
Review of Approaches to Satisfaction Surveys of Clients of Disability Services

Prepared for:

**Steering Committee for the
Review of Commonwealth/State Service Provision**

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The views expressed in this report are those of the consultants', and do not necessarily reflect those of the Steering Committee or the Productivity Commission.

TABLE OF CONTENTS

EXECUTIVE SUMMARY	1
1. INTRODUCTION	2
1.1 <i>Background of this review</i>	2
1.2 <i>The nature of nationally comparable information on client satisfaction with disability services</i>	3
2. NOTES ON THE SATISFACTION SURVEYS REVIEWED	6
2.1 <i>Disability Services Commission (WA) Telephone consumer satisfaction survey</i> ..	6
2.2 <i>Health and Community Services (VIC) ATSS consumer satisfaction survey</i>	6
2.3 <i>Department of Human Services (VIC) Public Mental Health Services consumer and carers satisfaction survey</i>	6
2.4 <i>Colorado Dept of Human Services (USA) Colorado Progress Assessment Review (COPAR)</i>	7
2.5 <i>National Association of State Directors of Developmental Disability Services (NASDDDS) and the Human Services Research Institute (HSRII) (USA) Core Indicators Project (CIP)</i>	7
3. CURRENT GOOD PRACTICE - ACHIEVEMENT AND LIMITATIONS OF LARGE SCALE SATISFACTION SURVEYS OF DISABILITY SERVICES	8
3.1 <i>Purpose of the Survey</i>	8
3.2 <i>Understanding of the Concept of Consumer Satisfaction with Disability Services</i>	9
3.3 <i>Understanding of the Properties of Consumer Satisfaction Ratings in the Disability Sector</i>	12
3.4 <i>Sampling Procedures</i>	13
3.5 <i>Ethical Issues</i>	14
3.6 <i>Data collection methods</i>	15
3.7 <i>Survey design and format for people with disabilities</i>	15

4. CONTEXT OF THE PROPOSED SATISFACTION SURVEY.....	19
4.1 <i>The population of CSDA funded services and their consumers</i>	19
4.2 <i>What state and Commonwealth disability services want from a national consumer satisfaction survey.....</i>	20
4.3 <i>Requirements on states to have quantitative measures of consumer satisfaction with disability services.....</i>	20
4.4 <i>Differences in the definition of disability and the populations served across states</i>	21
4.5 <i>Relationship between CSDA funded services and state services for people with disabilities</i>	21
4.6 <i>Co-ordination services and disability support services.....</i>	22
5. SURVEY OPTIONS - DESCRIPTION OF FEASIBLE OPTIONS WITHIN BUDGET RANGE	23
5.1 <i>General considerations.....</i>	23
5.2 <i>Option One - Consumer satisfaction (National comparison).....</i>	26
5.3 <i>Option Two - Consumer satisfaction plus family satisfaction mail survey (National comparison).....</i>	29
5.4 <i>Option Three - Consumer satisfaction plus family satisfaction phone survey (National comparison).....</i>	32
5.5 <i>Option Four - Consumer satisfaction plus family satisfaction mail survey (State comparisons).....</i>	35

ATTACHMENT A - ANNOTATED BIBLIOGRAPHY

ATTACHMENT B - SURVEY REVIEWS

ATTACHMENT C - CORE INDICATORS PROJECT: CANDIDATE INDICATORS

ATTACHMENT D - CORE INDICATORS PROJECT - CONSUMER SURVEY

EXECUTIVE SUMMARY

The aim of this review is to provide advice to the Disability Services Working Group of the Steering Committee for the Review of Commonwealth/State Service Provision on an appropriate mix of methodology for a survey to provide nationally comparable information on the satisfaction of clients of disability services. The outputs of the review are:

- a written report providing advice on previous research methodologies and options for a survey for the clients of disability services; and
- a verbal presentation of the main conclusion of this report to the disability services working group.

This review provides the required advice in the follows ways:

- a description of current good practice with regard to large scale satisfaction surveys with disability services;
- notes on the context of disability services in Australia; and
- outlines of four options to conduct a satisfaction survey of consumers and their family members/carers.

Our advice is based on:

- a literature review;
- a detailed review of five large scale surveys; and
- personal communication with experts working on similar surveys.

We suggest that the best way to obtain comparable satisfaction data across states for both direct consumers and family members/carers within the budget limit discussed (\$300,000), is to use a combination of telephone and face to face interviews with consumers, and a mail questionnaire with family members/carers.

1. INTRODUCTION

1.1 Background of this review

1.1.1 Aims and outputs of the review

The aim of this review is to provide advice to the Disability Services Working Group on an appropriate mix of methodology for a survey to provide nationally comparable information on the satisfaction of clients of disability services.

The Disability Services Working Group has commissioned the work on behalf of the Steering Committee for the Review of Commonwealth/State Service Provision. The outputs of the review are:

- a written report providing advice on previous research methodologies and options for a survey for the clients of disability services;
- a verbal presentation of the main conclusion of this report to the disability services working group.

Specific requirements of the review are to:

- report on all major attempts to measure client and carer satisfaction with disability services (and in related areas as mental health) and to report on specified aspects of these surveys;
- develop satisfaction survey options for a range of budget from \$100,000 to \$300,000; and
- provide an annotated bibliography.

The Report on Government Services

The Review of Commonwealth/Service Provision, develops and publishes an annual report on government services, which reports on a set of performance measures for a number of areas of service. The Report on Government Services aims to publish on-going, accurate comparisons across jurisdictions of government performance in the provision of services so as to promote continuing performance improvement. Government and service providers are able to use this information to help identify what improved level of service is possible, and to improve ways in which services are provided to the community. The report covers such service areas as education and training, health, justice, emergency management, community services and housing.

In the most recent edition, The Report on Government Services 1998, a separate section was devoted to services for people with a disability. The Disability Services Working Group oversees the preparation of this section.

1.1.2 The approach to performance measurement

The Report on Government Services 1998 outlines the current approach to performance measurement which is applied to all the service areas.

With regard to disability services, effectiveness is divided to three outcomes:

- participation outcomes;
- quality; and
- access.

Within the quality outcomes, client perceptions are separated from other quality assurances processes. Client perceptions are seen to be composed of 'client satisfaction' and 'carer satisfaction', the subjects of the present review.

'Client satisfaction with appropriateness' is also listed as one of a number of performance indicators for access to appropriate services on the basis of relative need.

The three areas of client perceptions; client satisfaction, carer satisfaction and client satisfaction with appropriateness are described as "yet to be developed or not collected" in The Report on Government Services 1998.

The present review is the first of a three stage process to enable client perception in the form of satisfaction indicators to be included in the 2000 Report on Government Services, which will be published in February 2000.

1.2 The nature of nationally comparable information on client satisfaction with disability services

Crucial to understand the comparisons that are to be made with the data. Comparisons could include:

- a) Comparisons over time across the whole of Australia - levels of client satisfaction with disability services in Australia at time A. could be compared with levels of client satisfaction at time B.
- b) Comparisons over time for each Australian state - levels of client satisfaction with disability services in each Australian state at time A. could be compared with levels of client satisfaction in each state at time B.

- c) Comparisons between states on levels of satisfaction with disability services as a whole.
- d) Comparisons across Australia on levels of satisfaction among sub-populations across Australia eg consumers of different service types, consumers of different age or gender, consumers in different geographical locations eg urban, rural and remote.
- e) Comparisons between states on levels of satisfaction among sub-populations within each state eg consumers of different service types, consumers of different age or gender, consumers in different geographical locations eg urban, rural and remote; and cultural backgrounds.
- f) Comparisons within states on levels of satisfaction among sub-populations within each state eg consumers of different service types, consumers of different age or gender, consumers in different geographical locations eg urban, rural and remote; and cultural backgrounds.

We would like to make the following points about such comparisons:

- A clear statement of the intended comparisons is required so that appropriate sampling procedures and sample sizes can be developed.
- Comparisons can only be made if the measurement tools/indicators have adequate discriminatory powers. For example, if it turns out that there are no statistically significant differences in the results achieved, then the indicator is said to lack discriminatory power - it provides no information concerning the extent to which one state's performance differs from another.
- Comparisons may be made against a predetermined target level of performance, that is, an absolute standard. Alternatively comparisons may also be made against a 'norm', that is, what is known about how other similar systems perform.

Such a norm may or may or may not be acceptable in terms of absolute performance. For example, 10% of people may be unemployed across all states, but this may not be an acceptable level of unemployment, and all states may agree to work towards lower levels of unemployment.

- Some comparisons rely on assumptions about satisfaction ratings that may not be true. For example, comparison of satisfaction with two different service types eg. accommodation and information services; at one point in

time, assumes that, all things being equal, similar levels of service quality may produce similar levels of satisfaction. This may not be the case. For example, there is some evidence from the surveys reviewed that information services may often attract lower ratings of satisfaction than accommodation services. Similarly with regard to geographical location, satisfaction ratings for rural services are often higher than satisfaction ratings for city services.

2. NOTES ON THE SATISFACTION SURVEYS REVIEWED

These notes provide a summary of the surveys reviewed and referred to in the next section: Current Good Practice.

The detailed reviews are given in Attachment B.

2.1 Disability Services Commission (WA) Telephone consumer satisfaction survey

This survey was carried out in 1997 primarily to fulfil the requirements of the WA Auditor General. Approximately 450 people responded through telephone calls to the homes of next of kin. The survey covered level of satisfaction with a wide range services and next of kin could respond on a five point satisfaction scale. Information was gathered about levels of family/carer satisfaction and client satisfaction with services. Comparatively few people with a disability responded on their own behalf (12%).

2.2 Health and Community Services (VIC) ATSS consumer satisfaction survey

This 1995 survey focused on the experiences of clients and families who used a defined service type; Adult Training and Support Services (ATSS). There are over 100 ATSS agencies in Victoria.

Consumers (n = 139) were involved through face to face interviews, (n = 72), or direct observation sessions (n = 67). Parents and carers (n = 269) completed a mailed out questionnaire.

2.3 Department of Human Services (VIC) Public Mental Health Services consumer and carers satisfaction survey

This large scale study reported in June 1997 measures both consumer satisfaction and carers satisfaction with Mental Health Services throughout Victoria. Large samples were achieved with questionnaires hand delivered to consumers at service outlets (n = 1757), and mailed questionnaires to carers (n = 1171).

The survey uses five point Likert scales for six components of service each with five service aspects.

This survey is being repeated on an annual basis and ties into a performance bonus system for services.

2.4 Colorado Dept of Human Services (USA) Colorado Progress Assessment Review (COPAR)

Colorado Progress Assessment Review (COPAR) is a complete system of performance indicators which have been developed in Colorado since 1986. COPAR includes a client satisfaction survey which is used with adult consumers. Adult consumers must answer some questions for themselves while others may be answered by people who know them well. COPAR continues to be used and there is an extensive series of reports.

2.5 National Association of State Directors of Developmental Disability Services (NASDDDS) and the Human Services Research Institute (HSRI) (USA) Core Indicators Project (CIP)

The Core Indicators Project is an attempt to create common performance indicators across 15 or more US States. The performance indicators include some elements of client satisfaction and quality of life. There is a consumer questionnaire for adults and questionnaires that can be answered on behalf of adult consumers by advocates and staff. There is also a separate family satisfaction questionnaire to be mailed out.

The result from the first field trials across a number of American States should be available in August/September 1998. The project draws from a large body of United States' work with consumer satisfaction measures and performance indicators. The Core Indicators and the Consumer Survey are given in Attachment C.

3. CURRENT GOOD PRACTICE - ACHIEVEMENT AND LIMITATIONS OF LARGE SCALE SATISFACTION SURVEYS OF DISABILITY SERVICES

This section of the report summarises findings from the literature review and survey reviews. The annotated bibliography and detailed survey review are given in Attachment A and Attachment B respectively.

3.1 Purpose of the Survey

3.1.1 Clarity about comparisons to be made

We outlined possible comparisons that could be made in our introduction. The intended comparisons will drive the design of the study. It is important that the Working Group creates a clear statement of intended comparisons rather than refer to the purpose of the survey as 'national benchmarking' or similar.

The COPAR report provides a clear statement of intended comparisons.

3.1.2 To measure Quality of Service, Quality of Life or both

Some surveys clearly measure quality of service (eg. Vic MH, DSC), while others measure quality of service and quality of life (eg. COPAR). The focus of measurement for quality of service is typically on aspects of quality of service such as:

- ease of access;
- information provided;
- intervention provided;
- participation in decision-making;
- staff behaviour; and
- ability to make complaints.

The focus for quality of life measurement is typically domains such as:

- personal relationships;
- contact with the community;
- material wellbeing;
- health;
- emotional wellbeing; and
- activity/productivity.

Specific quality of life scales eg. Comprehensive Quality of Life - Com-Qol (Cummins, 1997) and the Quality of Life Questionnaire - Qol.Q (Schalock and Keith, 1993) have been developed for use with people with a disability and used as outcome measures for accommodation and community living support services.

The argument in favour of quality of life measures suggests quality of life is the ultimate measure of service outcome (eg. Kozleski & Sands, 1992). Measuring quality of life in a way that can be used by other members of the community has the advantage that a standard of performance can be identified. The quality of life of people with disability can be compared with the quality of life of other groups in the community (Kozleski & Sands, 1992 and Cummins, 1997).

We suggest the consumer survey should focus on quality of life questions as well as specific aspects of service quality.

3.2 *Understanding of the Concept of Consumer Satisfaction with Disability Services*

3.2.1 Satisfaction as multi-dimensional

There is a general consensus that satisfaction with services is multi-dimensional and best measured using questionnaires that tap different dimensions.

3.2.2 Influences on satisfaction ratings

It is very probable that service performance is only one of a number of influences on consumer and carer satisfaction ratings. Other influences are:

- Frame of reference for the service - source of knowledge about the service, knowledge about alternatives and expectations, attribution of shortcomings etc.
- Frame of reference for the survey - understanding of how the information be used, perception of confidentiality, fear of retribution etc.
- Demographics - age, cultural background etc.
- Error in the measurement system.

Service performance or quality is itself multi-dimensional. It is probable that consumer satisfaction is heavily influenced by one dimension of quality, namely staff interaction with the respondent.

3.2.3 The nature of comparisons among samples from different jurisdictions

Granted that the level satisfaction in a given sample is a function of service performance plus the other influences listed above, significant differences in levels of satisfaction between two samples may not reflect differences in the level of performance of the two services from which the samples are drawn.

For example, the frame of reference for the service may well be a function of the service system. A good service system in Sample A may educate consumers by having some high profile, very high quality services which act to raise expectations of all consumers and lower the satisfaction levels of consumers able to access other services of adequate quality. Sample B may show higher levels of satisfaction in the context of uniformly mediocre services.

In this example, Sample B may show higher levels of satisfaction than Sample A although other objective indicators may suggest Sample A is drawn from a jurisdiction with higher quality services.

3.2.4 The satisfaction profile among consumers that disability services are aiming to achieve

Commercial models of consumer satisfaction generally accept that a high proportion of very satisfied consumers is desirable as these are the people who will provide repeat business (eg. Mowen & Minor, 1998). It is important for business enterprises to measure the level of satisfaction among their consumers and to know how to achieve high levels of satisfaction. In a competitive environment it is worth such enterprises expending effort to create more customers who are very satisfied.

Dissatisfied customers are undesirable as they represent wasted marketing effort ie. they have been recruited as customers and then lost.

A disability service system does not function to attract funds from a market of individual customers. It aims to use public funds to equitably meet the needs of a defined group who are in need of the services. In these circumstances it is arguable that the priority is to ensure as many consumers as possible within the defined group are reasonably satisfied, ie not dissatisfied, with the way the service system is meeting their needs. The creation of very satisfied consumers would only become of interest if there were no longer any dissatisfied consumers.

It is important to have a consensus about the goals of disability service systems with regard to levels of consumer satisfaction as this will drive the way in which the data may be manipulated, reported and interpreted.

3.2.5 The separation of carer satisfaction from consumer satisfaction

Consumer satisfaction ratings should not be made by proxy or vicarious responding by family members or other carers. Studies (eg. Cummins, 1997) show the correlation between consumers ratings and vicarious ratings to be unacceptably low.

Carers may be asked to separately rate services in their own right.

3.2.6 The relationship of consumer satisfaction to other performance indicators including indicators of service quality

Consumer satisfaction measures do not correlate highly with other performance indicators of service quality. Measuring consumer satisfaction is not equivalent to measuring overall service quality. Consumer satisfaction may best be thought of as one distinct dimension of service quality.

Consumer satisfaction may be best measured as part of an integrated approach to assessment of the quality of a disability service system as with COPAR or CIP.

3.2.7 The determination of importance of different service dimensions to consumers

One of the commonly noted limitations of satisfaction surveys has been that the dimensions of services for study have been chosen by administrators and other experts without the input of consumers themselves. While it may be argued that the important dimensions of service have been adequately researched, others (ATSS and Vic MH) suggest it is crucial to have consumer input into survey design.

Consumers could have input into the weighting of importance in at least two ways:

- Groups of consumers could be asked outside the survey process to weight the various questions for importance.
- Each consumer could be asked to provide their own rating of importance during the survey.

The latter approach is included in the subjective satisfaction scale of Com QoL. In Com-QoL each subjective domain score that contributes to the total subjective satisfaction score, is composed of an importance times satisfaction rating. This procedure increases complexity and lengthens administration. The ATSS survey abandoned an attempt to include consumer ratings of importance as part of their survey.

We suggest that while this is important to have consumer and family input into the design of the survey to ensure relevant areas are covered, we believe the issue of ranking areas by importance should be addressed in subsequent satisfaction surveys.

