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ABSTRACT
        During a 1-year period, a study investigated the
contributions made by 3 literacy-based supports (support circles, cognitive
compensatory tools, and cognitive enhancement tools) to the lives of 5 young
adults, aged 16-34, with FAS/FAE (Fetal Alcohol Syndrome/Fetal Alcohol
Effects). Four of the five subjects had IQs (intelligence quotients) above 70
(thus not qualifying for government help), but had major difficulties living
without support. Formal literacy-based support circles were created for three
of the subjects, and informal circles already existed for the other two. The
goals of these circles were to help the individuals cope with transitions
that youth with disabilities face (employment, living arrangements,
transportation, financial independence, making friends, sexuality,
self-esteem, and having fun). The circles were most successful with the
oldest subject, who understood her problems and welcomed help, while the
technique was least successful with one subject who wanted nothing to do with
it. These three literacy-based cognitive compensatory tools were designed to
help the subjects organize their lives: a weekly magnetic calendar, cleaning
support tools, and a student tracker system. In addition, two cognitive
enhancement tools, Directions Personal Planning Tool and chatrooms, were
used. The study found that although the circles and the tools used were
effective, one of the major difficulties was maintaining the commitment of
the circle members, who found it physically and emotionally draining. (Five
case studies and 54 references are included.) (KC)

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Literacy-Based Supports for Young Adults with FAS/FAE

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ABSTRACT

Over a one-year period, this study investigated the contributions made by three literacy-based supports (support circles, cognitive compensatory tools, and cognitive enhancement tools) to the lives of five young adults with FAS/FAE, ranging in age from 16 to 34 years. Each of these support systems was designed to help the young adults cope with daily living challenges such as everyday memory failure, disorganization, and social isolation. Based on the observation that many individuals with FAS/FAE who live satisfying, productive lives do so because they have tightly knit, devoted support groups (generally parents and siblings), the study set out to explore the role that literacy-based supports might play in these individuals' lives.

Five subjects and their families were recruited for the study and, at the onset, each subject was assessed using both the Vineland and the SIB-R scales. Four of the five subjects had reported IQs above 70, which placed them above the level which entitled them to assistance from social service agencies, but the Vineland and SIB-R results both suggested that each subject would have major difficulties living without support. Subsequent work with the subjects using the literacy-based supports bore this out.

Formal literacy-based support circles were created for three of the subjects, and informal circles already existed for the other two. The goals of these support circles were to help the individuals cope with the seven most common transitions that youth with disabilities face according to Wehman (1996): employment, living arrangements, getting around the community, financial independence, making friends, sexuality and self-esteem, and having fun. Five case studies in the report document the accomplishments of the support circles and suggest ways of making the circles more effective. The most successful circle was created for the 34-year-old who was well-aware of her problems and welcomed the help that her group provided. On the other hand, one of the subjects felt that a support circle would only highlight her disability and wanted nothing to do with it, despite her parents' urgings. One of the major difficulties with all but one of the circles was maintaining the commitment of the circle members: the experience was both physically and emotionally draining, and all but close family members found it difficult to sustain their participation.

Three literacy-based cognitive compensatory tools were designed to help the subjects organize their lives: the weekly magnetic calendar, cleaning support tools, and the student tracker system. These tools showed a good deal of promise because they presented a sequence of activities which the FAS/FAE subjects could follow seriatim. However, as the case studies of the individuals show, these are works in progress rather than finished products and as such require frequent adjustment and adaptation.

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During the course of the study, two additional supports were used, the Directions Personal Planning Tool and chatrooms. The Directions program provides a structure that can be used by the focal group to enable subjects to make life plans. Subjects begin by describing their present needs and strengths and, thereafter, projecting future dreams and goals that they would like to pursue. This technique helps overcome the limitations of deficit-thinking and provides the group the opportunity to bring hope and fun into each circle meeting. While unregulated chatrooms can pose serious risks for those individuals with FAS/FAE who have poor judgment and reasoning abilities, regulated or monitored chatrooms may help to upgrade their reading and writing skills, to broaden their social opportunities, to practice their conversational skills, and to improve their typing skills.

What was apparent throughout the study was that these subjects had fallen through the cracks in the social safety net. Because most of their measured IQ's were above 70, they received virtually no support from community and governmental agencies. This lack of support caused great hardship for the individuals and for their primary caregivers.

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The good that we set out to do is not always the good that we end up with.

Andy Albright

project consultant
support circles for adults
with developmental disabilities

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CHAPTER 1

INTRODUCTION

A. Background

Literacy is defined as: *"The ability to understand and use printed information in daily activities at home, at work and in the community; to achieve one's goals and to develop one's knowledge and potential"* (International Adult Literacy Survey, 1995).

The study reported below investigated the effects of using "Literacy-Based Support Circles" and "Literacy-Based Cognitive Tools" with five FAS/FAE affected adults ranging in age from 16 to 34 years. This chapter establishes the context of the study and notes relevant literature which demonstrates both the need for the study and the place of FAS/FAE affected adults in the community. Following a statement of the goals of the study, the subjects' scores on the Vineland Adaptive Behavior Scales and the SIB-R[1] tests, are presented as evidence of the level of functioning. "Literacy Based Support Circles" and "Literacy-Based Cognitive Tools" are then described briefly, and the plan of the report is outlined.

1. Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE) in British Columbia

a. **Prevalency**
Baumeister, Kupstas, and Klindworth (1990) cite many sources that claim that the rate of children being born with developmental problems is increasing. This phenomenon is referred to as the "new morbidity" which, in large part, is attributable to poor prenatal care (p. 1). Drug and alcohol abuse during pregnancy is a significant

[1] Scales of Independent Behavior-Revised

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factor contributing to this problem with a possible 11% of deliveries "*affected by illicit substance abuse*" (p. 7).

Throughout North America, inner-city communities and racial minorities suffer a disproportionate rate of substance-exposed births due to a number of interrelated factors including high poverty and low employment rates (Habbick, 1994; Streissguth, LaDue, & Randels, 1988). The average rate of 1/1000 for FAS is a commonly quoted statistic with rates of FAE estimated to be four to five times higher. Some British Columbia sources claim the rates for FAE, believed to be at least as damaging as FAS, could be much higher. For example, Dr. Loock, well-known FAS pediatrician and researcher from Vancouver, is quoted as saying, *The prevalence of fetal alcohol effects (FAE) is not as well known due to a lack of recognition and diagnosis, but it may be as high as one in 30 births and, in communities with an unusually high rate of alcohol abuse, it may be one in five births*" (McCreight, 1997, p. 1). The number of children from the Downtown Eastside of Vancouver born with "*effects of FAS or a related drug syndrome*," according to Vancouver medical officer Dr. John Blatherwick, could be as high as 30% (Sarti, 1992, p. B1). As well, rates of fetal alcohol affected children are considered epidemic in the northern and central regions of the province according to Hay, Olech, and Turpin (1998) in their article, "FAS/E Children in Northern BC: A Study of 148 Children in one Pediatrician's Practice" (p. 51). In the promotional literature for its "FOCUS" employment program for adults with FAS/FAE, The College of New Caledonia claims that: "*It is estimated that up to 30 percent of the population in northern BC and Yukon communities are affected with alcohol-related birth disorders*" (p. 1). Although no research-based information was found to verify this claim, it is clear that some well informed individuals are getting very concerned about the possible high rates of this disease in this province.

b. **Diagnostic complexities**
The most commonly known disorder stemming from prenatal alcohol exposure is Fetal Alcohol Syndrome (FAS). The following list provides the range of classifications that doctors use to identify prenatal alcohol exposure that does not qualify for the full FAS diagnosis:

FAE	Fetal Alcohol Effects,
ARBD	Alcohol Related Birth Defects,
ARND	Alcohol-Related Neurodevelopmental Disorder, and
pFAS	Possible Fetal Alcohol Syndrome

For the purposes of this report, we have chosen to use FAE as the diagnostic name to describe the disorders that do not qualify for a full syndrome diagnosis of FAS. Further, FAS/FAE will be used to designate the entire diagnosable spectrum of disorders that are associated with prenatal alcohol exposure. Nevertheless, the distinctions may be irrelevant because they all share the hallmark problem associated with prenatal alcohol exposure - brain damage. The Ninth Special Report to the U.S. Congress on Alcohol and Health (1997) described this non-FAS subgroup by saying

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that they *"share many of the characteristics associated with prenatal alcohol exposure, especially the 'central nervous system dysfunction and other cognitive abnormalities'* " (p. 3).

c. **Secondary disabilities**

An affected individual's successful functioning is frequently disrupted by inappropriate behaviour and socialization problems. (Berg, Kinsey, Lutke, & Wheway, 1995; Williams, Howard, & McLaughlin. 1994) Further, most affected people develop secondary behavioural and psychological problems while in their teens or early adult years. These problems threaten the quality of life of the individual and their families. (Steinhausen, Nestles, & Spohr, 1983; Steinhausen, Willms, & Spohr, 1993; & Streissguth, Barr, Kogan, & Bookstein, 1996)

Streissguth et al. (1996, p. 6 & 7) published what may be the most extensive longitudinal study into FAS/FAE populations to date. This study explored secondary disabilities among FAS/FAE affected populations and the findings indicate that we should be greatly concerned about FAS/FAE associated maladaptive behaviour problems. Streissguth's research project included 661 clients across a 22-year period. Two overlapping subject samples were included in the study, one investigating primary and the other secondary disabilities[2]. The IQs of the subjects ranged from 29 to 120 for those with FAS and 42 to 142 for those with FAE. Following are some of the findings:

♦ 415 individuals of all ages:
> Mental health problems: 94%.
> Inappropriate sexual behavior: 45%.
> Disrupted school experience: 43%.
> Trouble with the Law: 42%.

♦ Characteristics associated with *higher* levels of secondary disabilities include:
> Having FAE rather than FAS.
> Having an IQ above 70 rather than below.

♦ 90 adults studied (21 years and over):
> Living dependently: 83%.
> Problems with employment: 79%.

♦ Violence against individuals with FAS/FAE:
> Experienced physical or sexual abuse or domestic violence: 72%.

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[2] The study defines primary disabilities as those "that reflect the CNS [central nervous system] dysfunctions inherent in the FAS or FAE diagnosis." Secondary disabilities are defined as "those that a client is not born with, and that could presumably be ameliorated through better understanding and appropriate interventions" (p. 4).

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♦ 30 females with FAS/FAE had given birth to a child, and of these:
> No longer had the child in their care: 57%.
> Were drinking during pregnancy: 40%.
> Had children diagnosed with FAS or FAE: 17%.
> Suspected of having children with FAS or FAE: 13%.

d. Adults with FAS/FAE and program participation

It is possible that a relatively large number of adult clients receiving services from educational, employment, and social services in British Columbia have FAS/FAE and the problems commonly associated with the disorder. It is also possible that most of them are not diagnosed since the rate of occurrence is much higher than the present rate of diagnosis. The latest available statistics in Canada indicate that during the year 1993/94 only 18 newborns were diagnosed as having alcohol related birth problems (McKenzie, 1996).

Employment brings more challenges. Unless placed in a "supported" work environment, affected adults may find it very difficult to perform at a level of performance acceptable to the employer. "Reaching out to Children with FAS/FAE," Diane Davis (1994) describes the ideal work situation for a young person with FAS/FAE:

> *It is important to keep in mind that his job environment should be*
> *one where there is structure, order and routine, and where he will*
> *be supervised by adults who are patient and understand his*
> *limitations. (p. 137)*

e. Health issues

FAS/FAE is a disorder of tragic proportions. Young people with FAS/FAE experience disproportionately high rates of unplanned pregnancies, substance abuse problems, mental health difficulties, disrupted school experience, criminal behaviour, social isolation, sexual exploitation, and HIV infection. (Beaulieu, Andrea & Taylor, Rob, p. 194)

Dr. Streissguth (source unavailable) says that, as they grow older, many adults with FAS/FAE come to realize their predicament. They begin to understand how FAS/FAE has robbed them of a normal life and they live in despair.

> *Some adults with FAS/FAE reach some self-awareness of these*
> *complications. They have helped me understand the pain of having*
> *this disease - the pain of being not as smart or as capable as others,*
> *yet always wanting desperately to succeed; the pain of not feeling as*
> *loved or as wanted as others; the "pain of social banishment," as*
> *one adult with FAE described it. Therefore, it is not surprising that*

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*depression is the most typical mental health problem, characterizing
more than 50% of adolescents and more than 40% of adults with
FAS/FAE.* (p. 140)

Mental health problems are very common among this population; so common, in fact,
that many advocates want it to be included in the next edition of the <u>Diagnostic and
Statistical Manual for Mental Disorders</u>, or the DSM. (Huffine, 2000, p. 1)

2. The Bigger Picture: Adults with Minimal Brain Damage

*In many ways, people with traumatic brain injury (TBI) suffer similar problems as do
those with FAS/FAE. Chestnut et. al. (1999) in their exhaustive literature review of
TBI[3] research reveal that the onset of TBI "combines with extreme changes in
behavior, personality, memory, and general function to produce a catastrophic
perturbation in a person's social system" (p. 16). Chestnut et. al. cite many studies
which show that the resulting memory deficits and inappropriate behavior that
sometimes result from TBI can negatively affect the person's ability to return to work
or procure new employment. Their report also cites many more sources describing TBI
outcomes that closely resemble those that accompany the FAS/FAE disorder:*

> *Personality changes and behavioural problems mimic other pathologies such
> as mental retardation or psychiatric disorders. These behaviours in turn elicit
> negative reactions from family and friends that operate to impede the
> recovery process. Long-term consequences include financial dependence,
> social isolation,...divorce,...and various forms of incarceration such as
> lockup care facilities, State hospitals, or prisons. (ibid. p. 16)*

*Dr. Sterling Clarren (2000), professor of pediatrics and director of FAS Diagnostic and
Prevention Network in Washington State, believes that we should refrain from viewing
FAS/FAE in isolation. In his article, "Why we need to consider minimal brain
damage," he recommends that we view FAS/FAE as a subset in a larger group of
people who suffer minimal brain damage. He explains,*

> Children with exposure to lead, prenatal exposure to mercury or
> alcohol and many other things all seem to show similar kinds of diffuse
> problems in brain performance. Patients who have had brain trauma
> from accidents, or sometimes after brain surgery, may also show the
> same things. *(p. 8)*

*Clarren emphasizes that all people with minimal brain damage face some similar
challenges. They are challenged in their daily and social performances and they are
challenged with lack of services. Reporting on the proceedings of a recent meeting of
scientists concerned about 'people exposed to all sorts of 'neuro-toxins,'" Clarren
explains that participants "reported that their patients were not well understood nor*

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[3] traumatic brain injury

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did they seem to receive appropriate support and services...Everything becomes piecemeal" *(p. 8)*.

B. Purpose of this Study

This study sought to develop support systems to help five young adults with FAS/FAE cope with daily living challenges such as everyday memory failure, disorganization and social isolation. The project hypothesized that the development of literacy-based support circles and literacy-based cognitive support tools would help them to overcome some of these difficulties.

1. Goals

To investigate the role literacy-based support circles might play in the lives of FAS/FAE affected young adults, the study addressed the following five goals:

Goal #1: Assess the level of functioning of each subject in terms of their ability to live independently using the Vineland and SIB-R (Scales of Independent Behaviour-Revised) tests.

Goal #2: Design literacy-based tools and strategies, "Life Literacies," to help the subjects improve their everyday living capacities and to help improve their social, school and/or work outcomes. (Even if not employed, each of the subjects is compelled to work at some tasks, even if it just involves working around the house).

Goals #3: Develop literacy-based support circles to help extend and support the individuals' functioning in the community, using literacy tools whenever possible.

Goals #4: Evaluate the literacy tools and the literacy-based support circles after a minimum three month trial period in terms of their advantages and disadvantages.

Goal #5: Interview service providers to determine what services they can provide to each of the subjects.

2. Research Question

The major research focus of the study was to assess the success of the various interventions in terms of their advantages and disadvantages. Thus, the primary research question is:

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What are the advantages and disadvantages of literacy-based support circles that are designed to help enhance the functioning of young adults with FAS/FAE?

3. Vineland and SIB-R Assessments

The first major problem encountered in the study was obtaining valid, reliable initial assessments of the subjects' abilities to function in society. Discussions held with a number of parents before this project got underway, indicated to the researchers that these people all had different values and different definitions pertaining to their FAS/FAE affected children, and that their perceptions would not necessarily provide reliable assessments. For example, in discussions with parents outside of this study parents presented conflicting perceptions. Both parents of a thirty something daughter with FAE who is a college graduate and working successfully in a self-employed venture, described her as disaster because she has had 14 failed relationships. Conversely, the parents of a young man with a young son by an ex-girlfriend described their son as a "great" father despite the fact that he does not live with the child, is in jail on a regular basis, and does not provide any financial support. The mother of a male teenager described her son as an extremely stressful, overwhelming child who was going to bring them grief until the day they died. The father, on the other hand, described him as a *"miracle boy."*

It was also assumed at the onset of this study that despite the problems with subjectivity, parents were the only people who could provide a detailed description of their children's level of functioning. Therefore, it was decided to use the Vineland and SIB-R testing tools to help extract the detailed information only the parents could provide and to construct the most objective and useful assessment possible. We used this data to help guide the decision-making process and to help advocate for services for the subjects.

The project staff also decided to use these tests to support a third assumption. We assumed that although four out of five of the subjects had IQs within the normal range, albeit low average range, the IQ measures did not reflect their capacity to live a full and independent life. We based this assumption on research studies and conclusions drawn by experts in FAS-related fields. For example, Thomas et. al., (1998) conducted a clinical study in which they found FAS/FAE affected children suffered deficits that were not reflected by their IQ scores, no matter how low these scores were. In particular, these children expressed deep problems in their interpersonal and social skills. Further, these deficits were more pronounced in older children with FAS leading the researchers to conjecture that social abilities may not be simply delayed, but arrested for children with this disorder.

We decided to use both the Vineland and the SIB-R tests rather than choosing one or the other. We chose to use the Vineland because it is commonly used to measure the functioning of FAS/FAE affected individuals in other studies. We chose to use the SIB-R because it is considered to be a more adult-oriented test and was highly recommended by Dr. Robert M. Schacht of the Northern Arizona University, Institute Human

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Development, American Indian Rehabilitation Research and Training Centre (personal communication, September 21, 1999).

In order to present a picture of the functioning levels of the participants, we first present a summary of the test findings in Figure 1.1. This figure presents both the Vineland and the SIB-R test results for the five subjects in the study. It should be noted that most of the categories of the Vineland assessment are "low" or "moderately low" which suggests that the subjects will have major difficulties living without support. The large number of "limited" and "difficult" assessments in the SIB-R assessment support this judgment. In Appendix B we present details of the scores that the subjects received on the two tests.

Figure 1.1 Conclusions based on testing results of the five subjects tested

<u>Vineland</u>
1. All 5 had significant maladaptive behaviors.
2. All 5 subjects had at least 2 Domains where Adaptive levels showed at least a moderate deficit.

<u>SIB-R</u>
1. In total, 4 of the 5 subjects were rated as serious on the Maladaptive Index, 1 rated very serious.
2. All 5 subjects received a support score indicating some support would be needed. 4 of the 5 would need limited consistent support.
3. In total, 4 of the 5 subjects had a Broad Independence Level measured as being limited. At this level, age level tasks would be very difficult for these subjects.

C. Interventions Developed

The two interventions developed and assessed by this study were the Literacy-Based Support Circles and the Literacy-Based Cognitive Supports. The former are groups which meet with the subjects to devise individual methods of supporting them, while the latter are literacy materials designed to help the subjects focus on specific tasks, and sequences of tasks, required for daily living.

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1. Literacy-Based Support Circles

Five literacy-based support circles were formed to help the subjects explore their needs and interests. As Figure 1.2 shows, three of these circles were formal while two were informal. Membership in these circles was comprised mostly of the primary researcher, parents, extended family members, friends, and some service agency workers.

Figure 1.2: Literacy-Based Support Circles

Social Support Interventions	Bert	Mandy	Steven	Kathy	Brenda
1. support circles					
a) formal		Yes	Yes	Yes	
b) informal	Yes				Yes

Support Circle discussions focused on what Wehman (1996) lists as the seven most common transitions that youth with disabilities face:
1. Employment
2. Living arrangements
3. Getting around the community
4. Financial independence
5. Making friends
6. Sexuality and self-esteem
7. Having fun (p.8)

Literacy-Based Support Circles developed in this study are reported in Chapter 3.

2. Literacy-Based Cognitive Supports

Following through on a sequence of tasks often demands concentration and persistence but is essential to success in daily living and most jobs. We suspected that this "follow though" was

a challenge for individuals with FAS/FAE. Once we ascertained that the subjects in this study were able to follow a sequence of tasks once supported by a plan, we developed several literacy-based cognitive supports and piloted their use with the subjects. We called these tools or supports, Literacy-Based Cognitive Compensatory Tools. We also examined tools which may help improve cognitive abilities and we called them, Literacy-Based Cognitive Enhancement Tools.

An outline of these supports is presented in Figure 1.3. Chapter 4 of this report describes the procedures in detail and the subjects' successes and failures with them.

Figure 1.3: Literacy-Based Cognitive Support Tools

	Bert	Mandy	Steven	Kathy	Brenda
Cognitive Compensatory Tools					
1. weekly magnetic calendar	Yes	Yes		Yes	Yes
2. cleaning support tools	Yes	Yes		Yes	
3. student tracker system	Yes				
Cognitive Enhancement Tools					
1. Directions personal planner		Yes		Yes	
2. chatrooms	Yes				

D. Plan of the Report

The remaining five chapters of this report present the findings of the study in detail. First, Chapter 2 presents detailed biographies of the subjects which describe their family, educational, and work backgrounds, as well as their present state of affairs. Chapters 3, 4, and 5 present the major findings of the study: the first regarding the Literacy-Based Support Circles; the second, the Literacy-Based Cognitive Compensatory Tools; and the third, the Literacy-Based Cognitive Enhancement Tools.

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Each of these chapters is presented in three sections: first, the rationale for the procedure is discussed and documented; then the data are presented in the form of case studies; and finally, general conclusions are drawn regarding the administration and effectiveness of each procedure. Chapter 6 presents the conclusions, suggestions for change and recommendations for research. The Report concludes with the Epilogue and Appendixes A and B, which provide examples of the literacy tools developed for this project and the details of the Vineland and SIB-R testing.

CHAPTER 2

SUBJECT BIOGRAPHIES

This chapter introduces each of the subjects involved in this study. The information presented was drawn from conversations with the subjects and their parents regarding the subjects' adoptive history, educational experiences and present life circumstances.

The chapter is presented under the following headings:
1. Bert (16 ½ years at the close of the study)
2. Mandy (34 years at the close of the study)
3. Steven (20 years at the close of the study)
4. Kathy (20 years at the close of this study)
5. Brenda (19 years old at the close of this study)
6. Cyberspace Subjects

1. Bert (16 ½ years at the close of the study)

Bert is a status native, adopted when he was 10 months old. Prior to his adoption, he was repeatedly apprehended from his birth mother and placed in foster homes. His adoptive home was his seventh placement. Bert was adopted into a white home with two biological daughters who are four and five years his senior. Bert's sisters have now graduated and left home and he has had a hard time adjusting to this new loneliness. He phones them every night. And like them, he plans to graduate from Grade 12, win a lot of scholarships and go to University where he will *"find a lot of friends."*

Living in bigger urban centers when he was younger, Bert received extensive intervention during his preschool years, including physiotherapy, speech therapy, occupational therapy, and one-to-one child care in daycare and kindergarten. His mother used to refer to him as the *"million dollar baby."* Since Grade 1, Bert has been living in a small, rural community that offers fewer resources for him and his family.

Outside of school, there was no support or intervention for him or his family until he turned 15 and his parents contacted Social Services for a worker and some respite care. Their initial requests were denied, but when the mother threatened to take legal and media action, they were offered both a worker and respite support. A worker was

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assigned for four hours per week, but the worker was often late and even missed two of the appointments he had made with Bert. Consequently, the arrangement was discontinued after two months. The one-weekend-a-month respite care has worked out very well; however, the family has been informed as of November, 2000 that they no longer qualify for services, due to funding cutbacks. His parents have been assured that Bert will not be eligible for any special services when he becomes an adult as his IQ is 83, well over the cut off of 70.

