Review of the Problem Gambling Treatment and Support Service provided by Life Activities Inc

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Executive Summary

The Responsible Gambling Fund of NSW contracted the Disability Studies and Research Institute to undertake a review of Life Activities Gambling Support Project. The review aimed to identify best practice strategies in assessment, intervention and delivery of services to people with cognitive disability who have a gambling problem or are at risk of having a gambling problem.

A key requirement of the review was to examine how evidence based practice was implemented by the service and to develop recommendations for providing appropriate and accessible services to people with cognitive disability.

The project used a participatory methodology and involved consultation with staff and key stakeholders of the service.

Key themes

Key themes to emerge from the review of service practices were:

- Cognitive Behaviour Therapy is not necessarily the most appropriate intervention for people with cognitive disability
- Working with people with cognitive disability and problem gambling issues presents unique challenges which have yet to be fully explored
- Time, isolation and poverty of people with cognitive disability are underestimated
- The capacity of mainstream gambling services to provide counselling and support to people with cognitive disability is limited
- Identifying the unmet need of people with disabilities who have a gambling problem is a major challenge
- There are challenges to implementing a state wide service
- Education and planning processes are reactive not proactive
- There is a need for appropriate accessible resources for clients

Best Practice Model

Elements of a 'Best Practice' model were identified for consideration. These elements need considerable piloting with clients with cognitive disability to assess their effectiveness and provide the evidence necessary to develop a more structured approach to education and training for mainstream gambling counselling services. One of the defining elements of best practice is the ability of service providers to adapt to the unique and often complex needs of a person with cognitive disability.

Recommendations

Eight recommendations have been suggested by the research for improving gambling counselling services to people with cognitive disability:

1. Develop a multifaceted approach to working with problem gamblers with cognitive disability
2. Develop an information clearinghouse on effective counselling strategies for people with cognitive disability
3. Review assessment tools
4. Focus promotional activities
5. Develop program specific policies and procedures

6. Focus education and training to specific target groups
7. Target resources
8. Identify referral pathways
9. Develop secondary support services for families and carers

The report highlights the need for more qualitative and quantitative examination of the most effective counselling intervention and service system provision to people with cognitive disability who have problem gambling issues.

1. Introduction

The Responsible Gambling Fund of NSW contracted the Disability Studies and Research Institute to undertake a review of the Life Activities Inc Gambling Support Project (GSP) between April and June 2006. This report details the outcomes of the review. The review uses a participatory methodology to identify best practice in problem gambling counselling for people with cognitive disability, and identifies the intervention treatments offered by GSP to clients with cognitive disability who have a gambling problem.

2. Methodology and project plan

2.1 Methodology

The review set out to

- Undertake a literature search to identify recent international and local evidence based practice for counselling people with cognitive disability
- Identify evidence based assessment methods used by the Gambling Support Project (GSP)
- Identify evidence based methods and tools used in treatment interventions
- Prepare case studies which can be used to illustrate best practice
- Describe referral pathways, networking and information delivery to the disability sector and people with disabilities
- Recommend further actions

The focus of the review was on the Life Activities Gambling Support Project (GSP). The GSP offers a service to people who have a problem with gambling combined with an intellectual disability, acquired brain injury or psychiatric disability. Clients may obtain counselling, treatment and education from the project. Their families and carers are also offered support. Priority is given to those rating high on the risk assessment scale and those who are experiencing a financial crisis.

The welfare model approach formed the conceptual basis for the review (Figure 1).

Figure 1: Evaluation Conceptual Approach

Inputs	⇨	Production process	⇨	Outputs/Impacts	⇨	Outcomes
Policies, plans and infrastructure Literature Resources/funds Clients Support staff Other service providers and government programs		Management and planning Coordination Service delivery (assessments, interventions and methods) Facilitation and barriers to change		Types and amount of support, services and information provided Access to services Client satisfaction Support for staff		Assessment of effectiveness of current program Identification of good practice Identification of areas needing improvement or further review

The approach distinguishes four distinct but closely linked stages in the process of human service delivery: inputs, the production process, outputs and outcomes. In attempting to understand the complex interaction of government, individuals and providers, over time, the approach is particularly valuable because it helps draw attention to the way in which policy is implemented and how this leads to services being delivered, the consequences of which are eventually expressed in terms of outcomes for residents, communities, providers and government.

Applying this approach to the review of this program, the scheme draws attention to the importance of focussing not just on the outcomes of the program, but on the prior stages in the process of resourcing and providing supportive services to those clients who will benefit most.

The second approach utilised in the development of the research design is based on the ethnographic tradition of social research, applied to the study of contemporary complex societies. Sometimes termed 'administrative anthropology', the approach uses methods such as participant observation, in-depth interviews and the analysis of documentary evidence, to obtain and analyse data on the evolution of administrative and organisational processes involved in the program.

A participatory methodology was adopted. Stakeholders engaged in the research included staff and management of the service, clients of the service, other support organisations, other related government and non-government services, families, advocates and carers.

2.2 Data Collection

An extensive range of data on the operation of the service was collected during the course of fieldwork. This data is triangulated with qualitative data collected through interviews with key stakeholders to form the foundation of materials for analysis.

Written data collected includes:

- Gambling Support Manual
- Gambling Support Program
- Promotional brochure
- Intake and referral form
- Intervention survey
- Clinical process chart
- Assessment tools

- Consent forms
- Service agreement forms
- Flow charts
- Evaluation forms
- Case studies
- Educational programs
- Client file documentation
- Policy and procedure documents

A sample client file, which includes much of this data, is attached to the report at Appendix A.

2.3 Stakeholders engaged in the research

Staff and management of the Gambling Support Project were engaged in the research. The GSP has a manager and two 2 psychologists/counsellors. The Chief Executive Officer of Life Activities, the auspicing organisation, was also included in the review.

Two field work visits to the GSP at Life Activities in Newcastle were undertaken, on 27/28 April and 11 May. The purpose of the fieldwork was to gather data from the staff of the GSP through both group and individual face to face interviews, and also to liaise with the key stakeholders of the service.

Four staff of the service participated in the group and individual interviews. Semi-structured interviews were held, using an interview schedule to ensure all primary themes were addressed with all staff. A series of questions (Appendix B) were developed to help set the context for the interviews. These included questions relating to provision of service; assessment and evaluation processes; liaison with external services; promotional strategies; education strategies and evidence based methodology; policies and procedures.

Clients of the service were approached to participate in the review. In order to maintain high ethics standards in research with people who may have impaired capacity for consent, approaches were made through the service staff, as trusted gatekeepers. Interviews with clients were scheduled, but did not eventuate due to factors related to mental health issues. Anecdotal information was gathered from staff of the service, a video of a clinical session with a client of the service was examined, and dis-identified documentation on treatment interventions was provided for analysis.