3.2.8 The measurement of satisfaction with people with disabilities

Satisfaction may best be measured using direct questions about whether people wish to move house, change job etc. rather than through making satisfaction ratings as such (see discussion below on survey design and format)

3.3 Understanding of the Properties of Consumer Satisfaction Ratings in the Disability Sector

3.3.1 High ratings

It is generally accepted that consumers and carers will give high ratings (75-95% of highest possible score) on service satisfaction surveys. Such ratings reduce the sensitivity of satisfaction surveys and reduce their discriminatory power. The ceiling effect makes it hard to measure if new forms of service system lead to better outcomes for consumers.

With regard to quality of life Cummins (1995) reviewed 16 studies of life satisfaction and found they yield a mean of 75% score maximum and the standard deviation of just 2.74. This work again indicate the probability of gaining high scores with measure of satisfaction with services or quality of life.

All surveys reviewed reported high ratings of satisfaction with services.

3.3.2 Older people rate more highly

It is generally accepted that older people eg those over 45 years, will provide higher ratings of satisfaction with services. This has been the finding with the Victorian and Western Australian surveys reviewed.

It may also be the case however, that older people provide lower ratings on quality of life scales (COPAR).

3.3.4 The correlation with more objective indicators of service quality

Ratings on satisfaction surveys by consumers have little correlation with other more objective measures of service quality. Similarly, objective ratings of quality of life do not correlate with subjective ratings of quality of life (Cummins, 1997).

3.3.5 May produce counter intuitive findings

Satisfaction surveys may produce findings that seem out of step with common sense. For example, people from non-English speaking backgrounds indicated higher levels of satisfaction with information provided, than those from English speaking backgrounds, in the Victorian Mental Health Survey.

3.4 Sampling Procedures

3.4.1 The use of large client data-bases to generate samples

Local studies (ATSS, DSC) have reported difficulty in using large client data bases to generate samples. These data bases are often inaccurate and consequently inefficient. Issues related to consent are created when identifying lists from such data bases are passed on to external consultants in order to contact consumers or their families (see discussion under Ethical Issues)

State government data bases may not contain information on consumers served by some non-government agencies. The Productivity Commission will have to develop alternative ways to develop survey samples if it wishes to include consumers of services provided by the non-government sector. Systematic and area sampling provide approaches which do not rely on population lists.

3.5 Ethical Issues

3.5.1 Gaining appropriate consent for survey participation

We suggest there are two elements in many surveys for which valid consent should be given:

- providing contact details of consumers and their families to external consultants; and
- participation in the survey itself.

Australian surveys of people with disabilities (ATSS, DSC) have typically approached next of kin to give consent for both these elements. Written consent has been obtained before any other action has been taken. Gaining consent has been time consuming and where consent was not obtained replacement respondents could be used only after the same procedure had been completed.

The practice of requiring consent from next of kin for a person over 18 years to participate in a survey interview is open to question, on the grounds that the person is an adult and should be able to make such a decision for themselves. In principle, adults with disabilities should be taken to be capable of such decision making unless it is demonstrated otherwise.

Such an approach is adopted in the United States. For example, in Colorado the issue of gaining consent is dealt with at the time of interview with the consumer themselves.

There are similar precedents in Australia. For example, it is accepted practice for training and support agencies funded by the Commonwealth to approach consumers directly through employment services to comment on the quality of services provided.

With regard to passing on lists of consumers contact details to an external consultant this process may be avoided if the sampling procedure identifies selected service outlets from which respondent consumers may be drawn and interviewers select individual respondents from non-identifying lists through systematic sampling or some other pre-determined method. The requirement for 'master lists' to be forwarded to external consultants would be eliminated.

3.6 Data collection methods

3.6.1 Increasing response rates in mail surveys

Response rates of less than 70% commonly reported with mail surveys, represent a threat to the validity of the data through respondent self-selection. Some surveys eg. CIP family mail survey; expect response rates of as low as 40%.

We note that the VIC MH mail family/carer survey was able to achieve a response rate of over 60% using a selection of the following recommended procedures (Kinnear & Taylor, 1996):

- gaining prior consent to the survey;
- including a covering letter from the service outlet;
- using hand stamped return envelopes rather than reply paid;
- sending 'reminder' letters to all members of the sample (thus retaining anonymity of responses).

3.7 Survey design and format for people with disabilities

3.7.1 Written questionnaires, telephone interviews, face to face interviews and direct observations

Various methods have been used to elicit satisfaction information from people with disabilities including:

- written questionnaires;
- telephone interviews;
- face to face interviews; and
- direct observations.

Current US work with people with developmental disabilities clearly favours face to face interviews with the person themselves (eg. COPAR, CIP).

Experience with the DSC survey and our experience with gaining consumer input for Disability Services Standards assessments, suggest telephone interviews are quite possible with some people with disabilities.

We suggest a combination of face to face interviews and telephone interviews for people with disabilities. We recognise that valid responses may be restricted to 40 - 45% of service users who have an intellectual disability. The response rate from among those without an intellectual disability is expected to be higher.

We recognise the direct observation method used in the ATSS survey has promise and suggest this be developed at a later date.

3.7.2 Vicarious or proxy responding

One way to gain information about consumers who are not able to participate directly a survey interview is to ask others to complete responses from what they know about the person ie. vicarious or proxy responding. Most of the data reported as client data in the DSC survey was provided by someone else on the client's behalf. The empirical data suggests relying on vicarious responding could be misleading. Cummins (1997) found very low consistency between carer and carers responses and responses from people with disabilities themselves on the subjective scale of this quality of life measure. He concluded it is unwise to rely on vicarious responding. Rapley (personal communication) has also found consistent significant differences in carer responses and those of people with a disability on the empowerment/independence scale in QoL.Q. (Schalock and Keith, 1993). Carers significantly rated empowerment/independence as higher than that rated by people with disabilities themselves.

We suggest it is better to avoid vicarious responding with consumer satisfaction surveys. Vicarious responding could be acceptable if:

- The items are clearly known to be objective ie. able to be accurately rated by another person.
- The actual respondent has the required information.

3.7.3 Contextual information

The CIP protocol requires that the interviewer gains details of the services used and staff known to the person with the disability before the interview. This enables the interviewer to provide a concrete context for questions.

3.7.4 *Validity Checks*

Survey responses from people with intellectual disability may be invalid as respondents may:

- pick the most recent of alternatives offered (recency effect);
- tend to agree with questions (acquiescence);
- misunderstand questions; or
- adopt some other response set.

Consumer surveys for people with disabilities have therefore tended to include a validity check such as:

- Asking key questions in reverse (perhaps spaced by a few other questions).
Example from CIP:
“Do you like your job/ Do you dislike your job?”
- Screening for acquiescence. Example from Com-Qol:
“Did you chose who you live with”; “Did you chose your neighbours”,
Answer “Yes” to the second question will be taken as evidence of acquiescence
- Establishing ability to use 3 or 5 point scale (Com-Qol).
- Asking contradictory pairs of questions. Example from ATSS:
“Are you sad about....?” “Are you happy with?” in alternating order.

Such checks can lead to over 50% of consumer interviews being discarded (COPAR).

We suggest it is useful to develop an effective validity screen at the beginning of an interview to ensure valuable interviewing time is used as efficiently as possible.

3.7.5 *Flexibility in wording*

While the items that form part of any validity check should be presented as worded, for other questions interviewers can expect to rephrase or present the idea behind the questions in a number of ways. We have found it useful to provide pictures to support consumers to understand questions and express themselves.

3.7.6 Item styles

Various item styles have been used with people with disabilities, such as:

- Asking about overall satisfaction using a 5 point Likert scale, very good to very poor (plus don't know). Example from DSC:
"Thinking about accommodation and associated support services overall, please tell me what you think about the service that is provided."
(The consumer is supported by visual display of 5 point scale).
- Questions which ask for an opinion about specific aspects of life or a service. Examples from COPAR/CIP:
"Do you feel safe in your home" and "Do staff and other people who support you treat you with respect: are they nice and friendly?"
The interviewer then rates "yes", "in between" or "no" (or unclear response) on the basis of the consumer's reply.
- Questions which ask whether a person is happy or sad about a particular aspect of service or life. Example from ATSS:
"Are you happy because the staff are nice and friendly to you?" and "Are you sad because the staff are mean or rude to you?"
The interviewer then rates the response from "Happy", "Middle", "Sad", or "Don't know, unreliable".

We suggest the style of questions used by COPAR/CIP be adopted. We believe such questions will be readily understood by more consumers, may have more discriminatory power and provide performance indicators that are easier to interpret.

4. CONTEXT OF THE PROPOSED SATISFACTION SURVEY

This section is based on the results of a brief written survey about the purposes of the national consumer satisfaction survey, discussions held with members of the Steering Committee and the 1996 CSDA data set (Black, Maples, Wen, & Madden, 1998).

4.1 The population of CSDA funded services and their consumers

Estimates of the number of CSDA funded services and their consumers can be made from Black et al (1998). They suggest that in 1996 the number of CSDA funded services, excluding employment and other Commonwealth funded services was at least 5,160, the number of different services that returned Consumer Forms that year. Inclusion of employment services (both open employment and small business services) and other services plus allowance for services that did not respond to the AIHW survey and creation of new services would bring the estimate of CSDA funded services up to 5,800 to 6,000 services.

The number of service users is harder to estimate. Table 1.1 in Black et al (op. cit.) suggests a total of 266,491 consumers for CSDA funded services, excluding employment and other Commonwealth funded services. These include 66,661 people using respite or accommodation support services. If all those using respite or accommodation services are taken to be also using some other day support services, the total number of different service users may be estimated as approximately 200,000 (266,491 - 66,661) plus those using employment and other Commonwealth funded services. The best estimate may then be 220,000 - 230,000 different service users.

Of these service users, using proportions from the 'snapshot data', 75-80% or 175,000, may be expected to be aged 18 years or more. Approximately 65% (113,750 adults) may be expected to have a significant intellectual disability, suggesting that 35% do not. This proportion of service users without a significant intellectual disability could be expected to rise with the inclusion of data from employment services.

In summary, the target population, if restricted to adults, may consist of 175,000 people, of whom a little less than 65% have a significant intellectual disability, either as a primary disability or as one of several disabilities. These adults make use of up to 6,000 services, most of which are operated by the non-government sector.

4.2 *What state and Commonwealth disability services want from a national consumer satisfaction survey*

The written responses and discussions with members of the Disability Services Working Group indicated that the highest priority for state disability services is to be able to make internal comparisons that will be able to assist service improvement. Specifically states see that they could use level of consumer satisfaction data to:

- compare consumer satisfaction across service types at one point in time to identify areas for possible improvement;
- to compare satisfaction with co-ordination of services and services themselves at one point in time;
- to compare consumer satisfaction before and after a service model had been redesigned;
- to identify specific aspects of satisfaction with services eg. choice or waiting times; and
- to compare the levels of satisfaction among different disability groups at any point in time.

States were less uniformly interested in making comparisons of levels of satisfaction between their services and those in other states. Some states saw the ability to compare their services with a “national benchmark” for things such as different services type, services to different groupings or services to different types of locations (metropolitan, rural or remote). No state indicated it would not participate in a national consumer satisfaction survey. States recognised the quality of information would improve with successive surveys.

4.3 *Requirements on states to have quantitative measures of consumer satisfaction with disability services*

States may be facing requirements to have consumer satisfaction information from at least three sources:

- To monitor the quality of service provision by agencies they fund. This will often be in the context of the Disability Services Standards. We are aware the Commonwealth has commissioned a project to develop measurable performance indicators for the Disability Services Standards.
- To meet state Auditor Generals’ requirements for adequate performance indicators.
- To meet the needs of the present exercise with the Productivity Commission.

Clearly to meet all three requirements separately represents unnecessary duplication of effort. There will be benefits to states through rationalising their collection of consumer satisfaction data.

4.4. Differences in the definition of disability and the populations served across states

The information received from states suggest a general consensus in a way disability is defined across states. Typically disability in state disability services acts is defined as:

“disability” in respect of a person, means a disability -

- a) which is attributable to an intellectual psychiatric sensory or physical impairment or a combination of those impairment;
- b) permanent or which is likely to be permanent;
- c) which results in -
 - i) a substantially reduced capacity for the person for communication learning or mobility
 - ii) the need for engineering support services; and
- d) which may or may not be of a chronic or episodic nature.

Minor variation include the addition of cognitive or neurological in the list of impairments in subsection (a) above.

Within the above definition there may be differences of interpretation with such terms as “substantially reduced capacity.” In addition non government services provided under CSDA, may have their own eligibility criteria. States may also differ in the services available for those under 6 years of age, psychiatric disabilities, those with acquired brain injury or over 60 years of age.

Such differences may reduce the comparability of levels of satisfaction with services across states. However, the issue of who CSDA funded services may be supporting is a different issue to the level of consumer satisfaction with those services.

4.5 Relationship between CSDA funded services and state services for people with disabilities

As noted in The Report on Government Services 1998, measuring the level of consumer satisfaction with services provided under CSDA is not the same as measuring consumer satisfaction with the total state provision for people with disability. Two significant areas of activity for state disability services not included among CSDA services, are:

- The accessibility of other services in local government, other state government departments and the private sector to people with disabilities.

Such initiatives impact on access to transport, housing, recreation and leisure facilities and many other important influences on quality of life.

- Specialist disability services such as equipment services and HACC funded services which are not included as part of CSDA.

4.6 Co-ordination services and disability support services

Some states were keen to distinguish between consumer satisfaction with co-ordination services and specialist support services such as accommodation, respite and community access.

5. SURVEY OPTIONS - DESCRIPTION OF FEASIBLE OPTIONS WITHIN BUDGET RANGE

This section provides options for possible satisfaction surveys using budgets from \$100,000 to \$300,000. The options are:

- Option One - Consumer satisfaction (National comparison).
- Option Two - Consumer satisfaction plus family satisfaction mail survey (National comparison).
- Option Three - Consumer satisfaction plus family satisfaction phone survey (National comparison).
- Option Four - Consumer satisfaction plus family satisfaction mail survey (State comparisons).

5.1 General considerations

5.1.1 A learning curve

It can be expected that experience gained with successive consumer surveys will result in surveys becoming more useful and efficient. We have taken the view that it is better to start with a simpler process including limiting the target group to adults ie. people over 18 years, who are currently using services funded under CSDA.

The options described have used the sampling frame of users of both government provided and funded services. As noted in the previous section, non-government services have more service users than government provided services. The sampling procedures suggested do not rely on master data bases for each state.

5.1.2 The survey as a source of information for service improvement at the state level.

We suggest the survey should restrict its purpose to making comparisons between states. States may increase sample sizes to be able to answer questions related to service improvement within their state if they wish.

5.1.3 Related research initiatives

This review has highlighted questions that could be answered by empirical research. The steering committee may consider ways in which this research can be commissioned. The questions include:

- To what questions can people who know a person with disability well, give answers consistent with those given by the person with a disability

themselves, and what questions can only be answered by the person with disability themselves?

- Do people with disabilities give significantly different responses to similar questions if face to face or telephone interviews are used?
- What are the best ways to gain indications of satisfaction from consumers who are not able to participate in face to face or telephone interviews?

5.1.4 Pre-requisites

All the options described rely on the same prerequisites. The prerequisites include:

- Co-operation and support from relevant government agencies, consumers and non-government agencies. This pre-supposes adequate promotion of the survey among these groups.
- Participation of consumers (both people with disabilities and family members) in groups involved with the development and interpretation of the results.
- Adequate standards for confidentiality.
- Attention paid to capture the views of those from minority cultural backgrounds who otherwise may not respond to the survey.
- All aspects of the work to be carried out in a way consistent with state and Commonwealth legislation.

5.1.5 Planning of the Survey (Stage Two)

The tender brief outlines a three stage plan to conduct a national survey. Stage Two is described as the development of the survey instrument. We suggest this stage should be expanded to include development of the survey design, including the sampling procedures and statistical analysis.

5.1.6 Use of external consultants

Several states highlighted the need for interviewers to be independent of the other organisations involved. This is consistent with the use of external consultants.

Our review of surveys suggests that it is advantageous for the appointed consultant to have a sound understanding of the role of satisfaction surveys in human service systems.

5.1.7 Timelines

The 2000 Report on Government Services is expected to be available in February 2000. Data for inclusion in the Report is typically prepared by the October of the year prior to publication, with final submissions made up to December.

Work on Stage Two of the Satisfaction Review is unlikely to be able to start before September 1998. Stage Two could be completed by November/December 1998 and would be informed by the results of the CIP field trials which should be available in late 1998. Stage Three (the field arrangements, data collection, analysis and report writing) could be completed over a nine month period from January 1999 to September 1999.

5.1.8 Costings

The costing provided for each option are indicative only.

5.2 Option One - Consumer satisfaction (National comparison).

5.2.1 Brief description

Option One provides for the collection of consumer satisfaction data using face to face interviews or telephone interviews as appropriate, from a national sample of current consumers of services provided under the CSDA.

5.2.2 Comparisons provided

Option One will be able to provide a baseline of the level of consumer (ie service user) satisfaction with disability services across Australia that could be compared to a similar survey at a later date.

5.2.3 Other benefits

Such a survey would develop a consumer satisfaction instrument that would be available for individual states to use with larger samples should they wish to investigate consumer satisfaction with services internally.

5.2.4 Instrument development and design of study

Option One would feature:

- Development of the survey instrument from an established consumer satisfaction face to face interview format. Adequate reliability and validity would be assumed from previous work with the instrument. Development would focus on developing acceptable wording for Australian consumers and services. Where possible items would link to performance indicators for the Disability Services Standards.