Bert has always had Learning Assistant support in school, but never on a one-to-one basis. When he reached Grade 10, though, he became very resistant to Learning Assistant interventions. Since Grade 10, his academic subjects have been modified. In Grade 11, his favorite subjects are Math, Drama and Physical Education, and Bert performs well in these courses. He is less successful in English, Social Studies, and Science, but with a great deal of parental and teacher assistance, he is passing. Without constant intervention and supervision; however, he quickly falls behind and loses initiative.

Last year, his school converted to a self-directed program that demands he be more self-motivated and self-directed. Bert's parents describe this time as one of the worst years of their lives. Bert managed to pass the school year because his parents worked hard to get him through, pushing him every step of the way and doing most of his course work with him at home.

Last spring, the research team, Bert's parents and the school staff developed a cognitive support tool, which they named the student tracker system, to help him function more successfully within the self-directed system. The use of this tool, which is described in detail in Chapter 4, demanded months of trial and error before it became effective.

In addition to FAS, Bert has been assessed as having attention and learning problems. He is 5 foot, 7 ½ inches tall. Few people can tell that he has FAS or any other problem if they know him on a casual basis.

During the summer between his Grade 10 and 11 years, he worked his first full-time summer job under a special-needs youth grant for the local Regional Recreational program. Bert's parents received no complaints about his job performance but they had difficulty getting him to work on time during his last few weeks of work. Bert found it so hard to wake up and get ready that even with his parents driving him, he was often late. Bert faithfully deposited his pay cheques in his bank account for which his father has joint signing authority and bought a new computer with his earnings.

As Bert grows older, he is experiencing many problems controlling his anger. He has become very argumentative and often punches doors and walls at home and his locker at school. Recently, he bashed his head against his locker in the morning and kicked his locker later in the day. The reason for his first bout of anger was that he forgot his gym shorts at home and, therefore, could not go to gym class. The second outburst occurred when a girl he really likes told him that she did not want him to talk to her anymore. The

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latter situation reflects a big frustration in his life. Usually, Bert has a hard time making and keeping friendships.

Bert mother makes the following comments:

> *Bert has a difficult time with life. He understands that actions can have good or bad consequences, but this does not mean he is able to consider thoughtfully his choices when he acts. Instead, he tends to live "in the moment" and is unable to take command of his life. He is a huge responsibility. We often lose sleep worrying what will become of him and of us in the future.*

2. Mandy (34 years at the close of the study)

Mandy is a status native, adopted at the age of two into a white family with four older biological siblings. She was diagnosed with Fetal Alcohol Syndrome in 1979 when she was 9 years old. She was born with bilateral clubfeet that were operated on when she was young. She exhibits many features common to fetal alcohol exposure including facial features, some missing finger joints, and growth retardation - she is 4 foot 6 ½ inches tall. Her IQ is in the 80s.

Mandy has lived in the same, medium-sized city in the interior of British Columbia since she was adopted. Her parents, who are in their 70's, moved to another province about 18 months before the research project began. Their moving was a big loss for Mandy. Although Mandy has lived in her own apartment for the last ten years, her mother was a continual support with her daily living and emotional needs. Mandy keeps in regular contact with her family via the telephone. She is on Federal Disability Income, her mother having helped her apply for disability status before moving away. She sees her brothers and sister about twice a year; they visit her, and she visits them. She has a good relationship with an aunt and uncle who reside in a neighboring town. *"They care for me, and I care for them."* At the onset of this study, Mandy reported that she had two friends.

Mandy manages all of her own money, paying her bills regularly with the assistance of the staff at her local bank. However, she has had a number of relationships wherein men have taken advantage of her and her money. She also suffers from episodes of depression, anger and fear. She feels that FAS is very difficult because a lot of people say that there is nothing really wrong with her, and that she uses the FAS as an excuse to get attention. One ex-boyfriend threatened to go to "welfare" and get her kicked off because he felt she was too smart to be considered disabled.

She says,

> *FAS, I don't even know what it really is. If I had an MRI, I would know what part of my brain is missing... I feel like sometimes my mind is a wall and when I get upset I can't make heads or tails...I need to rely on someone who is sensible.*

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In the fall of 1999, Mandy decided to try to get some help for herself. She claims she phoned every agency in her town, but received no offer of support. Then she telephoned a Vancouver-based FAS group which, in turn, phoned an FAS education consultant in a town one and a half hours from Mandy. This person then telephoned Margaret, the lead researcher of this project, and passed on Mandy's request for assistance. Although Margaret lived two hours from Mandy, she contacted Mandy asking if she would like to become involved in this research project. Mandy readily agreed asking the question,

> *Why is it so hard for me to get help? I have FAS and people should know how hard that is...I call the Crisis Center and say that I have FAS and they ask, what is that?*

Mandy receives disability payments and has a social worker but never asks this person for help. She says that she and her social worker really do not know each other because her social workers get shifted around. When she goes to the social service office, they just discuss her financial situation.

> *They ask questions, like, 'Have you bought any houses or mutual funds?' and I say, 'No.' They ask if my rent has changed - questions like that.*

Mandy's experiences with governmental agencies would seem to have been unrewarding. Whenever the research staff tried to encourage her to seek help from Social Services, she resisted.

Mandy has worked in the past. She was a chambermaid off and on for a number of years in an exclusive hotel in Banff. She describes the situation as follows,

> *I needed to do 17 rooms per day, but I could only do 15. I was fired. I had four alarm clocks set for 7am but could not hear them. I could only hear the telephone which rang too late - 8:30 am. I was so exhausted I couldn't wake up.*

She says that she received no special support services during her years in public school even though she failed Grades 3, 4, and 10. Her siblings were "A" students. For Mandy it was, " 'D' all the way." She dropped out of high school and later reentered as an adult in the local college and was placed in a class for persons with disabilities. That program did not work for her because, it was "too slow. They treated me like I knew everything."

Mandy claims that four years ago she said to herself, "Hey, I've got to do this for me!" so she enrolled into the local ABE program. She claims her first ABE teacher was very impatient and made it difficult to learn. Mistakes typically resulted in reprimands. "Oh, you know better than that. You can do that!" She says her present instructor explains things to her in a way that helps her be successful. If she forgets something he will say, "Remember how I explained it before?" Despite having quit and restarted this program

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five times, she has almost completed all of her studies, having only a Literature and a Math course to finish before she writes her final exams.

Only recently has the research team been successful in getting Mandy help with her FAS-related challenges. Mandy's IQ is in the 80's, too high for the 70 IQ cut-off point for special support services. When the team called the local Health services branch and asked about FAS services, on two occasions the respondent asked, *"What is FAS?"* During the first nine months of the study, the team was not very successful in garnering assistance for Mandy. We learned that vocational rehabilitation and counseling from a community services agency was available to her, as it was to everyone else in the community. There was a vacancy with Community Living service, and they enrolled Mandy in one of their programs. Every week they invited her to dinner at a local restaurant to join some staff workers and other clients. Mandy went three times but decided not to continue with the program because she could not talk with the other clients, who were severely handicapped. As well, she was afraid that when the staff went to have a mid-meal smoke outside and left her alone with the other clients that one of the clients might choke to death.

No one from her immediate family lives in the region, but they often come to visit and help her. For example, in June, one of her brothers came and helped her clean her old apartment and move to a new one. Three months after the move she was still unable to organize her things, and was living with piles of clothes, and many unpacked boxes in her midst.

Mandy recently faced a crisis and said that she wanted to kill herself. The researchers had been told repeatedly that Mandy did not qualify for services unless she was in crisis, for example, threatening suicide. So they took this opportunity to lobby a range of agencies for support and achieved some success. Further details are provided in Chapter 3.

Discussing the difficulties she has experienced getting help, Mandy keeps saying, *"What do I have to do around here to get any help? Kill myself?"*

3. Steven (20 years at the close of the study)

Steven is a white male, adopted into his white family at the age of two. He had previously been removed from his biological home and placed in several foster homes. Steven has an older sister, also adopted, but they do not get along. He received a possible Fetal Alcohol Effects diagnosis when he was 17 ½ years old. He is 6 feet tall and exhibits no obvious signs of Fetal Alcohol exposure. In fact, he is exceptionally handsome. His performance and behaviour problems at home and school had the parents pursuing a diagnosis since he was 14. For the last two years, Steven has lived in and out of his family home, coming back when he is in need of food and shelter. His parents say he has an average IQ.

Steven received one-on-one help in school, often being placed in special classes. This was fairly successful; he passed every year and they said he was progressing. Behaviour

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problems were always a difficulty at school but less so at home. In Grade 8, Steven was assessed and found to be hyperactive. He started taking Ritalin and calmed right down, but his school performance did not seem to improve. By Grade 9, school became very challenging for everyone in the family. His parents claim the school no longer provided him with one-to-one learning support because he was expected to conduct himself like a mature student and assume more responsibility for his own learning. For example, he was made to look after his own homework book. Thereafter, the parents rarely saw it so they were unable to help him keep track of his school assignments. His father believes that Steven did not do the school work but the system pushed him through. *"To this day, I don't think he can even read the paper."*

Steven was asked to leave the regular high school, so he entered an alternative "Pathfinders" program. He did not like it, and did not stay long. Later, he moved to another small town, found a room and board situation, and enrolled in another "Pathfinders" program. His attendance was very sporadic and he soon quit that program too.

Steven moved again, this time into a motel with a roommate. He enrolled in ABE classes in a nearby larger community but was unable to attend because of transportation and motivational problems. He ended up moving to another province with his roommate, working for a few months at three different jobs which he lost, primarily, because of lateness. He claims he could not wake up in time to get ready for work. Eventually, he telephoned his parents and asked them to come and take him home. He lived with his parents for a couple of months but recently moved in with a friend and is trying to get social assistance. His parents say that he is abusing alcohol and possibly drugs and they are very afraid for his future. Steven tells them that he is thinking about asking the research team to work with him again, but at the time of publication, he had not made any calls to pursue this.

Mother: *"You can't keep forcing him; he is getting too big... You can only do so much."*

4. Kathy (20 years at the close of this study)

At the close of this study, Kathy was 20 years old. She is of Metis decent and was adopted into a white home at the age of 27 months. She was diagnosed with FAS at the age of 11. She has a sister with FAS, Brenda, also a participant in this study, as well as two older biological siblings. In Grade 6, Kathy had her IQ tested at Sunny Hill Children's Hospital in Vancouver and it measured 71. In Grade 11 the same tester at Sunny Hill measured her IQ to have dropped to 64.

Although Kathy went to high school, she did not graduate. At least her mother does not think she did. Her mother says the following of Kathy's high school experiences:

> *There were not marks, no tests, and almost no classes. She spent her time mostly in the resource room or out on a bit of work experience. She did get to go to all of the graduation activities but there was no graduation*

certificate or anything... She had no I.E.P., even with a dual diagnosis of Autism. Even with a dual diagnosis of Autism, they didn't see any problems except when she was in regular classes or even the hallway or the lunchroom.

The situation was desperate by the time she left her fourth high school in the city. No one seemed to understand FAS or make the effort to learn. Even with a dual diagnosis of Autism the schools did not recognize Kathy's problems. The fourth school was a big improvement. As her mother explains:

Going in, Kathy didn't trust anyone and neither did I. She was so depressed and suicidal in her last school...They did not understand the FAS at all and didn't try to... In the new school, they did a fine job in many ways and Kathy did blossom and became quite confident.

Now that Kathy is an adult, her mother does not think she can cope with an independent living situation in the foreseeable future so, for now, she is living in the basement suite receiving transitional support services. These services have been made available to Kathy because she is an adult with an IQ under 70. Her mother thinks that establishing a microboard that can hire its own staff to provide support for Kathy would be an excellent idea, but, presently, the family is too stressed and exhausted to initiate such a project.

Despite these support services, Kathy's mother often feels emotionally and physically overwhelmed by the burden of caring for Kathy. She is a stay-at-home mother because her daughters require extensive support and supervision, despite the support services. When things go wrong, which they do every day, Kathy's mother if forced to deal with the problems. She always asks herself, *"If I weren't here, what would happen?"*

Almost every week, Kathy's mother reports major problems with the support workers. Problems include: not showing up, leaving early, not finishing their work, fighting with Kathy, and changing of scheduling. The unpredictable nature of these services often upsets her daughter a great deal, leaving the mother to contend with the fallout.

Employment support is the most successful of the support services. Kathy has been working with an employment support worker at various jobs over the last two years, mostly in an intermediate care home which employs unionized workers. As yet, the employment support agency and her parents have not been able to place her in a wage-earning situation. Both Kathy and her mother are starting to feel that the situation has become exploitive, but, on the other hand, her mother realizes that Kathy can not work effectively enough to genuinely earn a union wage. In fact, she feels her daughter would have a very difficult time meeting regular work expectations for even a minimum-waged job.

Kathy requires a lot of energy and supervision. For example, she seems to need a lot of stimulation and has difficulty controlling her physical impulses and judging her strength. Despite continued efforts, the family has been unable to persuade Kathy to stop jumping

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on the couch. She has broken the supports in two couches in the last year. Recently, she pushed a male visitor through a large window in her parents' home. Luckily the man wasn't hurt badly, but this incident was, understandably, very upsetting for all concerned. Obviously, then, the care of Kathy is an expensive proposition.

Barbara West of Creston, BC, a Special Education consultant to this project, suggests that Kathy's frequent accidents might be attributable to proprioception problems stemming from Sensory Integration difficulties. Vancouver FAS educator and parent, Jan Lutke concurs. Barbara explains that FAS/FAE affected individuals frequently experience malfunctions with the receptors in the muscles and joints and, as a result, do not have an adequate sense of appropriate force when participating in activities. For example, young children might be unable to determine how much pressure to put on pens or erasers and, therefore, tear the paper and create frustration for themselves.

At the onset of this project, Kathy was taking a Math course in a special-needs college program. This was not a successful undertaking for a number of reasons. Her mother says many problems stemmed from the lack of understanding about her disorder. The behavioral and learning expectations were not reasonable. For example, the staff had a hard time accepting her inability to learn about money.

Kathy has a support circle that is very concerned about her future and the well being of her parents. Some of the local circle members have an expertise in community living services for adults with handicaps and have been actively advocating for more help for this family. Unfortunately, Kathy's social worker recently determined that Kathy is too high functioning to have a full range of services. He has offered $1400 per month for caretakers to take her into their home. These "caretakers" do not include Kathy's parents. Circle members believe that the services that Kathy requires cannot be provided for this amount of money. A local religious-based care provider agrees that this funding falls far short of the need and refuses to accept Kathy as a client.

The father, a professional man, quit his job to go into business for himself a few years ago. His stay-at-home-wife could not cope because of failing health – chronic fatigue syndrome and depression. Since then, they have struggled financially but managed to raise all of their children into adulthood. He has recently had to refuse a good job offer in Ontario because he and his wife cannot abandon their youngest children, their two FAS affected adult daughters who want to stay where they are.

As the mother explains,

> If we move, the girls would not be coming with us. It is impossible for them to live on their own or with minimal support. Kathy was out two unaccounted hours last week and came home with a cut lip and not a good story to go with it. She is not capable of being semi-independent. She is not capable of having down time. She requires and looks for activity in her life. When nothing is scheduled, she goes looking for activity. So... scary...Well, I am trying to fight off dizziness today. I get like that when I am over-busy...My health is

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sure at risk.

5. Brenda (19 years old at the close of this study)

Brenda, Kathy's younger sister, was adopted when she was 15 months old. Brenda successfully completed modified courses in high school and graduated in June. She has an IQ of 82. Brenda received little or no special help at school, but, according to her mother, managed to pass each year because, *"She did nothing, never said a word and didn't give anyone any problems."*

Brenda exhibits some serious cognitive challenges. For example, one day, Brenda's mother prepared dinner and asked Brenda to put it in the oven at 4:30 but when she and her husband returned at 3:30 pm, they discovered the dinner had already been cooked. When her parents asked why she had cooked the meal so early, she replied that she was afraid she might forget to put it in at 4:30. Her mother expressed regret at not setting a timer or writing it down for her. Recently, Brenda's mother was too ill to take their grandmother to an appointment so Brenda was asked to pick her up, take her shopping, then drive her to her appointment. This is how the mother describes the outcome:

> *Grandma phoned back twice in the next few minutes saying she would prefer to shop after her appointment which was a couple of hours later. I was way to sick to deal with it. Brenda got off the phone shrugged her shoulders and told me what Grandma said. She again shrugged her shoulders and promptly went to pick up Grandma. She could not problem solve that Grandma did not want to go shopping before the appointment which meant Brenda should pick her up later...*

After graduation, with her parents' help, Brenda found a job working with horses, a real passion for her. The first job was in another province. Her mother was cautiously optimistic that things would work out.

> *...being away will be good for her in many ways. I feel confident that if I set up the lists required and get the understanding that she works well with lists, that will go a long way. Having an older, very responsible friend there has given her confidence and me as well. There is still a lot to figure out and lots to do to get her organized. This may work out, and it may not. But it is worth a try.*

With her mother's visits and lists serving as her sole employment aids, Brenda had problems from the start with her job. Although the employers were aware that Brenda

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had some learning problems, they did no: know about her FAS disorder and they were baffled by Brenda's behaviour.

While visiting Brenda, her mother witnessed her daughter's struggle. For example, the supervisor gave Brenda an assignment that involved water and Brenda listened and assured her boss that the work would get done. Right after, Brenda's mother asked her what she was supposed to do with water and Brenda replied, *"I don't know."* Brenda would begin work, as requested at 5:00 a.m., but would stop work at 9:30 am for breakfast and to take a nap. She then returned to work at 2:30 to complete certain duties before stopping work for the day. Although Brenda's mother tried to explain that the breakfast/nap break was not a good idea, Brenda insisted that this is what she was supposed to do, and that it was part of the initial arrangements. In an email message, her mother described the outcome:

> *I think Brenda will be home by the end of the month. She is very lonely and there have been problems. Her boss says she forgets a lot. People have no idea what we mean by writing things down...There have also been problems with a saddle that cost us $200 because she used a new saddle to ride her horse. The saddle is no longer new.*

Despite these challenges, Brenda lasted six weeks at this job. Shortly after her return home, Brenda started another job working with horses. Difficulties have presented themselves, but this situation seems much improved over the last one. For one thing, the job is part-time, which is practical because the work is tiring. As her mother describes it,

> *Brenda is still working part-time but there appears to be problems starting. Her boss keeps asking her why it takes her so long to clean stalls, etc. Brenda does not know how to answer that. I have told her to tell her boss that she is trying to do a really good job. She does lots of things besides horse stuff like. weeding, painting, etc. She wakes up at 4:30 a.m. to be at work at 6:00 a.m. She gets home at 5:00 p.m. The good news is that last month she made over $800, so the pay is decent. Anyway she is still there. The boss is very good at lists which has really made a difference but I am certain that many people can work faster than Brenda. She comes home quite exhausted.*

Brenda has a boyfriend that the mother highly approves of. She describes him as *"very nice...he is so good to her, a real sweetie. He even clears his dishes from the table."* In summation of her present life situation, her mother says, *"She does seem happy with life in general."*

Despite the problems with memory and organization, Brenda did not welcome any interventions. Nor does she want to discuss FAS-related problems with anyone. However, she did ask her mother to get her a weekly magnetic calendar from the research team because she was impressed with the one her sister, Kathy, was using. She said that she thought this calendar might be useful to her.

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As an adult, Brenda does not qualify for any special support services. As the local Social Worker responsible for supporting adults with handicaps explained, *"She falls through the cracks."* Brenda and her sister Kathy do not get along and their constant, sometimes violent fights are stressful for the family. Their stay-at-home-mother spends much of her time keeping them away from each other and facilitating the details of each of their lives. She is often overwhelmed and worried that she may not be able to keep it up for too much longer.

6. Cyberspace Subjects

After learning about this project from a variety of sources, two other families expressed an interest in this project. Their primary interest was Support Circles but when they learned about the circles, they decided they were too exhausted and under-qualified to establish and conduct these circles on their own with only email support from the project staff.

CHAPTER 3

LITERACY-BASED SUPPORT CIRCLES

This chapter discusses the literacy-based support circles that were developed during this study. We begin the chapter by explaining why we thought these support circles were a good idea and why we wanted them to be literacy-based. We identify the needs we hoped the circles would meet, and the ways in which the circles would meet these needs. Next, we present case studies that examine how each of the subjects responded to circles. This chapter concludes with a discussion about the outcomes and includes an outline that identifies the advantages of support circles, as well as considerations in forming and administering support circles.

The chapter is presented under the following headings:
- A. Rationale and Guidelines
    1. Understanding the Need
    2. Intentions of the Literacy-Based Support Circles
    3. Circle Guidelines
- B. Case Studies
    1. Bert's Support Circle (16 year old student, lives with his adopted parents)
    2. Steven's Support Circle (20 year old, presently unemployed)
    3. Friends of Mandy Support Circle (34 year old part-time student, independent)

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A. Rationale and Guidelines

1. Understanding the Need

As explained in Chapter 1, developmental disability support services are not available to adults with FAS/FAE in this province unless their IQ is under 70. Therefore, many, if not most, of these people do not qualify for any special help. When support is required, the affected individuals, and their families when available, must use their own initiative to find assistance.

The project proposed two types of support to the subjects and their families. First we offered to help develop cognitive support tools such as schedules and task-lists that could help support the subjects' daily living challenges. But, as Schmucker (1996) points out, schedules and grocery lists can only go so far. These individuals also have needs that are more complex because they are often socially isolated, and overwhelmingly lonely. "Friendships tend to be mock situations created with paid providers" (p. 100). Each of our subjects has experienced social isolation and the resultant loneliness.

Schmucker also identifies victimization as another real fear that families have for their adult children with FAS/FAE. She explains that "A high rate of victimization seems to occur as a result of the ongoing pursuit for friendship by adults with FAS." She illustrates with the following example: "...a client bought a woman a television set because she "asked him to." She continued to ask for things until he had almost furnished her home, provided her with a summer wardrobe, and had let her boyfriend move in … after the boyfriend had beaten him up" (p.100).

The research team hoped that support circles might alleviate social isolation while providing guidance that might prevent the victimization of the subjects in this study. We hoped these circles might relieve the subjects' families of some of their considerable social responsibilities, as well as, help to develop some literacy-

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based support tools to help with the focal person's everyday living challenges.

2. Intentions of the Literacy-Based Support Circles

As mentioned above, the research team intended support circles to provide the subjects with social interaction and guidance. As well, we hoped the circles might remove some of the burden of support from the present caregiver(s). We hypothesized that the circles would help the subjects solve problems and strengthen the alliances between people wanting to help the individual.

Three formal support circles were organized; one each for Steven, Mandy and Kathy. Lead researcher, Margaret Raymond, organized the circle for Steven and Mandy, and Kathy's mother organized the circle for her daughter.

Consultant to the project, Andy Albright, guided the team through the challenges of constructing support circles. His philosophy is as follows:

> *The primary way a support circle works is by bringing together a group of people who already have a relationship with the focal person. Through this group, the focal person builds bridges into the community, as well as additional relationships.*
>
> *The primary manner of support involves focusing on the gifts, capabilities and capacities of the focal person while finding meaningful ways for the focal person to expand their world. The experience of the focal person is that of being valued and encouraged.*
>
> *The pitfalls of their present state of affairs are fairly self-evident: the primary caregivers burn out, the focal person becomes increasingly isolated, and their challenging behaviors limit the opportunities that are made available to them.*
>
> *Through being valued, encouraged and provided with a wide variety of opportunities and strategies to develop a meaningful lifestyle, the focal person has a good shot at a rich and fulfilling life. Skill deficits may present problems, but they should not prevent a person from having a decent, exciting life like the rest of us.*
>
> *Most of us have support circles and we often find work, shelter, friends and romantic partners through our circles. For folks with bigger challenges, these circles sometimes take a little extra effort and focus to get them to grow. In developing support circles, we're just giving the garden a little extra water and fertilizer and maybe keeping the deer at bay.*

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In addition, many institutions - like schools - are not set up to deal with exceptions. Consequently, atypical people often get branded as "problems" - which is unfair and counterproductive. Such labeling destroys dignity and can have a self-fulfilling prophecy effect.