It was difficult to consult with families and support workers as many of the clients did not have existing support systems. There was some reluctance on the part of some families to engage with an external consultant. Some evidence was gathered from GSP data and anecdotal evidence from the counsellors.

Consultation with external stakeholders included four telephone interviews with mainstream gambling counselling providers, two telephone interviews with mental health services and two telephone interviews with a government and non-government disability service. Four of these services were based in the Hunter region, two were in rural NSW and two in Sydney. Other data was gathered from previous consultations by the RGF with peak disability services into their knowledge and experience of the GSP.

3. Literature review

A literature review was undertaken at the outset of the review. Literature on gambling, counselling and people with cognitive disability was reviewed in both national and international contexts.

There is a significant absence of research or critical analysis into the treatment of problem gambling for people with cognitive disability. Research into treatment for problem gamblers from the general population supports the need for further gambling treatment research which includes better definition of outcomes and more precise definition of treatments. Key findings show that cognitive-behavioural studies received the best empirical support (Toneatto, Ladouceur, 2003). The Centre for Addiction and Mental Health in Ontario, Canada, a particularly high profile Centre for researching and evaluating interventions for problem gambling, conclude that 'few empirically supported treatments for pathological gambling have been developed'.

One of the major outcomes of research into the area is that cognitive behaviour therapy (CBT), which is extensively used for clients with problem gambling issues in mainstream services, (eg, Sylvain, Ladoucer & Boisvert, 1997 ; Breen, Kruedelbach & Walker, 2001) both conclude that CBT, while it significantly improves the gambling behaviours in problem gamblers in the mainstream population, may not be the most appropriate form of therapy for people with cognitive disability or learning disabilities.

Due to the absence of empirical studies in this specialized area, we draw some generalisations based on research of treatment of other disorders, namely anxiety disorders and substance abuse problems in people with cognitive disability.

Several researchers report that people with intellectual disabilities have cognitive deficits compared to mental-age matched controls, including poorer abstraction ability, poorer abilities to verbalise strategies, slower learning of information and possible limits in the ability to encode large amounts of new information (Degenhart, 2000; Weiss, Weisz & Bromfield,1986). Thus, special attention must be paid to the method and presentation of treatment, such as the length and organisation of information and avoidance of heavily cognitive-based therapy. Emphasis should be on the use of behavioural contingencies and reinforcement, and there should be little emphasis on abstract analysis of the client's reasons for drinking (such as psychodynamic approaches).

Dagnan & Lindsay (2004) surmise that people with intellectual disability have often been seen as unable to benefit from cognitive and other talking therapies, and the volume of published research in cognitive therapy does not match that of other populations. They suggest that there are good reasons that this type of therapy will be effective for some people with an intellectual disability. For example, it has been shown that many of the cognitive processes that mediate psychological and mental health problems in people without intellectual disability are also present in people with intellectual disabilities (eg. Nezu et al,1995; Dagnan & Sandhu,1999; Dagnan & Waring, 2004) and that some people with mild intellectual disability are able to work well with cognitive material (e.g. Lindsay, 1999). However, the outcome literature for cognitive therapy in people with intellectual disabilities is sparse (Dagnan & Lindsay, 2004).

The scarcity of literature on the core issues of problem gambling counselling and people with cognitive disability indicates that there are few, if any, empirically tested counselling and support strategies to assist this client group. It is challenging to identify evidence based best practice in this context. Consequently, the review draws conclusions on best practice strategies from those used for associated target groups, such as anxiety disorders and substance abuse problems in people with cognitive disability.

4. The unique nature of working with people with disabilities and their problem gambling issues

People with cognitive disability who have problem gambling issues present unique challenges to gambling counselling services. For many people, the traditional interventions employed by mainstream services will be inappropriate for the communication needs and expressive and receptive language of clients with cognitive disability. As stated previously, the research suggests that some of the issues for people with cognitive disability are 'poorer abstraction ability, poorer abilities to verbalise strategies, slower learning of information and possible limits in the ability to encode large amounts of new information' (Degenhart, 2000).

Further research is needed to evaluate the efficacy of interventions with this client group. However, the implications of these issues suggest that specialised skills are necessary in order to provide appropriate services to clients with cognitive disability, and that resources need to be directed at education and training of staff and into the development of appropriate skills based interventions rather than relying on highly cognitive based therapy.

The poverty, physical and social isolation in which many people with cognitive disability live are also important contributory factors to problem gambling in this group. GSP staff report it is often difficult for clients to give up the gambling behaviour as many of their clients have been in institutions and the 'club structure' provides them with an environment and structure they can relate to. From the GSP perspective the focus is always on the client's gambling issue, although the service uses an holistic approach. For a person with a disability it is often a matter of working out other parts of their lives before addressing the gambling issue directly as people are not always aware they have a problem. Rather they have been referred by family members or support workers who identify the gambling as problem in the person's life.

5. Findings

5.1 Service operating structure

The Gambling Support Project at Life Activities commenced in February 1999 with funding from the (then) NSW Casino Community Benefit Fund. It originated in recognition of the need for gambling support services specifically tailored to individuals with an intellectual disability or acquired brain injury.

The GSP provides counselling, education, treatment and support for individuals with an intellectual disability and/or acquired brain injury and a mental illness who have, or are at risk of having, a gambling problem. It also provides a drop-in service and counselling for families and carers. The GSP is a referral service of the National G-Line phone service and for Lifeline.

Life Activities also offers a short term Life Solutions Program to support people with disability and their carers with services and education when additional life support is needed; a Supported Living Program which provides direct care, skills building and education to people with disabilities; a Life Consultancy Group and Connections, a social group meeting weekly for people with disabilities. They also run a fee for service Psychological and Counselling Service. These services are relevant to the GSP as they refer many clients to other programs within Life Activities for education, skills building and support. These programs provide an important opportunity for clients of the GSP to access additional skills building programs as appropriate to their needs.

Three staff are employed by the GSP, a manager and two counsellors. One of the counsellors is also the intake officer for the entire Life Activities service.

5.2 Service management

The GSP is overseen by a senior manager and the counsellors are supervised in their counselling roles by the senior psychologist practitioner, who supervises and coordinates counselling for the whole of Life Activities.

Both counsellors within the service are accredited professional counsellors and/or psychologists. Their role is working directly with clients on a one to one basis. The counsellors attend clinical meetings and group supervision once a fortnight.

Each counsellor works with approximately eight clients each, but varies according to entry and exit times. The service intake officer completes the initial interview and then the client is allocated to a counsellor based on availability.

The service is currently undertaking gambling counselling accreditation training through the CCWT. Current staff completed the first stage of the process, the cultural awareness component. Counsellors do not see themselves as case managers. Many other people are often intervening and managing client's lives, and GSP counsellors see their role clearly as focussing only on the problem gambling issues.

GSP staff are qualified in Workplace Trainers Category 4 and attend professional development training on a needs basis and within budget constraints. They have undertaken training provided by Wesley Gambling training courses and those provided by Mental Health Services eg, most recently - motivational interviewing.