We suggest the consumer satisfaction scale from COPAR or CIP (including the decision making scale) could act as suitable initial tools for adaptation.

- Two or three small scale field trials with 8-10 consumers in each to develop a pre interview validity screening device, revise wording, develop scoring and data entry protocols etc. Pre-interview screening of consumers' capacity to respond to the survey will enable interviewing time to be used more efficiently.

5.2.5 Sampling procedure

The object of the sampling procedure will be to efficiently gain a representative sample of all current consumers of services provided under CSDA. We suggest:

- Developing a sampling procedure that does not rely on large consumer data bases, selects respondents within manageable geographical areas and allows for final selection of respondents at the service outlet level. A probability sampling procedure based around multi-stage systematic or area sampling, using stratification as appropriate to reduce sampling error, may meet these requirements.
- Combining smaller states and territories with larger neighbouring states when jurisdiction is used as a stratification variable.
- Allowing consumers to decide for themselves whether to proceed with a survey interview or not.
- Using telephone interviews with consumers who are being supported into lifestyles consistent with such communication skills so as to enable them to participate in telephone interviews.
- Determining the sample size according to the statistical precision requirements, concern for non-sampling error, and statistical comparisons to be made.

Taking the above into account we estimate the sample size required to be approximately 400 consumers.

5.2.6 Preparation of interviewers

One way to reduce non-sampling error is to increase the consistency of interviewers' behaviour. This is particularly important as local interviewers could be involved in the sample selection. We suggest:

- Selecting locally based interviewers who are experienced in working with people with disabilities to increase the participation rate of selected consumers.
- Providing a national training event to train interviewers/supervisors from each region.
- Providing resources eg video of national training, to enable nationally trained interviewers/supervisors to train local interviewers.
- Undertaking reliability checks with interviewers.

5.2.7 Indicative costs

Development costs (Instrument development and design of study including sampling procedure) are estimated to be \$20 - 30,000 plus input from participating government agencies.

Costs for conducting the study and analysis (preparation of interviewers, interviewing, analysis and report writing) are estimated to be \$80-100,000 plus input from participating government agencies.

The total costs for Option One are estimated to be \$100-130,000 plus input from participating government agencies.

5.3 Option Two - Consumer satisfaction plus family satisfaction mail survey (National comparison).

5.3.1 Brief description

Option Two provides for the collection of consumer satisfaction data as in Option One plus the collection of family satisfaction data through a mail survey to the next of kin of consumers using the same selected service outlets as the respondent consumers.

5.3.2 Comparisons provided

Option Two will be able to provide baselines of the levels of consumer (service user) and family (next of kin) satisfaction with disability services across Australia that could be compared to similar surveys at a later date.

Option Two will be able to provide a comparison between levels of consumer (service user) and family (next of kin) satisfaction with disability services across Australia at the time of the survey.

5.3.3 Other benefits

Such a survey would develop a consumer satisfaction instrument and a family satisfaction instrument that would be available for individual states to use with larger samples should they wish to investigate consumer and family satisfaction with services internally.

5.3.4 Instrument development and design of study

Option Two features:

- The development of a consumer satisfaction instrument as outlined under Option One.
- Development of the family survey instrument from an established family satisfaction written questionnaire. Adequate reliability and validity would be assumed from previous work with the instrument. Development would focus on developing acceptable wording for Australian consumers and services. Where possible items would link to performance indicators for the Disability Services Standards.

We suggest the family satisfaction scale from CIP could act as a suitable tool for adaptation.

- Two or three small scale field trials with 8-10 next of kin in each to revise wording, develop scoring, and data entry protocols etc. These field trials will also be used to assess the likely return rate for questionnaires mailed from service outlets known to families.

5.3.5 Sampling procedure

The sampling procedure for the consumer satisfaction survey will be as for Option One.

We suggest the following for the sampling procedure for the family satisfaction survey:

- The object of the sampling procedure for the family satisfaction survey will be to efficiently gain a representative sample of next of kin of all current consumers of services provided under CSDA.
- Using the sampling procedure adopted for the consumer survey to identify service outlets from which the next of kin to be posted questionnaires may be selected.
- Selecting next of kin to be mailed using pre-determined procedures from a non-identifying list of the next of kin of service users provided by the service outlet.
- Providing service outlets with mail ready questionnaires to which they will attach the addresses of the selected next of kin.
- Determining the sample size according to the statistical precision requirements, concern for non-sampling error, and statistical comparisons to be made.
- Determining the size of the mail out according to the required return sample size and the estimate of return rate.

Taking the above into account we estimate the sample size required to be approximately 400 families from a total mail out of 700-1,000 questionnaires.

5.3.6 Preparation of interviewers

As for Option One.

5.3.7 Indicative costs

Development costs (instrument development and design of study including sampling procedure) are estimated to be \$5 - 8,000 over and above the development costs for Option One (\$20 - 30,000) giving total development costs of \$25 - 38,000 plus input from participating government agencies.

Survey Options

Costs for conducting the study and analysis (preparation of interviewers, interviewing, analysis and report writing) are estimated to be \$10 - 15,000 over and above the study and analysis costs for Option One (\$80 - 100,000) giving total implementation costs of \$90 - 115,000 plus input from participating government agencies.

The total costs for Option Two are estimated to be \$115-153,000 plus input from participating government agencies.

5.4 Option Three - Consumer satisfaction plus family satisfaction phone survey (National comparison).

5.4.1 Brief description

Option Three provides for the collection of consumer satisfaction data as in Option One plus the collection of family satisfaction data through a telephone survey with the next of kin of consumers using the same service outlets as the respondent consumers. This option is provided to acknowledge telephone surveys as a superior approach for the present purpose (for example, less prone to response bias) than mailed questionnaires.

5.4.2 Comparisons provided

Option Three will be able to provide baselines of the levels of consumer (service user) and family (next of kin) satisfaction with disability services across Australia that could be compared to similar surveys at a later date.

Option Three will be able to provide a comparison between levels of consumer (service user) and family (next of kin) satisfaction with disability services across Australia at the time of the survey.

5.4.3 Other benefits

Such a survey would develop a consumer satisfaction instrument and a family satisfaction instrument that would be available for individual states to use with larger samples should they wish to investigate consumer and family satisfaction with services internally. A telephone family satisfaction instrument will provide a richer source of service improvement data for states.

5.4.4 Instrument development and design of study

Option Three features:

- The development of a consumer satisfaction instrument as outlined under Option One.
- Development of the family survey instrument from an established family satisfaction telephone survey. Adequate reliability and validity would be assumed from previous work with the instrument. Development would focus on developing acceptable wording for Australian consumers and services. Where possible items would link to performance indicators for the Disability Services Standards.

We suggest the family satisfaction scale from CIP could act as a suitable tool for adaptation.

- Two or three small scale field trials with 8-10 next of kin in each to revise wording, develop scoring and data entry protocols etc.

5.4.5 Sampling procedure

The sampling procedure for the consumer satisfaction survey will be as for Option One.

We suggest the following for the sampling procedure for the family satisfaction survey:

- The object of the sampling procedure for the family satisfaction survey will be to efficiently gain a representative sample of next of kin of all current consumers of services provided under CSDA.
- Using the sampling procedure adopted for the consumer survey to identify service outlets from which the next of kin to be telephoned may be selected.
- Selecting next of kin to be telephoned using pre-determined procedures from a non-identifying list of the next of kin of service users.
- Requesting service outlets to gain verbal or written consent from service users as to whether the service outlet may release the next of kin phone numbers to the interviewers for the purposes of the survey. Service outlets will record the time and date verbal consent is given.
- Determining the sample size according to the statistical precision requirements, concern for non-sampling error, and statistical comparisons to be made.
- Determining the number of next of kin telephone numbers needed according to the required sample size and the estimate of unsuccessful telephone contacts.

Taking the above into account we estimate the sample size required to be approximately 400 families from a total telephone contact list of 500-700.

5.4.6 Preparation of interviewers

As for Option One.

5.4.7 Indicative costs

Development costs (instrument development and design of study including sampling procedure) are estimated to be \$5 - 8,000 over and above the development costs for Option One (\$20 - 30,000) giving total development costs of \$25 - 38,000 plus input from participating government agencies.

Costs for conducting the study and analysis (preparation of interviewers, interviewing, analysis and report writing) are estimated to be \$35 - 40,000 over and above the study and analysis costs for Option One (\$80 - 100,000) giving total implementation costs of \$115 - 140,000 plus input from participating government agencies.

The total costs for Option Three are estimated to be \$140 - 168,000 plus input from participating government agencies.

5.5 Option Four - Consumer satisfaction plus family satisfaction mail survey (State comparisons).

5.5.1 Brief description

Option Four provides for the collection of consumer satisfaction data and the collection of family satisfaction data through a mail survey as in Option Two with the sample expanded to allow for comparisons between states.

This option is provided to demonstrate how interstate comparisons for consumer and family satisfaction may be achieved within the budget.

5.5.2 Comparisons provided

Option Four will be able to provide comparisons of the levels of consumer and family satisfaction with disability services across states at the time of the survey.

Depending on the discriminatory powers of the measures, comparisons may also be possible among particular groups across states. For example, it may be possible to compare the level of satisfaction with accommodation services in one state with the level of satisfaction with accommodation services in other states.

5.5.3 Other benefits

As for Option Two.

5.5.4 Instrument development and design of study

Option Four features:

- The development of a consumer satisfaction instrument as outlined under Option One
- Development of a telephone family survey instrument as outlined in Option Two.
- Small scale field trials as for Option Two.

5.5.5 Sampling procedure

We suggest a sampling procedure for the consumer satisfaction survey as follows:

- Using a probability sampling procedure based around multi-stage systematic or area sampling using stratification as appropriate, to identify each state sample.
- Taking separate samples from each state and territory. Sample sizes from the larger states (NSW, Vic, Qld, & WA) are expected to be almost 400 each, while those from smaller states (SA, Tas, ACT, & NT) will be a little less, depending on the size of the consumer population. As indicated sample size may be determined according to many factors (see Option One).

We have based costings on a total sample size of 2,500.

We suggest a sampling procedure for the family satisfaction survey as follows:

- Using the sampling procedure adopted for the Option Four consumer survey to identify service outlets from which the next of kin to be posted questionnaires may be selected.
- Using other procedures as outlined under Option Two.

Taking the above into account we estimate the sample size required to be approximately 2,500 families from a total mail out of 4,500 - 6,200.

5.5.6 Preparation of interviewers

As for Option One.

5.5.7 Indicative costs

Development costs (instrument development and design of study including sampling procedure) are estimated to be \$1,000 over and above those for Option Two, giving total development costs of \$26 - 39,000 plus input from participating government agencies.

Costs for conducting the study and analysis (preparation of interviewers, interviewing, analysis and report writing) are estimated to be \$200,000 for the consumer survey and \$34,000 for the family mail survey, over and above interviewer preparation and report writing costs of \$40,000. These figures suggest implementation costs of just over \$270 - 280,000 plus input from participating government agencies.

The total costs for Option Four are estimated to be \$300 - 315,000 plus input from participating government agencies.

ATTACHMENT A - ANNOTATED BIBLIOGRAPHY

Articles and books for inclusion in the bibliography were identified from similar reviews made available to us (DSC and KPMG for ATSS survey) and an electronic literature search. Details of the latter are given below.

Details of the Literature Search 5/5/98

A literature search was carried out at Murdoch University using PsycLit journal articles 1991-12/1997, PsycLit chapters and books 187 - 1297, Socio File 1/74 - 12/97.

The search terms were *consumer satisfaction*.

Socio File (sociology) abstracts articles from 1600 journals covering all aspects of sociology, including social planning/policy and development abstracts and enhanced disability abstracts. Period covered: 1974 +.

PsycLit (psychology) indexes and abstracts books and book chapters in English and 1300 + journals in over twenty languages. Professional academic and psychology related literature. Period covered: 1974 +, updated monthly.

The search produced 83 hits.

Another search was also done through ERIC (Educational Resources Information Centre) using the Clearing House on Assessment and Evaluation. ERIC is a national information system (US) designed to provide users with ready access to information. It includes over eight hundred and fifty thousand abstracts of documents and journal articles dated back to 1976.

The initial search was conducted using the terms: (*consumer, client*) and (*satisfaction*) and (*disability*). This search produced no hits. Another search (*disability*) and (*satisfaction*) produced sixty-two hits. However, as ERIC is a data base of educational materials, only two abstracts were relevant from this list of hits.

1. CONSUMER SATISFACTION AND PEOPLE WITH DISABILITIES

Black, K., Maples, J., Wen, X., & Madden, R. (1998). *Disability support services provided under the Commonwealth/State Disability Agreement: available data, 1996*. AIHW Catalogue No. DIS 7. Canberra: Australian Institute of Health and Welfare.

This report presents data about services directly provided or funded by the Australian governments under the Commonwealth/State Disability Agreement (CSDA). The data come from the CSDA Minimum Data Set collection in the second half of 1996. Much of the data comes from a 'snapshot day' on which records of 68,488 consumers using services were collected. Details are also provided about services.

Plans for future data collection are discussed.

Cummins, R.A. (1995). On the Trail of the Gold Standard for Subjective Wellbeing. *Social Indicators Research* 35, 179-200.

Cummins reviews sixteen unrelated studies that have investigated "life satisfaction" among large samples drawn from the general population. He concludes that population standard for "life satisfaction" can be expressed as 75 + or - 2.5% of the measurement scale maximum score.

Cummins, R.A., McCabe, M.P., Romeo, Y., Reid, S., & Waters, L. (1997). An Initial Evaluation of the Comprehensive Quality of Life Scale - Intellectual Disability. *International Journal of Disability, Development and Education* 44, 7-19.

This paper describes a new scale, the comprehensive quality of life scale - intellectual disability, designed to measure the quality of life of people with an intellectual disability. The scale includes objective and subjective measures of 7 domains: material wellbeing, health, productivity, intimacy, safety, place in the community and emotional wellbeing. There is a parallel form for the general population. This paper reports data from the use of the scale with 59 people with an intellectual disability. The results are compared with those from the administration of the scale to 69 university students.

The paper also reports on the level of agreement between ratings by people with disability themselves and ratings by carers on the subjective scale. A low level of agreement was reported with carers tending to consistently underestimate clients subjective wellbeing, in all domains, except for community, which they significantly over estimated.

Cummins concludes it seems wise at this junction to view most cautiously the vicarious responses provided by carers, which relate to the subjective state of people with intellectual disability.

Heinlein, K.B. (1994). Quality of care, quality of life: A rural perspective. *Mental Retardation*, 32, 374-376.

Describes Wyoming's Division of Developmental Disabilities multimethod approach to quality of care in relation to quality of life. It incorporates fiscal accountability, parental and consumer satisfaction, national accreditation standards, and broad measures of personal and system change. Collectively these measures have provided a mosaic of quality, responsive to the various stakeholders.

Kozleski, E.B., & Sands, D.J (1992). The yardstick of social validity: Evaluating quality of life as perceived by adults without disabilities. *Education and Training in Mental Retardation*, 56(3), 55-68.

133 Ss (aged 18-70 yrs) without disabilities completed the Consumer Satisfaction Survey, the same instrument that has been used to investigate the quality of life for adults with developmental disabilities. Results suggest that some quality of life indicators (eg., socioeconomic status (SES) may be inhibitors to achieving satisfactory quality of life. Other indicators (eg., personal development) may enhance or serve as contributors toward a positive quality of life. Differentiating between inhibitors and contributors may help service providers to focus services for individuals on those factors that will directly contribute to change in quality of life status. This data from a sample of the typical population can assist the effort to achieve social validity in services to persons with developmental disabilities.

Leibowitz, J.M., McLain, J.W., Evans, E.A., & Ruma, P. (1994). Client perceptions of quality of life in accredited and unaccredited community residential facilities. *Journal of Developmental and Physical Disabilities*, 6, 339-346.

Examined consumer satisfaction as an indicator of quality of life (QOL) relative to the certification/accreditation level of a community residential facility. 146 Ss residing in 47 separate centers for the developmentally disabled (CDD's) were surveyed by 2 trained interviewers using a QOL questionnaire. For 59 Ss who were unable to respond personally to the survey, staff members who knew the Ss well completed the questionnaire. A 3-way ANOVA determined the effects of location (urban vs rural), accreditation category (accredited, recently

non-accredited, non-accredited), and interviewee (client vs staff). Residents of accredited CDD's rated their QOL as superior to those clients living in non-accredited CDD's. However, location of facility, length of previous institutionalisation, cognitive level, and need status had no impact on QOL ratings. A link was found between consumer satisfaction and accreditation.

Parent, W., Kregel, J., & Johnson, A., (1996). Consumer Satisfaction: A Survey of Individuals with Severe Disabilities Who Receive Supported Employment Services. *Focus on Autism and Other Developmental Disabilities*, 11, 207-221.

Evaluated the effectiveness of supported employment from the perspective of individuals with severe disabilities whom it services, drawing on survey data from 110 disabled persons in VA. Results indicate that the majority of supported employment consumers like their jobs; most are happy with supported employment services and would use them again. However, close to 50% would like to change some aspects of their job & 50% feel that their current job is not the career they would like to have permanently. It is concluded that consumer involvement in all phases of supported employment delivery should be increased. 10 Tables, 46 References. Adapted from the source document.

Sands, D.J, Kozleski, E.B, Goodwin, L.D, (1991). Whose needs are we meeting? Results of a consumer satisfaction survey of persons with developmental disabilities in Colorado. *Research in Developmental Disabilities*, 12(3), 297-314

Examined 240 Colorado consumers with developmental disabilities to measure Ss' satisfaction with services and to investigate quality of life issues. Many Ss expressed dissatisfaction with information and referral services. Ss were dissatisfied with the quality of education and personal dignity afforded adults who received say services from community centred programs. The limited opportunities available to Ss choosing where they lived, who they lived with, and how they spent their money constrained the level of independence that they obtained in adulthood. Integration happened much less frequently than Ss desired and valued.