Finally, imagine the difference for a person when she has a group saying "We believe in you - you can do it - and we'll help when you need us". In Maslow's terms, that person is getting a lot of "esteem by others." I think this has a powerful effect in contributing to a person's self respect and optimism — one of the most useful tools a person can have when coping with life's ups and downs.

A group is always more powerful than an individual. As long as the group is committed to the focal person's dream, it really seems to generate a lot of energy. For example, agencies listen more when they know a focal person has the backing of many people. As well, each person in the group is an effective good-will ambassador for the individual.

Margaret led Steven's and Mandy's circle, and she and she and fellow researcher, Jennifer Cliff-Marks, lead Kathy's circle meetings. However, Kathy's mother determined, to a large extent, the course and purpose of the circle supporting her daughter.

The purpose and features of the support circles used in this study are outlined below, along with guidelines for members of the circle.

Purpose
- ◆ To increase successful independent functioning of subject/client.
- ◆ To build bridges into the community.
- ◆ To provide more opportunities for fun.
- ◆ To help with personal planning.
- ◆ To help fulfill personal dreams and goals.
- ◆ To help advocate for necessary supports and services.

Features
- ◆ Circle members consist of individuals who are friendly with and concerned about the focal person.
- ◆ The focal person is the central focus and purpose of the circle.
- ◆ Expectations for circle members, including the focal person, are reasonable.
- ◆ A literacy-based program, such as Directions may be used to help establish short and long-term dreams/goals.
- ◆ The circles are flexible and adaptable.
- ◆ A viable circle can consist of four or more people.
- ◆ Circles should be limited to less than 10 people. Too many people may make the circle proceedings time consuming, complicated and onerous.

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♦ The circle consists, primarily, of people with whom the individual is familiar (not too many strangers).
♦ New members should be acceptable to the individual before being introduced to the circle.
♦ Circles require strong leadership.

Focal Person Participation
♦ The individual is motivated to attend meeting and cooperate with the membership because the individual is the center of the circle's attention and receives continual, positive support.
♦ The individual's preferences are acknowledged and respected.
♦ The individual's problems are respected.
♦ The individual's personal interests, skills and talents are key to the circle's direction.
♦ Circle meetings are conducted in a consistent and positive manner to include the focal person's full participation.

3. Circle Guidelines

Circle guidelines are given to circle members and, prior to the meeting, are discussed with the focal member. See Figure 3.1 for the set of guidelines developed. A typical agenda format is illustrated on the following page in Figure 3.2.

Figure 3.1

Circle Guidelines

Positive environmental change can often lead to positive behavioral changes and personal growth.

Reminders:

♦ We are not here to fix or counsel; we are here to be friends.
♦ Support is the key - we are here to help each other.
♦ We must acknowledge all of (_____) friends, whether they are here or not.
♦ We are here to help (_____) build social bridges into the community.
♦ We are here to help (_____) connect to quality activities such as those involving recreation, volunteer work, skills building, etc.
♦ We are here to help (_____) achieve success with dreams/goals.
♦ Members may have values or beliefs that are not shared by other members, but which should be respected by all.

Rights of Circle Members:

♦ Members, including the focal individual, should have clear boundaries with each other.

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Figure 3.2

Typical Agenda

Host: focal person
Membership: family, friends, support workers, and anyone interested in focal person
Facilitator: people can take turns

1. Tea, organize (10 minutes)

2. Month in review (20 minutes) (Talking Stick or Talking Stone may be a good idea).

-   What good things have been happening with focal individual
                        (Focal person takes the lead).

-   Identify dreams and goals that have been achieved this last month.

3. New Business (40 minutes)

-   Issues to address:

    -   Upcoming events, new possibilities.

    -   Problems that have arisen over the last month.

4. Plans/goals for the next month (30 minutes)

-   Goals not achieved last month are carried over, if appropriate.

-   New goals identified during "New Business" session.

-   Directions plan is reviewed for new ideas.

-   Solutions are brain stormed for the problems raised under new business.

B. Case Studies

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1. Bert's Support Circle (16 year old student, lives with his adopted parents)

Researchers did not develop a formal support circle for Bert, although it was acknowledged that Bert enjoys a fairly effective informal circle of support. A number of adults in the community befriend him and provide him with opportunities for work and play. One man, who used to teach Bert's sisters, regularly hires him to mow his lawn or dig in his garden, paying him over $10 an hour. Another adult friend hires Bert to baby-sit her children when she mows her lawn or gardens. Last year, this same individual also acquired a special needs employment grant through the summer recreation program that she managed, with which she hired Bert as a full-time employee for the summer. He earned over a thousand dollars and was able to buy a new computer for himself when the job ended. She also invites him on school bike trips and camping trips with her elementary class. On occasion, a neighboring family invites Bert on their shopping or movie outings. He also is a regular participant at the local youth center and plays games with other children his age. Every two months, or so, Bert goes to a respite care home in a neighboring town and engages in a lot of fun activities with the care person and her foster children. However, in November of 2000, respite care for Bert was discontinued because of budget cuts.

The decision was made to continue with an informal circle for Bert for a number of reasons. His informal circle was working to a point. Bert's parents did not feel that they had the energy to organize and conduct the meetings, in addition to their parenting responsibilities. And most importantly, Bert was not interested in the process because he resents having FAS and resists any activity that he perceives will make him appear "different" from his peers.

2. Steven's Support Circle (20 year old, presently unemployed)

Steven has possible FAE but presents no obvious physical signs of the disorder. He is tall, well-built and extremely good looking. Writing to another researcher about Steven, Margaret provided a brief description of her first impressions of Steven's situation:

> **From my informal assessment of this young man, he is not very well prepared for independent living. He can't cook, clean, or shop for groceries. He has trouble making change for a dollar. I suspect this young man has significant reading problems, too.**

From the start, it was difficult to form a support circle for Steven. He kept moving from one community to another and he did not seem to have long-term relationships with anyone outside of his immediate family, thus reducing the number of potential candidates for circle membership. Regardless, his parents were anxious to get help for him and Steven readily agreed that he needed and wanted support, including a circle.

His father says that his family had formed a circle of support for Steven a few years ago. Immediate and extended family members all agreed to help support Steven by regularly taking him out and sharing time with him. Steven's father claims that this circle never

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had a chance of success because Steven would not cooperate and did not want anything to do with it.

A new support circle was formed with Steven, his parents, and Margaret as members. During the relatively short existence of the circle, the membership did not expand; nonetheless, the circle continued to function as a powerful advocacy body for Steven. To illustrate, Steven was living in a room-and-board situation in a small community about a two and half hours from his parents' home. His parents were worried that his landlord was exploiting him for money and that his social assistance income would soon come to an end. When his social worker announced Steven's support payments were to be discontinued, Steven's parents intervened earning him one more month of support.

At the time, Steven was attending a computer-based alternative high school education program, but his social worker eventually decided that supporting Steven in school was a waste of time and money because he rarely attended. This was the second such program Steven had failed.

The social worker decided that Steven would derive more benefit from a supported employment placement in a larger, nearby community. Steven was scheduled to have a meeting about these plans with the social worker in early January and his parents made an appeal to attend. They claim they were refused permission because Steven was an adult, having just turned 20, and was no longer their dependent.

Margaret intervened on behalf of the Circle and asked if circle members could attend the early January appointment with Steven. The social worker readily agreed, so Margaret and Steven's parents attended along with Steven. After discussions about Steven's fetal alcohol state of affairs, the social worker promised not to cut Steven off social assistance again. He also listened when Steven said he wanted to go to school, preferably in an adult setting. Steven argued that he needed his Grade 12 to make something out of himself and was confident that he would perform much better in a different educational environment. The social worker agreed that even if this educational pursuit proved unsuccessful, Steven could remain on social assistance.

The social worker then telephoned the local college and made an appointment that afternoon for the ABE instructors and the circle members to meet. At this meeting, everyone discussed the situation and assurances were given that every effort would be made to support Steven's success, including tutor services, if necessary.

Margaret and Steven also made plans to apply for disability status for Steven. Steven wanted this and claimed to understand that this would provide him with a life-long income while not interfering with his attempts to explore and sustain employment opportunities. His social worker also agreed to support this application for disability status. Plans were made to use the outcomes of Steven's Vineland and SIB-R assessments to help him qualify. Margaret met Steven on two occasions to help him locate, fill out, and start processing the complex forms involved with these applications.

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The staff at the college was optimistic about Steven's prospects because they had a young male student with FAS who was doing very well in a modified mechanics course. The special education teacher made an appointment with Steven for the next morning to conduct an assessment. The circle was assured that if the parents could provide documentation of Steven's FAE diagnosis, he could also qualify for special funding from the local social service agency that would pay for some special one-to-one tutoring.

Steven expressed a lot of enthusiasm for these new opportunities. He said more than once that he realized that education was key to his success in life. Without Grade 12, he felt he had very little hope for success or happiness in his life. He said he wanted to go to school despite his many unsuccessful attempts at it in the past because he knew his life would change if he graduated. He also expressed a vague interest in mechanics.

His parents left these meetings with ambiguous feelings. On one hand, they were grateful and hopeful for the new chances and the promises that were made. On the other hand, they were dubious about success. The father said, *"We'll believe it when we see it."* The parents had been supporting their son for years and had witnessed many promises that, for one reason or another, never came to fruition. The father explained that from his experience, promises were often made, but they turned out to be superficial with no substance or follow-up. As well, he maintained that his son is very adept at saying all the right things - the things that people want to hear, but his words do not necessarily reflect his commitment.

Neither time nor circumstances allowed the team a formal <u>Directions</u> personal planning session to help Steven with his personal planning. Instead, informal discussions revealed that Steven had a keen interest and an acknowledged aptitude with the technical side of drama. Plans were made to recruit some volunteers from the many drama groups in his new community. Steven was very excited about these possibilities.

Just before starting school, Steven moved into a motel about 30 kilometers from the college. His new roommate was in his mid-twenties and recently separated from his wife and three children. Knowing Steven has a very hard time waking himself up in the morning, the roommate promised to awaken Steven every morning and to drive him to school each morning, as he too, was a student at the college. Almost immediately, Steven's attendance fell off. He never did show up for the special education assessments. A few weeks after Steven enrolled at the college, his regular instructor reported that it was difficult to assess Steven's performance because he rarely came to school. Another instructor suggested that his roommate was a "bogus" student and seemed to come to the college more to talk on the pay phones than to attend any classes. This instructor added that regardless of any promises made, this roommate was not driving Steven to school on a regular basis. Not only that but, when he did bring him, Steven was sometimes forced to wait for him for hours after school while the roommate talked on the phone.

Steven's roommate planned to move to another province at the end of the semester so the Circle discussed the need to find a suitable room and board situation closer to the college. Margaret contacted many prospective landlords and produced a list of five room and

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board possibilities within walking or busing distance of the college. Steven and his parents were pleased with these prospects.

Before further plans could finalized, however, Steven moved with his roommate to another province to work at a resort. He later reported to his parents that he was receiving room and board and a small wage and was doing fine. Within a few months, though, Steven had been dismissed from three jobs, before calling his parents to come and get him. He lived at home for two months then moved in with another friend. His parents believe he is abusing drugs and alcohol. Recently he came to their home apparently under the influence and threatened violence against both of them. They are frightened for him and the trouble that lies in wait for him.

Steven is presently unemployed and having trouble getting back on social assistance. The social assistance representative wants Steven to provide documentation from his recent work experiences and he is unable to do so. Meanwhile, his parents wonder where he is getting money to live, drink, and smoke tailor-made cigarettes. Steven told them he was going to phone Margaret to get back on track with the plans made earlier in the year but, at the time of publication, he had not made the call.

3. Friends of Mandy Support Circle (34 year old part-time student, independent)

Mandy was very excited about the prospect of a support circle. The fact that it would be called, "Mandy's Circle of Friends" was particularly attractive to her. Mandy's parents, who had moved to another province the previous year, supported the circle idea too, hoping it would help their daughter.

Mandy's first circle meeting was conducted in February and introduced everyone to the concept of the literacy-based support circles. Five people attended: Mandy, her girl friend, the parents of another subject for whom a circle was planned, and one of the researchers (Margaret).

During the second meeting, Margaret implemented the Directions personal planning program (described in Chapter 5). In preparation, Mandy had been asked to think about some dreams she had for her life and to cut out pictures from magazines to help convey her visions for the future. She brought more than a dozen pictures to the first meeting. Since then, the Directions plan has been the focus of the meetings. Within four months, many of her "dreams" were realized. Some of her dreams were to get more friends for the circle, finish Grade 12, pursue more music, become a millionaire, and start a self-employment venture. The Directions plan and some of the outcomes are displayed in Appendix A.

Aside from the Directions program, Mandy used use other literacy-based tools including the magnetic weekly calendar and the cleaning support tools. However, these tools were all supplied by the literacy team and modified with input from Mandy. The support circle did not participate in the development of the literacy tools because they were not interested and did not feel the need to get involved. However, the circle members did

provide literacy support in that they helped Mandy fill out forms whenever she needed help.

During the first few months, the membership changed. The parents of the other subject no longer attended, and Mandy's girlfriend quit coming too. Mandy's girlfriend was the only circle member who had a prior relationship with her. The reasons for her eventual withdrawal from the circle were never made totally clear, but apparently, Mandy made the decision to exclude her. Mandy perceived her friend was not being secretive enough about some money Mandy had received through a small claims settlement. Mandy also contended that her friend was jealous of this money and the new friends in the circle. In addition to these grievances, Mandy also claimed that her friend, had breached "confidentiality" when she told Mandy the name of someone's mother who had committed suicide. However, the most important reason to Mandy was that the girlfriend was always trying to tell her what to do and how to run her life.

The research team was also able to interest a middle-aged woman who wanted to get some first-hand experience to complement her counseling courses. Mandy enjoyed this new member who loaned her self-help tapes, and who counseled her in person and on the phone outside of circle meetings. These counseling sessions continued until mid-October. As well, this woman brought clothes for Mandy to try on. On one occasion, she joined Mandy and Margaret for a luncheon.

When Mandy joined the Salvation Army, she started going to church, taking Bible lessons and singing in the choir. Once a week, the woman who played the organ gave Mandy free piano lessons. Mandy enjoyed her association with the church and claimed she was no longer going to the bars or having anything to do with friends who drank alcohol.

A fellow Salvation Army colleague decided to join the circle meetings. During her first meeting, this person expressed some concerns. She noted that Mandy was continuing a relationship with an older male friend with whom she had gone to the bar for a beer. As well, this woman objected to the support circle buying lottery tickets in order to pursue Mandy's goal of becoming a millionaire.

Margaret attempted to address these concerns. She said that she was pleased that Mandy had gained new friends in the support circle and in the Salvation Army. However, she worried about Mandy losing her former friends who had a much longer history and intimate connection with her. Margaret pointed out that the older male friend, who had taken Mandy to the bar, had, in the past, protected her from an old boyfriend who had been abusive to her on occasion. This male friend did repairs for Mandy and even replaced her fridge when it broke down. He was also available to her when she needed someone to talk to. Margaret added that the loss of this man's friendship, along with the loss of her ex- girlfriend's friendship, would deprive Mandy of support that other circle members could not provide. She worried that their loss might have some very negative repercussions in the future. The circle member from the Salvation Army eventually conceded that Mandy's relationship with this male friend might be beneficial, as long as

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he refrained from taking her drinking. After the meeting, the lead researcher told Mandy that circle members would discontinue buying her lottery tickets. Mandy objected. "Oh well, that is her belief...we can still do it." This was the only meeting that this church colleague or any other Salvation Army person attended.

After their break-up, Mandy's girlfriend phoned her and attempted to discuss their differences, but Mandy would not relent. She asked the phone company to "block" her friend's incoming calls and effectively stopped all communication. As Mandy told the researcher, "I don't need her friendship because I have new friends, now." Over the next six months, however, these two seemed to patch up their friendship and are now on good terms again.

During the first months of the project, Mandy telephoned Margaret on numerous occasions, day and night, often in a rage because of a particular challenge, issue or person. Margaret would continually threaten to hang up unless Mandy refrained from shouting at her. Mandy would always apologize but, invariably, had a hard time restraining herself. Mandy eventually acknowledged her anger problem seeking the help of her doctor who prescribed the anti-depressant medication, Paxil. Thereafter, she reported feeling less anxious, and the angry phone calls stopped. About a month later, the counseling student member of the circle reported that Mandy had telephoned her after midnight, waking up everyone in the house. At the next circle meeting, Mandy apologized and the incident has not been repeated.

On many occasions, Mandy told Margaret that she was often upset because people were always trying to boss her around and that people often had no "respect" for what she wanted. With this in mind, Mandy asked the lead researcher to tell everyone in the circle "not to tell me what to do."

Mandy has occasionally taken advantage of free counseling offered by a community services agency, a service available to everyone in the area. However, she has been unable to secure help based on the fact she has FAS. On behalf of the Circle, the research team tried to get additional support services for Mandy based on her special needs. In response to the Circle's / research team's appeal, the Director of the Community Living Agency attended a circle meeting and said that Mandy did not qualify for services from her department because her IQ was too high. However, because they had an opening, she said that they could take Mandy on group outings every week while the vacancy remained. Mandy was initially eager to participate but soon lost interest. She claims that the other clients were extremely handicapped, and that she could not even carry on a conversation with them. She claims she was also terrified that one of the clients would choke on their food when the staff went for a cigarette break during dinner.

Other agencies were unable to provide help, nor could any of their staff attend Mandy's support circle meetings. However, the local Mental Health agency did say they could help if ever Mandy threatened suicide. Margaret took advantage of this offer one day in September when Mandy telephoned to say that she was very upset about her ex-boyfriend. Mandy suspected he had come into her apartment the previous week and

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urinated on her walls. Mandy claimed that her ex-boyfriend regularly visited the two women who lived up stairs, and while there, he would yell at her and spy on her through the ceiling. She even expressed fears that he could read her thoughts. She said she wanted to kill herself if this harassment continued. She felt she was unable to leave her apartment because he might break in and steal things. Margaret promised that she would get help for Mandy. Residing two hours away and with family commitments of her own, Margaret was unable to travel to Mandy's home. Instead, she telephoned the local crisis line and the Mental Health agency for help. Meanwhile Mandy had telephoned the police. Staff fom each of these agencies responded by telephoning Mandy on a regular basis until they felt certain she was stable. The Mental Health agency also enrolled her in a biweekly day program that teaches life skills such as cooking and communication. As well, she was enrolled in a stress reduction course one evening a week from which she would be provided a ride home.

In an effort to extend the supports offered by local agencies, the research team re-contacted all of the local support agencies asking for cleaning support for Mandy. They explained that Mandy had moved to a new apartment months ago but was unable to clean her place because she was unable to figure out what to do with all of her boxes of belongings. The team predicted that as Mandy's apartment became more unmanageable, so would her life. Two months before publication, the director of the local community support services said that she would try to get weekly or bi-monthly cleaning support for Mandy. By publication time, this support had not materialized.

Mandy regularly expresses sincere appreciation for the friendship that we have given her ·and the help that we are trying to get for her. Although Margaret will continue to attend as many circle meetings as she can in the future, she is concerned about Mandy's well being. As of mid-October at the time of publication of this report, Mandy and Margaret are the only two people who attend meetings. When asked if we should try to get a social worker involved in her life, Mandy exclaimed to Margaret, "*I do not want a social worker. Besides, I don't need one because you are my social worker.*"

Margaret was unable to attend the most recent "Friend's of Mandy Support Circle" meeting so none was held. It is apparent that the circle's existence is, at least for the present, dependent upon her.

4. Kathy's Support Circle (20 year old, supported transition)

A number of literacy-based tools were introduced into Kathy's life, and the circle members (primarily her mother) monitored and altered them to fit Kathy's particular needs. The range of literacy-tools developed is discussed in the next two chapters.

Kathy lives in her parents' home and "rents" the basement suite; her 19-year-old younger sister also has FAS and lives with the parents in the main house. Kathy has finished high school and now receives a range of support for her employment and daily living needs. She is the only subject to receive this support because her IQ is less than 70. An employment worker finds Kathy volunteer job placements, gets her started in the

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position, and then occasionally monitors her progress. A cleaning worker comes in once a week to help Kathy clean her living area and another takes Kathy shopping for groceries and other needed supplies. Her mother feels physically and emotionally overwhelmed by the extra work that it takes to help manage and schedule Kathy's new, complex life.

It took almost four months, after the initial contact, to organize the first circle meeting for Kathy. The family was very busy and found it difficult to make the time to get everything arranged. It was also difficult for the family to recruit enough volunteers for the circle. Four other members are primarily friends of the mother and work in support agencies not directly connected to Kathy's case. Margaret's daughter volunteered for a few months before her work and school obligations became prohibitive. Kathy readily attached to this young woman and was unhappy and confused when Margaret's daughter no longer went on outings such as roller blading with her. The most recent members are a young cook and a housekeeper who are employed at the senior's care facility in which Kathy works. Kathy has become friends with both of them.

Margaret went over the Directions personal planning format with Kathy a month before the first circle meeting. Although she was asked to spend the next week looking for pictures to help generate ideas to brainstorm dreams and goals for the future, Kathy did not bring any to the first circle meeting. She was reminded to bring pictures for the subsequent meeting but neglected to do so. Kathy expressed little or no interest in the computer generated graphics that the research staff provided to help trigger ideas for dreams and goals. However, during the Directions session, Kathy was able to come up with some ideas with some support and prodding from other circle members. It is not clear whether she has ever achieved a clear understanding about what the Directions or support circle program is all about. Kathy's new friend, the cook, is helping her find pictures for this map and they are supposed to be used at the next meeting.

Kathy's first meeting took place at the family's church but subsequent meetings have been held in Kathy's apartment in the basement of her parents' home. Telephone calls and other personal distractions often interrupt these meetings, but the setting did allow for Kathy's uncle to join the sessions from Ontario via a speaker phone which was placed in the center of the living room during meetings.

The regular circle members include: Margaret, Jennifer, Kathy, Kathy's parents, Kathy's uncle, Kathy's ski coach (who is also a director of a government run community living program), Kathy's respite care-givers (a husband and wife team), a director of a church-run community living program, and the young cook and the housekeeper.

Since the formation of this circle, Kathy seems to have altered her relationships with some of the members. According to her mother, Kathy now considers her ski coach "a friend"; whereas she had previously thought of her as an "enemy" because she was always telling Kathy what to do. A breakthrough in their relationship apparently occurred a few months after the formation of the circle when the coach took

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Kathy out for a friendly outing. Kathy is presently very attached to the young hairdresser and her young son. Kathy accompanies them on shopping trips and, also, helps her out in her home. According to her mother, Kathy has become, for the first time, interested in hairstyles and in makeup. The cook and Kathy even plan to work together in an upcoming modeling show thus enabling Kathy to achieve her goal of becoming a model.

It is difficult to assess Kathy's enthusiasm for the support circle. She phones all of the circle members to remind them of upcoming meetings, but does so under her mother's direction. On her own volition, Kathy spends some of her weekly grocery money on juice and cookies for a circle meeting, which surely indicates some measure of interest.

Kathy's mother usually leads the circle discussions. She often spends a lot of the meeting time trying to explain some of the problems that have arisen for Kathy over the last month. Conflicts with male and female friends, work placement complications, and support worker problems seem to top the list of concerns. Kathy does not add much to these conversations except to express a dislike for fighting with friends or for working with certain support people. She has trouble concentrating and gets very restless with the proceedings.

At every meeting, Kathy's mother expresses grave concerns about the poor job she feels some of the support workers do. For example, the cleaning woman came in one week and left early, not completing the jobs that were to be done. The worker helped Kathy strip her bed but they did not remake it and unbeknownst to Kathy's mother, Kathy slept without sheets all week. Kathy's volunteer work situation is also plagued with problems. In an email message, Kathy's mother explains: *"It has also been a nightmare getting Kathy's schedule in place. Even today her schedule got changed again."*

Despite many discussions, the Circle has not been too effective in its attempts to address the service worker problems. The reasons for this are many. The closest research staff members live four hours from Kathy's community and have only been able to make telephone calls with no positive results. Most of the other circle members work for one support agency or another and hesitate, as one member said, *"to step on toes."* Kathy's mother has effected some changes as a result of lodging a number of complaints. She describes the outcome with the cleaning support:

> **The worker that comes now is great and they get along well. The boss at (the agency providing cleaning support services) was horrified to hear some of the things that happened with the last girl.**

New problems, however, always seem to arise. The latest crisis seems to be connected to one of the newest circle members, the housekeeper. According to the mother, the housekeeper has made critical remarks regarding Kathy's support services, remarks that have led to some interesting developments. She explains the situation as follows:

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She has told Kathy that she does not need anyone to help her clean her apartment. Perhaps she (the housekeeper) would like to come and do a food and used sanitary napkin search sometime???? So, now Kathy is objecting to having a cleaning girl come.