The service has been accredited as a Registered Training Organisation but no longer provides training under that mantle as their courses are tailored to individual service needs and do not fit into a structured competency based system.

Strategic planning is reviewed annually to adapt to the changing nature of the service.

5.3 Education and training

Educational sessions are provided on a 'one-off' basis to services on request. Currently the service provides approximately 40 education sessions per year. These programs are designed to educate people with cognitive disability, and those who work to support them, about gambling issues and indicators of problem gambling, see educational materials (Appendix C)

The GSP has also contributed to the development of training on gambling run by the Centre for Community Welfare Training.

The GSP designed and developed the Gambling Support Manual as a resource to provide introductory information on both disability and gambling issues; recommendations for working with clients with a disability who have, or are at risk of having a gambling problem; and training options offered to services by the GSP. The service provides workshops and training sessions to gambling support services based on the disability awareness component of the manual.

The service has presented at two international conferences, one on gambling and one on disability.

5.4 Promotion and networking

The purview of the service is to promote much more widely in mainstream services; the challenge they perceive is how to inspire services to engage with clients with a disability in a climate of high demand for services.

The GSP promotional strategy currently consists of a mailing campaign to gambling counselling services, and information sharing through the Hunter Disability Network and the Hunter Council on Problem Gambling.

The GSP links with mainstream gambling counselling services through the Hunter Council on Problem Gambling. The manager of the GSP attends these meetings and represents the interests of people with cognitive disability in discussing treatment modes and lobbying for people with disabilities. The current GSP manager is a past president of the network, is the current vice president, the president of the Hunter Council for Problem Gambling and the secretary of the NSW Council for Problem Gambling. The GSP were responsible for organising the activities for Gambling Awareness Week 2006 in the Hunter Region. The Hunter Council is also in the process of running workshops for gaming staff to give them insight into interacting with people with disabilities. The GSP give regular input into national and state conferences of The National Association of Gambling Studies. The manager of the service does most of the liaison with problem gambling counselling services and attends these meetings. He also has strong links with other disability services.

The GSP identified raising the awareness of mainstream gambling counselling services to disability issues as an important component of promoting the service on a state-wide basis. In 2005 the GSP designed a questionnaire (Appendix D) for mainstream services which was sent out to a large number of services (100) from the RGF mailing list. Of these, only five questionnaires were

returned and of these only two gambling services had identified a client who presented to their service as having a disability. This has reinforced the belief of the GSP that mainstream gambling counselling services have little interest in disability issues. It should be noted that the perceptions of mainstream gambling counselling services were not canvassed as part of this review.

As a future strategy, the service intends promoting through education to, and liaison with, gaming and services clubs in NSW. The current manager of the GSP has a very high profile in the geographic area. This is relied upon to promote interest in and support for the service.

5.5 Client assessment, interventions and review

The GSP implements an individualised multi-element approach with clients. This includes a holistic assessment of factors which may contribute to the problem gambling behaviour (Appendix E).

5.5.1 Intake

Most referrals to the GSP are made by family members or support workers. Occasionally Mental Health and Gambling Counselling Services refer clients they have assessed as appropriate to the service. The service gets almost no referrals (maybe one per year) from G- Line.

Many of the clients' seen by the GSP have a dual diagnosis ie, a mental illness and an intellectual disability or an acquired brain injury. The clients who self refer tend to have a mental health issue rather than an intellectual disability, and of these some are attending other Life Activities programs. Where clients are referred from external agencies there is no follow up from that agency once the referral process is completed.

The intake procedure for clients is conducted by the Life Activities Intake Officer using a structured face to face interview. The information from this interview is recorded on the Intake and Referral Form. The Intake Officer is responsible for the intake to all programs offered by Life Activities. The current intake officer is also a part time staff member of the GSP. There is no separate intake procedure or documentation for the GSP. Clients must give verbal consent to be accepted into the program.

The initial intake meeting is between the referrer, the client and the intake officer. At this meeting a needs assessment is conducted.

The assessment tools are sophisticated instruments for reviewing the requirements of clients based on their stated needs and life experience. The main tool of assessment used by GSP is the Global Ecology Assessment Tool. This tool has been developed by the GSP for use with clients with cognitive disability. The service adapts the tool as necessary based on a client's communication needs. The Maroondah Assessment Profile for Problem Gambling (G-Map), Modified South Oaks Gambling Screen plus observations and discussion is used to identify appropriate intervention strategies and direct counselling sessions. A brief explanation of each of the tools is below.

Global Ecology Assessment Tool (Appendix F): This assessment tool has been developed by the GSP as a lifestyle environment review. It has been designed to assess the needs of people with disabilities and is not directly related to problem gambling issues. The service is in the process of reviewing this assessment.

G-Map (Appendix G): This assessment provides a profile of motivations for gambling to develop an individual client profile. GSP are in the process of reviewing the G- Map to analyse its effectiveness. They consider that many of the eighty five questions posed in the questionnaire could be answered on the basis of a person's disability and not their gambling issue. The

assessment takes about forty minutes and needs adaptation to be accessible to a person with a cognitive disability.

Modified South Oaks Gambling Screen (Appendix H): The GSP considers this to be the most basic assessment and more appropriate for use with a person who has a cognitive disability as it is short it takes little time to complete and provides some useful insights into the gambling issue. However, on examination, the questions posed by this assessment are abstract in their design and would be unsuitable to use with a person who has learning and conceptual difficulties. This tool needs reworking to be accessible to this client group.

SCIP: This assessment was developed by the Department of Psychology, Uni of Sydney. It is designed to follow up client progress by retesting client progress over a period of time. It is more useful as an evaluation tool but often requires support staff to fill it in on behalf of the client.

5.5.2 Interventions

The GSP provide a range of intervention treatments to clients including mainstream approaches such as controlled gambling and abstinence through skills building, financial, social and lifestyle education; and offer support groups and telephone counselling to clients on an ongoing basis.

Interventions are adapted to the individual needs of clients and include motivational interviewing, skills building and some CBT.

After the initial intake meeting a three month service agreement is negotiated with the client and the counsellor sets goals in collaboration with the client which are reviewed after three months. Many clients attend the GSP for an extended period of time, often a number of years. This is the procedure for all Life Activity programs and is not specific to the GSP. The counsellors of the GSP then develop a support plan and identify relevant interventions through discussion with the client, a support person if appropriate and in consultation with other staff. Data continues to be collected to provide statistical and empirical evidence and enable reflection and follow up.

Individual face to face counselling is provided and may be done in an outreach capacity within the client's home or other venue. The focus is on skills building and may consist of a controlled gambling plan; a gambling diary and a gambling support plan. Sample copies of these can be found in Appendix A.