Sands, D.J. & Kozleski, E.B. (1994). Quality of life differences between adults with and without disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 29(2), 90-101.

131 persons without disabilities and 86 persons with disabilities (aged 18-70 yrs) completed the Consumer Satisfaction Survey. The 2 groups differed on several dimensions of quality of life. Ss with disabilities overwhelmingly lacked spouses, although the number of adults living together were similar. Although the standard of living varied for both groups, SES was not linked to involvement in social and community activities. The degree of choice that Ss with disabilities were able to exercise was significantly limited when compared with Ss without disabilities. Although both groups reported that they were satisfied with life, Ss with disabilities treated themselves as having moderate to low independence, even though they felt that being independent was important. Ss with disabilities were also dissatisfied with the frequency and variety in their community, recreation, and leisure activities.

Schalock, R.L., & Keith, K.D. (1993). *Quality of Life Questionnaire*. Worthington, OH: IDS Publishing Corporation.

The Quality of Life Questionnaire (QoL.Q) is one of the most widely used quality of life measures in the intellectual disability literature. The scale has been designed specifically for people with an intellectual disability. The scale is structured around four quality of life dimensions: satisfaction; competent/productivity; empowerment/independence and socio belonging/community integration. Each factor has ten items which is scored between 1 (low) and 3 (high). Studies in the UK and US have suggested the QoL.Q is Psychometrically robust.

Speller, C. (1996). A consumer satisfaction survey: Effects on a community team and on service provision. *British Journal of Developmental Disabilities*, 42, 80-84.

Evaluated consumer satisfaction with a community learning disabilities team (CDLT). 49 consumers, mostly parents, who had had contact with the CDLT in the previous 2 yrs were surveyed. Results provided mainly positive feedback, as well as highlighting both common and individual concerns.

Wilhite, B., Sheldon, K., (1997). Consumer satisfaction for individuals with developmental disabilities. *Activities, Adaption and Aging*, 21(3), 71-77.

Consumer satisfaction is a significant measure of the quality of service provision. Little information is available on consumer satisfaction for individuals with developmental disabilities, however. The authors suggest that the information that is available may paint an overly optimistic view of the service system. Reasons for the tendency of service recipients to report high levels of satisfaction are presented.

Results from the Georgia Council on Developmental Disabilities Consumer Satisfaction Survey Project are discussed, as are suggestions for obtaining meaningful consumer satisfaction data.

2. CONSUMER SATISFACTION WITH MENTAL HEALTH SERVICES

Corrigan, P. W. (1990). Consumer Satisfaction with Institutional and Community Care. *Community Mental Health Journal*; 26, 156-165.

Studies that have evaluated consumer satisfaction with components of psychiatric treatment are reviewed, focussing on four dimensions: characteristics of staff, treatment services, the physical environment, & activities that foster autonomy. Results show that inpatients are pleased with the quality of staff relationships & the hospital surroundings, but find that talk therapy can be a nuisance & do not like the loss of freedom & privacy characteristic of a locked ward. So little research has been completed on outpatient samples that comparisons along the four dimensions cannot be readily made. Community consumers express similar approval of staff & are less critical of medication interventions than inpatients. Research -suggests, however, that consumer satisfaction in part reflects patient characteristics. Results of this summary have implications for addressing development in both institutional & community settings.

Dudley, J.R., Calhoun, M.L., Ahlgrim-Dezell, L., & Conroy, J. (1997). A consumer satisfaction survey of people with mental retardation and mental illness. *Psychiatric Services*, 48(8), 1075-1077.

Investigated consumer satisfaction among 98 members (mean age 39.4 yrs) of the Thomas S. class action lawsuit in North Carolina, in which the court ordered implementation of habilitative and residential service plans. Class members have mental retardation and most also have a mental illness. Before the court order, 83 of the consumers were inappropriately placed in state psychiatric hospitals; 1 yr later, 82 were living in community residences. Ss were interviewed at baseline and 1 yr later using both forced-response and open-ended questions and were asked about living arrangements, relations with staff, food, freedom, safety, privacy, and contacts with others. Ss were significantly more satisfied with where they lived, the food, and the level of freedom, They also felt that staff were more helpful, and that more staff were nice rather than mean.

Grau, L., Teresi, J., Burton, B., Chandler, B. (1995) Family members' perception of the quality of nursing home care. *International Journal of Geriatric Psychiatry*, V 10(9), 787-796.

Investigated the extent to which factors not directly related to the care giving situation predicted family members' perceptions of the quality of nursing home care their elderly relative received and tested out a conceptual model based on theories of consumer satisfaction (R.L Day, 1977; D.J. Hill, 1986; R.W. Olshavsky & J.A. Miller, 1972). 452 relatives of patients at 2 skilled care facilities were assessed on perception of quality of nursing home care and on factors likely to affect expectations for nursing home care. The model accounted for 27% of the variation in quality assessments. Ss with more negative attitudes towards homes tended to be more critical of the quality of care given. The amount of caregiving provided by Ss before nursing home placement was not significantly related to perceptions of quality, while ethnic congruity, caregiver burden, and emotional distress were significant predictors of it.

Holcomb, W. R., Adams, N. A., Ponder, H. M., & Reitz, R. (1989). The Development and Construct Validation of a Consumer Satisfaction Questionnaire for Psychiatric Inpatients. *Evaluation and Program Planning*; 12, 189-194.

Emphasis on consumer satisfaction as a measure of the effectiveness of outpatient psychiatric treatment has increased. Various scales have been developed, but there have been problems of standardisation & reliability of data. Reasons for the importance of consumer satisfaction as a measure are presented. Data obtained via the Inpatient Consumer Satisfaction Scale from 366 patients discharged from 8 mental health institutions are analysed, leading to identification of 3 meaningful factors: satisfaction with services, respect & dignity, & satisfaction with the environment. A high level of satisfaction was found.

Koponen, H., Veijalainen, A., Laitinen, H., & Kontunen, J. (1996). Consumer satisfaction with outpatient mental health care. Impact of an organisational change in mental health centre function from hospital district to basis health care. *Nordic Journal of Psychiatry* , 50(4), 329-332.

In Finland the administrative responsibility for outpatient psychiatric care has in part been recognised from specialised psychiatric treatment organisations to health centres. This change has been encouraged by economic pressures, but data about its impact on the quality of treatment and patient satisfaction are limited. WE carried out a follow-

up study by using the UKU Consumer Satisfaction Rating Scale and qualitative interviews, among 22 patients in 1994 and 12 in 1995, to estimate consumer satisfaction with the psychiatric outpatient care just before and 1 year after such a change. The results suggest that dissatisfaction may emerge if too little attention is paid to the longevity of the treatment relationships and the special needs of the therapeutic environment.

Larsen, D. L., Attkinsson, C. C., Hargreaves, W. A., Nguyen, T. D. (1979). Assessment of Client / Patient Satisfaction: Development of a General Scale. *Evaluation and Program Planning*; 2, 3, 197-207.

A general empirical scale to assess client satisfaction (CSQ) was constructed in response to several problems that currently cloud the measurement of consumer satisfaction in health & human service systems. Among the problems are: 1) questionably high levels of reported satisfaction, (2) lack of meaningful comparison bases, (3) lack of a standard satisfaction scale, (4) difficulty in avoiding sampling biases, & (5) high cost & low relevance. Practical experiences in using the CSQ are briefly discussed, as are the general psychometric qualities of the scale & correlations of CSQ results with client characteristics, service utilisation, & service outcomes.

Lebow, J. L. (1983) Similarities and Differences between Mental health and Health Care Evaluation Studies Assessing Consumer Satisfaction. *Evaluation and Program Planning*; 6, 3-4, 237-245.

A comparative review of other literature in the fields of consumer satisfaction with health care, & with mental health treatment. Similarities & differences are noted in the quantity, origins, quality, methodology, results, & utilisation of findings, but the similarities far outweigh the differences. The trend toward carefully constructed high quality studies in health care offers a promising direction for future research.

Lebow, J. L. (1983) Client Satisfaction with Mental Health Treatment: Methodological Considerations in Assessment. *Evaluation Review*; 7, 729-752.

The evaluation of consumer satisfaction in mental health treatment settings is critically assessed. Methodological problems addressed include uniformity myths, inclusion of items not measuring satisfaction,

ambiguity in response alternatives, lack of precision in the use of terminology, failure to distinguish dissatisfaction & lack of satisfaction, failure to identify norms for satisfaction, lack of control over procedure, sampling bias, biasing responses, the lack of variability in responses, & primitive design, analyses, & reporting. Consumer satisfaction emerges as an important indicator of the quality of care, but one that must be interpreted with caution. 63 References. HA

Lebow, J., (1984) Assessing Consumer Satisfaction in Mental Health Treatment Settings: A Guide for the Administrator. *Administration in Mental health*; 12, 3-14.

Presented is a guide for administrators of mental health facilities who seek to obtain consumer evaluation data. A number of specific choices in setting up the research, inclusion of Ss, instruments used, data collection methods, presenting the survey to clients, timing of the assessment, & handling ethical issues are considered. It is recommended that a trained methodologist be used in developing the research, that S choice be related to the purpose of the study, & that a well-validated instrument previously developed be used. The choice between mail & phone data collection methods should be based on resources available & the study population, & clients should be surveyed at several points in time when resources allow. The importance of clarifying the use of the data to the client & obtaining consent for follow-up research are discussed. Several additional pragmatic suggestions are offered. 30 References. Modified HA.

Lebow, J. L., (1987) Acceptability as a Simple Measure in Mental Health Program Evaluation. *Evaluation and Program Planning*; 10, 3, 191-195.

A review of simple measures of acceptability in mental health facilities, focusing on measures of consumer satisfaction. Specific methodological guidelines are offered.

Milne, D., & Kennedy, S. (1993) The utility of consumer satisfaction data: A case study in organisational behaviour management. *Behavioural and Cognitive Psychotherapy*, 21(3), 281-291

Eight staff members and 59 patients at a psychiatric day hospital served as Ss in a study of organisational behaviour management. Patients completed a client satisfaction questionnaire, while staff completed an

instrument designed to measure their views on the utility of the satisfaction data. The final measure was a structured interview 15 months later designed to assess the staff's awareness, use, and perceived consequences of the satisfaction data. Feeding back the results of the client satisfaction survey to staff had most utility when more specific multi-dimensional information was provided. This had an equal impact at the levels of awareness of results, perceived value of results, implementation, practical outcomes, and consequences. Findings illustrate how behaviour therapists can apply their routine clinical skills to systems.

Polowczyk, D., Brutus, M., Orvieto, A.A., & Vidal, J. (1993) Comparison of patient and staff surveys of consumer satisfaction. *Hospital and Community Psychiatry*, 44(6), 589-591.

Patients and staff conducted surveys of patients' satisfaction to determine whether psychiatric patients would respond differently to other patients than to staff when surveyed about the care they received. Ss were 530 patients (aged 19-85 yrs) with serious and persistent mental illness. In general, Ss surveyed by both groups of surveyors reported a high level of satisfaction with outpatient services. However, Ss surveyed by patients reported significantly less satisfaction. The patient-patient survey may have permitted more openness or truthfulness by minimising socially desirable or acquiescent response sets.

Srebnik, D., Hendryx, M., Stevenson, J., & Caverly, S. (1997). Development of outcome indicators for monitoring the quality of public mental health care. *Psychiatric Services*, 48(7), 903-909.

Attempted to develop a brief and integrated set of reliable and valid outcome measures that could be used by both consumers and providers to assess the quality of public mental health care. A model of outcomes in 4 domains--consumer satisfaction, functioning, quality of life, and clinical status--was developed from the literature and from the priorities expressed by members of an advisory group of stakeholders. Based largely on extant measures, a consumer survey and a case manager survey were then created to assess these domains. A total of 236 mental health services consumers (mean age 47.9 yrs) were surveyed. The 4-item case manager survey to rate consumers' clinical status was completed by 163 of the Ss' case managers. Scores and ratings on the survey were analysed using correlation analysis and principal components analysis to determine whether the data provided empirical support for the 4-domain model. Results show that the principal components analysis

demonstrated support for the 4-domain model. Internal consistency of the outcome indicators was adequate, and their concurrent validity was partly supported.

Stallard, P. (1996) Validity and reliability of the Parent Satisfaction Questionnaire. *British Journal of Clinical Psychology*, 35(2), 311-318.

Reports the development of a postal consumer satisfaction questionnaire for a child and adolescent psychology service. Responses to the Parent Satisfaction Questionnaire were scored for 57 families who had participated with a community child and family service. A preliminary analysis of content, construct, and concurrent validity suggests that the questionnaire has an acceptable degree of validity. Factor analysis identified 5 factors were minor dyads which were difficult to interpret. Results indicate that the questionnaire has good reliability and utility, and is a useful way of identifying service shortfalls and directing service change. The need to methodologically evaluate consumer satisfaction questionnaires is stressed and their route use in monitoring and assuring service quality highlighted.

Stallard, P. (1996) The role and use of consumer satisfaction surveys in mental health services. *Journal of Mental Health UK*, 5(4), 333-348.

Examined the role and use of consumer satisfaction surveys to evaluate mental health services. Although satisfaction would appear useful way of evaluating outcome and monitoring service quality significant methodological shortfalls severely limit the conclusions of many studies. Issues of reliability and validity are seldom considered, response rates are low, and studies are typically one-off events which render comparison between or within services extremely difficult. Recommendation for future research are highlighted in order to address these issues.

Stallard, P., Hudson, J., & Davis, B. (1992). Consumer evaluation in practice. *Journal of Community and applied Social Psychology*, 2(4), 291-295.

89 users of community child and adolescent mental health services were surveyed 3-4 weeks after their last contact to determine their satisfaction with the service that they had received. High levels of overall satisfaction were obtained by general ratings, which tended to mask specific critical comments to open-ended questions suggesting ways in which the service could be improved. Thus, ongoing post-contact consumer satisfaction questionnaires seem to be useful in eliciting the views of service users.

Sullivan, G., & Spritzer, K.L. (1997). Consumer satisfaction with CMHC services. *Community Mental Health Journal* , 33(2), 123-131.

Examined the relationship between consumer satisfaction with Community Mental Health Clinic (CMHC) services and patterns of outpatient service use. 210 schizophrenics (aged 18-55 yrs) in Mississippi, the majority of whom were African American, completed a survey to assess satisfaction with care. Data was also collected from CMHC records. Ss with lowest CMHC satisfaction were those who did not identify the CMHC as their primary source of outpatient mental health care. They were more likely to be White, single, and to either receive no outpatient mental health care (46%) or to seek care from sources other than the CMHC (54%), many of which might prove substandard care, such as family doctors, ministers, folk healers, or hospital emergency rooms. Among those who identified the CMHC as their primary source of mental health care, the authors found little evidence that satisfaction was associated with type, variety, frequency of services. Even though clinics offered similar services, there were differences in consumer satisfaction ratings by clinics, suggesting that qualities of the clinic itself may influence consumer satisfaction.

Tanner, B. A., & Stacy, W. Jr. (1985). A Validity Scale for the Sharp Consumer Satisfaction Scales. *Evaluation and Program Planning*; 8, 147-153.

Because of the apparently inflated scores commonly reported for consumer satisfaction with mental health services, a 5-item validity scale was developed for the SHARP questionnaire. The scale discriminated significantly between those former clients who offered suggestions for improvement of services & those who did not (n = 38). In another experiment, the scale significantly improved the ability to predict the 46 clients' true scores from their obtained scores via stepwise regression. Weights were obtained from that sample of former clients, which significantly reduced the deviation of the obtained satisfaction scores from the true scores. In two successive experiments (n = 49 & 26 clients), weights were applied to new samples, reducing deviation from the criterion scores for 5 of the 6 scales, & new weights were then derived. A final set of weights was derived from the combines samples of the three experiments (total n = 121), which improved prediction of the criterion & lowered the mean on all scales.

Young, S.C., Nicholson, J. & Davis, M. (1995). An overview of issues in research on consumer satisfaction with child and adolescent mental health services. *Journal of Child and Family Studies*, 4(2), 219-238.

Reviews the literature on consumer satisfaction with child and adolescent mental health services. Conceptual issues include comparisons between adult & child satisfaction, & considerations unique to the latter, eg, the cognitive immaturity of younger children and the dependence of children on adults. It is observed that C/AMHS research shows methodological variations used to investigate this topic area. A review of research findings serves as a guide for suggestions about the most fruitful directions for future research.

3. CONSUMER SATISFACTION AND GENERAL HEALTH SERVICES

Judge, K., & Solomon, M. (1993). Public Opinion and the National Health Service: Patterns and Perspectives in Consumer Satisfaction. *Journal of Social Policy*; 22, 299-327.

Data from national surveys conducted 1983-1992 are used to analyse trends in the nature of public opinion & determinants of satisfaction concerning the British National Health Service. A range of demographic, socioeconomic, & health status characteristics, as well as media coverage of health-related issues, are found to be significantly related to satisfaction. The complexity of the formation & expression of public opinion is acknowledged.

Shaffer, T.R., & Sherrell, D.L. (1997). Consumer satisfaction with health care services: The influence of involvement. *Psychology and Marketing*, 14(3), 261-285.