Apparently, the housekeeper also made negative comments about Kathy's volunteer placement and her employment worker at the senior's home. In response, Kathy did not want to go to this job placement again. This problem required considerable intervention by Kathy's mother before Kathy would return to this work situation. Now Kathy's mother complains this friend is becoming a "God-like figure" to her daughter but does not seem to understand the implications of Kathy's disabilities. She provides some other examples:

> *We also can't get Kathy to come to church anymore because her new friend says that she doesn't place much importance in church...She is also carrying a condom in her wallet now, just in case. That is good maybe, but again she was totally convinced to "wait until marriage" before her new friend came along...*

Two members of the support circle work as directors of programs that support adults with disabilities. They have been invaluable informants, helping everyone else understand the policies and restrictions surrounding the maze of programs offered in the area. One of them has met with Kathy's social worker and discussed her challenges and needs. She was disappointed to report to the group that his agency will only offer $1400 a month for a full time support home for her. The social worker does not consider Kathy so disabled as to require more support than this amount of funding would provide. The circle members conclude that it will be impossible to find adequate care and housing for Kathy with this amount of funding. This situation forces the parents to continue their role as caretakers unless there are changes to local policy.

The circle plans to meet every two months during the winter; however, the members intend to stay in touch with each other by telephone or email in order to communicate concerns and new information to one another.

5. Brenda's Support Circle (19 year old living with parents)

We assumed that Kathy's sister, Brenda, would be eager to participate in Kathy's circle meetings and then be inspired to have one of her own. In an email message to the mother, Margaret wrote, *"I am hoping Brenda will think it is pretty cool and want a circle for herself."*

Apparently, Brenda did not think Kathy's circle was "cool". She wants nothing to do with Kathy's circle, nor does she want one for herself. Like Bert, she seemingly does not

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want to be involved in an organization that has anything to do with singling her out because of her FAS challenges.

As was noted in Chapter 2, Brenda has graduated from high school and is trying different jobs with horses because they are her passion, and she has an accomplished skill, performing very well in many horse events in her region. Brenda does not seem to have trouble getting jobs but does have trouble keeping them. In July, she started work in a neighboring province. It was a dream job as it involved working with horses and provided room and board and a small wage. Her parents moved her and her horse to this new location with high hopes but, from the start, Brenda had many problems with her new employment challenges. For example, she kept forgetting things and was not working the hours that the employer expected. Her mother flew to the ranch and stayed a week to put in some interventions but Brenda was resistant to this perceived interference. Brenda was let go in August, having to forgo her final wages. Her parents had to go and get Brenda and arrange for her horse's return. They estimate that the job cost them many times more than the amount Brenda earned.

After returning home, Brenda got another job working with horses. She still has this position but is having trouble meeting her boss's expectations. Her parents take heart in that she is performing better than she did at her last job. They believe this is due to her boss's predilection for lists. Regardless, the job is a real struggle, but Kathy was still working at the time of publication. This job experience is described more fully in Chapter 2.

C. Outcomes – General Conclusions

As was suggested above, one of the most difficult parts of the project was recruiting and retaining circle members. The focal person's motivation and participation also posed problems. The Circles also left us with a number of unresolved dilemmas. To conclude this section we list the advantages and considerations informing and administering support circles.

1. Recruiting Circle Members

We entered this project assuming that recruiting and sustaining a healthy circle membership would not be too difficult. We were wrong.

Mandy's circle started with five people but within six months it was down to two - Mandy and the lead researcher. Kathy's mother described the problems she had trying to organize a circle for Kathy:

> **I have not reached everyone yet and some people are
> very worried about the commitment time factor and**

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have not committed. They also want to know about how often the meetings are, etc. ... Everyone is so... busy.

Eventually, Kathy's mother was successful in recruiting five regular members aside from her immediate family and the research team. However, she is having trouble keeping everyone connected to her daughter's circle.

In an email, Kathy's mother described the situation as it was developing for one circle member after four month's attendance:

> **I had lunch with (a circle member) on Thursday and I feel she is rather intimidated by FAS individuals. I clued her in to Kathy's appearance being so 'with it' and then the truth. I also gave lots of examples of her thinking deficits. I likely made her more scared.**

Of the three circles, Kathy's is the most intense. In fact, both Margaret and Jennifer experienced migraine headaches after every meeting. Perhaps it is because these meetings focus so much on problems. However, this circle may have no choice. The family is not getting the support it needs. If the mother's health fails further, it is hard to imagine what will happen to her daughters because her husband is forced to take short-term jobs away from home. Because of the lack of services for their adult daughters, the parents can not leave their present home in order to find work, but at the same time they cannot afford to stay financially. Indeed, they are caught in a difficult, if not impossible situation and the circle is motivated to help all of them. Unfortunately, none of us know quite what to do. We are haunted by Kathy's mother's plea, " What is going to happen to our future?"

Mandy's circle is generally more positive, avoiding problems and focusing on plans for the future. As well, the meetings provide Mandy an opportunity to share the details of her life and chat with friendly people. Although progress is often slow, and the

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circle membership has dropped drastically in numbers, Mandy remains highly motivated to attend- insisting on bringing the coffee maker, coffee, cream and sugar for the meetings, despite having to carry all the supplies from her home, almost a mile away.

2. Focal Person's Motivation and Participation

B.

C. We assumed that all of the subjects would be eager to have a support circle of their own. It seemed reasonable to conclude that they would connect to the obvious benefits of having friends and family members help them pursue their dreams. This was not the case. Only three of the five subjects expressed an interest in circles, one of whom moved before a thriving circle could be formed for him.

D.

E. At the time of publication, Mandy, the oldest of the subjects, remains intent on her support circle even though she and Margaret are the only remaining members. Kathy, the other circle support recipient, is not so enthusiastic. Although she has the most viable and active of the two circles, she has had her reservations about participating. As Kathy's mother communicated in an email message:

> *I am having difficulty with Kathy who sees this as another insult to her from FAS. She thinks it really makes her look stupid. I think she will get over it. She will likely shut down in the meeting because of it being overwhelming with talk.*

F. 3. Unresolved Dilemmas

Margaret was unable to resolve the following dilemmas that arose as a result of creating and using Support Circles:

- ♦ Should every member of the circle be informed about FAS/FAE and the typical behaviour challenges that are associated with the disorder?
- ♦ Should every member of the circle be forewarned about aberrant behaviours that a e or have been expressed by the individual such as stealing, sexual promiscuity, or lying?
- ♦ How many and what kind of problems should the members of the circles address?
- ♦ Should the circle focus solely on building more social connections for the focal individual rather than on resolving problems?
- ♦ Should the circle meetings be fun, carefree and forward-looking or should they be problem-solving sessions? Can they be both?
- ♦ How much stress and responsibility can the circle membership assume in attempting to help the focal person and their family with their stress?

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4. Advantages of the Literacy-Based Support Circles

We designed the circles to be focused and conducted around the Directions cognitive enhancement tool described in Chapter 5. The Directions program provides several invaluable ways to structure meetings as well as to help the focal people with various aspects of their lives, including self-assessment and the planning of their futures.

a. Strengths of the Directions program:

i. General contributions:

- Easy to use and easy to follow.
- Easy for individual to contribute ideas (prompts).
- Can be motivational.
- Structured planning tool in terms of personal growth, employment, and education.
- Pragmatic, sequential tool.
- Prioritizes goals and dreams.
- Not focused on behavior problems and challenges, yet recognizes limitations.
- Concrete, does not judge.
- Versatile.
- Looks at every aspect of a person's life—i.e. recreation, employment, social life.
- Can help the individual conceptualize the connections between action and outcomes.
- Provides individuals a method/tool to plan other aspects of their lives i.e. a business, etc.
- Helps identify individual interests, preferences and strengths.
- Puts everything 'on paper' and makes it real and concrete.
- Avoids the 'scatter gun' approach.

ii. Personal evaluation:

- Helps the focal individual conceptualize their future and look at their current life situation is a positive way.
- Helps the focal individual realize there are other people in their lives who can help.
- Helps the focal individual examine their present state of affairs and visualize a future scenario, and helps them to identify goals and plans that should help make this scenario achievable.

iii. Supporting other members of the circle:

- Gets everyone on the same page regarding performance expectations for themselves and the focal individual.

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♦ Clarifies roles of support people.

iv.   Needs served by the broader community:
♦ Helps identify service needs.

v.   Planning for the future.

vi.   Organization of meetings.

5. *Considerations in Forming and Administrating Literacy-Based Support Circles*

This study revealed a number of problems and concerns regarding forming, administering, and maintaining the circles.

i.   *Requirements for effective literacy-based support circles:*
♦ *Demands strong leadership and good facilitation.*
♦ *Leader requires insight into disorder, i.e. FAS.*

ii.   Concerns expressed by circle members:
♦ Difficult for some members to see "dreams" session as valuable; they prefer "goals."
♦ Planning focuses on little things that are doable; lots of participants want focus on big things - they see "baby steps" as a waste of their time.
♦ Meetings can be emotional and highly stressful for all participants.

iii.   Concerns about the organization of the circles and recruitment of members:
♦ Difficult for a family member or focal person, himself/herself, to administer.
♦ Requires group dynamic and support that is difficult to obtain and sustain.
♦ Difficult to recruit a wide spectrum of support people.
♦ Meetings can attract professionals whose sophisticated conversation can exclude focal individuals and other circle members.
♦ Meetings were not attended by support workers; therefore, circle members felt disconnected or feared "stepping on toes" and, thereby, interfering with service agencies.

iv.   Concerns about the conduct of the meetings:
♦ Family members or friends with an issue can hi-jack sessions to address their personal problems with the focal person or other circle member(s).

v.   Concerns about special interests:

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♦ Some members may represent a certain religious or political point of view and try to force this point of view onto other members.

♦ Some members may not understand the limitations of the focal person and will undermine attempts to provide support (e.g., cleaning services).

♦ Some members may respond very negatively to weaknesses of the focal person and undermine attempts to provide support (e.g., warn the community about possible sexual deviant tendencies and hamper attempts to build social bridges into the community).

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CHAPTER 4

LITERACY- BASED COGNITIVE COMPENSATORY TOOLS

This chapter presents the literacy-based cognitive compensatory tools that the research staff and circle members developed for this study. We explain the nature of these tools as well as the rationale for their use, and incorporate into the discussion, information from other cognitive support studies. We then examine the tools and show how subjects responded to their use. The chapter ends with a section we entitled, "Recapitulation" in which we discuss the objectives and successes, and caveats and shortcomings of the intervention systems that were implemented.

The chapter is presented under the following headings:
A. Rationale and Guidelines
    1. Understanding the Need
B. Literacy-Based Cognitive Compensatory Tools
    1. Weekly Magnetic Calenda
    2. Cleaning Support Tools
    3. Student Tracker System
C. Case Studies
    1. Weekly Magnetic Calendar
    2. Cleaning Support Tools
    3. Student Tracker System
D. Recapitulation: Objectives and Successes; Caveats and Shortcomings
    1. Assessment of the Magnetic Weekly Calendar
    2. Assessment of the Cleaning Support Tools
    3. Assessment of the Student Tracker System

A. Rationale and Guidelines

Understanding the Need

Cognitive compensatory tools are simple devices designed to help compensate for memory problems. These tools are designed to, in the words of scientists from the field

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of TBI[1], *"have the potential to prosthetically improve memory for a person..."* (Chestnut, R.M., Carney, N., Maynard, H., Patterson, P., Mann, N.C., Helfand, M., 1999, p. 63).

Two studies conducted with TBI patients provide evidence that cognitive compensatory supports helped improve their memory performance. Using personally adapted tools such as an electronic device, a notebook, and an alarm wristwatch, researchers proved that these tools could *"reduce everyday memory failures for people with TBI"* (Chestnut, et al., 1999, p. 6).

Memory failures often overwhelm the lives of children and adults with FAS/FAE. In their website devoted to FAS/FAE, The British Columbia Special Education Branch describes the many problems that memory deficits can bring to affected students:

> *A student with FAS/E may experience difficulty with:*
> * *retaining and using information,*
> * *retrieving previously stored information,*
> * *utilizing sequences of information, and/or*
> * *following through on instructions from others*
> >   *(British Columbia Ministry of Education, website)*

This information indicates that memory problems can have a negative effect on a wide range of functioning. It can affect the extent to which an individual with FAS/FAE can recall information, organize and use information, and/or follow instructions from others.

According to the British Columbia Ministry of Education's website on FAS/FAE, *"...Often, memory for visual information is stronger than memory for information presented orally"* (British Columbia Ministry of Education, website). With this understanding, we used literacy-based cognitive support tools in this study. Because literacy-based information emphasizes the visual, it was postulated that these tools would be effective.

Literacy-based interventions have long been recognized as effective strategies to counter memory deficits and the other cognitive problems associated with memory failure. For example, Schmucker (1996) recommends that care managers working with adults with FAS/FAE try these simple strategies:

> Write things down for people and keep the rules simple. Have a list of things that have to be done that gets checked off daily or weekly. Put the list where it will be seen and call to remind the person that they should check the list. (Schmucker, 1996, p. 99)

Literacy-based tools provide very inexpensive, easily constructed, concrete supports. The instructions are obvious and can help individuals in a number of ways. If the individual has difficulty initiating a task, they can refer to their literacy-based support tool and read

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[1] traumatic brain injury

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how to begin. If they forget the order of the steps, they can read over the support tools and easily remind themselves of the next step to take. They help provide what Dr. Sterling Clarren, one of the world's foremost FAS medical researchers, says is crucial for the successful functioning of FAS affected people – "*an external brain*" (Kleinfeld, 2000, p. 336).

Support people may also find these tools helpful. They can easily review the tool and remind themselves of the tasks to be performed and how best to help the individual. Many of the tools provide clear guidelines as to how the support person can best help the individual. They provide a template for performance that can be easily assimilated by new workers, who can then adapt their services to the patterns and expectations already familiar to the affected individuals. Not only that but, disruptive effects frequently associated with staff changes can be ameliorated. As Schmucker explains, "*Routine is extremely important and things can instantly go haywire with just the smallest change to the routine*" (p. 99).

Lists are probably the most common cognitive compensatory tools used with people who suffer memory problems. In a study with students with mental retardation, a computerized matching activity, using lists of pictures and names, was successful in helping these learners perform memory tasks. Although performed in an institutional setting without relevance to everyday living challenges, this study suggested that such methods could be established to help build a "rudimentary repertoire" of performances that *could* be used in more natural settings (Stromer, Mackay, McVay, & Fowler, 1998).

We hypothesized that literacy-based cognitive support tools might have a number of other advantages. We thought they might help to depersonalize intervention thus reducing the potential for conflict between the subject and their support person(s). Further, we hoped that an increased level of independence might result, and that the individual's self-confidence might thereby be bolstered. Cognitive therapy studies with patients with TBI suggest that both of these outcomes may be possible. In the research report, *Evidence Report/Technology Assessment Number 2, Rehabilitation for Traumatic Brain Injury*, the authors, Chestnut, et. al. (1999) state that "*There is evidence from one study (Class II {a}) that compensatory cognitive rehabilitation (CCR) reduces anxiety and improves self-concept and relationships for people with TBI*" (p. 6).

B. LITERACY-BASED COGNITIVE COMPENSATORY TOOLS

These simple word-based tools (lists, etc.) support certain cognitive processes such as remembering, organizing or planning. These tools and their accompanying intervention

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Literacy-Based Supports for Young Adults with FAS/FAE

strategies are designed to improve daily functioning and, with extended use, may result in long-term beneficial effects if the desired behaviours becomes habituated.

Purpose:
- ◆ To support memory and organizational functions.
- ◆ To increase independence of the individual.
- ◆ To increase confidence of the individual.
- ◆ To reduce the need for constant reminders and repeated instructions from support people.
- ◆ To depersonalize intervention and possibly decrease interpersonal conflict.
- ◆ To provide a standard of performance that is clear and consistent regarding everyone's role and responsibilities.
- ◆ To provide a constant support system that does not change when support personnel changes.
- ◆ To provide a support system that does not require extensive knowledge of, or experience with, FAS/E on the part of the support workers.

Features:
- ◆ Simple, concrete, predictable; can be used in diverse ways.
- ◆ Expectations are reasonable, never onerous, and are presented in a logical sequence.
- ◆ Flexible and adaptable.
- ◆ Externally developed, in consultation with the subject/client.
- ◆ Illustrations can be used, when appropriate and inspiring.
- ◆ Stimulus control factor– can help set a framework indicating when, and under what conditions, certain behaviors are appropriate.
- ◆ Requires everyone involved to be aware of and to understand the tool, as well as its purpose and mechanics.

Support:
- ◆ Consistent and positive.
- ◆ Does not require a deep understanding of FAS/E.

Hypothesis of motivation which guided this study:
We hypothesized that the biggest obstacle to the success of the cognitive support tools would be the individual's lack of motivation to use them. To help address this concern, most of tools were designed to integrate reward-based incentives. 'Choice" was also built in to most of the tools. We postulated that "choice" is a motivator, when individuals can negotiate what tasks they do each day.

- ◆ Positive motivators (reinforcers) may be effective in developing a wide range of desirable skills/behaviours and in reducing some inappropriate behaviours.
- ◆ Positive motivators (reinforcers) are usually more effective and lasting than are negative consequences or deterrents.

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◆ Concrete rewards may be the most effective reinforcer for some individuals.
◆ Immediate rewards may be more effective than delayed rewards for some individuals.
◆ Personal interest, skills, and talents must be considered when selecting effective motivators/reward systems.
◆ Obsessive interests can serve as effective motivators.
◆ Motivators may be changed when necessary.
◆ Motivators can be eliminated when behaviours become habituated or when intrinsic motivation takes hold.

Hypothesis of intervention which guided this study:
◆ Positive environmental changes can lead to positive behavioral changes and personal growth.
◆ Developing the individual's existing strengths and interests is a more productive approach than trying to repair or upgrade the deficits.
◆ If the intervention is not working and the desired behaviours are not occurring, attempts to change the intervention tool or implementation methods may be more productive than trying to change the individual.

Seven practical cognitive compensatory support tools were developed for and tested by the FAS/FAE affected subjects in this study. They are listed below and all are illustrated in Appendix A:

1. magnetic weekly calendar
2. cleaning support tools
3. student tracker system
4. grocery aid
5. task lists
6. problem journal
7. telephone message board

In this report, we will examine three of these tools - magnetic weekly calendar, cleaning support tools, and student tracker system. All were designed to help the subjects bring sequence and order to their daily lives and to accomplish the tasks they need to do with a minimum of minute-to-minute monitoring by others, particularly others in authority. While these tools proved to be advantageous for those who used them, the tools themselves require ongoing adaptation to maintain their effectiveness. Case studies of the individuals' uses of these tools are reported below.

1. Magnetic Weekly Calendar

Purpose:
◆ To establish a daily schedule of tasks and rewards (optional).
◆ To determine an appropriate sequence of activities and events.
◆ To provide a visual record of what has or has not been done through the use of simple manipulatives (e.g., medications taken).

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♦ To provide a visual cue to determine when rewards (optional) are due.
♦ To depersonalize directives and reduce the need for constant reminders from support people.

Description:
(See illustrations in Appendix A)

Cleaning Support Tools

Purpose:
♦ To increase independence.
♦ To increase confidence.
♦ To depersonalize expectations and interaction, thus reducing the potential for conflict with the support person.
♦ To provide a concrete, literacy-based support that the individual can refer to continually, without having to ask for direction.
♦ To provide a concrete support that does not require highly developed judgment or reasoning skills to use it effectively.
♦ To provide a standard of performance that is clear and consistent, and does not allow individual or worker to evade expectations.
♦ To provide a constant support system that does not change when support personnel change.
♦ To provide a support system that does not require support workers to have a lot of knowledge or experience with FAS/FAE to be successful.
♦ To provide directions on how to clean each room.
♦ To determine an appropriate sequence of tasks.
♦ To provide a visual record of what has or has not been done through the use of simple erasable check marks on the laminated surfaces of each sheet.
♦ To provide a visual cue to determine when rewards are due (optional).
♦ To depersonalize directives and reduce the need for constant reminders and repeated instructions from support people.
♦ To help the client clean each room as quickly and successfully as possible.

Description:
(See Appendix A for illustrations.)

Features:
♦ Comprehensive: includes all of the details necessary for task completion.
♦ Patterned: the same expectations and sequence every time.
♦ Simple and concrete: no room for interpretation.
♦ Choice: individuals can choose to do some or all of the tasks and decide for themselves, which jobs they would prefer to do. The support person does the rest.
♦ Reasonable re: expectations.
♦ Reasonable re: time frame.
♦ Reward-based (optional): provides a satisfying reward for performance
  Recommendations:

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i. rewards can be offered on a sliding scale (great performance earns full reward, mediocre performance earns half reward, very poor performance earns no reward).

ii. rewards can be immediate, postponed, or both – for example, full performance all week can earn immediate rewards each day plus a special outing Saturday.

iii. rewards can include a favourite TV program, special snack, desired outing, computer-time, or money.

♦ Nonjudgmental: provide positive feedback in response to all levels of performance (poor performance elicits reassurances for better success next time).

♦ Adaptable: these tools are more flexible than are individuals with FAS/FAE. If the desired behaviours are not forthcoming, adapt the literacy tool, reward or the implementation process. Do not try to force the individual to comply.

♦ Function Focus: aim for improving the level of function not for perfection.

◊ Prioritize: some things are more important than others.

Student Tracker System

The student tracker system includes four components. The first two are mandatory and the last two are to be used if and when necessary to reinforce instructions given during class or homework time.

1. Schedule for the week's classes.
2. Student agenda book.
3. Task sheets for classroom regimes (if required).
4. Short instruction notes (e.g. sticky notes for reinforcement, etc.).

3.1 Schedule for the week's classes

This is the simplest tool to prepare and to implement. Every Monday morning, with a learning assistant, the student fills in a blank weekly class schedule. The student then photocopies this sheet and puts a copy in each of the relevant teacher boxes. As well, the student *faxes* a copy home, puts one in his/her binder, and tapes one to the inside of his/her locker door, or writes the schedule in his/her agenda book. If it is not possible to fax a schedule home, then some way must be devised to insure that the parents receive a copy of the schedule so that the parents know what classes their child has on a day-to-day basis.

3.2 Student agenda book

This student agenda book must have one important feature: it has to look like every other student's agenda book. If this book distinguishes the student from the other students, he/she may start hiding it, or even losing it.

Teachers must write in this agenda book every time the student is in their class. Later that day, when the student presents his/her book at home and every teacher has made notations, he/she will be allowed to enjoy specific rewards such as treats or privileges. Missing notations will trigger certain negative consequences at home,

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such as the loss of the specific rewards. If the agenda book is filled out appropriately every day of the week, the student may be offered a significant reward on Friday night.

These rewards need not be monetary. TV, computer, phone or Nintendo time could work. A trip to the local aquatic center or a movie could be considered a significant reward for the end of the week. The reward system is crucial It will help the student to comply with the expectations and help the teachers insure that the agenda book gets filled in every class. As well, the loss of rewards helps the teachers remember to sign the book knowing that the student will be punished if they do not.

Teachers' notations should include a brief description of the student's performance in the class as well as the student's homework assignment. These comments are important because they keep the teachers and the parents informed of the student's progress, or lack of progress, in all classes. The student may perform well in some and poorly in others, and the agenda book may heighten a general awareness about the student.