Clinical experience provides the evidence on which counsellors base their practice. Counsellors use a range of strategies tailored to individual learning needs. Therapies are adapted to individual needs and counsellors expressed that one of the major challenges in their work is to capture all the strategies and interventions for diverse disabilities in a comprehensive format.

A number of counselling supports may be implemented including individual face-to-face, group, telephone, financial and life skills counselling. A client may be referred to other programs within Life Activities or to external agencies for support services.

Support groups for clients with problem gambling issues are implemented when clients are at a similar stage in the therapeutic process.

5.5.3 Exit

Once a client exits the program there is a 3 month monitoring period which consists of phone support. A client has the option to come straight back into the program if they are not coping but after the 3 month period they need to go through the referral process again. Clients complete the Life Activities general satisfaction survey.

6. Evidence based strategies

Examples of evidence based counselling practice for people with cognitive disabilities are very limited, but research into other addictive behaviours such as substance abuse may be used to highlight common factors. For example, adults with intellectual disabilities report using alcohol for the same reasons as the general population ie. to overcome loneliness and to be liked. These motives might be more important for an adult with an intellectual disability because of the greater social isolation they often experience due to stigma, because of limited avenues for contact with non-disabled peers, and because of limited social skills (Selan, 1979, cited in Christian & Poling, 1997).

There are distinct challenges for providing therapy to people with cognitive disabilities who have problem gambling issues. Research suggests (Dagnan, 1997) that a person with an intellectual disability will have a greater chance of developing an anxiety disorder than a person in the general community. This is often related to the negative self- image that at person with a disability has developed through social interactions and negative stereotyping of their intellectual disability. As anxiety is commonly an underlying disorder of any form of addictive behaviour, it becomes clear that treating anxiety will be a significant aspect of therapeutic intervention for problem gamblers.

In the book 'Cognitive Behaviour Therapy for People with Learning Disabilities' (1997), contributions from experienced practitioner researchers offer an informed approach to cognitively based treatments for a wide range of clinical problems. This includes the work of Dagnan, Novaco and others. They stress that since cognitive therapy is usually understood to be language based, its application to people with learning difficulties has been limited due to the communication difficulties often experienced by these clients. They explore the challenges of working with CBT and provide practical examples for training.

6.1 Elements of best practice

Leading directly from the review of best practice strategies, it is possible to draw out some key elements of a best practice model.

A best practice model would offer direction in the development of effective support for people with cognitive disability who have gambling problems. It requires significant development, analysis and piloting before any broad scale implementation.

Some of the key elements of such a model would include:

- A reduced reliance on traditional therapeutic models, recognising they may not be an effective intervention for a person with cognitive disability.
- Ability to adapt to the often complex needs of individuals
- Examination of the effectiveness of an educational rather than a counselling approach
- Placing the emphasis of any intervention on skills training
- Paying special attention to the method of presentation of treatment such as length of organisation of information and avoidance of heavily cognitive based therapy.
- Placing less emphasis on the abstract analysis of a client's reasons for gambling

- Taking a whole of life approach and look at strategies for overcoming disabling factors in a person's life eg, isolation, difficulty with social skills, financial planning

- Looking at what needs are being met with the gambling and identifying how to support the person to have their needs met in a way that enhances their independence and wellbeing

- Translating assessment and evaluation tools, and counselling resources into accessible language

- Networking with other services to support a positive outcome for the person – identifying what services are available to a person with cognitive disability and actively linking the person in to those supports

- Undertaking community development in a way that engages the community and disability services in constructive and proactive strategies for supporting people with disabilities who have problem gambling issues

A scenario which uses these elements of best practice has been detailed below. This scenario is an amalgam of several individual case studies of people who have used the GSP.

Sample application of 'Best Practice' model:

Client enters service after being referred by self, service provider, family member, support worker or carer, gambling counselling service, G-line.

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Assessment process commences, using assessment tools developed specifically for a person with cognitive disability. Take into account: nature of disability, communication issues, learning styles, time needed for assessment including possibility of more than one assessment session, what supports a person might need to increase their comfort, trust and confidence in the process, what resources are needed to maximise an effective assessment process, consideration given to confidentiality and consent issues.

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Develop a contract with the client as to the engagement process for counselling. Take into account: accessibility of resources, time frames, goal setting, learning needs, difficulties of the counselling process in regard to a person's disability, flexibility of approach, style of counselling, appropriateness of intervention treatments, evaluate what skills need to be developed for the client to achieve a positive outcome, examine strategies for managing immediate imperative concerns. Respect client as central to their process and support them to self determine their desired outcomes of the counselling process where possible.

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Examine appropriateness of interventions in sessions using feedback, reflection, open questioning, motivational interviewing, situational role-play, reinforcement, behavioural contingencies and cognitive behaviour therapy where appropriate. Avoid heavily based CBT, psychodynamic approaches and abstract conceptualising.
Explore networking opportunities with client to enhance or develop support systems

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Link client to other support groups or systems, reflect on and evaluate progress with client, provide ongoing support, evaluate intervention, self reflect

The following section of the report reviews the effectiveness of GSP interventions against these evidence based strategies.

7. Analysis of findings

7.1 Review of evidence based strategies

The GSP incorporates many of these best practice elements into their service provision. Through experience, they have developed a model of practice that takes into account the individual needs of a diverse range of clients. Their holistic approach allows for a great deal of flexibility in responding to client needs.

The cognitive difficulties experienced by clients are often complex and completely unique to the individual. Consequently no one model will work for all clients. If a service is treating each client as an individual then in the early stages of engagement with the client they are making an assessment as to what elements will be most useful to the client and to the practitioner in the education/counselling process. The GPS assessment processes need to be reviewed and the tools redeveloped to be accessible to people with cognitive disability and to allow more insight into individual learning styles. If we accept that much of the service that is provided by the GSP is in skills building then it is essential to assess how a person accesses new information to design the best process for that individual.

Having the ability and service structure to adapt to individual need is a key element of best practice. The GPS show a high degree of adaptability especially around flexibility in service delivery. They provide an outreach service where necessary and appropriate. Counsellors may meet with clients in their homes on a regular basis. They also adapt to individual circumstances and will participate in informal sessions at the client's convenience eg, at a client's workplace in their lunch hour. This can enhance a person's motivation to attend sessions on a regular basis.

While clinical supervision is highly regarded in the service and provided on a regular basis, any rigorous evaluation of the effectiveness of interventions is not obvious in the data collected.

The structure provided by the service may be beneficial to clients, particularly those with an intellectual disability. Some processes of the GSP tend towards a behaviour management model. This may be appropriate for some clients but the service needs to maintain vigilance in ensuring that clients are self- determining their therapeutic process to the best of their ability.

The GSP have worked very productively on promotion and undertaking networking opportunities in the Hunter region. They maintain a high profile, are well regarded and actively involved in community development. At the time of this review, however, they are not strategically promoting the service throughout NSW and are not widely known outside the Hunter region.