Examined the level and process effects of involvement on consumer satisfaction with 2 dimensions of a health-care service. Ss were 131 patients from a large, specialised medical clinic. Rating scales were used to measure expectation, performance, dis-confirmation, and satisfaction responses for physician's behaviours and access mechanisms. It was found that higher levels of customer involvement were associated with greater expectations and performance ratings for the ambiguous dimension of the service. (Physicians). Customer involvement had no influence on ratings for the non-ambiguous aspects of the service (access mechanisms). Perceived performance was found to be most influential predictor of satisfaction for low involvement Ss. High-involvement Ss used dis-confirmation and performance to evaluate physicians and only dis-confirmation in forming satisfaction judgements for access mechanisms.

Russell, M.N., (1990). Consumer satisfaction: An investigation of contributing factors. *Journal of Social Service Research*, 13(4), 43-56.

Conducted a consumer satisfaction survey assessing access to resources for clients, quality of care, access to service, and continuity of service in the outpatient delivery of services to patients with arthritis. 413 patients (mean age 61 yrs) and 128 referring physicians responded to a modified version of the Patient Satisfaction Questionnaire. In physician ratings, quality and accessibility emerged as important factors. Analysis of patient satisfaction ratings indicated quality of care, resource availability, and accessibility emerged as important. A

multidimensional assessment of consumer satisfaction can be used for program planning and modification. The range of satisfaction factors needs to be increased so that consumers have the opportunity to evaluate services as comprehensively as possible.

Williams, B. (1994). Patient satisfaction: A valid concept? *Social Science and Medicine*, 38(4), 509-516.

Over the past 10 yrs consumer satisfaction has gained widespread recognition as a measure of quality in many public sector services. This has become manifest in the National Health Service (NHS) in the call by the 1983 NHS management inquiry to ascertain how well the service is being delivered at the local level by obtaining the experience and perceptions of patients and the community. Patient satisfaction is now deemed an important outcome measure for health services; however, this professed utility rests on a number of implicit assumptions about the nature and meaning of expressions of "satisfaction". A review of past research findings suggests that patients may have a complex set of important and relevant beliefs that cannot be embodied in terms of expressions of satisfaction. Consequently, many satisfaction surveys provide only an illusion of consumerism, producing results that tend only to endorse that status quo.

Williams, S. J., & Calnan, M. (1991). Convergence and Divergence: Assessing Criteria of Consumer Satisfaction across General Practice, Dental and Hospital Care Settings. *Social-Science and Medicine*; 33, 707-716.

Mail questionnaire data from 454 residents of Canterbury & Thanet, England, are used to examine aspects of consumer satisfaction with general practitioner services, dental care services, & hospital inpatient care. The findings show that, despite high levels of general consumer satisfaction, there was greater dissatisfaction with general practitioners across the three settings. Issues concerning professional competence, together with the nature & quality of the patient-professional relationship, were key predictors of overall consumer satisfaction with care. The theoretical significance & policy implications of these findings, particularly in light of recent National Health Service reforms, are discussed.

4. GENERAL TEXTS ON SURVEY DESIGN AND MARKETING

Kinnear, G.C., & Taylor, J.R. (1996), *Marketing Research an Applied Approach (5th Edition)*. New York: McGraw-Hill Inc.

Marketing Research provides prospective Marketing Managers an understanding of marketing research. The book has been designed for either undergraduate courses or first graduate courses in marketing research. The book is divided into five parts: Introduction into Marketing Research; Determine Research Design and Data Resources; Develop the Data Collection Procedure; Sampling Plan and Data Collection; Data Analysis and Reporting Research Findings; Applications. The section on Sampling Plan and Data Collection were useful in the present review.

Martin, L.L., & Kettner, P.M. (1996), *Measuring the Performance of Human Service Programs*. One Thousand Oaks: Sage Publications.

Measuring the performing of human service programs is one of the sage human services guide which provide brief overviews (139 pages) of chosen topics. This book looks at four types of outcome performance measures within a quality framework. Which performance measure is evaluated against seven criteria. The performance measures are numeric counts, standardised measures, level of functioning scales and client satisfaction. The seven criteria are utility , validity, reliability, precision, feasibility, cost and unit cost reporting. Measuring client satisfaction is discussed in terms of quality performance measure and outcome performance measure. Adding a good style of client satisfaction questions to existing surveys is discuss. Martin and Kettner also discuss how client satisfaction outcomes can be translated into numeric counts, eg “78 of respondents are very satisfied with”

The ratings on the seven criteria for client satisfaction as a performance measure are all either low or medium, apart from unit cost reporting, compared with the three other types of performance measures. Numeric counts are described as superior or equal to client satisfaction on all criteria.

Mowen, J.C., & Minor, M. (1998). *Consumer Behaviour (5th Edition)*. New Jersey: Printer Hall Inc.

Consumer behaviour (5th Edition) is an example of a current text produced for undergraduates, marketing courses that might be included in business studies or similar. The text book covers a full range of topics dealing with the purchase of goods and services.

Consumer satisfaction is treated as a post acquisition (or postpurchase) process related to brand loyalty and repurchasing decisions. Consumer Satisfaction is defined as: "The overall attitude customers have towards goods or services after they have acquired or used them. It is a post choice evaluative judgement resulting from a specific purchase selection and the experience of using/consuming it." Maintaining or enhancing consumer satisfaction is critical as empirical evidence shows that small increases in consumer satisfaction can be associated with big increases in profits.

Seven dimensions of service quality used by consumers to make evaluations are described. The factors in the formation of consumer satisfaction including expectancy disconfirmation, equity perception, attributions of causality, actual product performance and the consumers' affective state are discussed.

The clear message is that actual product (or service) performance is only one of the whole range of influences on express consumer satisfaction as defined.

5. THEORETICAL STUDIES OF CONSUMER SATISFACTION

Andaleeb, S.S. & Basu, A.K. (1994) Alternative scales for measuring service quality: A comparative assessment based on psychometric and diagnostic criteria. *Journal of Retailing*, 70(3), 201-230.

Compared 3 alternative service-quality (SQ) measurement scales on psychometric and diagnostic criteria. All formats (3-2-, and 1-column) included 22 items measuring SQ along reliability, responsiveness, assurance, empathy, and tangibles dimensions to obtain scores for service superiority and service adequacy. The scales were pre-tested through focus groups and sample of customers of retail chain. They were then mailed to customers of a computer manufacturer, retail chain, auto insurer, and life insurer. Response rate was 25% (3,069). All formats were shown to possess non convergent and predictive validity, but only the 3-column format was capable of indicating the position of a zone of tolerance and the perceived service level relative to the zone. It was suggested that companies adopt SQ measurement systems that produce separate measures of adequate-service and desired service expectations and perceptions.

Cronin, J.J., Taylor, S.A. (1992) Measuring service quality: A re-examination and extension. *Journal of Marketing*, 56(3), 55-68.

Investigates the conceptualisation and measurement of service quality (SQ) and the relationships among SQ, consumer satisfaction, and purchase intentions. A literature review suggests that the current operationalization of SQ confounds satisfaction and attitude. Hence, data were gathered from 660 personal interviews on the quality of service offered by 2 firms in each of 4 industries: banking, pest control, dry cleaning, and fast food. Data were analysed for an alternative method of operationalizing perceived SQ and the significance of the relationships among SQ, consumer satisfaction, and purchase intentions. Results suggest that a performance-based measure of SQ may be an improved means of measuring the SQ construct; SQ is an antecedent of consumer satisfaction, and SQ has less effect on purchase intentions than does consumer satisfaction.

Gotieb, J.B., Grewal, D., & Brown, S.W. (1994). Consumer satisfaction and perceived quality: Complementary or divergent constructs? *Journal of Applied Psychology*, 79(6), 875-885.

Conflicting models exist in the literature of the process through which perceived quality and / or satisfaction affect behavioural intentions. Further, virtually no theoretical framework has been explicitly developed to help combine perceived quality models with satisfaction

models. This article applies a theoretical framework to help build a model that attempts to explain the relationship among dis-confirmation of expectations, perceived quality, satisfaction, perceived situation control, and behavioural intentions. The study compares the ability of two models to help explain the relationship among these variable. The results of the study suggest that the focal and contextual dimensions of dis-confirmation of expectations affect perceived quality en-route to their influence on behavioural intentions. Additionally, the results indicate that perceived quality affects satisfaction and behavioural intentions are affected by satisfaction.

Iacobucci, D., Ostrom, A, Grayson, K. (1995) Distinguishing service quality and customer satisfaction: The voice of the consumer. *Journal of Consumer Psychology*, 4(3), 277-303.

Presents two studies that rely on divergent methodologies to examine whether or not quality and satisfaction have distinct antecedent causes, consequential effects, or both (ie., whether or not they should be considered a single construct or distinct, separable constructs). 120 graduate students participated. Study 1 used the qualitative “critical incident” technique to elicit service attributes that are salient to respondents when prompted to consider quality and satisfaction as distinct. Responses to these open-ended survey questions were coded to examine whether quality can be teased apart from satisfaction, from the respondents’ (consumer’) perspective. Study 2 experimentally manipulated a number of service attributes drawn fro both Study 1 and from the literature to see whether or not they have differential impacts on judgements of quality and satisfaction. Results offer fairly robust consumer definitions of quality and satisfaction.

Mooradian, T.A., & Olver, J.M. (1997) “I can’t get no satisfaction”: The impact of personality and emotion on postpurchase processes. *Psychology and Marketing*, 14(4), 379-393.

Emerging theory and empirics in personality psychology have related enduring traits with transient affective experiences or states. The research reported in this article integrates these findings with recent consumer research models linking consumption-based emotions with consumer satisfaction and postpurchase behaviours (including complaints, recommendations, and repeat purchase intentions). The authors’ result support a model relating broad, fundamental personality traits to specific consumer behaviours via mediating affective experiences. These findings may help identify consumer segments included toward satisfaction or dissatisfaction, and consequently, toward loyalty, word of mouth, and complaining. Further, they suggest

a general approach for relating broad traits to specific behaviours by incorporating mediating processes.

Oliva, T.A., Oliver, R.L., & Bearden, W.O. (1995). The relationship among consumer satisfaction, involvement, and product performance: *The catastrophe theory application*. *Behavioural Science*, 40(2), 104-132.

Extends the work of T. Oliva et al by developing and testing a catastrophic model of consumer satisfaction / dissatisfaction. Data were obtained from R.L. Oliver and W.O. Bearden's (1985) study of 91 users of a 4-week supply of a new brand of appetite suppressant capsules (ASCs). Results support a non-linear satisfaction response function to product performance, which may extend the current satisfaction theory. The value of a catastrophe interpretation for this study and other managerial problems is suggested. The model may be useful in identifying exact locations of response regions so that a strategy may be designed accordingly.

Peterson, R.A., & Wilson, W.R. (1992). Measuring customer satisfaction: Fact and artifact. *Journal of the Academy of Marketing Science*, 20(1), 61-71.

Discusses the difficulties in measuring consumer satisfaction by self-reports. It is concluded that measurements of customer satisfaction are very context-dependent. To a large extent., the level and shape of customer satisfaction rating distributions are functions of the research methodology employed, apart from the product or service being studied. As a result, these measures are not very informative or diagnostic.

Spreng, R.A., Mackoy, R.D. (1996). An empirical examination of a model of perceived service quality and satisfaction. *Journal of Retailing*, 72(2), 201-214.

Discusses the conceptual arguments for the distinction between perceived service quality satisfaction, and examines the empirical distinction by testing a recently proposed model of service quality and satisfaction (R.L Oliver, 1993) among 273 undergraduates. Students' assessments of undergraduate advising were examined. Questionnaires were filled out before and after a service encounter with an adviser. Desires, predictive expectations, perceived performance, desires congruency, and expectations dis-confirmation were each measured for 10 attributes (convenience in making an appointment, friendliness of the staff, the adviser listening to questions, etc). Results show that service quality and satisfaction are, in the present case, distinct, and they have different antecedents. Findings also provide some support for the model, with several modifications.

Taylor, S.A. & Baker, T.L. (1994). An assessment of the relationship between service quality and customer satisfaction in the formation of consumers' purchase intentions. *Journal of Retailing*, 70, 163-178.

Tested the hypothesis, that the interaction between service quality and consumer satisfaction would explain more of the variance in consumer' stated purchase intentions than would the direct influences of either service quality or satisfaction alone. Mail intercepts were used to survey 426 consumers regarding their perceptions of 2 firms in each of 4 service industries: health care, recreation (amusement park), travel (airlines), and communications (long-distance telephone). The hypothesis was generally supported. For communications, travel, and recreation, the inclusion of the satisfaction/service quality interaction term in moderator regression analyses significantly added to the explanation of purchase intentions. Results suggest that satisfaction moderates the relationship between service quality and purchase intentions, and that purchase intentions are highest when both service quality perceptions and satisfaction judgements are high.

ATTACHMENT B SURVEY REVIEWS

The survey reviews are provided in this Attachment. We have outlined how the particular surveys were selected for review below.

Major satisfaction surveys with people with disabilities and their carers in Australia

Information Sources

Information about satisfaction surveys concerning disability services in the Australia was located through members of the Working Party and the Internet.

Summary of major surveys

These investigations produced the following information:

- There had been two large scale satisfaction surveys of people with intellectual disabilities and their carers: the DSC telephone survey about state provided disability services in Western Australia; and the survey of consumers of Adult Training and Support Services (ATSS) in Victoria. Details of these studies were readily available.
- Hearing Services Australia has conducted at least two national consumer satisfaction surveys. In addition to the commissioned reports, Anthony Hogan in Sydney has carried out detailed analysis of these results. As yet Hearing Services Australia has not released copies of the reports to E-QUAL.
- A well documented study of consumer satisfaction with public mental health services throughout Victoria is carried out annually. The reports were readily available.
- Other states reported many service level studies, usually directed at service improvement and with a strong qualitative component. Some of this work relates to the Disability Services Standards.

We decided to review the DSC, ATSS and the Victorian Mental Health study as examples of Australian consumer satisfaction studies.

Major satisfaction surveys with people with disabilities and their carers in the United States

Information Sources

Information about satisfaction surveys concerning disability services in the United States was located through:

- Bibliographies of relevant literature reviews eg. those conducted by DSC and KPMG for their surveys.
- The Summary of National and state Databases on Residential Services for persons with Developmental Disabilities (1994) produced by the Institute for Community Integration at the University of Minnesota.
- Re-inventing Quality - The 1995 Sourcebook of Innovative Programs for Quality Assurance and Quality Improvement of Community Services (1995) also produced by the Institute for Community Integration at the University of Minnesota.
- Screening the NIDRR and other University Affiliated program websites for relevant projects.
- The literature search conducted by E-QUAL.
- Email correspondence with the Executive Director of the National Association of State Directors of Developmental Disability Services, Inc. (NASDDDS), a non-profit organisation devoted to expanding and improving public services to individuals with mental retardation and other developmental disabilities.

Summary of major surveys

These investigations produced the following information:

- The Temple University Affiliated Program conducted a major study to monitor consumer outcomes in association with the closure of Pennhurst State School and Hospital and the relocation of all residents into community based options. This study has had a major influence on later work concerning consumer satisfaction. The Consumer Satisfaction Scale was developed as part of this work.
- The Developmental Disabilities Assistance and Bill of Rights Act Amendment of 1987 required states to present a comprehensive picture of service delivery for persons with developmental disabilities to the US Congress. In response to this legislation all states used the Consumer Satisfaction Scale to survey their clients in 1989/90.

- Colorado regularly uses the Colorado Progress Assessment Review (COPAR) as the basis of its state disability Service data-base. The COPAR was developed by Colorado's Division for Developmental Disability to evaluate actual outcomes for persons perceiving support with respect to the divisions mission statement, which establish community inclusion, responsible choice, control, belonging, relationships, confidences talent, security and self respect, these are the primary values that should be reflected in services.

COPAR includes 23 questions related directed to satisfaction.

- Oklahoma regularly uses the Developmental Disabilities Quality Assurance Questionnaire annually on approx 3,700 individuals at residential sites throughout Okalahoma.
- The Human Services Research Institute (HSRI) in Cambridge Massachusetts is collaborating with the NASDDDS on an across states project aimed at identifying and testing a core set of indicators that can serve as a foundation of a assessing how well the states' public developmental system is performing. There are 15 participating states. The project is called the Core Indicators Project.
- New York and California both have consumer orientated quality initiatives which include a consumer orientation. Compass developed in New York has four elements including consumers and outcomes. California is developing the California Consumer Outcomes.

We decided to review the COPAR and the CIP as examples of US satisfaction studies. The COPAR has been used and refined for almost ten years. The CIP represents new work to develop indicators that will be used in many US states.

Survey Review No 1. - DSC Telephone Survey

Administrative details	
Title	Consumer Satisfaction Survey
Jurisdiction	WA
Date reported	September 1997
Agency	Disability Services Commission
Authors	Donovan Research
Contact details for information	Noela Taylor, DSC. Tel (08)9426 9200
Survey developed by	DSC
Survey conducted by	Donovan Research
Ownership of the survey	DSC
Availability	By Arrangement with DSC
Aims & Scope	
Study population	Consumers of disability services ie people with disabilities, carers or next of kin of those people currently using services.
Goals	1. Provide measures for key performance indicators 2. Identify strengths and weaknesses in current service provision and direction for DSC to develop policy.
Quality of life or Quality of Service	Quality of Service
Services covered	All services including local area co-ordination, respite, accommodation, general medical, social work/trainer/psychologist, specialist health and therapy. All age groups. In addition support to carers by DSC and grievance procedures were canvassed.
Context - reason for survey	As part of reporting to Auditor General, required to report on key performance indicators. A benchmark survey of consumers i.e. people with disabilities, carers or next of kin of those people. Also highlight areas in need of improvement.