The agenda book is the most important aspect of this cognitive support tool system. It is also the most difficult to implement because it demands that teachers remember to fill in the book every day. Teachers are often busiest at the end of classes- the most appropriate time to have the agenda filled out. As well, students are unlikely to approach teachers when they anticipate negative comments. The student may claim to have misplaced the agenda book in order to avoid receiving negative comments or to foil parental scrutiny of said comments. In the former case, the teacher writes comments on a Post-It or other small piece of paper, and asks the student to take that home to parents.

At home, the parents must try to insure that their child produces this agenda book every night as soon as the child gets home from school. If possible, the parents should send the child back to school every time he forgets the book. When distance precludes this step, the student should be asked to phone the various teachers and obtain the required comments in that way. Whenever necessary, the parents will write notes for the teachers and tape them in the appropriate page in the agenda book for teachers to read.

3.3 Task sheets
If the student has a class with routine procedures that may have to be performed on a regular basis, it may be a good idea to give him a very clear list of the tasks that are expected of him. He may memorize the list in a few weeks, but it might be a good idea to enforce its use every class. The student might otherwise avoid doing required tasks, and unless the list is used, tracking of performance can become difficult. Laminated sheets containing required tasks and spaces for checkmarks at the conclusion of each task might prove useful, especially in classes such as Home Economics and Industrial Technology.

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3.4 Short notes (e.g. sticky notes)

FAS/FAE affected students often do not process auditory information very well even though they may claim to have heard and understood all of the instructions that were given. Sticky notes pasted into the agenda book or on the corner of the desk may give the student the support he needs. Some hints for these short notes are:

- Keep them simple and concrete: leave no room for interpretation.
- Make them sequential- in order of tasks to be performed.
- Make them reasonable regarding expectations.
- Make them reasonable regarding time frame.
- Keep them nonjudgmental- provide positive feedback in response to all levels of performance -poor performance elicits reassurances for better success the next time.
- Focus on function- aim for improving the level of function not for perfection.
- Prioritize items- some things are more important than others.

Description:
(See illustrations in Appendix A)

C. Case Studies

1. Magnetic Weekly Calendar

a. Bert's magnetic weekly calendar (reward-based):

Mother's report on the tool:

Every day, Bert has certain jobs to do. He used to put a great deal of effort into avoiding them, often spending more time and energy avoiding the work than the work itself required. Sometimes, he resisted so vehemently that he would start yelling, throwing things or even punching holes in doors. It would have been much easier for me to do most of the jobs myself, but we think it is important that he learns to look after himself.

When we started to use this calendar, the change in behaviour and attitude was immediate, especially between after-school and bed-time. He started doing his jobs, showering and brushing his teeth before bed, and we no longer had to get angry and force him to do what he was supposed to do. I think the magnetic calendar had a significant impact on our lives, quite remarkable for something so simple.

In large part, the secret to its success is the reward we used at the end of every day: email and chatroom access. When his computer crashed, a few months after starting to use the magnetic calendar, his behaviour crashed, as well, instantaneously. We were back to square one, trying to force him to get ready for bed. He reverted to lying and trying to sneak out of his showers.

Two months later, he got a new computer, and the program began to work again.

I suppose the <u>magnetic calendar</u> will work as long as he is consumed by his interest in chatroom, email, and playing computer games over the modem, and as long as we can control his access to the internet. He can only get on-line when I unlock our bedroom door and plug him into that room's phone line.

He is now in Grade 11 and plans to leave home when he graduates. If he does, I doubt he will want to take the calendar with him and things will unravel for him. But for now, it is quite a God-send to our family. Maybe when he gets a lot older, he will realize that he needs this kind of help to keep his life together.

A replica of Bert's calendar is in Appendix A: Literacy tools.

b. Mandy's magnetic weekly calendar (self-directed, not reward-based)
Mandy, now 34 years old, also uses a <u>magnetic weekly calendar</u> but without support or rewards. For the other subjects, these calendars were externally developed, demanding considerable time, trail, and error for the staff. However, after a few verbal instructions, Mandy seemed to understand the underlying concept and value of this support tool and was able to individualize the calendar. She seemed to have no trouble identifying what needed to go on it and has been using it for the last nine months. She says it really helps her remember medications, household chores, and appointments.

Mandy was already in the habit of using a monthly calendar, but she didn't always remember to consult it. As well, her monthly calendar did not provide enough space for regular tasks such as laundry or shopping. Now, she comes face to face with her weekly calendar every time she goes to her fridge in order to see what she has planned for the day.

Mandy's calendar items are minimal but over the week, they include such items as: Rx (for her medication), vacuuming, church, and meetings. We conclude that she is supportive of this calendar concept because she made one for each circle member and for her parents, too.

See Appendix A for a replica of her calendar.

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c. Steven's magnetic weekly calendar

Steven did not remain with the project long enough to receive this support tool.

d. Kathy's magnetic weekly calendar (reward-based):
Mother's email message:

Well, Kathy sure likes her chart. I know now is a bit of a honeymoon time with it but all jobs are done. Her reward is a pop. I never would have allowed that with my other kids. With Kathy, if it works I will give it a try even if it isn't great for nutritional value.

For whatever reasons - Kathy's mother's nutritional concerns, or Kathy's subsequent loss of infatuation with the reward- pop proved to be an insufficient stimulus for continued use of the calendar.

After three months, Kathy quit using her <u>magnetic weekly calendar</u>. Her mother says that Kathy does not use it unless 'Mom' enforces its use on a consistent basis. Since Kathy lives in her own apartment in the house, her mother is not able to enforce its use as required.

e. Brenda's magnetic weekly calendar (self-directed, not reward-based)
Mother's email message:

Now, Brenda wants one...Usually Brenda would think it was babyish so this really surprised me. Let me know. Thanks.

Brenda did not make much use of this calendar.

2. Cleaning Support Tools

a. Bert's cleaning support tools (random monitored, reward-based)
Mother's report:

Bert is expected to clean a portion of the basement every Sunday morning. He was usually very compliant with this request but the quality of his job performance varied. As well, he needed to be supervised to insure that when he vacuumed, he also included the corners and the entranceway to the sliding door, which was always full of dust and fire wood debris. Eventually, he was also asked to vacuum the downstairs storage room and clean the downstairs bathroom. Initially, Bert refused to comply with this request. "That's not what I am supposed to do," he complained. These additional responsibilities lay outside of the pattern and expectations he had established for himself. He wouldn't reconsider, even when a greater financial reward was offered. To help Bert clean the basement more effectively and to provide him with a "cognitive shift" so that he could accept a broader perspective of what "cleaning the basement" meant, a <u>cleaning support tool</u> was developed. Bert

was then able to re-conceptualize the job of cleaning the basement and to accept the challenge of these extra duties.

He was especially receptive to the "choice" given to him with this new system. He could choose to complete a certain set of tasks for four dollars or an extended set of tasks for six dollars. Over the last three months since this support tool has been in place, he has never chosen to work for the six dollars but seems to enjoy the opportunity to decide for himself.

Now Bert performs this job with little or no supervision. He resents having to check off each job but does so when reminded. Occasionally, his mother checks that he has done each job sufficiently well. He doesn't rebel when he is asked to do a certain job again.

Once a week, Bert is also expected to clean his bedroom and the downstairs bathroom. Initially, he did little in the downstairs bathroom other than to vacuum the floor. To improve his performance in this room, he was given the cleaning support tools that had been designed to help Kathy clean her bathroom and bedroom. Bert followed the guidelines closely except for the stipulations that he was to change bedsheets and wash the bathroom floor every second week. This became problematic as Bert would always insist that he didn't have to do these jobs because he had done them the week before; consequently, the cleaning tools were changed to indicate he was to do these jobs weekly. Bert now changes his sheets every week without resistance or reminders. He washes his bathroom floor every week, as well, but needs more encouragement for this job. According to Bert's parents, these tools work exceptionally well.

b. Mandy's cleaning support tools (self-directed, reward-based)
Thirty four-year-old Mandy recently received a set of the cleaning support tools that had been designed for Kathy. Although Mandy has lived on her own for over 10 years, she still has a lot of trouble cleaning her apartment. This is especially true since her move a few months ago. Unpacked boxes are still piled high and many of her belongings are heaped around her living space. She doesn't seem to know what to do with everything and the mess is growing exponentially.

She eagerly accepted the offer of the cleaning support tools and during the coffee break at one of her circle support meetings, she read aloud each page with occasional exclamations such as, "*Wow, I didn't know that!*"

Although she was told that these sheets had been formulated for another individual, and that she should feel free to ignore the line on the bottom that says, "Reward ". Mandy enjoys that aspect and bought a package of red licorice sticks to reward herself after cleaning her apartment the first time.

A month after receiving these tools, Mandy found them too difficult to use because the mess in her apartment made cleaning far too difficult. The support circle tried to

get some cleaning support services to help Mandy and the Director of the Community Service agency in her community promised to try and get weekly or bi-weekly cleaning help for Mandy. Two months later, cleaning services have not been made available.

c. Steven's cleaning support tools
Steven left the project before these cleaning tools could be developed for him.

d. Kathy's cleaning support tools (fully supported, immediate reward-based)
Kathy is involved in a supported transitional living situation, but housecleaning remains problematic, even though she receives the assistance of a support worker to help her clean her dwelling once a week.

Mother's report:

I phoned the place the cleaning girl is employed with and they told me that if a worker is supposed to be here 2 hours, she is supposed to be here 2 hours. Interesting... She didn't finish the list again last week. Didn't even get Kathy's bed remade, clean sheets were available. So Kathy has slept without sheets all week. (July)

I have just about given up on the cleaning girl thing. (early August)

I am still trying to work with the worker. She cannot follow my list... She cannot stay in a room with Kathy until the cleaning is finished. She does several things at once and is continuing to leave 1/2 hour early. I will talk to her again today. (mid-August)

Cleaning support worker did not show up for three consecutive weeks. As an emergency support, one was sent today, August 31st, but at a time when Kathy was not at home, so was not able to engage in this activity.
(August 31)

During circle meetings, Kathy made it apparent that she did not enjoy working with her regular cleaning support worker. From her comments at the meeting, it would appear that the interactions were negative.

In September, the agency contracted to supply support workers for Kathy replaced the worker and Kathy and the new worker get along fine. Both Kathy and her worker were using the cleaning support tools very successfully until one of the new support circle members told Kathy that she did not need a support worker for cleaning. Thereafter, Kathy became very resistant to working with this new cleaning person and the tools.

e. Brenda's cleaning support tools

Brenda had no interest or perceived need to use these <u>cleaning support tools</u>.

3. Student Tracker System

a. Bert's student tracker system

Bert was the only subject regularly attending school during the course of this study. Bert's situation at school began to deteriorate during his Grade 10 year. At that point, his parents met with his teachers to propose a system that would monitor his performance while allowing him the freedom to choose his own work sites and to avoid the constant supervision of learning assistants. Thus, the <u>student tracker system</u> was initiated. It took months to develop and refine, but the system enabled Bert to complete his Grade 10 studies and is now being used to help him complete Grade 11.

Mother's report:

School was a real problem last year when Bert was in Grade 10. Bert's entire high school adopted "Pathfinders," a self-directed system that demands better reading comprehension skills and more self-motivation than he was able to produce.

Last year, I am sure he was sincere in stating that his goals are to graduate and earn scholarships but he seems unable to connect his ambitions with his actions. He skipped classes, evaded all-but-the-most-enjoyable work assignments, mislead staff and parents about work expectations and accomplishments, and rebuked all efforts by the special education staff to help him.

With the research team, Bert's mother devised a plan in the spring of his Grade 10 year to help keep better "track" of Bert and insure that he stayed on task in school and successfully complete Grade 10. She presented the plan to the school, and it was readily accepted. Bert's mother then presented the following update on the situation:

Mother's report:

This morning, I found the learning assistant, Marilyn, and we talked. She said that Bert is getting impossible these last few months in all of his classes. He is in learning assistance for one-half a course (modified

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Science) and in regular classes the rest of the time. As I understand it, the situation is as follows:

1. *No one can keep track of him. When he gets an assignment, he often disappears. Everyone agrees they are sick of trying to track him down.*
2. *It is difficult to monitor his progress as he is always disappearing.*
3. *He is miserable and rude, especially to the learning assistance staff. He avoids them whenever he can.*
4. *He hates working in the LA room and often refuses to do so.*
5. *Because the high school is now under a "self-directed" system, Bert always argues that he should be able to do what he wants and can come and go out of classrooms as he pleases. Unfortunately, that means he doesn't get much done.*

I suggested the following task-list program to the learning assistant and she was very supportive:

1. *Meet in a neutral place – perhaps the library, because meeting with the learning assistant in Bert's regular classroom embarrasses him, as does being seen in the learning assistance room.*
2. *Rather than directing Bert to carry out tasks, negotiate the list with him; let him have some say; make sure that he is in agreement with what he is expected to do.*
3. *Keep all tasks very, very concrete and provide as much detail as possible. He needs to know exactly where to start, and the steps he needs to follow to accomplish each task.*
4. *Make sure he knows where he can go and cannot go and whom to contact when he runs into a snag.*
5. *Do not make him work in the learning assistance room. Allow him to take his assignment to a room such as the library where he can work by himself.*
6. *Meet with Bert each day after school to assess his success with the daily task list. Give him a dollar (which I will provide) if he accomplishes everything on the list, give him fifty cents if he got some reasonable amount of work done, but do not reward him if he accomplished little.*
7. *Insist that he meet you at an appointed time and place each afternoon. I think it is less likely he will try to avoid staff and assignments if it is his responsibility to meet you.*
8. *Always keep the task list the focus because it determines expectations and sets the rules. If he earns the dollar it is because he fulfilled the expectations on the list. If not, it is his problem and he needs to accept responsibility for it.*
9. *Do not let Bert's behaviour and accomplishments become personal. If he doesn't get anything done some days, it is not personal. Perhaps the*

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task list wasn't realistic or concrete; maybe he was just tired. Encourage him by letting him know you think tomorrow will be better.

10. *Avoid arguing with him; merely point to the task-list and what he has managed to accomplish.*

Outcome: After school, the first day of the new tracking program, Bert phoned home to ask if he could attend a sporting event. I asked him how it went with the new system. His response was:

"Fine. I got a dollar. I got everything done. Thanks Mom."
"For what?"
"For coming and doing that this morning. It worked out."

I think that that is the first time Bert ever volunteered an unrehearsed "thank-you." I was really moved.

In the weeks that followed, problems arose.   The notes provided by Burt's mother indicate that four of these problems involved difficulties inherent in the <u>student tracker</u> program. Bert created two additional problems.

Problems inherent in the student tracker system:

1. Teacher's expectation of more than one accomplishment per session.

    Because he accomplished only one of the two tasks that the teacher expected, Bert received only 50 cents as a reward.   Bert, however, reported that was just a bookkeeping slip up on his part: : *"Session 2, I wrote the Grade 10 provincial Math exam but I didn't put down two things on my list for S2"*

2. Unclear expectations.

    A few days after this, he received 50 cents again. Bert said, *"It has something to do with (the special education teacher) saying I didn't do what I said I did - I don't know. I said, 'I caught up in Science' and she says I didn't. I don't know. Mom, it's really messed up. She doesn't know the procedure, only Marilyn, the learning assistant teacher does.... The one I would prefer to work with is Marilyn[4]. With others, it's a lot more difficult."*

3. Regular teacher's absence.

    The next week, Marilyn, the learning assistant was absent for three days. She was not replaced the first day and Bert could not find anyone to check his work or pay his reward.   The second and third day, the substitute learning assistant teacher continually checked on Bert in the classroom, contrary to the agreement we had established in this program.   He was very upset.   The learning assistant teacher later told Bert's mother, *"It didn't go well when I was gone..."*

4. Diminishing effects of rewards.

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[4] His attitude towards Marilyn, the Learning Assistant, is a dramatic turnaround from previous years when he refused to work with her.

At first, the loonie was a powerful incentive. Each night, Bert would take his loonie and buy a Pepsi in the school's pop machine. But the loonie was not an effective long-term reward for Bert. Two reasons for this were identified:

a. Whenever Bert had money from other sources, for doing work at home or elsewhere, he would lose interest in the school-based loonie reward.

b. The true object of his desire, the can of Pepsi, lost its appeal to Bert. This was discovered one day as Bert's Dad witnessed Bert trying to borrow 50 cents from passersby, including teachers, so that he could buy a mega-sized pop instead of the regular 8 ounce sized can. Bert's parents assumed Bert had heard a peer say that this bigger size was "cooler" or something. Discussions with Bert about this neither confirmed nor refuted this theory but one week later, in a discussion with Bert, the real reason for his change of heart became apparent. He wanted the Pepsi with the possible prize under the cap and the $1.50 size was the only one that had such a feature.

Problems Created by Bert:

1. **Not being truthful:**

    One day, the learning assistant teacher reported:

    > *Bert didn't get the full loonie today because I caught him lying, saying he did something that he didn't do. But I didn't get mad at him and he was okay with it. He accepted the 50 cents without any problem and didn't argue with me.*

2. **Student resists intervention efforts:**

    Shortly after the program began, Bert started to resist meeting with the learning assistant in the library in the morning. Without an opportunity to establish expectations in the morning, it was difficult for her to evaluate his progress after school.

    Learning assistant, Marilyn:

    > *And then I told him that this system is difficult for me. I felt that he should agree on how much work he plans to do at the beginning of each day, rather than just scribbling down "I did this" or "I did that" at the end of the day. It is too difficult to keep track of his progress.*

    Bert agreed and promised he would meet her. However, he often did not show up to the morning meetings and Marilyn had trouble trying to track him down. In a matter of weeks, he refused to meet her at all. In response to his behaviour, a new rule was instituted at home to try to support the school and get him through Grade 10. Bert either met with Marilyn both before and after school or he was grounded for the night and could not use his computer or the telephone. This worked, to a point, but he very unhappy and miserable at home and school for the three remaining weeks of classes.

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Revisioned system

Several meetings between Bert's parents, the new principal, and the new special education teacher took place a few months ago, in September, Bert's Grade 11 year. The "Pathfinders" self-directed system is now modified and much more structured than it had been last year. These changes have helped Bert's performance and helped the learning assistant keep track of him. In preparation for Bert's IEP on October 11, a revised student tracker system was prepared. The program was written up and copies were given to Bert's teachers the day before the meeting to help everyone prepare. This set of papers is presented in Appendix A.

Some of the features of this revised system include a changed role for Marilyn, the learning assistant. She no longer meets with Bert every morning but acts as an information liaison among the teachers, Bert, and his parents and helps him to schedule his classes every week to make effective use of his time. The teachers write in Bert's agenda book every day and keep Bert's parents and each other informed about Bert's daily functioning. These and other features of this revised system are described in detail earlier in this chapter and are illustrated in Appendix A.

D. Recapitulation:

Objectives and Successes: Caveats and Shortcomings

In this study, the literacy-based cognitive compensatory support tools showed a good deal of promise in helping FAS/FAE affected adolescents and adults order their lives. These tools have a number of advantages that are grounded in theoretical and practical understandings of the needs of individuals with FAS/FAE. However, they are works in progress rather than finished products and as such require frequent adjustment and adaptation.

1. Assessment of the Magnetic Weekly Calendar

As the calendars were being developed and when they were being used, it became apparent that they had many advantages. However, a number of problems – particularly the reward concept – required ongoing adaptation and adjustments.

 a. *Advantages*
 ♦ Tailor-made to an individual's needs and interests.
 ♦ Include the individual in the development of expectations and rewards.
 ♦ Support independent functioning.
 ♦ Can help motivate the individual to perform certain tasks.
 ♦ Can help organize the individual in the performance of their daily tasks.

♦ Can reduce conflict and improve relationships between individual and support person.
♦ Seem to be acceptable to subjects
♦ Are relatively simple to develop and to use.
♦ Have no "handicap" stigma.
♦ Do not need regular revamping week to week.
♦ Provide constant reinforcement in a place (i.e. the fridge) that is easily and frequently accessed.
♦ Manipulative – multi-sensory reinforcement.
♦ Help support planning and preparing for upcoming events.
♦ Establish behaviour patterns based on seven-day increments.
♦ Allow support persons to view weekly plan, and the individual's progress, without being intrusive.
♦ May reduce some problematic obsessive-compulsive behaviours, especially if they are somehow incorporated into the system as a reward.
♦ Do not require much training for individual or support person to use effectively.
♦ Permit easy evaluation of the tool's effectiveness.

b. Ongoing development
♦ Some individuals need to be rewarded in order to use this tool, and effective rewards are difficult to identify.
♦ Rewards may need to be daily and weekly.
♦ Rewards may lose their appeal over time and need to be replaced.
♦ Trial and error may be the only way to determine the effectiveness of the reward.
♦ May require a monthly calendar as supplement.
♦ Very difficult to identify why affected person does not use the tool.
♦ Requires deliberate and consistent monitoring.
♦ Requires continual development and adjustments.
♦ Does not build comprehension capacity, is not a meaning maker, is not a transformative tool.
♦ Not intended to address problems such as stealing and lying.
♦ May increase opportunity/perceived need to deviate from the truth with respect to self-reporting.

2. Assessment of the Cleaning Support Tools

For the FAS/FAE subjects in this study, the cleaning support tools were generally very effective both from the point of view of accomplishing tasks necessary for living and for the buffers they provided between the subjects and their caregivers. These tools do, of course, require ongoing development.

a. Advantages
♦ Tailor-made to personalized needs.
♦ Do not need regular revamping week to week.

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- Afford constant reinforcement in a place (i.e. taped to inside of cupboards) that is easily accessed.
- Can help motivate and organize.
- Allow support persons to see weekly plan and completion of tasks without being intrusive.
- Can reduce conflict and improve relationships between individual and support person.
- Seem to be acceptable to subjects who offer little resistance to using the tools.

b. *Ongoing development*
- *May need to integrate an effective rewards system.*
- Rewards may need to be daily and weekly.
- Reward may lose appeal.
- Trial and error may be only way to determine effectiveness of reward.
- Require a monthly calendar as supplement.
- May need support person to regularly check that tasks were actually performed.

3. Assessment of the Student Tracker System

For Bert, the only subject in the study to use this tool, the student tracker system was generally very successful in that it kept his learning assistant, his parents and other teachers informed of his progress (or lack of progress), in all of his classes, on a daily basis. The system was particularly valuable because it equipped his parents with the information they needed to keep him up-to-date with his assignments, whether he had been productive in class or not. These tools also provide important buffers between Bert and those who want to support his learning and accomplishments.

a. Objectives and successes
- Are relatively simple and easy to use and do not require much training.
- Are easy to evaluate in terms of effectiveness.
- Provide choice of tasks, which is often a strong motivator.
- May habituate certain positive behaviours.
- Enhance performance.
- Support independent functioning.
- Include affected individual in development of performance expectations, and, therefore, promote motivation.
- Depersonalize intervention, therefore, reduce resentments over personal intrusiveness.
- Reduce the occurrence of certain negative behaviours such as lying.
- Reduce the need for supervision and/or support.
- Reduce some problematic obsessive-compulsive behaviors.
- Utilize obsessive-compulsive interests to encourage a range of other positive behaviours.
- Extinguish negative behaviours, even though the intent of this system is only to promote positive behaviours.
- Put subject and his parents and support workers, on "the same page."

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b. Caveats and shortcomings

◆ Extrinsic rewards are crucial components for some individuals.

◆ The opportunity/perceived need to deviate from the truth with respect to self-reporting may be increased.

◆ Individual may resist their use if their purpose is not apparent or desirable.

◆ The individual rewards may lack appeal, or lose appeal over time if their purpose is not apparent or desirable.

◆ A professional behavioural/functional assessment may be required to determine factors leading to individual's resistance.

◆ They require deliberate and consistent monitoring.

◆ They require continual development and/or revision.

◆ They are not intended to address problems such as stealing and lying.

◆ If they are externally manufactured, and/or externally monitored, the individual may not commit to them.

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CHAPTER 5

LITERACY-BASED COGNITIVE ENHANCEMENT TOOLS

This chapter examines two literacy-based cognitive enhancement tools that we investigated during the course of this study. We begin with a brief explanation of the theoretical underpinnings of these cognitive enhancement tools and describe the literacy-based features of each of them. We identify the needs of each subject, the ways in which we hope these tools can meet those needs, and the manner in which each subject responded to these tools.