7.2 Consent to Treatment

Many clients are not aware at the initial intake interview what they are actually consenting to. These clients need help in understanding the implications of interventions regarding their problem gambling. This presents a major challenge as many clients do not have an awareness that a problem actually exists. A written consent is obtained at the initial meeting. The consent form is not written in accessible format and needs to be redeveloped. As the intake procedure is generic for all Life Activities programs each client who is entering the service undergoes the same intake procedure. None of the assessments undertaken are specific to people with cognitive disabilities.

The Gambling Support Project uses what they refer to as a holistic approach in their interventions with clients. Many of their clients are not aware at the outset of their intervention that they have a

serious gambling issue. To enable clients to engage more realistically with their gambling issue there is a need to develop a supportive relationship with a counsellor in a safe environment. The service provided therefore needs to be: responsive to individual needs, flexible in its approach, adaptable to changing dynamics, accessible to diverse learning styles, transparent in its processes, ethical in its delivery.

7.3 Accessibility of assessment tools to people with cognitive disability

Discussion with counsellors of the GSP indicates that the clients experiencing the most positive outcomes from therapeutic intervention are those with a mental illness, as their learning difficulties do not limit them as they might for a person with an intellectual disability. These clients are often very insightful of their underlying issues and motivational interviewing and CBT may be very effective.

Feedback from staff indicated that the expectations placed upon clients with an intellectual disability, from families and support services, to overcome their gambling problem are often unrealistic in terms of short term outcomes.

The GSP are in the process of reviewing all assessment tools utilised by the service. Their intention is to design and develop tools specific to individual disabilities. This model may be flawed, as perceiving each disability as being a homogenous group could lead to individual communication and learning styles being overlooked. On analysis it is clear that the available assessment tools need to be reviewed and adapted to be more accessible for clients with cognitive disability. The challenge is how to capture the same information without engaging with an abstract framework.

It is impossible to review the effectiveness of the interventions used with clients of the GSP without accessing client files and interviewing clients in depth. This is not appropriate to this form of review. This is a review of the degree to which the strategies are based on evidence that has been gathered from the field. Many clients are not aware at the initial interview that they have a problem gambling issue as it has been identified by family, a support worker or a support service and not by the client him/herself. In this circumstance it is essential for the counsellor to develop a trusting relationship with the client prior to exploring their gambling issues. Clients are not always able to gain insight into their issues and it may be more imperative to support them to sort out other parts of their lives to enable them to see the gambling as a problem.

The GSP design and develop their interventions based on their own experience and expertise developed over time. There is little evidence base (refer to literature review, above), although research into the impact of interventions on clients with cognitive disability who have substance abuse problems and anxiety disorders could/should be drawn upon in a more vigorous manner. There are no competencies developed at this stage to support interventions for people with cognitive disability and problem gambling issues.

7.4 Interventions and education

Most clients of the service who have a cognitive disability have low to moderate support needs, as those with high support needs generally have little independence, which makes progression towards uncontrolled gambling behaviour unlikely.

The GSP uses an holistic approach by individualising counselling models when working with clients. For clients with a mental illness the preferred model is cognitive behaviour therapy, which is solution focussed and relies heavily on motivational interviewing. For clients with cognitive disability some of the above is utilised but the focus is more on practical educational strategies which are heavily orientated towards skills building and working with support systems.

The time spent working with individual clients is usually much more extensive than working with clients in mainstream services. Clients with disabilities are not always aware that they have a serious gambling problem, and may need support working out other parts of their lives before addressing the gambling issue directly. The GSP experience has been that it is often an enormous challenge for clients to give up the problem gambling behaviour. Many of their clients have been institutionalised at some stage in their life and the club structure provides them with an environment to which they can relate.

9.5 Perception of external stakeholders

Mainstream gambling counselling services contact GSP if they identify a client with a disability. G Line provides mainstream services with the contact details. The mainstream service does the initial interview and offers the client a specialised service. Of the four mainstream services interviewed, only one reported that they have had a few clients who did not want to acknowledge that they have a disability and therefore did not want to attend a specialist service.

One counsellor in the Hunter region had referred at least six clients to the GSP, other counsellors in the same service had also referred. The mainstream service makes the initial contact with the GSP and gives the client's name and nature of their disability. An intake appointment is arranged at the GSP and the mainstream service notifies the client that it is organised. Mainstream services have no further contact with GSP regarding the client.

Services in the Hunter region unanimously stated that the GSP was an essential service and is well respected in the region. The networks in this region are strong and utilised effectively based on evidence from the GSP and anecdotal evidence from external stakeholders.

Another service acknowledged that although they are trained gambling counsellors they always refer to the GSP as they have no experience of counselling people with cognitive disability. One service stated that mainstream services 'will say people with disabilities don't want special services in order to maintain their client numbers' as they believe their funding relies on these numbers.

Another service acknowledged that they were unable to provide a service to clients with cognitive disability as it was necessary to liaise much more with families and support workers of these clients and they did not have the resources to do this.

Mainstream services maintained that they struggle with clients with cognitive disability as their main treatment intervention is cognitive behaviour therapy. They stressed that this intervention has had limited success with clients with cognitive disability as it is person – centred and requires a high level of insight.

8. Emerging themes

8.1 Cognitive Behaviour Therapy is not necessarily the most appropriate therapeutic intervention for people with cognitive disability

Gaining insight into the causes of problem gambling and analysing the impact of past emotional experience on present behaviour is a major requirement of Cognitive Behaviour Therapy. A small number of clients within the GSP appear to have benefited from cognitive behaviour therapy and the most positive outcomes are achieved with skills based training which allows clients access to practical strategies to enhance their ability to resist problem gambling activities. To date, the greatest degree of success with CBT has occurred with people with mental illness, not people with cognitive disability.

CBT is not commonly used with people who have cognitive disability. The bulk of interventions for people with cognitive disability focus more strongly on education and support over time to change behaviour.

If an approach which focuses on education and skills building is taken, it is likely the length of time each individual client requires may be reduced, and consequently more clients could be seen with measurable results.

8.2 Working with people with cognitive disability and problem gambling issues presents unique challenges which have yet to be fully explored.

These challenges are in the areas of appropriate intervention and support, how to evaluate the impact of interventions on peoples' experiences, how to create an environment of support which minimises loss of independence and self determination while enabling a therapeutic healing process to take place.

Due to the diverse communication needs of people with cognitive disability, finding an appropriate language that is respectful, non directive, upholds the rights of people to take control of their lives and their experiences and relies on respectful and healthy boundaries with a practitioner remains a major challenge.

It is likely that these interventions will take longer to take effect than for the general population of people without cognitive disability. Resource allocations for counsellors working with people with cognitive disability need to be considered, to ensure realistic timeframes are developed for treatment.