Methodology - Development	
Composition advisory network	Project Steering Committee in DSC - consultant and DSC together.
Previous work drawn on	Other State services and literature.
Model of satisfaction used	No explicit model.
How validity established	
Construct validity	Not known
Discriminatory powers	Not known
Internal validity	Not known
Other validity	Face validity and limited field trials to assess clarity, duration, question format, etc..
Field trials - comprehensiveness	Initial questionnaire pilot (n=6) by DSC. Two discussion groups (n=15) with carers of DSC clients. Revised questionnaire piloted (n=20) DSC carer/clients. Revisions based on these experiences. Final check on refusal/participation rates and length of questionnaire after 100 interviews conducted.
Setting of standards/benchmarks	This was considered a benchmarking study.
'Risk analysis'	Nil.
Reliability results	Not assessed.
Improvements resulting from trials	Improved wording, assessment of satisfaction scale used. The scale moved from the specific to the general in asking about satisfaction. The carers section was much more detailed than that asked of clients. The scale used plain language i.e. good, okay and poor, rather than degrees of satisfaction.
Methodology - Implementation	
Sampling	
Frame	Drawn by DSC. 400 clients receiving services through accommodation program (DSC provided), and 400 clients receiving DSC-provided services under individual and family support from metropolitan and country south west postcodes from the DSC

Report Attachment B

	database.
Procedure	These two N=400 groups drawn at random. The list of 800 sent to regions for verification resulting in reduction to 607. Process repeated to gain final list of 820 families. Of these some requested non-participation (109), others could not be contacted (109), and for other reasons, the final sample size was 442, comprising 17 personal interviews and 425 telephone interviews.
Size	442 , 425 x telephone plus 17 x face to face interviews.
Ability to draw within group comparisons	The reports provide an extract from an ABS document indicating the size of differences for various sample sizes and percentage scores which may be taken as being statistically significant.
Survey tool	
Medium - Tel, person to person, face to face, net	Mainly telephone.
Balance quantitative/qualitative	Mainly quantitative with opportunities for comments on three or four questions.
Data from primary consumers	Poor. Only 12% of people with disabilities answered for themselves. This was thought to be one in four of those able to talk. Carers acted as the gate-keeper. As the first call was to a family home, interviewers were required to make another phone call to talk with consumers in accommodation services.
Data from others	Family members provided most responses, both for their own opinions and second-guessing the views of people with disabilities.
Question format	Five point Likert scale - very good, good, just okay, poor, very poor. Followed by some open ended probing questions - "Why do you describe ... as ..?"
Validity/consist check	Nil.
Quality of life or Quality of Service	Quality of Service
Validity issues	
Validity is not addressed specifically. However, client/carers answering on behalf of clients were asked to give a reason for their own or the perceived overall level of satisfaction with services provided by DSC. The most common	

positive reasons were:

- client is content/seems happy (25%);
- good service/prompt service/well looked after (19%);
- staff are good(nice to clients, always helpful, caring and gentle) (17%);
- client enjoys mixing (9%);
- client enjoys recreation/social activities (6%).

Those who made a neutral/can't assess response(16%). The most common negative reason was services in general don't provide what you need (6%).

The report comments satisfaction relates to the reported happiness of the client, both in general or in relating to staff in other social and recreational activities. Clients themselves tended to focus on *The staff are good* and *Mixing with other people*, i.e. focusing on enjoyable personal contact.

There are also comments in the report about how little family members with people in accommodation services know about the services the person with a disability is getting.

Expressed satisfaction also varied with age. Carers age 64 + rated their satisfaction very good significantly more often than younger carers. They also reported lower levels of dissatisfaction.

While this might be expected, high levels of satisfaction overall were recorded.

One in ten people were less than satisfied. Interestingly 99 people had had cause to make a complaint, yet a proportion of these people still rated their level of satisfaction as good or better.

Reliability	Not addressed.
Resources required	Considerable time in chasing up contacts with families.
Time	No comment on time of questionnaire.
Quality of interview staff	
Selection crit	Trained Surveys Australia staff
Preparation	Instruction from DSC staff member on communication with people with disabilities or intellectual disability and written instructions on same. Training also included dealing with stressed families etc.
Quality control	Not discussed. De-briefing session was planned as some interviews emotional - but did not happen.

Ethical issues	
Identification	Anonymity. No problems reported.
Consent	Comparatively high rate of refusal - 109 (16%). Families gave consent for adult consumers to participate.
Anonymity	
Intrusion	See consent.
Benefits for participants	Not explicit. Need ways to deal with serious/life threatening concerns raised during interviews
Outcomes	
Bias in actual sample	Over one quarter of carers were aged 65 or over - this rose to 36% for those in accommodation services. There was no attempt to match the demographics of the sample against WA families in general. Although the sample is treated as two - those using Accommodation Services (AS) and those using Individual & Family Support (I&FS) in practice 167 clients received both services and so overlapped. Again this was not checked against other DSC data. In practice low numbers of direct consumers (12%) responded.
Response rate (& how non-response was dealt with)	See above notes.
Data aggregations made	The two separate random populations of accommodation services and I&FS are aggregated together as though they were a random sample of DSC clients as a whole. Combined figures for the two samples are often quoted for various service types.
Comparisons made/questions answered that supported by data	Comparisons between AS and I&FS samples by service type, carer support, grievance procedure and elements e.g. access, quality, information within the service types.
Unsupported conclusions drawn ie misuse of data	Nil. Only once or twice does the report take high levels of carer satisfaction to mean that services are of a high standard. Although there are comments throughout describing what is being done, the data given

Report Attachment B

	directly by people with disabilities and by carers on their behalf is not separated and is typically referred to as clients data, which it is not.
Service improvement use	At one point the report starts talking about what DSC can do to increase the level of satisfaction among carers. Given that ratings of satisfaction may be heavily loaded towards client happiness and positive social interaction, policy may be skewed towards these goals rather than other aspects of quality services. The report provides policy recommendations aimed to improve satisfaction in areas where these are reported as low (albeit not always statistically so).
Costs	
Development costs	In-house ~\$15,000
Implementation costs	Est. Consult \$50,000 + In-house \$5,000 Probably \$45,000 on doing survey and basic analysis.
Cost per respondent	Approx \$45,000 for 442 respondents ie \$100 per respondent.

Survey Review No 2. - ATSS Consumer & Carer Survey

Administrative details	
Title	ATSS Consumer Satisfaction Survey
Jurisdiction	Victoria
Date reported	Dec 1995
Agency	Health & Community Services, VIC
Authors	KPMG Consulting
Contact details for information	Bernie Ross, Dept of Human Services, GPO Box 4057 Melbourne 3007 Tel (03) 9616 7794 Fax (03) 9616 8329
Survey developed by	KPMG & H&CS
Survey conducted by	KPMG Consulting
Ownership of the survey	Adult Support Services, Dept of Human Services, VIC.
Availability	Through Bernie Ross, Dept of Human Services.
Aims & Scope	
Study population	Clients of all ATSS centres Families and carers (staff of accommodation services in which clients lived) for above clients. The ATSS Sector provides training and day time support for adults with an intellectual disability. There are currently more than 140 ATSS agencies providing services to approx 4,000 people across the State. Centres are run by a diverse range of organisations.
Goals	To give consumers the opportunity to voice their satisfaction or dissatisfaction and express their views in a range of issues in relation to ATSS delivery - for the first time. To inform the department and service providers in the development of policies and guidelines to enhance the quality of services and increase level of satisfaction and participation in ATSS delivery.

Report Attachment B

Quality of life or Quality of Service	Consumers survey: Consumers indicated being happy or sad with program activities and with aspects of service quality e.g. choice, cost, staff friendliness and friends. Family and Carers Survey: perceived standard of care and aspects of management and structure of ATSS Services or ATSS Programs level of satisfaction with ATSS.
Services covered	All ATSS services in VIC
Context - reason for survey	The survey was conducted as part of a process of re-development including a disability services branch quality services project. ATSS Sector was developing more flexible and responsive and client focused models.

Methodology - Development	
Composition advisory network	Reference group with consumer, parent/carer, provider and departmental representatives. Also an academic. A steering committee consisting of a sub-group from the reference group.
Previous work drawn on	A literature review was carried out with a particular emphasis on consumer satisfaction with services with adults with an intellectual disability. There were also clearly contacts with academics including Bob Cummins, and others from Deakin University and La Trobe University.
Model of satisfaction used	Consumer survey: Consumers were asked whether they were happy or sad about a particular aspect of the service.
How validity established	
Construct validity	The topics to be included were developed following 5 focus groups 1 x Professional 1 x Consumers and Advocates 3 x Parents & Carers - Total N=38 Aspects of services to be covered were influenced by these focus groups for both the Parent & Carer and Consumer surveys. ie they covered the same topics.
Discriminatory powers	
Internal validity	
Other validity	Some work was done to establish the likelihood that the four interview forms did not lead to consistent differences in responses.
Field trials - comprehensiveness	3 Centres
Setting of standards/benchmarks	Not done before hand - seen as benchmarking study
'Risk analysis'	Nil
Reliability results	No test, re-test reliability
Improvements resulting from trials	Shortening of questionnaire due to random responses, fatigue or stress. Development of process for deciding which method to use for each consumer - prior gathering information about communication,

	<p>use of language, sensory handicaps etc. Also used group meeting in centre on day of interview to assist with selection of data gathering method.</p> <p>Four different styles of questionnaire produced - an interview schedule one with COMPIC like symbols, observation and conversational style.</p>
<p>Methodology - Implementation</p>	
<p>Sampling</p>	
<p style="text-align: right;">Frame</p>	<p>Consumers: All those who use ATSS services in Victoria Parents & Carers: Parents and carers of ATSS Consumers. These details are available on H&CS Consumer information.</p>
<p style="text-align: right;">Procedure</p>	<p>Consumers: Original attempt to get 5% of ATSS Consumers reduced to 3.5% because of difficulties obtaining consent. Consumers selected from 20 out of 140 centres across the state. Centres selected to cover a range of locations, sizes, program types. A random stratified sampling method in accord with a client data set held by H&CS was used for each centre.</p> <p>Work was created for the consultants by consumers who indicated an unwillingness to participate or did not return the consent form. Replacement consenting consumers had then to be located.</p> <p>Parents & Carers (P&C): drawn from all 140 centres. 15% of each centre's total population or 2 where consumer numbers were less than 10.</p> <p>The sample was chosen to include P&C of clients with:-</p> <ul style="list-style-type: none"> • Different age groups • Gender balance • Different living arrangements • Different level of disability • Different disability types

Size	<p>Consumers: Total 139, 72 consumers by questionnaire, 67 by observation. Those administered questionnaire were more likely to be older than 35, living in a private home and have more functional communication skills. Approximately 1.4% of consumers were able to answer the main questions on the questionnaire. Reliable responses to the main questions were gained from approximately 1.4% of the total population, perhaps 2.8% of those with enough skills to complete the questionnaire.</p> <p>P&C: 269 completed questionnaire out of 590 sent out (7% of the total population of parents and carers [45% parents] and [44% carers] most female 71%)</p>
Ability to draw within gp comps / letters	Consumers: Sample sizes within program areas was very small.
Survey tool	
Medium - Tel, person to person, face to face, net	Consumers: Face to Face interview or 20 minute observation period. P&C Questionnaire mailout.
Balance quantitative/qualitative	The Consumer questionnaire provided 2 open ended questions.
Data from primary consumers	Great effort was taken to get adequate data including having various forms of the survey including a 20 minute observation option where there was no vicarious responding.
Data from others	P&C were surveyed for their own opinions and aspects of service as related to their experience.
Question format	<p>Consumers: For each known program name and location (previously established by interviewer) Consumer was asked "Are you sad about.....?" and then again "Are you happy with?" - the order of these two questions are alternated.</p> <p>Notes were also taken on any direct quotes from respondents and the manner in which the response was made.</p>

	<p>There were then 12 questions on aspects of the program, eg friends, activities, staff, etc. again reversal questions were asked and client responses were scored on a 3 point scale or don't know or unreliable. Direct quotes and interview comments were noted. There were then open-ended questions on what makes you feel good or happy/or sad at the centres? Finally interviewers provided they're own assessment of overall client satisfaction on a 5 point Likert very dissatisfied/very satisfied scale.</p> <p>There was also an individual client record in which instances of positive and negative affect were noted over a 2 x 20 minute period. Observers also rated happiness, calm/agitated, distracted/attending.</p> <p>Observation sessions were converted into a 5 point Likert very dissatisfied/very satisfied scale. This score was averaged across the 2 x 20 minutes periods.</p> <p>Carers: Comprehensive 17 page questionnaire based around Likert scales <i>very satisfied to very dissatisfied, all the time to none of the time etc.</i></p> <p>Data on personal details, the service offered and the consumers use of service was also collected.</p>
<p>Validity/consist check</p>	<p>Consumers: The question reversals we used to cope with the issue of compliance and break up response sets.</p> <p>In practice, interviewers quickly established whether consumers were giving reliable responses, ie acted more like a screening. If apparently more reliable responses were being obtained single questions would be asked. The procedure allowed contradictory/unreliable responses to be counted and discarded.</p> <p>The preparation of unreliable responses must</p>

Report Attachment B

	have been quite high.
Quality of Life or Quality of Service	See above
Validity issues	<p>As mentioned above the topics in the questionnaire/interview were elicited through focus groups of carers and consumers and gained validity through this process.</p> <p>Comparisons are made between parents and carers responses.</p> <p>The authors claim the consistency of relationship between different indices supports the validity of the instruments.</p>
Reliability	<p>No test, re-test reliability assessment. The reliability of the observation periods may well have been quite low.</p> <p>Future test, re-test reliability checking is recommended.</p>
Resources required	Trained interviewers, flexibility, COMPICs and other supports.
Time	Time taken for whole project 8 months
Quality of interview staff	<p>Consumers: Two interviewers visited and held an initial group meeting with respondents. Each consumer interview took 30 minutes observations 2 x 20 minutes.</p> <p>Observers also travelled to other program sites away from centres as appropriate.</p>
Selection crit	Not clear
Preparation	The report stresses the need for consumer interviews to be carried out in places familiar to the consumer and by people they are familiar with. It is recommended interviewers have longer time to develop trust with consumers e.g. four visits over a four week period.
Quality control	No comment

Ethical issues	
Identification	Well handled - KPMG did not see names of people who did not consent.
Consent	Legislation required that valid consent be gained for each consumer before being interviewed. Adequate time needs to be allowed to do this, i.e get returns from parent / guardians and to allow consent to be gained for replacement clients this is a particular issue the consumer population with cognitive disabilities.
Anonymity	Well handled
Intrusion	
Benefits for participants	The consultants comment that many participants seem to have been concerned about the future use of the information obtained. They do not know degree to which this may have influenced responses to the survey and interviews. The benefits for the participants were not tangible.
Statistical analysis	
Tables produced	There are tables for the profiles of the consumers surveyed and characteristics of P&C sample etc. Bar charts are produced for consumers and P&C showing percentages satisfied (very satisfied + satisfied, percentage dissatisfied + very dissatisfied) and other possible responses. Other possible responses for questions in various sections of the questionnaire.
Methods for aggregation of groups up	No indication is given of any special procedure to enable reporting of the combined consumer and combined P&C samples, the sampling procedure did not produce a random sample for each of these populations, although results are reported as though there were no issues around aggregation.