The two literacy-based cognitive enhancement tools we worked with are:
     1. Directions personal planner
     2. Chatrooms

The chapter concludes with a short discussion about the outcomes and includes a table identifying the advantages and other considerations of the cognitive enhancement tools with which we worked.

The chapter uses the following headings:
    A. Rationale and Guidelines
    B. Cognitive Enhancement Tools
        1. Directions Personal Planning Tool
        2. Chatrooms
    C. Case Studies
        1. Directions Personal Planning Tool
        2. Chatrooms
    D. Recapitulation
        1. Directions: Advantages; Requirements and Caveats.
        2. Chatrooms: Advantages; Other Considerations
    E. General Conclusions

A. Rationale and Guidelines

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We did not set out to investigate Cognitive Enhancement Tools. Instead, we intended to develop and examine only cognitive compensatory tools such as lists and schedules designed to help individuals with remembering, organizing or planning. Through the course of this study, however, we became aware of two other 'tools', - Directions personal planners and chatrooms. As these learning aides seemed to have some cognitive building potential, so we called them Cognitive Enhancement Tools, in order to distinguish them from cognitive compensatory aides. These tools seemed to be enhancing and/or stretching cognitive capabilities, not just compensating for deficits.

B. Cognitive Enhancement Tools

The two literacy-based tools examined in this chapter - the Directions personal planning program, and "chatrooms," were originally used to facilitate other programs developed for this study. When the researchers realized that these tools were performing functions beyond original intentions, they began to scrutinize them more closely.

Cognitive Enhancement Tools are literacy-based as are Cognitive Compensatory Tools. As such, C.E.T.'s provide the individual with a clear and concrete reference from which to operate. But C.E.T.'s differ from C.C.T.'s in a number of ways. Firstly, they are designed to take advantage of the individual's strengths and interests. Consequently, these tools are inherently rewarding, and no special inducements are required in order to sustain their usage. Because C.E.T.'s are not deficit-oriented, they operate as capacity expanders rather than "prostheses". In order to use them, the individual must continually expand and stretch abstract thinking abilities as well as complex physical skills.

1. Directions Personal Planning Tool

Like many of the other life planning tools available for people with disabilities (such as "PATH" -planning alternative tomorrows with hope), the Directions tool is used to make short- and long-term plans with and for the focal person[5] of a support circle. The Directions tool is the foundation of each support circle meeting, helping everyone make relevant plans and take doable action to help fulfill the dreams and goals of the focal person.

Using the Directions tool, the facilitator is able to help the focal person and her support circle make a life plan based on the following two considerations:
1. her present needs, and
2. her desired state of affairs.
As well, the individual's strengths and interests were used to guide the plans that were made every month.

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[5] In this section we refer to the subject as the "focal person" if the subject is discussed in the context of a support circle.

The <u>Directions</u> program begins by inviting everyone to have fun dreaming about the "perfect" future for the focal person. This visualizing technique helps overcome the limitations of disability-thinking that may have prevented such dreaming in the past. These dreams then become the driving force behind the circles because they provide some "directions" for the planning sessions and they bring an element of hope and fun into each circle meeting.

In addition, visualizing this "perfect future" may help the focal person's stretch and build cognitive capacities. These capacities include the ability to:

♦ Conceptualize their own futures and personal life trajectories.
♦ Understand better their personal life trajectories.
♦ Distinguish between dreaming and planning and the importance of both.
♦ Make plans for the individual's own future.
♦ Connect cause and effect relationships by seeing that taking action on plans can change the future.
♦ See their social connections and how these people fit into their lives, and develop insights into their own complex social contexts.

Purpose:

♦ To allow the individual, family, friends and support workers to explore fun and interesting possibilities for the individual's future.
♦ To help visualize and plan the future.
♦ To help the individuals assess their present state of affairs, including barriers, obstacles and limitations that may restrict ability to pursue their dreams.
♦ To provide a visual cue system (optional) to help inspire the individual.
♦ To provide a monthly, pragmatic planning system which will help the individual overcome barriers and achieve specific goals which, in turn, lead to fulfillment of their dreams.

Description:
(See illustrations in Appendix A.)

Features:

♦ Simple and concrete.
♦ The individual's interests, strengths and needs guide the process.
♦ Flexible and adaptable - dreams and goals and plans can change.
♦ Collaboratively developed and maintained.
♦ Reviewed regularly.
♦ Multisensory – text, pictures, and oral reviews.

Support:

♦ Consistent and positive.
♦ Facilitator requires a deep understanding of FAS/E.

2. Chatrooms

Chatrooms are, indeed, literacy-based tools. Like email, chatrooms allow people to send written communications to one another. Unlike email, chatrooms allow them to communicate in real time and carry on a written conversation. For people with FAS/FAE, chatrooms may be more engaging because there is the reinforcement of an immediate reply to every message. Because a record of the conversation can remain as a printed reference on the computer screen, individuals have the opportunity to scrutinize the content and direction of the conversation, perhaps more easily than they could in an oral conversation.

Unregulated chatrooms can pose many risks to young people. They are particularly dangerous to the young person with FAS/FAE with poor judgment and reasoning abilities. The trick is to take advantage of the benefits that the Internet can bring to a lonely person's life without the potential dangers present in many public chatrooms.

Chatrooms were introduced into the study because they are used each day to reward one of the subjects, Bert, if he successfully fulfills the expectations of his magnetic weekly calendar. It was observed that the chatrooms may have had a positive educational impact on communication, literacy and even typing skills.

Purpose:
♦ To broaden social opportunities and experiences.
♦ To practice conversational skills.
♦ To upgrade literacy skills (both reading and writing).
♦ To improve typing skills.

C. Case Studies

1. Directions Personal Planning Tool

a. Bert
Bert did not have a formal support circle so he did not use the Directions tool.

b. Mandy
A support circle was organized for Mandy early in the year 2000. From the beginning, Mandy was enthusiastic about the Directions concept. When asked to bring some pictures that might add pizzazz to her Directions wall map, she brought about a dozen that she had cut from magazines and catalogues. She was so attached

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to these pictures that she had us paste them all to her map although it required an extra sheet of flip chart paper.

Mandy articulated most of her own dreams. She expressed a keen interest in starting her own music-based business, buying a portable piano, finishing her Grade 12 through GED, owning her own home, getting a pet, and becoming a millionaire. She wanted to go roller blading, skating, swimming, and hiking. She wanted more friends, especially for her circle. She also wanted to have her parents come to her apartment and cook dinner for them.

Every month the group tried to come up with plans that would connect to some of her dreams. Becoming a millionaire was the easiest dream to pursue; we just bought lottery tickets. In anticipation of new recreational opportunities, Mandy used some money she had recently received from a government back payment and bought a new bathing suit and a set of roller blades. During the summer, she went swimming a few times at a local lake but we were unable to find anyone to roller blade with her. She did roller blade by herself several times, but she discontinued skating because the skates were painful. Having bi-lateral clubfeet, roller blading may not be a practical activity for her.

She purchased a portable keyboard. After she joined the Salvation Army, she enjoyed free piano lessons from the organist for months. She wanted a computer and within four months, one of her brothers sent her one. At first, the computer was overwhelmingly complex but after she bought an encyclopedia CD, she was able to use it and enjoy it very much. She wanted a pet and within 10 months time, got a kitten.

Although Mandy's circle is presently reduced to two participants, Margaret from the research team, and Mandy, herself, she is still keenly dedicated to her Directions plan. When the original plan was constructed, she insisted on keeping the four sheets of flip-chart paper and sticking them to her living room wall. She kept them there, until she moved to a new apartment, six months later. By the end of October, Mandy had managed to fulfill many of her "dreams." She even cooked supper for her parents in her own kitchen, fulfilling one of her most cherished dreams.

Mandy's Directions plan needs to be revised and will most likely have to be constructed and sustained without the support of a substantive circle of support. Regardless, Mandy is enthusiastic.

c. Steven
Steven was eager to have a support circle to help him pursue dreams such as completing high school through the GED program and working in theater productions as a technical support worker. Steven moved to work in another province before the circle could be organized or the Directions program could be implemented.

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Steven is now back in British Columbia, living with a friend, unemployed and trying to get back on welfare. He has expressed an interest in working with the project again. At the time of publication, he had not contacted anyone.

d. Kathy

Although her life is full of sports and volunteer work placements, Kathy's mother is anxious about her daughter. Kathy is a very energetic, high-maintenance young woman who requires a lot of supervision and support. She presently lives in her parent's self-contained suite and receives transitional support, but her mother says that it is still a full-time job for her supervising and keeping Kathy safe and healthy. Her mother hoped that a circle would provide support to both Kathy and her family, which also includes a younger sister with FAS.

It took almost four months, after initial contact, to organize the first circle support meeting for Kathy. The family was very busy and had difficulty finding time to get everything arranged. The closest research team member lived four hours away and was not able to provide much help. The team telephoned the various agencies associated with Kathy's support needs but none were able to send a representative to the meetings. It was difficult for the family to recruit enough volunteers for the circle but the end result was a circle of eight to ten people, who have sustained their attendance for seven months.

When the arrangements were finally in place to hold the first circle meeting, Margaret reviewed the Directions format with Kathy. As part of this review, Kathy was asked to take the next month to prepare for the first circle meeting by looking for pictures that might illustrate some of her dreams for the future.

Kathy did not cut out any pictures, and the project staff opted, instead, to give her computer-generated graphics to help trigger her ideas during the dream session.

Initially she showed little interest in or understanding of the connections we were trying to make. Midway through the first meeting, however, Kathy started to understand the process and as she heard other circle members discuss possibilities for her future, she was eventually able to formulate some dreams of her own.

Kathy greets everyone when they arrive and serves refreshments during the meetings but she has difficulty concentrating on all of the proceedings of the meetings. During the-in-review session, she recounts, to the best of her ability, what has happened to her since the last meeting. Otherwise, she does not contribute a lot at many of the meetings.

During the initial Directions planning session, Kathy's first dream was to become a model. This surprised Kathy's mother who has to supervise Kathy to insure she bathes, combs her hair, brushes her teeth, and opts for fashion choices other than jogging pants. Recently, she entered a fashion show with a new circle member and achieved, at least in part, her dream to become a model. Kathy's second dream is to

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eam money playing her piano. Although she cannot read music, Kathy does play piano "by ear" and has composed some very complex and beautiful pieces of music. She loves to play the piano, almost to the point of obsession. She played for two research members, Margaret and Jennifer, and her surprisingly extraordinary ability brought Margaret to tears. In June, she played at a local high school's graduation ceremony and later this year, she may be able to play with a local harpist. Some of her other dreams are less concrete, and include having better relations with her often highly conflictual group of friends.

The Directions plan is intended to serve as a focus of all support circle meetings. Instead, much of the session time is lead by Kathy's mother and is devoted to problem solving. The conversation continually drifts away from Kathy's dreams, and toward the overwhelming day to day challenges associated with supporting her two adult daughters with FAS. Circle members devote a considerable amount of the energy to trying to help with these problems but it is obvious to most of the members that the family is in deep crisis and that the Directions planning tool is not an inappropriate diversion at this time, under these circumstances. Regardless, some members continually work at building Kathy's bridges, attending exercise sessions, fashion shows, or going to the movies.

e. Brenda

Kathy's sister, Brenda, did not want a support circle, nor did she want to become involved in the Directions process. As well, Brenda's mother was fully engaged and fully extended in the operation of Kathy's support circle.

2. Chatrooms

a. Bert

As an end-of-the-day reward for completing required chores including homework and a shower, Bert is allowed to connect to the Internet each evening between 8:30 and 9:30 pm.

Bert presently has an obsessive interest in chatrooms. In the past, despite parental efforts to keep him away from this interest, he did whatever he could to connect, including breaking into his mother's office computer.

Now Bert's parents have turned things around by offering chatroom access as a reward for good behavior at the end of the day. This is not as easy as it sounds. First, the parents have to restrict his access to chatrooms so that the reward is effective. Their efforts have been quite successful because the closest telephone line access to Bert's computer is in his parents' bedroom, across the hall. Because they keep this door locked at all times, Bert is compelled to follow expectations outlined on his magnetic weekly calendar in order to earn the opportunity to engage with his cyberspace acquaintances.

In many ways, chatrooms have become a powerful learning tool for Bert. When he gets too silly or boring in his communications, the other chatters do not

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hesitate to chastise him. He quickly stops and revamps his approach in order to stay involved. Using the computer, Bert is able to see the conversation and analyze successes or failures. As well, he is able to witness other people's communications and ascertain which approach is successful and which is not.

In a conversation with Bert, he had the following to say:

I have learned how to start conversations by asking questions like, "How's it going?" I spell it "Howzit going?" And sometimes they don't reply for a while cause they are already chatting to someone else. But when they reply we chat for a while until I have to get off the computer.

If we have a long pause then I just ask them what they want to talk about. And they usually ask me what are my favourite sports, what my favourite music is...And I ask them the same things. And I ask them if anything interesting is going on with them.

Although Bert suffers memory problems, he remembers and recounts in fine detail – often to his parents' chagrin – endless descriptions of the conversations he has with others. Perhaps he has a clear recall of these events because these conversations are reinforced by visual (computer screen) and tactile (typing) experiences. When he retells his chatroom experiences, he often asks for advice on how to improve his communication performance and even accepts unsolicited advice (not criticism) on how to improve his conversational skills. For example, he was told, *"Try asking the other person about details of their lives - where they live, their school, the weather, their siblings, their work, their favorite music instead of just talking about yourself."*

Bert's parents believe that he is likely increasing his social interaction skills, at least as they apply to the chatrooms. As well, his ability to conjure up something to write and his typing speed and accuracy have improved immensely.

Because of his interest in chatrooms, Bert has been asked to preview a chatroom/internet safety computer-based program for the school. This interactive program teaches "street smarts" about the Internet highway, including about perverts and con-artists who may intrude into chatrooms. Working with this three-hour computer program will earn him credits in a health/career development course.

Although it serves as a very effective reward, Bert's parents are worried about unsavory people that often visit chatrooms. Consequently, they approached Bert's principal to determine whether it might be possible, within the curriculum of the school, to create a "private" chatroom for young adults with FAS/FAE. In this way, they hoped that Bert might be able to continue enjoying his cyberspace social engagements while earning credits for Science/Technology. Other chatroom participants would include some of the subjects in this study, as well as older children with FAS/FAE children from families known to Bert's parents.

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Although some school staff initially welcomed this proposal, they have not put any perceivable effort into making it a reality. Bert's parents are looking elsewhere for assistance.

b. Mandy

Although Mandy's brother bought her a computer a few months ago, she has not accessed email or chatrooms for a number of reasons. She feels she cannot afford the internet service charges and Mandy's mother is opposed to her using the internet and chatrooms because of the safety risks and lack of supervision. Although Mandy is eager to engage in chatrooms, she remains hesitant to do so because she has heard stories about perverts using the format .

It is hoped that these concerns can be addressed so that Mandy will be able to use the internet and chatrooms safely. We plan to approach the local library and the local college to ask if Mandy can access the internet one day a week to join Bert's chatroom.

c. Steven

Steven said that he would very much like to exchange email addresses or participate in chatrooms with other participants so that they can talk about such things as fetal alcohol related issues. Steven did not stay with the project long enough to engage in this activity.

d. Kathy

Kathy had never engaged in a chatroom but she was introduced to Bert and the concept of the chatroom for young adults with FAS/E. Kathy was very hesitant expressing fears about all of the "bad" people who use the Internet. Not until a close friend assured her this would be safe, did she agree to try.

Kathy's mother likes the chatroom idea. In an email message she said the following:

I really want to get Jen involved in Bert's chatroom. She would benefit by
it, I just know it, and it would also give her something more to do. I will
have to spend the time getting her going. When you are finished the
project, perhaps you can help us with this?

e. Brenda

At present, Brenda has not expressed any interest in this chatroom. Brenda expresses a great resentment about the topic of FAS/FAE and does not want to be associated with it. However, if her sister, Kathy, enjoys this internet engagement, she may change her mind.

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f. Other interested young adults

Via a listserve that discusses issues related to older children with FAS/E, five parents within and outside of the province have informed the project that their adult children would like to get involved in Bert's chatroom.

E. Recapitulation

1. <u>Directions Personal Planning Tool</u>

   a. **Advantages**
- Helps individuals conceptualize their future and look at their current life situation in a positive way.
- Helps the individual conceptualize the connections between action and outcomes, and thus "see" and experience cause and effect relationships.
- Easy to use and easy to follow.
- Easy for individual to contribute ideas (prompts can be used).
- Helps motivate individuals to become more involved in their life plans.
- Helps motivate circle members to engage in the focal person's life.
- Provides structure to planning for personal growth, employment, and education.
- Prioritizes goals and dreams.
- Does not focus on behavior problems and challenges, yet recognizes limitations.
- Is concrete, easy to understand - helps 'unscatter' and 'unclutter' people's complex lives.
- Does not value or judge the focal person.
- Gets everyone on the same page in terms of the focal person's needs and desires.
- Looks at every aspect of a person's life—i.e., recreation, employment, social life.
- Helps identify individual interests, preferences and strengths.
- Helps identify service needs.
- Helps set time lines.
- Helps to develop realistic goals.
- Helps organize and focus each circle meeting/planning session and brings everyone back to the plan.
- Clarifies roles of circle members.
- Provides the focal person with a greater spectrum of support people.

   b. **Requirements and Caveats**
- Circle members may need to learn about FAS and the specific behaviour challenges associated with the focal person.
- Demands strong leadership and good facilitation.

- Leader requires insight into FAS/FAE.
- Difficult for a family member or individual himself/herself to administer.
- Requires a group dynamic that may be difficult to obtain and sustain.
- Often involves many "baby steps" which may exasperate some circle members.
- Involves a considerable time commitment for meetings and volunteer support time.
- Difficult to recruit a wide spectrum of circle "friends" to provide social connections.
- Difficult, if not impossible, to recruit agency support representatives to help make plans.

2. Chatrooms

a. Advantages
- Builds communication skills.
- Builds literacy and typing skills.
- Can be made a relatively safe activity.
- Can establish friendships.
- Allows an avenue for people to discuss personal issues.
- Chatrooms can be set up to include individuals with similar life situations and challenges, such as FAS.
- Can be supervised, if everyone in agreement.
- Unlike e-mail there is immediate reward and gratification.
- Can be used as a reward to encourage other behaviour and habits

b. Other considerations
- To make the chatrooms relatively safe, they need to be structured or even monitored.
- If in an uncontrolled environment, the individuals can be exposed to dangerous situations and people.
- Basic literacy skills are required to communicate (reading and writing).
- Good typing skills are required to be an effective participant.
- Computers and internet access are required.

E. General Conclusions

Both Directions personal planning and chatrooms have the potential to be used as educational tools for people with FAS/FAE. Both provide the opportunity for real-life experimentation and repetition so that the lessons learned are reinforced. Both have multisensory features that may accelerate the internalization of information and skills. These tools also have a strong self-directed component that can be both empowering and mind expanding.

Perhaps the elements of *fun* and *relevance* are crucial features of both the Directions program and the chatrooms. They provide the individual with enjoyable encounters that actually make a real difference in the focal person's life. They are, in themselves, powerful motivators for the individuals to learn and to develop their expertise.

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CHAPTER 6

CONCLUSIONS AND RECOMMENDATIONS

This chapter reviews the major aspects of this study in order to draw conclusions and to make recommendations for change and for further research.

The areas that will be discussed are:
A. Present State of Affairs – Subjects and their families
  1. Conclusions
  2. Recommendations for Change
  3. Recommendations for Further Research
B. Literacy-Based Support Circles
  1. Conclusions
  2. Recommendations for Change
  3. Unsolved Dilemmas
  4. Recommendations for Further Research
C. Cognitive Compensatory Tools
  1. Conclusions
  2. Recommendations for Change
  3. Recommendations for Further Research
D. Cognitive Enhancement Tools
  1. Conclusions
  2. Recommendations for Change
  3. Recommendations for Further Research

A. Present State of Affairs – Subjects and their Families

1. Conclusions

This study did not set out to investigate the basic living needs of FAS/FAE individuals and their families. However, the sheer desperation of many of these individuals and the lack of even the most basic forms of social assistance to help them with their plight was a problem so overwhelming that it needs to be described in order to set the literacy investigation in context. Consequently, the first section of this chapter describes the current levels of agency support these individuals and families receive.

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a. **Capacities**

The five subjects possessed IQs that ranged from the low 60s to the low 80s. Their IQ levels determine whether they are eligible to receive support services as adults living in the community. Of the four subjects, only one 20 year old young woman qualifies for special help because her IQ falls below the 70-demarcation. A Social Worker has determined that her independent living needs do not exceed $1400. per month. However, this amount has not been sufficient to allow the family to find any agency, group or foster-family placement that will assume her support, structural and supervision needs.

This study suggests that people's IQ scores are not an appropriate measure for determining support needs for adults with disabilities, particularly those with FAS/FAE. Advocates have been making this point for years. A more practical and fair measure of their capacity to function as participants in family, community and work life is to be found in test results that measure factors such as adaptability and sociability. Tests like the Vineland and Scales of Independent Behavior-Revised (SIB-R) provide these kinds of findings. Using a richer sampling of skills, these tests provide a detailed assessment of each individual's strengths and weaknesses. The test results for the subjects in this study are shown in Figure 1.1 on page 7 and in Appendix B. Despite having relatively "high" IQ scores, compared to the 70 IQ ceiling established for community living support, every subject demonstrates high needs for support.

In this study, IQ measures did not determine levels of dysfunction, nor did they demonstrate intervention needs. For example, these FAS/FAE affected individuals were often challenged by difficulties with behaviour, cognition, social skills, adaptability, problem solving, phobias, obsessive interests, inattentiveness, impulsivity and hyperactivity. The Vineland and SIB-R tests did point out these dysfunctions. This knowledge is critical because the lower ranges of ability are sometimes masked by the individual's verbal acuity. Unlike IQ measures, these test results can be used to develop individual plan recommendations and to determine how much time and energy should be invested in trying to modify the behaviour, alter the environment, or simply change expectations.

b. **Burden of care**

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Responsibility for the subjects rests primarily with the families, regardless of the subjects' ages. There is evidence of high stress in these families. In this study, the two subjects who do not live with their parents exhibit high levels of stress as a result of at-risk life styles. Both seem vulnerable to abuse and exploitation. As the subjects age, their parents do not know how to help their children lead more successful lives. The research team attempted to get help for these individuals and their families but discovered that such help is not readily available, and is almost nonexistent for those individuals whose IQs do not fall below 70, qualifying them for Mentally Handicapped status.

The burden of care and intervention lies primarily with the parents. The degree and quality of the help they are able to recruit depends on their ability to advocate and educate service providers about FAS/FAE. For one of the parents, a lab technician, this responsibility has kept her out of the workforce since the adoption of her FAS affected daughters. She explains, *"I have not had a paying job in 18 years but more than that, I have not been able to pursue and advance in a meaningful career."* When the 34 year old subject's parents moved to another province to retire, and she was left on her own, she was unable to get help with her many FAS-related secondary disabilities. She has remarked on a number of occasions, *"What do I have to do around here, kill myself to get any help?"* In desperation, this individual finally located a non-profit FAS support group in Vancouver and phoned them for help. This organization, staffed mostly by parents of FAS affected children, referred her to a private education consultant in a small city 1 ½ hours away from the subject. This consultant, in turn, referred her to the research team, of which the closest member was 2 hours away from the subject. Based on subsequent advocacy of the research team and, after the subject threatened suicide and became a high risk individual, she was recently enrolled in some local services such as life skills and stress reduction training. Cleaning support was also promised, but after two months, has yet to materialize. She and the 20 year old independent living subject continue to live in a state of extreme social isolation and are at high risk for exploitation.

c. **Existing support services**
   Home and school support services provided to the subjects are limited and plagued with problems. They are generic services that do not seem to know how to deal with the baffling and difficult challenges presented by FAS/FAE related behaviours. Further, the only subject with a low enough IQ to qualify for community living support services frequently received help of such an incompetent, even negligent, nature that her living situation was made even worse.

d. **FAS strengths undermine reality of weaknesses**
   Through the course of this study, we commonly encountered low-level staff at health or human service facilities who had never heard of FAS and were not certain how to respond to calls for FAS-related assistance. However, these problems were insignificant compared to those posed by people, professional and

otherwise, who claimed to fully understand the FAS/FAE related struggles involved in each person's life. Indeed, the maxim "a little knowledge can be dangerous" seemed to apply in these situations.