8.3 Time, isolation, poverty are underestimated

There is an underestimation of the impact of these issues on the ability of people with disabilities to take control of their lives and acquire equitable access to services and modes of service delivery that meet their needs. The environment which provides much of the social structure in the lives of people in the general community ie, the club structure, may provide a structure and be a significant positive reinforcement to a sense of belonging for people who are marginalised and stigmatised.

Gambling counselling support to people with cognitive disability is more likely to involve other people, such as family, friends and disability support workers, in the identification and addressing of gambling problems. Many families of people with significant needs rely on small amounts of service to prop up highly stressful lives. The use of gambling support services may go beyond the benefit usually expected by a person without disability, and play a role in the development of other interventions which support people with disability and their families.

8.4 The capacity of mainstream gambling counselling services to provide counselling and support to people with cognitive disability is limited

There is a lack of expertise and experience within mainstream gambling services that inhibits their capacity and willingness to work with clients with cognitive disability. As the principle model of intervention in mainstream services relies on CBT, the effectiveness of which may be limited with people with cognitive disability, there is little confidence within the system to engage with these clients. Staff attitudes and beliefs regarding disabilities may act as a barrier. Staff may not interact confidently with people with disabilities and this may be perceived as rejection.

8.5 Identifying the unmet need of people with disabilities who have a gambling problem is a major challenge

Low participation rates in mainstream gambling services and in the GSP may be misinterpreted as indicators of the absence of serious gambling problems among people with disabilities. However, their limited use of these services may be attributed to a number of other factors. The assessment process may be inaccessible to people with cognitive disability as they have not been adapted to allow for learning difficulties and communication problems.

Also, the commitment to coordinate a continuum of services to enable ongoing support is not always available, particularly in regional and rural areas.

8.6 Challenges of implementing a state wide service

There are many challenges to implementing a service for people with cognitive disability which operates across the state. These include;

- Lack of disability awareness in mainstream gambling counselling services
- As working with clients with cognitive disability is a specialist area, it is difficult to promote the service if funds are not available to commit to staff training
- Due to the demands of providing appropriate services to people with cognitive disability, generic gambling services may be reluctant to take on these clients.
- The counselling therapeutic model as used with clients from the general community may not be appropriate for a person with cognitive disability.
- There is a need for accessible resources to be developed and/or adapted for use with clients with cognitive disabilities in mainstream services
- Supports for a person with cognitive disability may be restricted due to all of the above and the level of isolation and poverty experienced by people with disabilities in the community.

8.7 Reactive education and planning processes

Mainstream services and people with disabilities, their families and support workers outside of the Hunter region are not generally aware of the existence of a specialised service for problem gamblers. The community education currently provided to disability services and their clients are by request only and are a once off session for a limited time frame. This response does not enable real engagement with the disability or gambling sectors.

A key element of exploring this lack of engagement might be to ask what questions does a service need to ask to take them to a new level in working with people with cognitive disability?

8.8 Need for appropriate accessible resources for clients

Lack of accessible resources for people with cognitive disabilities prohibits their ability to make informed decisions regarding their gambling issues and when confronted with gambling counselling service assessments they are disadvantaged further by communication difficulties. Due to stigmatisation and negative stereotyping applied to their learning difficulty, people with cognitive disability may wear a 'cloak of competence' when engaging with mainstream service providers. Hence, their communication difficulty may not be identified during an initial interview.

Much of the literature available, and counselling resources utilised in mainstream services is inaccessible to a person with a cognitive disability and serves to limit their access to appropriate, consistent service pitched at their level of comprehension.

What learning has come out of the experience of the Gambling Support Project?

- People with intellectual disability are often unaware they have a gambling problem and need a trusting relationship with a counsellor/educator to support them to examine their issues
- Self referral is unusual for a person with intellectual disability who has a gambling problem
- Methods of assessment need to be tailored to the needs of a person with an intellectual disability and designed in an accessible format
- Rather than fearing that promoting the service creates a pool of unmet need which cannot be serviced, it is important to use that need to lobby for additional funding for counselling services for people with disabilities
- It is impossible to create a state-wide service without a comprehensive promotional strategy to highlight the special needs of a problem gambler who has a cognitive disability
- Use an individualised approach, use outreach services, be flexible in providing services, address problems that may underlie the gambling problem (including isolation, loneliness, poverty, depression, limited social skills)
- Encourage group activities, such as group counselling and support groups that give peer support and the opportunity to develop friendships and reduce isolation

9. Recommendations

For providing better services to people with cognitive disability who have a gambling problem:

9.1 Develop a multifaceted approach to working with problem gamblers with cognitive disability

Cognitive Behaviour Therapy is not always the best means of counselling for a person with a gambling addiction who has a learning difficulty. Rather than counselling, a new model of intervention could be developed which reframes intervention as a process primarily of education, which identifies how the person might gain equanimity in their lives and who can support them in this. For treatment to succeed, clients need support to see what particular strengths they bring to the recovery process. A strengths based approach to treatment is especially important to people with disabilities who may have learned to define themselves in terms of their limitations and inabilities.

For people with cognitive disability some adaptations to counselling sessions will be necessary depending on the individual's capacities and learning style. For instance, session times should be flexible, so that sessions can be shortened, lengthened, or occur more frequently depending on the individual treatment plan. More frequent, less formal contacts may benefit the client and as such, drop-in policies may improve motivation to succeed.

This approach includes liaison with other health professionals and mental health practitioners to take into account underlying pathology that may impact on an individual's ability to cope with post traumatic stress, anxiety disorders, depression, social isolation and stigma. Develop strategies for intervention treatment that significantly addresses whole of life issues.

9.2 Information clearinghouse on effective counselling strategies for people with cognitive disability

As counselling for problem gambling among people with cognitive disability is an under-researched and resourced area, it is important that new information and tools are gathered and shared as they emerge.

As part of its operation, a specialist gambling counselling service should take on a clearinghouse role for identifying and sharing information on effective counselling strategies and support processes for people with cognitive disability.

9.3 Review assessment tools and consent processes to treatment

Assessment tools need to be reviewed as matter of priority, and adapted to be more accessible and to allow flexibility for diverse needs. They also need to reflect the best therapeutic approach for the client more accurately.

Consent processes need to be developed which are accessible, ethical and which ensure people with cognitive disability are able to provide informed consent to treatment. Processes also need to address situations where people are not able to provide informed consent.

9.4 Focus promotional activities

Promotional activities need to be developed and implemented strategically. Broad promotion across disability services, mainstream gambling services, legal networks, services, clubs and the police service can effectively put the unmet needs of people with gambling problems on the agenda.

To promote as a state wide service there is a need to participate in problem gambling forums for mainstream services and network within gambling counselling services meetings, activities which have not systematically occurred to date. Promotion is increasingly important in a decentralised model, where the focus is on specialist support of mainstream services across a wide geographic region.

There is a danger that the current level of resources available to address problem gambling in people with cognitive disability may be insufficient to support a large influx of clients with disability. This will be partially managed by the change in focus of the program to provide supports to mainstream counselling services, although regular review of the adequacy of resources is recommended.

