQ is 86. He also suffers Depression and Opposition Defiant Disorder (ODD).

Eric has a severe processing problem. He must be repeatedly shown how to do even routine tasks, such as brush his teeth. Through the grade school, his teachers were very good about working with him. In addition to addressing his speech and language needs to satisfy his IEP, they worked with him on processing skills. When he transitioned to junior high school, he met the requirements for speech

and language, so his IEP was dropped. Tammy fought to keep the IEP in place because he needed help with other things. She asked the school to check his IQ (they didn't).

Referred by her primary care doctor, she took him to a Lifeways (Umatilla County's contracted health provider) psychiatrist in Pendleton where he was diagnosed with Depression. He takes medication. She has used all of her vacation to take Eric to Pendleton for treatment. He also meets weekly in Milton-Freewater with a Lifeways counselor, who "just listens" to him. She feels he needs more in-depth help.

Because the school refused to continue an IEP, the psychiatrist classified Eric as a "504" patient (the school is required to provide services) and required the schools to provide an advocate. Eric attends the alternative school now (Pleasant View). The alternative school is the only school that has been interested in what he does outside the classroom. There are no after school or summer programs for any child in Milton-Freewater, much less for those with special needs.

Tammy has tried on her own to access services (e.g. respite care, extra tutoring) through Social Security, but was denied. She will reapply. The only help she received with this process was that, upon denial, Eric's counselor told her she had prepared the listing of issues incorrectly.

Tammy and Eric have both participated in counseling, but no one has suggested that her other children participate. They have learned to live with the situation, but she would like to see them have some counseling. She feels her oldest son would not participate, because he feels Eric is "just making it up".

Twice Eric has been suicidal. Breaking up with his girlfriend led to the most recent incident, and Tammy is worried that unless he finds a way to cope with life issues, he'll succeed. She is not always able to see when his depression deepens. With his suicide attempts he was brought to a Walla Walla hospital. The crisis team came in, but because it was the weekend, they were not able to transfer him to Oregon. The first time he was given a choice of a diversion bed in the psychiatric ward or in foster care. He chose foster care and ran away the next day. Because of that, if he is hospitalized again, he will be placed in the psychiatric ward.

Eric is insured by the State of Oregon and Tammy knows that he will be covered until he is 19.

Both noted that structure support groups would be helpful in sharing/learning about resources, but there are none either in Walla Walla or Milton-Freewater. Listening to the each other's presentation, they garnered new information. Tammy learned that there is counseling for ODD. Neither parent realized that there is respite care, and neither has anyone with whom they are comfortable leaving their sons.

Neither parent knows what to expect for their child's future. Tammy sees her son continuing to live with her and hopes that he will live to a "ripe old age", procure and maintain a job. Because Paul's son is so young, he is hopeful they will find successful medication to enable a productive life.

Definitions given during the presentation:

Psychologist—can't prescribe medication; offers parenting techniques; interprets symptoms; emotion management.

Psychiatrist—medical doctor who can prescribe/manage medications

IEP—Individual Education Plan, federally funded

504 (federal disabilities act)—federal designation without federal funding. School is required, at its own expense, to provide the resources.

Findings

1. There is great need for child psychiatrist(s) in the area, both Walla Walla and Milton-Freewater.
2. There is need for respite care, advocacy, centralized coaching, parent support groups, and summer and after school care options.
3. Starting in middle school in the Milton-Freewater School District, it is difficult to access individual education attention for a child.
4. The support from Walla Walla schools is good, a team approach.
5. There are no psychiatric beds in Walla Walla.
6. Insurance coverage is limited for mental health.
7. The cost to cover mental health treatment out-of-pocket is exorbitant. (For Apostiliidis, \$500/mo.)
8. Dealing with mental health issues is very frustrating for families and causes them much stress.
9. The alternative education program in Milton-Freewater is good.
10. Paul Apostilidis has experienced good coordination between schools and outside services.
11. The transition between elementary and middle schools is difficult in Milton-Freewater.
12. Both parents have difficulty envisioning the future for themselves, the student and their families.
13. There is a definite link between mental illness and behavior problems and the ability to progress in school and succeed in a social context.
14. Behavior programs can only be effective if medication is stabilized. Behavior is only part of dealing with a child with mental health needs.
15. These parents were not aware of all programs and services available to them.

Questions

1. To what age does Lifeways coverage last?
2. Are there in-patient psychiatric beds in Pendleton or is that facility closing?
3. Why is there an increase in bi-polar diagnoses among children?
4. When diagnosed, why were Eric's ADD and ODD not added to his IEP?