Kathy, whose IQ measure qualified her for community living services, was refused full service support even though the social worker responsible for Community Living admitted that the few FAS affected clients in his care were the most difficult to place because of their extraordinary behavioural challenges. Yet this same social worker defended his position to minimize her level of services by declaring that Kathy was not a high needs individual. Aside from his conversations with Kathy at a number of meetings, it is difficult to determine the evidence or rationale he used to support this claim. One supposes that Kathy's verbal acuity masked her other weaknesses. The result is that Kathy's parents are forced to provide for her and do not qualify for the money offered to non-family service providers who contract to the Ministry.

Friends and casual acquaintances who know little or nothing about FAS/FAE were continually influencing major life changes for the subjects. For example, Steven was convinced by his roommate to move to another province and work at a resort rather than continue with ABE courses and Support Circle pursuits. The roommate convinced Steven that these job opportunities held more promise than anything else he had going on. After working three jobs, from which he was readily fired, Steven ended up back on his parents' doorstep, broke and dejected. Not surprisingly, his roommate had abandoned him shortly after their move because Steven presented more challenges than the roommate anticipated.

After her mother's tireless efforts to get help, Kathy was moved to her parents' basement suite and started to receive transitional support services from Community Living including an employment support worker and workers to help Kathy learn how to shop and clean her living space. An apparently well-intentioned Support Circle member convinced Kathy that she did not need help with cleaning. Consequently, Kathy refused these services, and her mother had to, once again, assume these responsibilities until she could turn things around.

Throughout this study, a definite pattern emerged -- the parents worked hard to set up healthy living situations, but were thereafter undermined by service cuts and/or the negative influences of "friends". The affected individual would then reject parental guidance and meet with failure. In the end, the parents would be left to pick up the pieces and try to build yet another workable life scenario for their child.

e. Employment

Bert held a full-time summer job with a local regional recreation program earning $7.50 per hour. His bosses and co-workers had known Bert since he was a little boy and were tolerant and supportive of his work efforts. They even overlooked the fact that he occasionally arrived late for work, despite his parents' best efforts

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to wake him up and get him ready. He bought a new computer with his wages. Not all of the subjects have enjoyed such positive work experiences.

Mandy worked off and on for a number of years at an exclusive resort in Banff but was eventually let go. She had difficulty fulfilling job expectations, and she had great difficulty getting up in the mornings. Mandy has no desire to look for work at the present time. She is concentrating her efforts on trying to graduate from an ABE program. It has taken her years, but she is hoping to finish and write her two remaining exams within the year.

Steven has also had a number of jobs, three during the past summer, but he has been unable to hold any of these jobs for long. He did not meet work expectations and was often late for work because he had trouble getting out of bed in the morning.

Brenda has been lucky enough to secure two jobs over the last four months each working with horses, a particular passion. The first job was far from home, and she lost it for the same reasons that Mandy and Steven lost theirs. She was simply unable to perform the required tasks in the prescribed manner and within the allotted time. She also found it impossible to get out of bed when her alarm rang. As well, she took occasional naps during undesignated breaks. However, she is coping more successfully with her latest job. She is back at home and her mother gets her up at 4:30 am to ensure she gets to work on time. Although never late, she is still having problems meeting work expectations.

Kathy, despite having donated her labour for over one year in various employment placements, has been unable to find a paid position. Support Circle friends, who work in programs that support adults with disabilities, claim Kathy will never find paid employment in British Columbia because recently mandated laws stipulate that a minimum wage must be paid to handicapped people.

The parents in this study believe their children may never be able to find gainful employment. They fear that their children may never be able to meet normal job expectations, let alone compete successfully with non-handicapped earners.

Our findings are compatible with those that deal with individuals who suffer TBI[6]. In their report on TBI, Chestnut et. al. (1999) conclude:

> *Without appropriate employment support, survivors may experience*
> *additional psychosocial problems because of misinterpretation or*
> *lack of understanding about the symptoms. For instance,*
> *concentration and memory problems may be perceived as lack of*
> *motivation, insensitivity, or mental illness. Most survivors need*
> *assistance developing career goals, learning work skills, and seeking*

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[6] traumatic brain injury

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and maintaining employment. This is based on evidence of improvement with declining long-term unemployment and underemployment rates being attributed to employment support and work reentry programs. (pp. 73-74)

f. General conclusions

Our findings support the conclusions of Jan Lutke (2000) a staff member of the FAS/E Support Network of B.C. and mother of FAS/FAE affected children who makes the following comments about services for alcohol affected adults in British Columbia:

The short answer is that there is nothing at all in any of the areas of housing, employ... , or support services for people with FAS. Programming is non-existent. Unless they are MH [Mentally Handicapped] - and most of them are not even close – they are on their own or with whatever we [parents] can do/give. They MAY however, qualify for disability pensions through MSDES.

Human Resource Development Canada (HRDC) sometimes will share the cost of an employee with an employer if that employer hires someone with a disability. It is not common with FAS, as obviously, they need much more on-the-job support than say, an adult with Downs Syndrome who just needs a simple job. Employers need a lot of on-site support for themselves, and that is not available through this system. Job coaches, where they exist – and they are rare as hen's teeth – usually only are in place while the person is learning the job. As we all know, with FAS, pull the on-site support and disaster happens.

The services that do exist – and even they are scarce – simply don't work for those with FAS. They are based on a disability model applicable to a group of disabilities unlike FAS, and are only for those with mental handicap or mental illness. They don't cover any of the areas that really need addressing.

2. Recommendations for Change

a. Intervention policies
 ♦ This study suggests that FAS/FAE must be recognized as a disorder which demands diagnostically-driven treatment services and programs that do not end once the individual reaches adult status.
 ♦ This model of intervention must include expertise in identifying the function of the problem behaviors, and in providing amelioration for every day behavioural challenges.

b. Individualized, adult oriented support

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The findings of this study support the recommendations made by Brenda
Copeland and Deborah Rutman (1996) based on their study, "Young Adults with
Fetal Alcohol Syndrome or Fetal Alcohol Effects: Experiences, Needs and
Support Strategies."

> *Individualized supports, enabling people to gain and enhance*
> *practical living skills, should be available to alcohol-affected*
> *persons without age limits or restrictions. There also needs to*
> *be greater appreciation, in the policies and practices of human*
> *service ministries, that alcohol-affected persons require*
> *additional time and support in order to make the transition to*
> *independent living. (p. 35)*

c. **Support families affected by FAS/FAE**
    This study illustrates the point that relevant ministries must recognize and
    understand the enormous stress endured by families with FAS/FAE affected
    children, and help provide these families with the support they need in order to
    cope and be healthy. Timely intervention is important.

    Again, the findings support the recommendations made by Brenda Copeland and
    Deborah Rutman (1996) based on their study, "Young Adults with Fetal Alcohol
    Syndrome or Fetal Alcohol Effects: Experiences, Needs and Support Strategies."

    > *It is important the person with FAS/E and their families have*
    > *access to adequate, appropriate and flexible support and resources,*
    > *that families need not be close to crisis before they become eligible*
    > *for support services such as respite care, that supports be available*
    > *throughout the life span... (p. vi)*

3. Recommendations for Further Research

a. **Assess professional awareness**
    This study found that many education and social assistance providers lacked even
    a basic understanding of FAS/FAE. Consequently, as a first step to remedy the
    problem, we recommend that Ministries responsible for any level of educational
    or social assistance, need to assess the degree to which their workers are aware of
    the particular difficulties faced by FAS/FAE affected individuals.

b. **Determine professional educational needs**
    Once these assessments have been completed, the educational needs of each
    ministry can be determined and addressed.

c. **Assess health of families**
    This study found that most families supporting children with FAS/FAE were
    desperate for help; many were living on the edge. Consequently, we suggest that

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studies are needed to determine the levels of stress (and associated health problems) suffered by individuals and families affected by FAS/FAE.

B. Literacy-Based Support Circles

1. Conclusions

a. Literacy-based designation

The literacy-based focus of the Support Circles proved to be confusing to many of the circle members. Although members frequently conducted literacy activities such as helping the focal member fill out forms, none expressed an interest in developing literacy-based tools. However, Mandy, the independent-living subject, and Kathy's mother appreciated the significance and intent of the literacy-based focus that we sought to achieve. They were valuable contributors to the development of many of the tools. We concluded that calling the Support Circles, literacy-based, served no purpose.

b. Building social bridges

The primary focus of two of the Support Circles was to build bridges with the subjects' communities. This proved to be difficult. In addition to attending the Support Circle meetings, most of the members did not have an abundance of time to share with the focal person. A small number joined the focal person in sporting activities or accompanied them to various events. Behavioural issues often dissuaded circle members from getting too involved in the focal person's life. Some feared that the focal person would phone them incessantly or even start visiting their houses, uninvited.

The circle sessions encouraged the focal person to join clubs or church groups. One of the members joined the Salvation Army and made exponential gains in her connections with people in her small city. A few months later, for some inexplicable reason, she lost interest and stopped attending. Two focal people attended ABE classes for short intervals, but did not make social connections there.

One of the Support Circles tried to get help from government sponsored social service agencies in an attempt to break down the social isolation of one of the focal people. Consequently, despite having an IQ in the 80s, this person was

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allowed to participate in some Community Living activities but ultimately found the other clients were a poor fit for her because their disabilities restricted their ability to communicate. Another focal person was already involved with Community Living before her circle was initiated, but these Community Living services do not address social needs.

It was difficult to find appropriate social settings for the young adults in this study. They readily exercised their free will and resisted attending social activities that they did not find to be socially rewarding. One social event that the focal people did enjoy was the circle meetings, themselves. Although only two long term circles were established, both of the focal people involved have maintained their enthusiasm for their particular Support Circle meetings for more than six months.

c. Advocacy

The circles provided powerful support in terms of advocacy. Circles were able to open doors previously closed to the parents. The parents of two of the adult subjects had been prevented from attending their son's and daughter's meetings with social workers and other support service representatives because it contravened the rights of their adult children. As a result of intervention by one of circle member, however, all circle members (including the parents) were invited to attend these meetings. As well, circle members were able to arrange a solid school placement for one of their subjects. Circle members are presently negotiating with Social Services on behalf of another subject.

d. Sustainability

As anticipated, the Support Circles were difficult to establish and operate. Only one Support Circle remains a vital entity with approximately eight regular members still attending on a regular basis. Another dissolved because the focal person left the province, and a third circle now operates with only two members, including the focal person.

Below, we have listed some factors that may enhance the sustainability of the Support Circles:

- ◆ Support Circles needs strong leadership with an abundance of time and energy to commit to circle business.
- ◆ Circle members need at least a rudimentary understanding of the challenges and complexities of FAS/FAE.
- ◆ Circle members need to support similar goals and share similar expectations for the focal person.
- ◆ At least half of the Circle members should care, in a deeply personal way, about the subject and the subject's family.
- ◆ The circle functions more successfully when some members are professionally connected with social service agencies.

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- ◆ The circle functions more successfully when some members have extensive social connections in the community.
- ◆ The circle meetings are more effective when conducted in such a way that positive, forward-looking attitudes are encouraged.

2. Recommendations for Change:

a.   **Professional Circle Coordinator/Advocate**
The average parent or lay person may not be equipped to establish and lead most Support Circles for adults with FAS/FAE. The circles are too demanding in terms of time, energy and expertise. Parents are already too exhausted from caring for their children. Other lay people would not understand the deep and complex challenges that the disorder can bring to a situation.
We make the following recommendations:
- ◆ Hire professional coordinator/advocates, knowledgeable about the specific problems associated with FAS/FAE to establish and operate Support Circles for adults with FAS/FAE.
    - ◆ Perhaps these Support Circles could be lead by a professional team of people who function as Coordinators/Advocates for a number of such circles. FAS/FAE is such a complex, demanding disorder that it may not be practical to expect one person to do the job.

b.   **Local leadership**
The professional coordinator/advocate who leads the Support Circle must be a person who lives in the local area.
- ◆ The circle leader should be well-connected to the local community and the agencies that provide the relevant services.

c.   **Social support programs**
- ◆ A day program designed for people with challenges similar to those suffered by adults with FAS/FAE may prove beneficial. These programs could include training in life skills, social skills, and employment skills and would, ideally, connect people to others who share similar difficulties, and perhaps similar interests.

- ◆ It may be helpful to establish facilitated emotional support groups for people with FAS/FAE. Mental illness is a very common secondary disability for those who suffer this condition. The affected individuals, whether living at home or on their own, can enjoy a reprieve from all too frequent social isolation. As well, a day program would give the supporting families some respite from the stresses that these mental health problems may bring.

H. 3. Unresolved Dilemmas

Working with the circles, Margaret was unable to resolve the following dilemmas:

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◆ To what extent should each member of the circle be informed about FAS/FAE and the typical behaviour challenges that are associated with the disorder?

◆ Should every member of the circle be forewarned about aberrant behaviours if they are or have been expressed by the individual?   Stealing?   Sexual Promiscuity? Lying?

◆ How many and what kind of problems should the members of the circles address?

◆ Should the circle focus solely on building more social connections for the focal individual?

◆ Should the circle meetings be fun, carefree meetings or should they be problem-solving sessions? Can they be both?

◆ How much stress and responsibility can the circle membership take on regarding the focal person and helping the family with their stress?

4. Recommendations for Further Research

a. Pilot project
Study the outcome of four Support Circles that have been organized and managed for a two year period by a professional coordinator/advocate.

C. Cognitive Compensatory Tools

1. Conclusions

a. Efficacy of the tools
There was evidence that all of the compensatory tools worked to help the subjects overcome some daily living challenges. They encouraged certain preferred behaviours and often discouraged some negative ones. They allowed the subjects to perform more independently and often motivated them to do the job well. In addition, they helped to guide the people providing support.

These tools were particularly useful for those subjects who resented the intervention of parents or other support people during the commission of certain tasks. The tools helped cultivate more positive relationships between the subjects and their helpers.

The magnetic weekly calendar changed the dynamics of one family in positive ways. As well, the independent living individual reported that the calendar was an invaluable daily living support. In order to be effective, however, this tool needs to be updated on a regular basis, and needs to be monitored and supported.
This study suggests that the earlier the tool is implemented in a child's life, the more accustomed they will be to using it. However, there is no question that is is also valuable to introduce to older independent living adults.

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Rewards were used to help motivate some of the subjects and proved to be successful. Further, the promise of rewards seemed to reduce subject resistance to many tasks that they had previously resisted doing. Both immediate and long-term reward systems were established, some tasks offering both. "Choice" also proved to be a successful motivator.

b. Compensatory tools designed but not studied
A range of tools were developed for this study, but were not studied in any detail because of time and resource restraints. These tools are presented below along with a short description and explanation of their use.

i. Grocery Aid
A grocery support tool was developed to address the problems one of the subjects encountered with purchasing her weekly groceries. This subject, in the presence of her support worker, spent most of her weekly grocery fund on a coffee maker, even though she does not drink coffee. The subject's Support Circle concluded that she was at risk of ignoring nutritional factors when making grocery purchases.

We developed a magnetized grocery support tool that sticks to the subject's fridge and has the following features:
- a visual cueing system to help the subject select a range of necessary or desirable food products,
- a reusable, portable grocery list (Velcroed to the nutritional sheet) on which the subject can write the grocery list with an erasable felt pen,
- nutritional information based on the Canada food guide.

Outcome: The subject claims that she uses this tool all of the time; however, we were unable either to confirm this claim nor discuss with her why or how she uses it. The subject for whom this tool was originally designed, never did use it and we were unable to ascertain why she did not.

ii. Task Lists
With the help of one of the researchers, Bert's mother made a series of Task Lists for her son to help him perform during paid and unpaid work assignments. She claims they work very well, but they have to be changed whenever the work situation changes as Bert seems unable to make adaptations on his own. She says that Bert seems unable to "see work" so the Task Lists literally "spell" out his duties for him. She claims that before using the sheets, Bert would just sit and do nothing until someone asked him to do a specific job. Now, he is able to follow his list of instructions and contribute significantly to his job satisfaction.

iii. Problem Journal

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Two of the subjects had difficulties with other people who they claimed were threatening or harassing them. It was difficult for the research team oOr relevant authorities to comprehend the context and motivation behind these problems, so the subjects were asked to keep a written record of problems as they occurred. They were given small, bound, journal books and asked to date each submission. It seemed that this practice helped the subjects keep the details of each event clearer in their minds. Reporting the problems became less difficult. We hypothesized that these journals could help authorities respond more effectively. As well, we hypothesized that these journal accounts could be useful during therapeutic intervention situations, in that therapists might use the journals to identify reasoning flaws, problem solving short-comings, and other cognitive difficulties the subject might be experiencing.

iv.   Telephone Message Board

As soon as Bert and Kathy's mothers implemented the telephone message board, it was an instant success. Each message board was purchased from a dollar store and consists of a small, wipe-off board with magnets on the back so that it can stick to a fridge. Bert and Kathy were asked to write down telephone messages on the board with an erasable pen and for each message they would receive a reward if the message was for someone other than the ·child. At the top of the board, the parent wrote the following to guide the message taking: name, date, and message.

The message board eliminated the problems that resulted from forgotten phone messages. They were simple to use and did not require much judgment or reasoning skills to be used successfully. It also provided a visual cue that indicated how much money the parent owed the child for taking messages. We hypothisize that the message board also helps develop listening and note taking skills.

Bert's mother reported that it worked very well all winter but when he started to earn money washing cars or mowing lawns, the 50 cent reward for each phone call did not appeal to him enough to write down a message for every phone call. Bert instantly became reliable about telephone messages once his parents decided to fine him 50 cents every time they discovered he had failed to write a message for them.

Kathy's mother made the following report:

> Jean is using the message board on the fridge like crazy. It is on the fridge, near the phone. On Sunday, she was alone for quite a while because we had her sister at a gymcana event and it took a lot longer than we expected. When we got back Jean had written down messages from seven different callers.

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Unbelievable. We could never get her to take messages before. Problem: I always forget to pay her.

In response to Jean's mom, we suggested that she use the same kind of recording system as was developed for Bert and set up another laminated sheet on the fridge which records what money and other rewards are due for the week.

c. Summary of findings:

◆ Many of the Cognitive Compensatory Tools developed for this study are still being used by some of the subjects at the time of publication. Some are being used voluntarily; most are being used in a less voluntary manner.

◆ These tools helped offset memory problems and made positive differences in the lives of the subjects.

◆ The student tracking system, although providing an effective support, is extremely high maintenance, especially for the parents. The subject does not necessarily appreciate the system, but the various rewards and reward-loss contingencies compel him to use it, anyway.

d. Implementation

The oldest subject who was living independently readily accepted the tools that were offered to her. She altered them to her needs, and used them without support or monitoring. She seemed to understand their purpose and appreciated the benefits of using them. She was unable to use the cleaning support tools effectively because she required help organizing her new apartment. Months after her move she was unable to find places for her belongings and unpack her many boxes.

Most of the subjects needed external help to individualize the tool during a trial and error procedure. This was a quick and easy procedure with simpler tools such as cleaning support tools.

Also, simple tools, like the cleaning support tools, were relatively easy to implement. The subjects found them easy to use and their performance improved with continued use. Some of the subjects required only intermediate support or supervision. Problems arose, but usually occurred when support staff did not use the tools correctly, or (in the case of replacement workers) did not understand how to use them.

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When rewards were used, their effectiveness sometimes diminished with familiarity, and they had to be replaced by other incentives that held greater appeal to the subject.

The most complex tool, the <u>student tracker system</u>, took months to develop and put into effect. The greatest obstacle was always the student's tendency to find ways to avoid work he did not want to do and to avoid the people who wanted him to do it. To overcome this problem, everyone involved in this intervention system, especially the teachers, had to provide constant input, on a class to class basis. In turn, the Learning Assistant had to act as liaison between the student, teachers and parents. She also had to insure that the student's classes were effectively scheduled each week. The system worked extremely well when everyone did their job, but whenever there was a substitute for the Learning Assistant or a teacher, the system bogged down. Essential information was not relayed and the student easily evaded responsibilities.

Many of the Cognitive Compensatory Tools developed for this study are still being used by the subjects and their families. Some tools were easy to implement but others demanded a high level of discipline from the families and/or workers to keep the tool in use. The factors that determined the success of a tool included the simplicity of the tool, the motivation level of the subject, and the ability of the support people to encourage continued use of the tool. The oldest participant used all of the tools with no external motivators.

e. **Implementation problems**
Although many of the tools were comparatively simple in design, they were all difficult to implement. A trial and error developmental phase and ongoing assessment were necessary to insure effectiveness. When problems arose, the support person (invariably the parent) had to conduct a rudimentary functional analysis to figure out what went wrong and how to correct the tool or intervention. When the individual seemed to lose motivation to use the tool, it had to be determined whether the reward had lost its appeal or whether there was something in the environment of the behaviour performance, that was causing problems. Ascertaining why FAS/FAE individuals make the choices they do, is not usually easy. However, the father of one of our subjects (Bert), contends that,

> *Although the affected person is not always able to explain why he does what he does, he usually does have a reason for doing it. My son is refusing to do any serious work on his Biology right now. I get angry with him because I feel he is slacking off. Then he gets mad because I'm getting mad at him. His anger makes him unable to articulate the real reason why he is not working on Biology- he would rather concentrate on finishing his Math before he begins his Biology course. And he attends a school were he is allowed to do his courses one or two at a time. Now that I know the real reason why he is balking at*

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doing any Biology, the ball's in my court. Sometimes I suspect that his reasoning is not suspect. His reasoning process is so basic that my so-called sophistication prevents me from seeing the obvious.

The use of "packaged" approaches to support the learning and behavioural issues associated with this disorder may not be enough to address the challenges and needs of this population.

2. Recommendations for Change

The monitoring of these tools and the necessity for their continual adaptation to changes in the environment or subject, require considerable training and support. This project was not always able to devote the time for these requirements. Nor were existing support systems equipped to provide this training and support. Inevitably, the parents were forced to take on this responsibility. However, it is not reasonable to expect all parents to have the skills, time, energy, or devotion requisite to this task. Initiating the use of tools at a younger age may be one way to help motivate young people to use them and to habituate parents to support their use.

3. Recommendations for Further Research

♦ Study the outcomes of the use of Cognitive Compensatory Tools, such as the magnetic weekly calendar, developed to help the general learner population in ABE and Adult Literacy programs.
♦ In a longitudinal study, investigate whether or not the early introduction and long term use of cognitive compensatory tools can habituate the use and improve the general performance of children with FAS/FAE in home and/or school settings.
♦ Introduce cognitive compensatory tools to older populations of individuals with FAS/FAE (aged 30 and older) to discover if these subjects have an age advantage and are equipped to make effective use of these tools.
♦ Study the outcomes of using Cognitive Compensatory Tools, such as the magnetic weekly calendar and the student tracking system, with students entering junior or middle schools to determine if they perform more successfully and require less support and supervision.
♦ Study the outcomes of using Cognitive Compensatory Tools to help develop skills and achieve a higher level of independence for young people entering supported independent living situations. Train the support workers to use the tools, too.

D. Cognitive Enhancement Tools

1. Conclusions

When we began this project, we did not intend to use cognitive enhancement tools. However, as the study progressed, two such tools - the Directions personal planner and

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chatroom activities - came to our attention. We hypothesized that these tools could have a possible cognitive impact on the subjects. We did .ot intend to use them as prosthetics to support certain every day cognitive performances. Instead, we hoped they would expand the individuals' abilities to conceptualize, comprehend and practice complex cognitive functions.

a. **Directions Personal Planner**

The Directions tool, used to help facilitate Support Circles, provided many opportunities for the subjects to contemplate their futures and explore cause and effect relationships relative to their own lives. Once a month, the Directions tool gave subjects the opportunity to practice goal setting and outcome evaluation. Throughout the project, there was no tangible evidence to indicate that this tool did what we hoped it would do - enhance the subjects' cognitive abilities to perceive and plan for the future, and make strong connections between actions and outcomes.