9.5 Develop program specific policies and procedures.

Policies and procedures need to be developed specifically for the gambling support service, rather than generic ones used by the whole organisation. Independent living principles need to be included with these key aspects: inclusion rather than segregation, freedom to fail, access to sufficient knowledge to enable informed choices regarding treatment, using an holistic approach, and maximising the role of self help. This will enhance the ability of services to respond with competent proactive strategies to the needs of clients with disability.

9.6 Focus education and training to particular target groups

There are a number of groups who would benefit from focused education and training, including:

· *People with disabilities*, who need direct access to objective information regarding healthy and unhealthy gambling behaviours and treatment of gambling problems. A comprehensive and accessible training strategy for informing people with disabilities about issues associated with gambling and how to access support is needed.

· *Mainstream gambling counselling services*, who require training in disability awareness and the attitudes and values that drive responses to people with disability. A training package which builds on the existing education strategies used by the GSP should be developed for mainstream gambling counselling services to enable them to support people with cognitive disability, particularly in regional and rural areas. Training to mainstream gambling counselling services should include proactive and reactive components, such as induction training for new counsellors, and education and support for counsellors already working in the field.

· *Disability support workers*, who need an increased level of understanding of gambling problems which may impact the lives of the people whom they support. A train the trainer package should be developed and delivered to disability support workers to enable them to provide information and education to people with disabilities and those who support them (such as families and friends) to recognise gambling problems and how to address them.

9.7 Targeted resource development

A portfolio of resource materials pitched at people with varying levels of expertise and experience would be of greater value than one manual which aims to meet the training and information needs of disparate groups. A series of smaller resources can be distributed appropriately as the need arises. These may include

- Fact sheet on gambling for disability support workers
- Fact sheet on disability for mainstream gambling counselling service
- Fact sheet on supporting a problem gambler families and support workers
- Fact sheet on dealing with debt and accessing financial counselling for people with cognitive disability
- Fact sheet on managing your gambling for people with cognitive disability

All resources should be developed in collaboration with key stakeholders. Resources specifically for people with cognitive disability should be developed by agencies with specific expertise in accessible information development.

9.8 Identifying referral pathways

Pathways for referring people with cognitive disabilities for problem gambling issues should be formally mapped and promoted to both gambling services and disability services. A broad range of service models should be included (e.g. services that provide outreach to an individual in her/his home and supportive counselling). This may need to include a review of the roles and responsiveness of service providers in identifying, assessing and treating their clients who are experiencing difficulties with gambling. Services for people with disabilities need to be knowledgeable about other social services in the community and make appropriate referrals.

9.9 Secondary support services

People with cognitive disability are more likely to be referred to a gambling counselling service by family, friends and support workers than are people without disability. They are also more likely to be actively involved in the implementation of strategies to resolve gambling problems. Therefore, consideration should be given to developing and implementing support services for families and carers of problem gamblers who have cognitive disability. Resources and referral information should be developed and made available to them.

Consideration should also be given to involving clients, carers, family members, advocates, service providers, planners and funders in the planning and delivery of problem gambling services to people with disabilities.

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Appendix B: staff interview questions

Staff group interview questions

What information to you think is relevant to assist us to review the processes you employ in the service?

How do you access your clients? What are your referral pathways?

Are the other services you refer to, other services of Life Activities?

What assessment tools do you use?

How does the service adapt these tools to make them accessible to a person with cognitive disability?

How do you adapt the Global Ecology Assessment Tool for individual clients?

Which tools have you developed to evaluate the effectiveness of your program?

Do you design your programs using evidence - based methodology?

If so, have you developed your own competencies and what are they?

What is the content of your educational workshop?

Do you provide 'train the trainer' education to other agencies as offered in the manual? If so, to whom?

How do you get the GSP and mainstream gambling services working together?

How do you go about promoting the service?

Have you taken on promoting the state - wide service?
If so, how? If not, why not?

Individual staff interview questions

How do you define your role within the service?

What do you believe are the strengths and weaknesses of the program?

How do you think you can build on the strengths?

What are the interventions you practice with clients? How do you determine their appropriateness for individual clients?

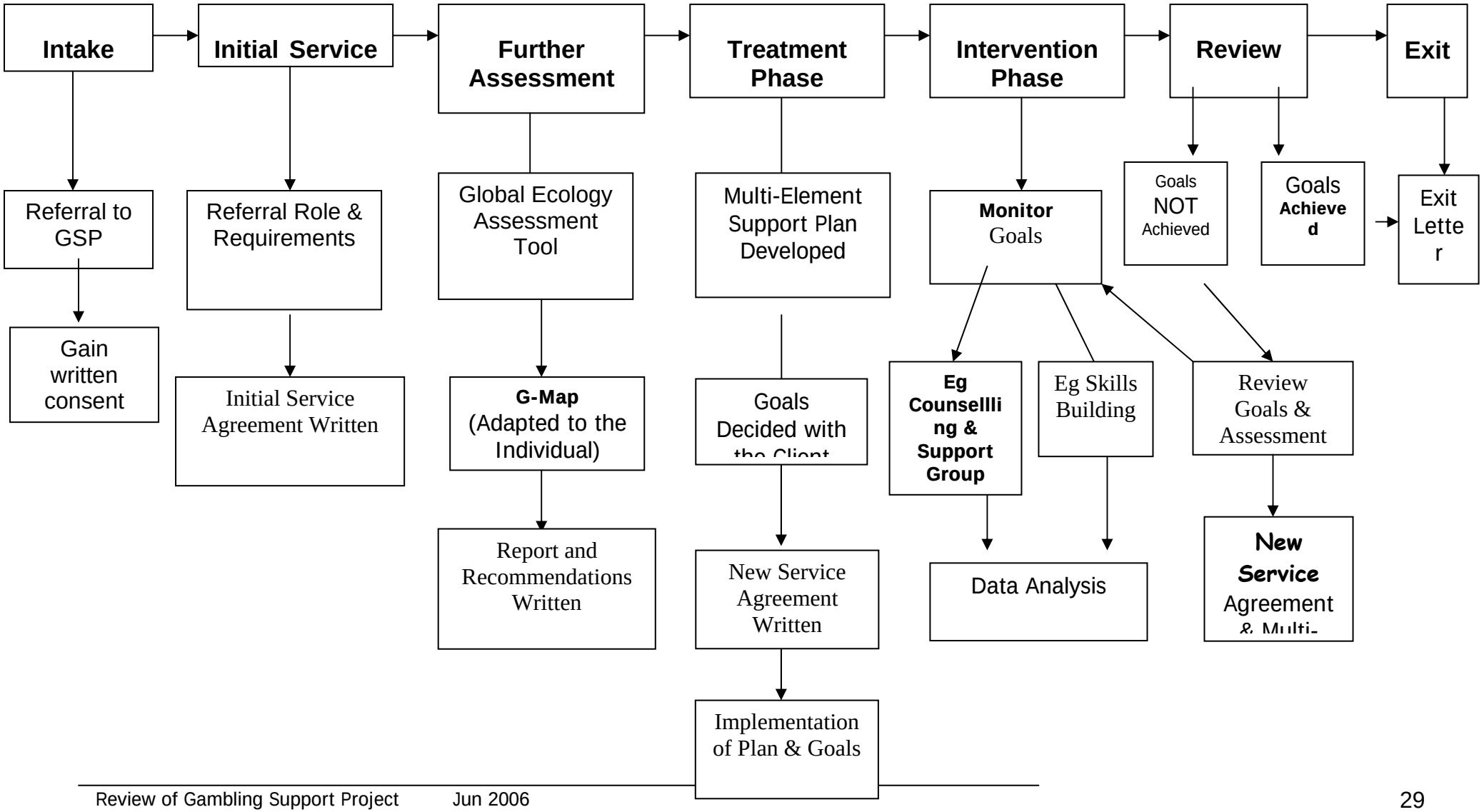
How do you personally evaluate a client's progress in therapy?