Methods for analysis of subgroups	<p>The sub-groups analysed include parents verses carers. This is approached by running two-tailed tests (t-tests and chi-square) on most the items on the questionnaire. Differences at 95% confidence limits are reported. Given the number of tests it is not surprising that some statistically significant differences occur.</p> <p>A similar comment can be made about significant differences reported in levels of satisfaction for other questions and interviews. The analysis could be challenged on the large numbers of t-tests and chi-squares that appear to have been run.</p>
Indices created/used	<p>The 4-point satisfaction scale has simply collapsed into 2-points, i.e very satisfied and satisfied into satisfied and very dissatisfied and dissatisfied into dissatisfied and percentages reported.</p>
Linking of qualitative & quantitative data	<p>There is very little reporting of the qualitative data</p>
Special features	<p>N/A</p>
<p>Outcomes</p>	
Bias in actual sample	<p>Consumers: Clearly the interviews were completed by those with better functional communication skills and the data represents their views.</p> <p>P&C tables suggest approximately 50% of the sample was aged 60+ years.</p>
Response rate (& how non-response was dealt with)	<p>See above under sampling procedure</p>
Data aggregations made	<p>See above</p>
Comparisons made/Questions answered that supported by data	<p>Interestingly parent and carer comparison are made, showing that carers tend to be much less satisfied/more often dissatisfied than parents. Carers also reported being in more frequent contact with ATSS staff altogether carers may have been younger (associated with less higher satisfaction) have better information, P&C often commented they did not have enough information, and have less to</p>

	lose by making critical comments.
Insupportable conclusions drawn ie misuse of data	
Service improvement use	Bernie Ross reported at least one agency had taken up the focus on information to be provided to P&C
Benchmarks created	The study has provided a replicable benchmark of satisfaction in this area.
Limitations acknowledged	<p>1) Respondents asked about current services and not about ideas for better service options or improvements.</p> <p>2) Validity of consumer data - only consumers with communications skills could respond to questions. (However the strength of this survey is that there is not vicarious respondents)/</p> <p>3) Was the validity of data affected by concerns about the future use of information obtained.</p> <p>4) High rate of unreliable responses combined with small samples in some types of programs reduced the generalisability of findings concerned with programs in domain areas in consumer surveys.</p> <p>5) Time taken in gaining consent and ability to quickly substitute alternative consumer respondents. Also absentee rate of consumers from centres when interviewing team visited.</p> <p>6) Requirement to limit time taken with each consumer to reduce likelihood of unreliable responses in a single session. This restricted topics covered. More topics could be covered if interviews conducted over several sessions. Also in-depth case studies could be carried to further investigate issues raised by quantitative data.</p> <p>7) No investigation of importance of the various domains for consumers. Original methodology included use of an important scale but this proved to be too unreliable. Further development of the consumer questionnaire could also include randomisation in order of questions to allow for fatigue.</p>

Report Attachment B

Survey improvements planned	
Sampling	See above to gain a larger consumer sample
Instrument	See above including use of more than one session with each consumer
Other	
Side or unintended effects	Nil
Commit/recommend to repeat	Recommends to repeat study within 12 months to compare with existing baseline and then use follow up qualitative studies. Two approaches suggested:- Larger sample & more time with consumers before conducting interview sessions.
Costs	
Development costs	Total fees paid to KPMG \$75,000 -
Implementation costs	
Cost per respondent	

Survey review No. 3 - Mental Health Services (Vic)

Administrative details	
Title	Consumer and Carer Satisfaction with Public Mental Health Services
Jurisdiction	Victoria
Date reported	June 1997
Agency	Dept Of Human Services (MH Branch)
Authors	Quadrant Research Services (Frank Stafrace)
Contact details for information	Tracey O'Halloran 03 9616 7189
Survey developed by	MH staff and Thomas & Assoc
Survey conducted by	Quadrant Research Services & MH staff
Ownership of the survey	Dept of Human Services (MH Branch).
Availability	Refer to contact.
Aims & Scope	
Study population	Consumers and carers in all 22 MH areas in Vic.
Goals	<ol style="list-style-type: none"> 1. Measure consumer satisfaction with services from Area MH services & to provide advice on how satisfaction can be improved 2. Measure carer satisfaction with services from Area MH services 3. Provide advice on how consumer and carer satisfaction can be improved.
Quality of Life or Quality of Service	Quality of Service
Services covered	Out patient and hospital mental health services.
Context - reason for survey	<p>Reform within Victoria's public mental health services aimed at making services more effective and responsive to consumer needs. This approach includes involving consumers and carers in the evaluation of public mental health services to ensure accountability and quality standards.</p> <p>The survey was also used as one of three performance indicators for the quality bonus strategy within mental health. Scores on consumer and carer satisfaction received the</p>

Report Attachment B

	highest weighting to enable area mental health services to attract part of a \$1.1m. funding pool.
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Methodology - Development	
Composition advisory network	A reference group was established including consumers, carers representatives from participating services, experts and psych services staff.
Previous work drawn on	A lit review was carried out including a comprehensive listing of consumer satisfaction surveys with mental health services.
Model of satisfaction used	Multi dimensional direct rating of satisfaction on five point Likert scales each. Various topics each have a sub scale of five or six questions. Topics such as availability, getting information, about staff, treatment and assistance, participation, about hospital and an overall satisfaction rating.
How validity established	
Construct validity	
Discriminatory powers	Field trials included factor analysis which more or less confirmed the sub scales of the questionnaire.
Internal validity	High internal consistency found.
Other validity	
Field trials - comprehensiveness	Quite extensive field trials with consumes and carers with a particular emphasis on identifying the best means to recruit respondents.
Setting of standards/benchmarks	Consultants were aware of the typical high levels of satisfaction expressed. The field trials were not large enough to set benchmarks.
'Risk analysis'	N/A
Reliability results	N/A
Improvements resulting from trials	The draft carer and consumer satisfaction questionnaires were found to be satisfactory. It was decided that the recruitment of consumers was best done at the point of service. It was also decided to restrict the initial survey (1996/97) to adult mental health services, i.e. not child or aged mental health services, as these would require development of simplified questionnaires.

	The field trials also demonstrated shortcomings in databases of consumer and carers contact details.
Methodology - Implementation	
Sampling	
Frame	Adults who used the centres operated by twenty two area mental health services (both clinic based and outreach consumers) and their family carers.
Procedure	Clinic based consumers were given the self administered questionnaire at the clinic. Outreach consumers were given the questionnaire by an interviewer who accompanied a member of staff on one of the regular visits to the person's home. Area mental health services sent names and addresses of carers who had given consent to the consultants. The questionnaire was then mailed out by consultants.
Size	Consumers: Aimed for 75 from each of 22 centres. Final sample of 1,757 achieved. Carers: Aimed for 50 carers from each of 22 services. 1,171 questionnaires sent and 1,090 (61.5%) received.
Ability to draw within gp comps	
Survey tool	
Medium - Tel, person to person, face to face, net	Consumers: Self administered hand delivered questionnaire. Carers: Mailed questionnaire.
Balance quantitative/qualitative	Mainly quantitative, but with substantial space for comments.
Data from primary consumers	Yes.
Data from others	Carers completed questionnaires about their own experiences - not those of the primary consumer.
Question format	Five point Likert scale - <i>very dissatisfied</i> to <i>very satisfied</i> , plus <i>don't know/N/A</i> .
Validity/consist check	Nil
Quality of Life or Quality of	Quality of Service

Report Attachment B

Service	
Validity issues	
Reliability	
Resources required	
Time	
Quality of interview staff	
Selection crit	
Preparation	The consultants interviewing team were trained by a mental health services counsellor. The training session was recorded on video tape and each interviewer in country Victoria received a copy. All area managers also visited by trainer.
Quality control	

Ethical issues	
Identification	No names or telephone numbers on questionnaires.
Consent	Carers were required to provide consent before having a questionnaire mailed to them. There was a comment that this may have biased results.
Anonymity	No names or telephone numbers on questionnaires.
Intrusion	
Benefits for participants	
Statistical analysis	
Tables produced	Bar charts showing the ranking of different area health services on combined index and inpatient index. Comparison tables between metropolitan areas, country areas and Victoria as a whole. Comparisons between consumers and carers in the metropolitan and country areas. As expected, older consumers report higher satisfaction as do older carers.
Methods for aggregation of groups up	There appear to be no special procedures for aggregating the groups although it is not a random sample at the whole of Victoria level. There is no discussion of this.
Methods for analysis of subgroups	
Indices created/used	The consultant developed a “completely satisfied consumer” model in which a completely satisfied consumer is a respondent who did not actually use the rating <i>very dissatisfied</i> to <i>neither satisfied nor dissatisfied</i> in answering items on overall satisfaction with each of the five components - availability of service, getting information, about the staff, treatment and assistance and participation. Levels of satisfaction with in-patient services were analysed separately and differently. The consumers performance index and carers performance index were also combined. The combined index was the sum of completely

Report Attachment B

	satisfied consumers and completely satisfied carers divided by the total number of customers (consumers plus carers).
Linking of qualitative & quantitative data	Comments were able to be reported under each component. However, this is done away from the quantitative data.
Special features	
Outcomes	
Bias in actual sample	There was concern that the process of gaining consent from carers led to bias.
Response rate (& how non-response was dealt with)	The response rate from the carers mail out was high (61.5%). When insufficient consumer numbers were gained from a centre, an attempt was made to make up the difference through mail survey. It is not clear how much this was used.
Data aggregations made	
Comparisons made/Questions answered that supported by data	
Insupportable conclusions drawn ie misuse of data	
Service improvement use	
Benchmarks created	
Limitations acknowledged	
Survey improvements planned	
Sampling	
Instrument	To allow consultant input in design to reduce coding time.
Other	Improve co-ordination between consultants and area managers.
Side or unintended effects	
Commit/recommend to repeat	The survey has been repeated in broadly similar form in 1997/98 with the results expected July - August 1998. It was extended to child and aged psychiatric services with alternative forms of the questionnaire. There are some questions about the discriminatory power of the instrument to assist in service improvement at the local level. The branch is waiting until the 1997/98

Report Attachment B

	analysis has been carried out to see whether this can be overcome. If not they may review the survey instrument in the context of other performance indicators being developed.
Costs	
Development costs	Not known.
Implementation costs	The 1996/97 survey cost less than \$100,000 for implementation and analysis.
Cost per respondent	

Survey review No. 4 - Colorado Progress Assessment Review (COPAR)

Administrative details	
Title	Studies using COPAR, the Colorado Progress Assessment Review
Jurisdiction	Colorado, USA
Dates reported	Various through mid 90's, including outcomes of services and supports for persons with developmental disabilities.
Agency	Division for Developmental Disabilities of Colorado Department of Human Services (CDHS).
Authors	Much reporting done by Kozleski and Sands as well as others.
Contact details for information	Judy Brown, email: judy.brown@state.co.us
Survey developed by	CDHS
Survey conducted by	DDD of CDHS
Ownership of the survey	CDHS
Availability	Through Judy Brown, Program Evaluation Information Services Section.
Aims & Scope	
Study population	All adults with developmental disabilities using CDHS services.
Goals	<p>In general to meet requirements of the Colorado Auditor General and expectations set out in Colorado legislation about outcomes to be achieved through services.</p> <p>More specifically, in the report to be reviewed, DDD sought to make four basic comparisons:</p> <ol style="list-style-type: none"> 1. Comparison of outcomes across various service approaches to determine the relative effectiveness of these service approaches for achieving legislative goals. 2. Comparison of actual service performance against a performance target. 3. Comparison of outcomes longitudinally to see if there were statewide improvements in outcomes across time. 4. Comparison of outcomes by characteristics of persons in services, including differing

Report Attachment B

	demographic characteristics or support needs.
Quality of life or Quality of Service	Quality of Life information from consumers is assessed within the context of a wide range of performance indicators for the quality of service.
Services covered	Residential, medical, supported living. Day programs, school, etc.
Context - reason for survey	<p>COPAR originally developed in 1986 in response to a legislative mandate for evaluation of consumer progress by State Auditor's Office. Many changes since that time. COPAR has been used to focus on different aspects of services during different years. For example in 1995 a version was specifically designed for:</p> <ol style="list-style-type: none">1. The second year of longitudinal studies.2. Annual resident review of persons residing in nursing home facilities.3. Evaluation of supported living services.

Methodology - Development	
Composition advisory network	Not known.
Previous work drawn on	Consumer Satisfaction Scale (Temple University); QoL.Q; Outcome Based Performance Measures (Accreditation Council, Maryland); Client Employment Screening Form (Virginia); Client Developmental Evaluation Report (California); Consumer Interview and Consumer Opinion Questionnaires (New York).
Model of satisfaction used	Consumer satisfaction in the context of total quality improvement the self advocacy movement is taken to be the key to service quality. It is taken that subjective satisfaction issues e.g. Do you like where you live? must be answered by the consumer themselves. Satisfaction has always been measured in the context of the complete COPAR tool.
How validity established	
Construct validity	
Discriminatory powers	
Internal validity	
Other validity	
Field trials - comprehensiveness	The satisfaction scale of COPAR has been developed continuously for over ten years with a series of large scale (N=700) surveys.
Setting of standards/benchmarks	COPAR has been concerned that its quality of life standards for its clients are comparable with people in the general community. In 1992 DDD randomly sampled 1,000 adults in the Colorado general population asking them many of the same questions as COPAR. Questions included life satisfaction, decision making activity levels. The survey was repeated in 1993 including questions related to relationships, self esteem, personal security and talents. Results for DDD clients can therefore be compared with adults in the general population.

Report Attachment B

'Risk analysis'	COPAR has been used to study whether satisfaction varies by geographical service area, age category, gender, ethnic status or functioning level.
Reliability results	
Improvements resulting from trials	
Methodology - Implementation These notes relate to the 1994/95 Report Outcomes of Services and Supports for Persons with DD. This report concentrates on surveys in summer 1992 and 1993.	
Sampling	
Frame	Adults receiving services funded by DDD.
Procedure	Stratified random sample of adults receiving services based on stratified random sample of thirty adults or 10% of the service population for community centred boards and regional centres. Samples found to be statistically representative of the populations from which they were drawn and age, gender, ethnic status, adaptive skill, level residential setting, day program and funding type. The same individuals were re-surveyed in 1993. The original sample of 781 in 1992 was reduced to 743 in 1993.
Size	In 1993 743 adults represented 13% of the active adult population.
Ability to draw within gp comps	
Survey tool	
Medium - Tel, person to person, face to face, net	Face to face interviews with consumers (or carers for parts) on satisfaction. The staff completed other performance indicators.
Balance quantitative/qualitative	Mainly quantitative. Responses to qualitative questions regarding ways in which services could be changed are coded into established categories.
Data from primary consumers	Consumers are the only people who contribute to the consumer satisfaction scale.
Data from others	Staff who know the consumer well can answer a scale on decision making, although direct information from the consumer is preferred. Staff complete other performance indicators.

Report Attachment B

Question format	Plain English questions, e.g. Do you want to keep on living here? Interviewers can rephrase some questions but not others, although they may be repeated. Interviewers rate the response from the consumer and sort it into three possibilities - (Yes), (Maybe, Sort Of, Not Sure), (No). Sometimes the options are - Happy, In Between, Sad.
Validity/consist check	Consistency of consumer response is established by asking reverse questions, e.g. Do you like living where you live? and Do you want to keep on living here? and Would you like to move and live somewhere else?
Quality of Life or Quality of Service	Quality of Life is measured in the context of Quality of Service. Quality of Life is taken as the ultimate measure of Quality of Service.
Validity issues	There is some doubt of using carers to rate decision making opportunities.
Reliability	
Resources required	
Time	
Quality of interview staff	
Selection crit	Interviews done by market research agencies.
Preparation	Not known.
Quality control	Not known.

Ethical issues	
Identification	From DDD database.
Consent	Personal communication with Judy Brown indicates that consent is simply not an issue. Non-government services sign agreements accepting the quality assurance process. The consumers are taken as adults able to make their own decision on whether to be interviewed or not. DDD appears to use external consultants to carry out surveys.
Anonymity	No comments.
Intrusion	No comments.
Benefits for participants	No comments.
Statistical analysis	
Tables produced	Numerous comparison tables are produced for the whole sample showing statistical significance where appropriate between people using different sorts of services and adults in the general population. These tables show percentages for each of the three positions on a three point rating scale. Level of satisfaction is generally very high though still often significantly lower than general population. The percentages of people dissatisfied with different areas of their life or service are highlighted. Statistical significance is gauged through chi-squared.
Methods for aggregation of groups up	
Methods for analysis of subgroups	
Indices created/used	
Linking of qualitative & quantitative data	
Special features	
Outcomes	
Bias in actual sample	The consistency checks lead to a large proportion of the sample being discarded

Report Attachment B

	(only 45.4% of adults in 1992 sample and 38% in the 1993 sample remained in for analysis.) The satisfaction sample therefore has a smaller percentage of individuals at lower levels of functioning than does the whole COPAR sample. Not surprisingly, it also includes a higher proportion of individuals residing in community settings than in the total sample. Only thirteen people in institutional settings remained in the satisfaction sample.
Response rate (& how non-response was dealt with)	See Above - High rate of discarding but no replacement process.
Data aggregations made	
Comparisons made/Questions answered that supported by data	Questions addressed include: 1. Are persons satisfied with the services they receive? 2. Does their satisfaction vary on the service approach? 3. How the satisfaction with life compares for persons with developmental disabilities to other citizens of Colorado? 4. The satisfaction levels vary by age category, gender or minority status? 5. Are people with DD more satisfied with services in 1993 than they were in 1992? 6. What would persons like to change about their homes and work or other day program activities?
Insupportable conclusions drawn ie misuse of data	
Service improvement use	
Benchmarks created	No statistically significant differences were found on basis of gender or minority status. However there was noted the general trend of satisfaction levels to go down with increased aged. This is unusual when quality of service is measured by level of satisfaction. But no reflected difference between the quality of life measures and satisfaction with services measures.
Limitations acknowledged	The lack of input with people with poorer

Report Attachment B

	communications skills.
Survey improvements planned	
Sampling	
Instrument	
Other	Judy Brown is involved in field testing CIP scales in Colorado for HSRI.
Side or unintended effects	
Commit/recommend to repeat	COPAR has been used annually for over ten years.
Costs	
Development costs	No information.
Implementation costs	No information.
Cost per respondent	

Survey review No. 5 - Core Indicators Project (CIP)

Administrative details	
Title	Core Indicators Project
Jurisdiction	15 US states
Date reported	June 1998
Agency	National Association of State Directors of Developmental Disabilities Services (NASDDDS) & Human Services Research Institute (HSRI)
Authors	Valerie Bradley and others
Contact details for information	Valerie Bradley HSRI 2336 Massachusetts Ave CAMBRIDGE MA 02140 USA E-mail: vbradley@concentric.net (alternative contact: Sara Taub E-mail: staub @concentric.net)
Survey developed by	HSRI
Survey conducted by	Participating states (7)
Ownership of the survey	NASDDDS & HSRI
Availability	Contact Valerie Bradley
Aims & Scope	
Study population	Adults with developmental disabilities and their families in 15 participating states.
Goals	To establish a nationally recognised set of performance indicators that will provide solid, reliable information concerning the effectiveness of a state's DD service system along various dimensions of performance and support valid comparisons with results being achieved in other states.
Quality of life or Quality of Service	Both
Services covered	Accommodation, employment, recreation, advocacy etc.
Context - reason for survey	CIP is a response to trends in long term support for people with DD including growth, decentralisation, privatisation and