Interestingly, both of the subjects for whom the Directions program was developed kept their Directions wall map on their living walls for a considerable length of time. One subject had the four flip chart sheets stuck to her walls for five months, and made constant reference to this map in her circle discussions. The second subject still has her Directions map on her living wall, but her parents and the researchers suspect she is not very interested in it.

b. **Chatrooms**

There was strong anecdotal evidence that the chatrooms did improve one subject's communication abilities. The subject's parents claimed that they witnessed a number of improvements in their son's learning after he had began to frequent chatrooms.

They noted a "remarkable" improvement in his ability to type, particularly his speed, within two months of chatroom involvement. More importantly, his skills at initiating and sustaining conversations improved. The subject regularly asked his parents how he could improve his communication skills so that he would be able to enhance his internet discussions. He would ask questions such as, *"How do you talk to girls?"* or *"How do you keep someone talking to you?"* His parents were able provide him with certain advice, advice they suspected would have been unwelcome previous to his chatroom interests. They helped him devise questions to ask strangers in chatrooms such as, *"What is your school like? What are your favourite subjects, favourite computer games, favourite TV shows, etc."*

Safety concerns compelled the subject's parents to curtail their son's chatroom involvement. This was a great loss to everyone in the family. The parents lost a highly effective motivator that they used to get their son to do chores and complete his homework. The subject, a very socially isolated young man, lost his major social outlet.

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The research team considered this problem and, with the parents, tried to find a way that the subject could set up his own chatroom that could operated safely. Other young people with FAS/FAE in the study also expressed an interest to become involved. A decision was made to restrict the participants to young people with FAS/FAE from the study or from families that were known to the researchers or the parents.

The boy's principal, as well as one of his teachers, initially offered to help him set up such a chatline, but, at the time of publication, three months had passed and no action has yet been taken.

2. Recommendations for Change

The Directions Personal Planning program was limited in its success by the limitations of the Support Circles. Stronger Support Circles, including members whose main function was supporting the Directions Personal Planning, might provide more positive impacts on the subjects' cognitive functions.

The chatroom activity would have had a better chance of success if a safer chatroom environment could have been created for the subject. As it was, the positive affects on behaviour were cut short because of safety concerns.

3. Recommendations for Further Research

a. Directions Personal Planning
Test the long-term affects that a program such as Directions Personal Planning might have on children or adults and their ability to understand cause and effect relationships.
Researchers shall investigate whether this tool affects planning and outcome behaviours in subjects' personal lives.
Explore whether the successful employment of this tool leads to more effective cause and effect understandings.

b. Chatrooms
Researchers shall examine the social implications that safe and regulated chatroom experiences can have on socially isolated children or adults who suffer communication challenges such as those with FAS/FAE.
Investigators should determine whether chatrooms improve their communication skills.
Investigators should examine whether chatrooms improve their social understandings.
Investigators should explore whether chatrooms alleviate social isolation.

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EPILOGUE

As this study has demonstrated, Literacy-Based Support Circles, Cognitive Compensatory Tools, and Cognitive Enhancement Tools can help adults with FAS/FAE live more productive and fulfilled lives. As well, these tools enable the families and support workers to function more effectively. The interventions did not effect major changes in the overall life situations of the subjects but they did help, and this is an important finding. This research project has also shown that those suffering from FAS/FAE are seemingly invisible to the educational institutions and social service agencies which should be helping them and their families. Indeed, this was such an overwhelming problem in the research that we began our conclusions by summarizing the inequities that FAS/FAE victims and their families face.

FAS/FAE is a difficult disorder both to identify and to support. It is highly complex and the behaviours are often very deceiving. Consequently, parents and professionals require a high level of FAS/FAE knowledge as well as skills related to understanding and managing challenging behaviours. Unfortunately, parents seem to be the only people acquiring this expertise and often carry the burden of care with little help or understanding from the outside world. If these children meet with success, the parents are usually responsible for engineering this outcome.

For all such parents, the FAS/FAE disorder is a major factor defining their lives. Some have been driven to the brink of financial, emotional, and physical ruin. And yet, rather than helping these families, front line agencies have often ignored them or insulted them by suggesting that they were trying to claim resources which they did not deserve.

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In the province of British Columbia, FAS/FAE is a serious problem that is not being adequately addressed on any front. In British Columbia, as in many other jurisdictions, an arbitrary IQ measure dictates the level of service needs required by young adults with FAS/FAE; if the IQ is below 70, they get services, otherwise, they get nothing. Most of our subjects (and this may be the case for most people suffering from disorders related to prenatal alcohol exposure) do not have a low enough IQ to qualify for help. Those who do qualify for assistance often receive services that are not designed for the specific challenges associated with FAS/FAE and, as a result, are not very effective.

The Vineland and SIB-R tests indicate that all of the subjects, regardless of IQ, have a challenged capacity for successful functioning and, therefore, require some level of support services. Local service providers seem to sympathize with this reality but, unless they can find a loophole, profess to have their hands tied because of policy restrictions. A social worker, a health service professional, a director of regional community living services and a director of a community services program were all quoted as saying that this was a population of people that "falls through the cracks."

Our research suggests that unless these gross inequities are rectified and unless social service agencies begin to recognize that FAS/FAE victims require significant help, both the affected individuals and their families will continue to be marginalized. We thought it would be fitting to include, at this time, a letter by one of the parents of the subjects involved in a support circle.

> We, of course, need FAS/FAE affected children diagnosed as early as possible and these children need to be serviced from a birth defects model just like spina bifida or cleft palate. That way, the child or adult with FAS/FAE can be directed to services that are already there from the Child Development Centre, occupational health, to social services, to orthodontal work. Further, orthodontal procedures would be paid for because it is a birth defect; "it would just happen".

> Right now, we have to prove that our children need services. We are forced to run from agency to agency, usually without much success, instead of taking our children to a birth defects clinic where everything would be there. We need a place to go where parents are seen as part of the support required instead of part of the problem. Kids would be seen routinely, whether or not there are problems. It would be assumed that parents will need support, just like they do when their child has Down's Syndrome. This would change the system for the FAS child. Instead of reacting only when the problems become huge, the system would be pro-active and actually help prevent problems from developing.

> With the disability model, the FAMILY is provided service along with the child. The family wouldn't have to beg or fight for respite or respect. I would love to see the end of the same old, same old, "bad kid, bad parent." With early diagnosis and integrated supports, families would be so much

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healthier. So many of our parents have very serious medical and financial problems...We burn out our extended family members. We doubt ourselves, it puts stress on our marriages, and there is family breakdown - divorces & adoption disruption.

Some jurisdictions are taking steps to address the specific needs of adults with FAS/FAE. For example, Yukon and Nunavit each has a number of supported housing programs for FAS affected adults. These houses are equipped to handle five adult men each. This is encouraging, but in light of the fact that some sources contend that as much as 30% of the population of these regions may suffer from the disorder, these measures hardly qualify as even respectable Band-Aid solutions to the problem.

By failing to provide proper services for the many individuals with FAS/FAE in our midst, we are placing these people and their families in an almost impossible position. By ignoring the bigger picture, we may be creating an impossible struggle for us all. We think it fitting to close with a quote from Dr. Anne Streissguth. She presents a rather sobering prediction of the consequences of our neglect. Over ten years ago, in her testimony for Senator Brock Adam's Hearing on Drug and Alcohol Exposed Babies on April 11, 1990, Dr. Streissguth declared:

...the problem is already escalating at such an alarming rate that we must immediately begin mobilization of secondary prevention or intervention efforts. Without better remedial interventions than exist now, every child with FAS (and many with FAE) is at serious risk for life-long disabilities... The wildly proliferating problem of prenatal alcohol and drug abuse is damaging the brains of the next generation, overwhelming the schools entrusted with their education, and creating a new class of dependent people unable to provide for their own needs, yet too "high functioning" for our present remedial programs.

Ann Pytkowicz Streissguth, Ph.D., Professor
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University of Washington School of Medicine

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Appendix A

Literacy-Based Cognitive Support Tools

MAGNETIC WEEKLY CALENDARS

Bert's Calendar
(externally developed, reward negotiated, externally enforced)

Monday's View

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Clean Basement	Chop Kindling					
Supper	Homework Book					
Homework	Supper					
Shower	Homework					
Make lunch						
Calendar						
Computer						
		Homework Book	Homework Book	Homework Book	Homework Book	Clean Bedroom
		Supper	Supper	Supper	Supper	Supper
		Homework	Homework	Homework	Dungeons Dragons	
		Shower	Shower	Shower		Shower
	Make lunch	Make lunch	Make lunch	Make lunch		Computer Or TV
	Computer	Computer	Computer	Computer		

Work Appt $

L. Extra Magnetic Strips: Change Birds $2

Appointment

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MAGNETIC WEEKLY CALENDARS

Mandy's Calendar
(self developed, self directed)

Friday's view

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
RX	RX	RX	RX	RX	RX	
Feed Cat	Feed Cat	Feed cat	Feed Cat	Feed Cat	Feed Cat	
RX	Meeting	Vacuum	RX	Appointment	Homework	
	RX	RX		Shopping	Meeting	
				RX		
						RX
						Laundry

RX   RX

Pay bills

M. Extra Magnetic Strips: Meeting

Appointment

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CLEANING SUPPORT TOOLS

Bert: CLEANING THE BASEMENT

$4 DOLLARS

<u>Everywhere</u>
- pick up all debris and put away

TV room
- carefully vacuum without nozzle near the sliding doors
- vacuum the sliding door sliders
- vacuum all of the rug area
- vacuum around the wood heater

Hallway
- vacuum the hallway to the stairs

Stairs
- vacuum to TOP

Bathroom
- see "Bathroom" cleaning sheet

Blue room
- vacuum the rug in this room

Cold room
- vacuum the floor in this room

OR $6 DOLLARS *(do above jobs plus the following)*

Dust
- vacuum with the little brush attachment:
- TV (screen, top, and back), VCR
- wood heater and area
- cobwebs on walls or ceiling
- treadmill
- CD player
- computer and computer desk
- window sill in TV room

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- book shelf ledges in TV room and hallway

CLEANING SUPPORT TOOLS

<u>Kathy: Cleaning List # 4</u>

<u>KITCHEN:</u>

1. Wash, dry, and put away dishes.

    ___ ___ ___ ___ ___ ___ ___

2. Put away everything on counters and table.

    ___ ___ ___ ___ ___ ___ ___

3. Spray and wipe counters.

    ___ ___ ___ ___ ___ ___ ___

4. Spray and wipe table.

    ___ ___ ___ ___ ___ ___ ___

5. Spray and wipe stove.

    ___ ___ ___ ___ ___ ___ ___

6. Spray and wipe top and outside of fridge.

    ___ ___ ___ ___ ___ ___ ___

7. Empty garbage and take to outside garbage can.

    ___ ___ ___ ___ ___ ___ ___

8. Vacuum floor.

    ___ ___ ___ ___ ___ ___ ___

9. Wash floor every second week.

    ___ ___ ___ ___ ___ ___ ___

10. Spray and wash sink and taps.

    ___ ___ ___ ___ ___ ___ ___

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REWARD: _____

CLEANING SUPPORT TOOLS

N.   The following set of guidelines was developed to help overcome the many problems that arose from attempts to provide transition support for Kathy.

Guidelines for Support Workers

1. Orientation
- Each session, the worker and client review the details of what they will accomplish that day.

2. Shared work
- Teamwork is important.
- Work together, completing each task, step-by-step.

3. Choice
- If possible, let the client choose which of the required tasks he/she would like to perform.
- For example, the client could choose three out of six or seven required tasks and you do the rest.

4. Positive support
- Provide continual encouragement.
- For example, "You're doing a great job. We'll get done in no time."

5. Reward
- Consider providing a reasonable reward for a job well done, something to look forward to.
- Rewards can be everything from sincere praise, money, or an outing.
- If possible, consider something simple that you can both enjoy such as sitting down to a friendly chat with cookies and milk.

6. Order of Activities (Predictability)
- Every session, try to complete tasks in the same order.
- For example, if cleaning, go room by room, in the same order every time.

7. Times (Predictability)
- Try to adhere to a strict and predictable time table.
- Avoid changing the day or the times, if possible.
- If you must miss an appointment, try to provide ample notice or try to arrange for a replacement, if possible.
- Never leave before you are scheduled to do so.
- Lack of adherence to strict schedules can really set off problematic behaviours that can last a long time and be very stressful for other caregivers.

8. High Standards
- Make sure the client learns to work towards consistent standards.
- All tasks should be performed as well as possible, every session.
- All tasks should be completed.

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- Help make sure that every completed task is one to be proud of.

STUDENT TRACKER SYSTEM

The following pages in this section were given to Bert's teachers.

Intervention Guidelines

Rewards:
The parents are primarily responsible for developing and maintaining the reward systems that will be used to motivate Bert this year. They will endeavor to negotiate with him to determine which rewards he wants. Some of these rewards may have to be changed, on a regular basis, as Bert loses interest in them.

The most important daily reward that will likely be used this year will be computer access to games and chatrooms. As a weekly reward, his parents will grant him permission to go to "Dungeons and Dragons" at the Youth Centre from 7 to 11 pm on Friday nights.

Money is a very powerful reward, as long as Bert needs it. If he already has money, then his interest in earning money is diminished. Other rewards will include videos, dances, telephone time, and the movie theater. Rewards such as money can be offered on a sliding scale (great performance earns full reward, mediocre performance earns half reward, very poor performance earns no reward).

General recommendations:
- encourage Bert when he is in a good mood; don't push him when he is in a bad one.
- check that Bert understands the concepts and the processes involved in what he is supposed to do (he will often surprise you with what he doesn't know or understand).
- check that Bert has indeed completed his work, as he may claim to have done.
- keep school and homework assignments **reasonable**. If he is avoiding work or the class, it could be because he doesn't understand what he is supposed to do or is overwhelmed by the challenge he feels it holds for him.
- make your inter-personal encounters as **pleasant** as possible.

Points to remember:
- Bert tends to think simply about cause and effect relationships. For example, it seems to occur to him, "if my parents don't know about my homework assignment, then I won't have to do it."
- Bert has obsessive tendencies which causes him to have intense, all-consuming interests. Rarely can he be dissuaded from pursing them, but they can sometimes serve as very effective rewards to encourage positive behaviours. Some of these

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obsessive interests include, social interactions with certain peers, computer games,
Pepsi with prizes under the cap (never out of date and never Coke), and PE.

STUDENT TRACKER SYSTEM

Student Tracker System

Purpose
- To help staff and parents "track" Bert's whereabouts and his progress in school.
- To increase independence and confidence of the individual.
- To depersonalize directives and reduce the need for constant reminders and repeated instructions from support people.
- To reduce the potential for conflict with support people, including parents.
- To provide a concrete support that the individual can refer to continually and does not require a lot of judgment or reasoning skills.
- To provide a standard of performance that is clear and consistent regarding everyone's role and responsibilities.
- To provide a constant support system that does not change when support personnel change.
- To provide a support system that does not require support workers to have a lot of knowledge about or experience with FAS/E to be successful.

Maxims for Successful Intervention:
- No exceptions to the rules because exceptions will automatically become the rule and the whole program will collapse.

TOOL	SUPPORT
Weekly class schedule	*Learning assistant:* a. fill in the weekly class schedule sheet b. help Bert select classes which will insure the best use of his time c. have Bert fax the schedule home each Monday
Agenda book	*Teachers:* a. will write in Bert's agenda book at the end of every class. *Parents:* a. will examine Bert's agenda book every afternoon. b. will reward Bert or withdraw privileges depending on whether or not all teachers have signed. c. will permit no exceptions such as field trips, call-out-teachers, etc. – some school official must write in the book and account for Bert's whereabouts at all times. *Bert:* a. will try to insure teachers sign his book. b. will try to locate teachers on the phone or go to their homes after school to get their comments for his class performance and for homework assignment confirmation if he fails to get their written comments during school time.
Task lists - routine	*Teachers:* a. will provide Bert a task list(s) which is sequential and

concrete if required for routine expectations such as may exist

in Home Economics or Shop (optional).

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- daily instructions   a. will write on a note and attach it to Bert's agenda book or
                                        the corner of his desk if special or multiple instructions are
                                        needed for a specific assignment

STUDENT TRACKER SYSTEM

Bert's Agenda Book

Expectations: Every day all teachers comment and sign Bert's
                              agenda book.
Rewards: If all teachers sign then Bert gets computer and phone time
in the evening.
Consequences: If one or more teachers have not signed the book, Bert
will not get computer or phone privileges for the night.
If teacher comments are negative Bert still gets computer and telephone
time.

Second week in November

O. Monday (Foods, Learning Group, Humanities)

Foods: - Bert did a good job on his demonstrations and the end product was excellent. Good Work!! No homework. By the way, Bert lost his assignment again. 2nd time.

(No other teacher signed the book this day. Consequence: Bert was not allowed computer or telephone time in the evening.)

P. Tuesday (Humanities, Learning Group, Math)

Note from Home: Bert must hand in his CAPP to Ms. Owens today before he loses it!

Humanities: No homework.

Learning Group: Received CAPP assignment. Excellent work. Good work in Humanities this afternoon. Well Done.

Math: Worked (somewhat) on Math.

Wednesday (P.E., Learning Group, Biology)

PE: Do 5 goals for basketball for getting better. Bert is missing some assignments and some classes.

Learning Group: On task.

Biology: Bert should do the Labs on slides - one using water from pond/aquarium and one on onion skins. Bring onion skin to school.

Thursday (Biology, Learning Group, Math)

Biology: Bert did not hand in 10 questions from Ch. 5. We are now on Ch. 7.

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Learning Group: Teacher's Initials. **Math:** On task.

DIRECTIONS
PERSONAL PLANNING TOOL

Mandy's Directions Wall Chart, page one.
February, 2000

Mandy's Life – Now

WORK
Volunteer   Paid - Nothing
 School – part-time

CHURCH
Exploring

FUN
Not much
Dependent on girlfriend

HEALTH
Depressed, seeking help
"Open to information-not persausion"

LEARNING
ABE – 2 courses to go

INDEPENDENCE
Disorganized, increasing independence, 10 years
in my own apartment, parents are my only help,
parents have moved.

SPORTS
Bicycle by myself

SOCIAL LIFE
2 friends, basically very lonely

HOUSE/HOME
Tiny, crowded apartment for 10 years

PROBLEMS
Overwhelmed and scared
Anger problems, grief issues

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DIRECTIONS
PERSONAL PLANNING TOOL

Mandy's Directions Wall Chart, page two.
February, 2000

Mandy's Dream Life (Mandy decorated original sheet with many pictures from magazines)

WORK
Self Employed in
  a CD business
(Nov. – Still my dream)

CHURCH
Join the Salvation Army
(April – joined the S.A., quit by fall)
(Nov. – No formal church affiliation)

FUN
Play the piano & Make my parents dinner in my home
(April- bought a new portable keyboard, taking piano lesson)
(Sept.- had my parents to dinner in my new apartment)

HEALTH
Happy   Active
(Nov.- On medication,
  depression improved)

LEARNING
ABE – graduate
(Nov.- nearing end of 2 courses)

INDEPENDENCE
Time when I don't have to worry about people
  leading me astray.
(Nov. Still a concern)

SPORTS
Ice skating, hiking...
(August – new bathing suit, gone swimming,
new roller blades – hurt feet, hiked Red Mountain)

SOCIAL LIFE
Lots of circle, email and internet friends
(March – five circle members, brother bought her a computer)
(Nov.- one circle friend, working on library connection to internet for Bert's chatroom)

HOUSE/HOME
Bigger place to rent or own
(June – moved to bigger apartment)
Pet   (Oct.- got a kitten)

TRAVEL
Trips to Vancouver and Calgary
(May – trip to Calgary. Sept. – trip to
Vancouver see David Foster tennis event)

HAPPINESS

OTHER

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Respect for my FAS condition & my preferences	Millionaire Swimming pool
No more blatant criticisms	*(Circle buys lottery tickets)*
No more people always telling me what to do.	
(Nov.- choosing to avoid bossy people, still looking for understanding)	

DIRECTIONS
PERSONAL PLANNING TOOL

Mandy's Directions Wall Chart, page three.
February, 2000

Mandy's Friends and Helpers
(continually add to this list)

Parents
Brothers
Sisters
Aunt
Uncle
Godmother
Rita – girlfriend
Ann – Salvation Army
Salvation Army friends
Roseanne – counselor
Community Living
ABE instructor

(separate 11 X 17 paper glued to this page)

Goals for next month
(examples given: May, 2000)
1. Help with S.A. bake sale (Ann & Mandy)
2. Continue Community Living Outings
3. Make GED exam arrangements (Mandy)
4. Mother's Day Card (Roseanne/Mandy)
5. Lunch arrangements June 6 (Maggie)
6. Continue piano lessons
7. Continue S.A. activities

(examples given: August)
1. More chatroom information (Maggie)
2. Huckleberry picking (Godmom/Mandy)
3. Buy greeting card software (Mandy)
4. Get info on hospital courses (Maggie)
5. Resubmit GED exam form (Mandy)

6. Meet with Roseanne at her

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Appendix B

Vineland and SIB-R
Test Results

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Vineland Adaptive Behavior Scales
(Interview Edition)

Domain	Adaptive Level: Bert	Adaptive Level: Mandy	Adaptive Level: Steven	Adaptive Lev
Communication	Moderate Deficit	Moderate Deficit	Severe Deficit	Profound Defi
Daily Living Skills	Mild Deficit	Moderate Deficit	Moderate Deficit	Severe Deficit
Socialization	Moderate Deficit	Mild Deficit	Moderate Deficit	Severe Deficit
Adaptive Behavior Composite	Moderate Deficit	Mild Deficit	Moderate Deficit	Severe Deficit
Maladaptive Behavior	Significant	Significant	Significant	Significant

Scales of Independent Behavior: Bert
(Revised)

	Skill Level with Age-Level Tasks	Age Level Ta
Motor Skills	Age Appropriate	Manageable
Social Interaction	Age Appropriate to Limited	Difficult
Personal Living Skills	Age Appropriate	Manageable
Community Living Skills	Limited	Very Difficult
Broad Independence	Age Appropriate to Limited	Difficult ,
Maladaptive Index	Serious (serious problem behaviors which would usually be seen as	
Support Score	Limited Support (individual requires limited but consistent support an	

Scales of Independent Behavior: Mandy
(Revised)

	Skill Level with Age-Level Tasks	Age Level Ta
Motor Skills	Age Appropriate to Limited	Difficult
Social Interaction	Limited	Very Difficult
Personal Living Skills	Age Appropriate to Limited	Difficult
Community Living Skills	Limited	Very Difficult
Broad Independence	Limited	Very Difficult
Maladaptive Index	Marginally Serious (marginally serious problem behaviors)	
Support Score	Intermittent Support (individual requires limited intermittent or periodic	

Scales of Independent Behavior: Steven
(Revised)

	Skill Level with Age-Level Tasks	Age Level Ta
Motor Skills	Age Appropriate	Manageable
Social Interaction	Limited .	Very Difficult
Personal Living Skills	Limited to Very Limited	Very Difficult t
Community Living Skills	Very Limited	Extremely Diffi
Broad Independence	Limited	Very Difficult
Maladaptive Index	Moderately Serious (moderately serious problem behaviors thet sign	
Support Score	Limited Support (individual requires limited but consistent support an	

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Scales of Independent Behavior: Kathy (Revised)

	Skill Level with Age-Level Tasks	Age Level Ta
Motor Skills	Limited to Very Limited	Very Difficult t·
Social Interaction	Limited to Very Limited	Very Difficult t·
Personal Living Skills	Very Limited	˙Extremely Diffi
Community Living Skills	Very Limited	Extremely Diffi
Broad Independence	Very Limited.	Extremely Diffi
Maladaptive Index	Very Serious (very serious problem behaviors which would usually t	
Support Score	Extensive Support (individual requires extensive or continuous supp	

Scales of Independent Behavior: Brenda (Revised)

	Skill Level with Age-Level Tasks	Age Level Ta
Motor Skills	Age Appropriate	Manageable
Social Interaction	Limited	Very Difficult
Personal Living Skills	Limited	Very Difficult
Community Living Skills	Limited	Very Difficult
Broad Independence	Limited	Very Difficult
Maladaptive Index	Serious (serious problem behaviors which would usually be seen as	
Support Score	Limited Support (individual requires limited but consistent support an·	

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