What professional development have you undertaken?

What professional development do you need/would you like to have made available to staff of the GSP?

Appendix E: GSP Process Flow Chart

GSP Process Flow Chart

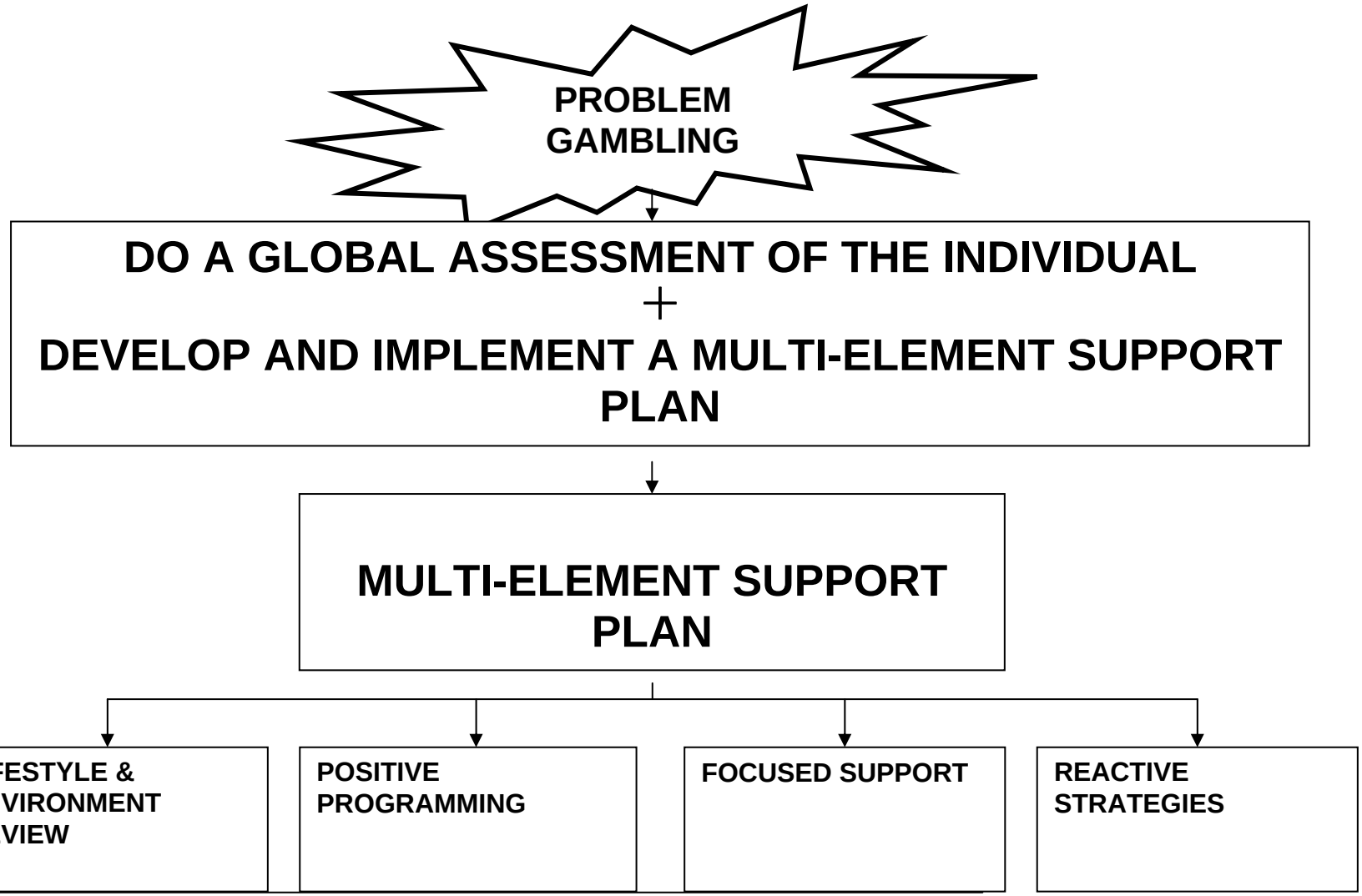


a multi element approach to problem gambling

PROACTIVE STRATEGIES			REACTIVE STRATEGIES
ECOLOGICAL CHANGES	POSITIVE PROGRAMMING	FOCUSED SUPPORT	SITUATIONAL MANAGEMENT
SOCIAL NETWORKING PROGRAM	**INTERPERSONAL SKILLS PROGRAM**	**COUNSELLING / FINANCIAL**	**TRIGGER CONTROL**
CHOICE / SELF DETERMINATION	**GENERAL LIVING SKILLS PROGRAMS**	**COGNITIVE BEHAVIOURAL THERAPY**	**EARLY INTERVENTION STRATEGIES**
LEISURE ACTIVITIES PROGRAM	**LEISURE SKILLS PROGRAM**	**GROUP THERAPY**	**ACTIVE LISTENING**
RECREATIONAL ACTIVITIES PROGRAM	**RECREATIONAL SKILLS PROGRAM**	**ON-GOING CONSULTATION WITH PSYCHOLOGIST / PSYCHIATRIST**	**CRISIS INTERVENTION**
OTHER ALTERNATE ACTIVITIES	**BUDGETING SKILLS PROGRAM**	**MEDICATION**	
FAMILY RELATED ACTIVITIES	**MONEY MANAGEMENT PROGRAM**	**RELAXATION THERAPY**	
		DIFFERENTIAL REINFORCEMENT	

Appendix E: Multi-Element Support Plan

A MULTI-ELEMENT APPROACH TO PROBLEM GAMBLING



Appendix E: Multi-Element Support Plan

A MULTIMODAL EDUCATIVE APPROACH TO PROBLEM GAMBLIN