	<p>diversification. These pose significant system management challenges for service directors particularly in the context for greater accountability and demand for information of service systems performance.</p> <p>State directors require valid, reliable and robust performance outcome indicators for monitoring and evaluating performance so that they can by result rather than programs.</p>
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Methodology - Development	
Composition advisory network	Very extensive national advisory network.
Previous work drawn on	Similar to COPAR i.e. draws on extensive base of US work.
Model of satisfaction used	Satisfaction is taken as a performance indicator that can be obtained only from individuals who are receiving services. Access is another such indicator. Quality of life is taken as one of a number of areas of consumer outcomes for which specific indicators haven written. The consumer survey instrument is given in the context of the complete CIP tool.
How validity established	
Construct validity	The CIP materials gain considerable validity through their close association with previously well accepted instruments.
Discriminatory powers	Extensive field tests are being conducted in the first part of 1998. Items without discriminatory powers will be discarded.
Field trials - comprehensiveness	The field trials are taking place in at least 7 states with samples of 400 adult consumers in each state. These trials will provide detail information on the reliability and validity of the instruments.
Setting of standards/benchmarks	One of the aims of CIP is to establish norms and standards to serve as a basis for assessing and interpreting a set of performance and outcome indicators. These “yardsticks” and “benchmarks” will permit end users to assess performance both within the state and against results being achieved in other states.
‘Risk analysis’	The project recognises that the extent of functional impairment of the individuals served affects both performance and costs. Ignoring these differences can mean misleading results with systems serving higher functioning individuals tending to perform better than those serving persons with greater functional limitations. The project aims to “risk adjust” the data in order

Report Attachment B

	to identify norms in respect to both performance and cost by grouping consumers based on differences in functioning level and severity of impairment. The project will investigate whether there is a meaningful correlation between level of impairment (however measured) and service outcomes.
Reliability results	
Improvements resulting from trials	Results from trials not yet available
Methodology - Implementation	This refers to version one being used in extensive field trials - the results are not yet available.
Sampling	
Frame	Adults receiving services funded by 7 participating states and families in each state who have an adult family member with a disability living at home who receives publicly funded service.
Procedure	Adult consumers in each state will be settled by random sampling. Consent will be obtained from respective participants.
Size	400 consumers from each of 7 participating states plus 400 families from each state (from a mail out to 1,000 families per state).
Ability to draw within gp comps	
Survey tool	
Medium - Tel, person to person, face to face, net	Face to face interviews with consumers or carers for parts of the consumer survey. The consumer survey is divided into sections all of which are completed by the consumer but some of which may be completed by other people. Staff complete other performance indicator information. Family survey is a mailed out questionnaire.
Balance quantitative/qualitative	Mainly quantitative
Data from primary consumers	Consumers are the only people who can contribute to section one of the consumer survey.
Data from others	Advocates may complete Section Two and family or staff may complete Section Three. Interestingly Section Three contains the

Report Attachment B

	questions on decision making and choice.
Question format	Plain English format with most questions to be answered by Yes, sometimes No. The interviewer selects the rating in the light of the consumers' response.
Validity/consist check	As for COPAR.
Quality of Life or Quality of Service	Quality of Life is measured in the context of Quality of Service. The consumer survey covers areas such as community inclusion, health, safety, work, housing, transport, relationships and choice.
Ethical issues	
Identification	
Consent	Consumers themselves
Anonymity	
Intrusion	
Benefits for participants	
Statistical Analysis and Outcomes	Data not yet available
Costs	
Development costs	
Implementation costs	
Cost per respondent	

Report Attachment C

Note: These performance indicators are in draft form. Seven states are testing the indicators as part of the Core Indicators Project, co-sponsored by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI).

<p style="text-align: center;">Candidate Indicators FIELD TEST VERSION - 10/31/97</p> <p>Note: All indicators will be reported for the past year or point-in-time, unless otherwise noted.</p>	<p style="text-align: center;">Data Source</p>
<p style="text-align: center;">CONSUMER OUTCOMES</p> <p><u>Working</u>¹ <i>Concern: People receiving vocational supports find and maintain employment in integrated settings and earn increased wages.</i></p> <ol style="list-style-type: none"> 1. The average hourly wage of people in vocational programs.² 2. The average number of hours worked per week (for those weeks worked) in the previous year. 3. The average number of weeks worked in the previous year. 4. The percent of people earning above and below minimum wage.³ 5. Average duration of time in this job for people who are employed. 	<p style="text-align: center;">Provider survey</p> <p style="text-align: center;">Provider survey</p> <p style="text-align: center;">Provider survey</p> <p style="text-align: center;">Provider survey</p> <p style="text-align: center;">Provider survey</p>
<p><u>Choice/Self-Determination</u> <i>Concern: People make life choices and participate actively in planning their services and supports.</i></p> <ol style="list-style-type: none"> 7. The proportion of people who make choices about important life decisions, such as:⁴ <ol style="list-style-type: none"> a) Housing 	<p style="text-align: center;">Consumer survey</p>

¹ This data will be collected only for state DD clients receiving employment services from DD or VR agencies. Work is defined as *paid* work, not including volunteer work. Indicators will be reported out by employment categories.

² Point in time measurement.

³ Point in time measurement.

⁴ A scale may be constructed to measure this indicator.

Report Attachment C

<p>b) Roommates c) Daily routines d) Support staff or provider (residential, work, and service coordination) e) Social and recreational activities</p> <p>8. The proportion of people reporting that their service plan reflects/includes/is about things that are important to them.</p>	<p>Consumer survey</p>
<p><u>Supporting Families</u>⁵ <i>Concern: Families improve their capacity to provide support for family members living at home.</i></p> <p>9. The percentage of families with an adult family member living in the home who report satisfaction with the supports they receive.</p>	<p>Family survey</p>
<p><u>Independence</u> <i>Concern: People experience personal growth and increased independence.</i></p> <p>10. The proportion of people reporting access to adaptive equipment, environmental modifications, and assistive communication devices.</p> <p>11. The proportion of people reporting that they control their own income and earnings and spending money.</p>	<p>Consumer survey Consumer survey</p>
<p><u>Relationships</u> <i>Concern: People gain and maintain friendships and relationships.</i></p> <p>12. The proportion of people who report having friends and caring relationships with people other than those in the service system (e.g. paid staff, co-workers in segregated settings, and roommates with disabilities).</p> <p>13. The proportion of people who report having someone they can talk to about private matters.</p> <p>14. The proportion of people who are able to see their families and friends when they want to.</p>	<p>Consumer survey Consumer survey Consumer survey</p>

⁵ The family survey will target families a) who have an adult family member living at home *and* b) who are receiving any type of service, *including* service coordination.

Report Attachment C

<p>15. The proportion of people reporting feeling lonely.</p>	<p>Consumer survey</p>
<p><u>Quality of Life</u> <i>Concern: People are satisfied with the supports they receive and experience a high quality of life.</i></p> <p>16. The proportion of people in current residential arrangements who express a desire to stay vs. a desire to move.</p> <p>17. The proportion of people reporting satisfaction with their job, day program, or school.</p> <p>18. The proportion of people reporting that they worked as much or as long as they wanted to.</p> <p>19. The proportion of people reporting that they received support to learn or do something new that was important to them.</p> <p>20. The proportion of people who report having adequate transportation when they want to go somewhere.</p>	
<p style="text-align: center;">SYSTEM PERFORMANCE</p> <p><u>Service Coordination</u> <i>Concern: Service coordinators are accessible and support consumer participation in service planning.</i></p> <p>21. The proportion of people who are able to see their service coordinators when they want to.</p> <p>22. The proportion of people who report that they participated in the development of their service plan.</p>	
<p><u>Utilization and Expenditures</u>⁶ <i>Concern: People are being served in a manner which aligns with public developmental disability agency goals (including self-determination, inclusion, and natural supports) and resources.</i></p> <p>23. The average annual expenditure per person overall, by living</p>	

⁶ Includes *public* expenditures only.

Report Attachment C

<p>arrangement, type of service and category of support.</p>	
<p>24. The annual expenditure for each living arrangement, type of service and category of support, as a percent of total expenditures.</p>	<p>System</p>
<p>25. The range of annual per person expenditures, by living arrangement, type of service and category of support.</p>	<p>System</p>
<p>26. The amount expended on vocational services compared to wages of people receiving vocational services by type of service.</p>	<p>System</p>
<p>27. The number of persons, age-adjusted and risk-adjusted, receiving services and supports by type:</p> <ul style="list-style-type: none"> • Large (>16) State-Operated Residential Facilities • Large (>16) Privately-Operated Residential Facilities • Medium (7-15) Public and Private Residential Licensed Group Home Facilities • Small (<6) Public and Private Licensed Residential Group Home Facilities • Foster Care/Family Home Settings • Other Residential Programs Owned/Operated by Public/Private Agencies (Apartments) (Non-consumer controlled housing) • In-Home Supports furnished to primary consumers in their own residence (supported living) • Family Support (services delivered in the family home; cash subsidies) • Service Coordination/Case Management • Facility-Based Vocational Services (Sheltered Workshops, Work Activity Centers) • Group Vocational/Employment Services (enclaves and mobile crews) • Individual Integrated Employment Supports (supported employment, job coach model) • Facility-Based Non-Vocational Services (day habilitation, day treatment, "seniors programs", etc.) • Non-Facility Based/"Non residential" community participation/training services • Other community integrated activities (e.g., health club memberships, etc.) • Clinical services (therapies, behavior management, psychological services and so forth) 	<p>System</p>

Report Attachment C

<p>¥ ¥42. Period since last physical exam. ¹⁴ ¥ ¥ ¥43. Period since last OB/GYN exam. ¥ ¥ ¥44. The percentage of people who have a primary care physician. ¥ ¥ ¥45. Period since last routine dental exam. ¥ ¥ ¥ ¥Concern: Medications are administered safely and appropriately. ¥ ¥ 46. The proportion of people receiving psychotropic medications, with or without a psychiatric diagnosis.¹⁵ ¥ ¥Concern: <i>The system makes limited use of restraints or other restrictive practices.</i>¹⁶ ¥ Frequency of use of mechanical restraints. ¥ Frequency of use of emergency chemical restraints.</p>	<p>System/ Consumer survey</p> <p>System/ Consumer survey</p> <p>System/ Consumer survey</p> <p>System/ Consumer survey</p> <p>System</p>
<p><u>Respect/Rights</u> <i>Concern: People receive the same respect and protections as Others in the community.</i></p> <p>47. The proportion of people who feel that their rights are respected by others.</p> <p>48. The proportion of people who have attended activities of self-</p>	<p>Consumer survey</p> <p>Consumer survey</p>

14* Kaiser Permanente Preventative Care Guidelines for Adult Comprehensive Health Assessment, based on recommendations of the American College of Physicians and the US Office of Disease Prevention, are as follows: Age 18-45: Every 3 years; Age 50-65: Every 2 years; Age 65+: Yearly.

15* For people receiving residential supports only.

16* The committee agreed th at project staff would do a survey of state policies on mechanical and chemical restraints this year and develop indicators for version 2.0. These are suggested indicators and definitions for future consideration. According to the Oklahoma Physical Status Review Manual, Draft 3/7/97, mechanical restraints are defined as the restriction of movement. Chemical restraint is defined as the use of any drug to restrict function or movement. It is useful to differentiate between drugs used in emergency situations to control behavior vs. drugs used prior to medical or dental procedures to reduce pain or anxiety.

Report Attachment C

<p>advocacy groups or other groups that address rights.</p> <p>49. The proportion of people reporting satisfaction with amount of time alone.</p>	<p>Consumer survey</p>
<p><u>PROVIDERS</u> <u>Acceptability</u> <i>Concern: The system is sensitive to consumer preferences and demands.</i></p> <p>50. The proportion of direct service providers who have consumers on their boards or advisory committees.¹⁷ (Also measure <i>number</i> of consumers on boards and <i>total size</i> of boards, if applicable.)</p> <p>51. The proportion of providers who have family members on their boards or advisory committees. (Also measure <i>number</i> of family members on boards and <i>total size</i> of boards, if applicable.)</p> <p>52. The proportion of people who are informed about and satisfied with the grievance process.</p> <p>53. The proportion of people indicating that staff were sensitive to their disability.</p>	<p>Provider survey</p> <p>Provider survey</p> <p>Consumer survey</p> <p>Consumer survey</p>
<p><u>Stability</u> <i>Concern: Direct contact staff turnover ratios and absentee rates are low enough to maintain continuity of supports and efficient use of recruitment and training resources.</i>¹⁸</p> <p>54. The crude separation rate, defined as the proportion of direct contact staff separated in the past year.</p> <p>55. The average length of service for all direct contact staff who</p>	<p>Provider survey</p> <p>Provider survey</p>

¹⁷ For indicators 50-51, the denominator would be the total number of direct service providers. Service providers are defined as agencies serving more than 10 people.

¹⁸ Direct contact staff are defined as employees who spend at least 50% of their time providing hands on, face-to-face contact with consumers. It excludes psychologists, nurses, and others whose primary job duties are not the provision of direct care, as well as managers/supervisors who are responsible for the supervision of staff.

¹⁹ Restricted as well as non-restricted assets should be included as part of these figures.

²⁰ Restricted as well as non-restricted assets should be included as part of these figures.

Report Attachment C

<p>separated in the past year.</p> <p>56. The vacancy rate, defined as the proportion of full time, direct contact positions that were vacant as of a specified date.</p> <p>57. The proportion of people who have changed residences more than once in the past year.</p> <p><i>Concern: Providers must have adequate and stable financial resources in order to provide services.</i></p> <p>58. Current ratio: the ratio of current assets to current liabilities.¹⁹</p> <p>59. Total liabilities to net worth.</p> <p>60. Total assets to liabilities.²⁰</p>	<p>Provider survey</p> <p>Consumer survey</p> <p>System</p> <p>System</p> <p>System</p>
<p><u>Staff Qualifications/Competency</u></p> <p><i>Concern: Direct care staff are properly screened and are supported to develop competencies necessary for providing services.</i></p> <p>61. The proportion of providers with staff available who can communicate with individuals who use modes of communication other than spoken English.</p>	<p>Consumer survey</p>

Core Indicators Project

CONSUMER PRE-SURVEY FORM – VERSION 1: FIELD STUDY

This pre-survey form is intended to collect information which is needed by the surveyor PRIOR to interviewing the consumer. It can be completed by the State or Surveying organization using any combination of information sources appropriate in that State, such as: data systems, provider pre-survey, telephoning a case manager, etc. The consumer survey question number that the pre-survey question relates to is indicated for your reference at the end of each pre-survey question.

Return this form to: _____ **by** _____ **(date)**

Please complete the following information:

Consumer Name: _____ **SSN/ID Code:** _____

Guardian: Does the consumer have a guardian? _____ Yes _____ No

If yes, Name of Guardian: _____ Phone: _____

Does the consumer have a financial guardian/conservator? _____ Yes _____ No

Was consent obtained from consumer or guardian, if necessary? _____ Yes _____ No

If so, please attach copy of consent form and return to state coordinator with the pre-survey form.

- 1 **S-Contact** – Who should the surveyor call in order to make arrangements for an interview with the consumer?
Name: _____ Phone: _____/_____
- 2 **S-Arrangements** - Are there any special arrangements needed for communicating with the consumer? (Example: primary language other than English, sign language, communications board, etc.) Please explain what arrangements are needed: (Question 63) _____

- 3 **S-Service Plan** - What is the annual service plan called in your organization, by what term would this individual best know this document? (Questions 34,35,36,37)

- 4 **S-Case Manager** - What is the name and phone number of the case manager/service coordinator for the consumer? (Question 32,52) Name: _____ Phone: _____/_____
- 5 **S-Advocate** - If this individual has a person who helps to represent him/her at planning meetings and in making important decisions, please provide this person's name, phone number, and relationship (Example: an advocate, guardian, personal representative, family member, etc.) (Section II, Question 33)
Name: _____ Phone: _____/_____
Relationship: _____
- 6 **S-Other Interviewees** – If this individual is unable or unwilling to complete sections of the survey that may be completed by other interviewees, please indicate the name and number of the individual(s) who would be best to complete those other sections (see Questions 31-66). Besides this individual, who next knows what decisions he/she makes, activities he/she does in the community, health indicators, and rights restrictions that may be in place?
Name: _____ Phone: _____/_____
Relationship: _____
- 7 **S-Lives Alone/ With Family/With Roommates/Housemates** – Please indicate if he/she lives alone or with parents or other relatives, and if not, please provide the first names of individuals he/she lives with. (Questions 17, 47, 49)
Lives alone? Y N Lives with parent/other relatives? Y N
If not, then provide first names of room/housemates: _____
- 8 **S-Support Staff in the Home and for Day Services** – If there are any people who are paid to provide supports in the consumer's home, please indicate their first names. If there are several staff, please list the primary staff who

Report Attachment D

spend the most time with or who have the closest relationship to the consumer. Also indicate the first names of any day program/job support staff. (Questions 50, 51) Home Support Staff: _____
Day Support Staff: _____

- 9 **S-Job/Day Activities** – Please indicate if he/she works or is in a particular school, training or other day program. Please indicate the term by which he/she would be most familiar with this job, school or program. (Questions 19, 20, 21, 51)
Works? Y N Goes to School? Y N If not, then provide Name of Other Day Program:

Core Indicators Project

CONSUMER SURVEY – VERSION 1: FIELD STUDY

Project Background: This survey was developed in conjunction with the *Core Indicators Project*, co-sponsored by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The purpose of the project is to identify and measure *core indicators* of performance of state developmental disabilities service systems. This survey is intended to measure a subset of the performance indicators identified by the project Steering Committee. The instrument is being field-tested in seven states: Arizona, Connecticut, Missouri, Nebraska, Pennsylvania, Vermont, and Virginia. Results from this pilot test will be used to refine the survey in this first year, and ultimately to improve services and supports provided for persons with developmental disabilities.

IDENTIFYING INFORMATION

- Name** (*Last, First, MI*): _____
- Social Security Number** (*or other unique identifier*): ____ - ____ - _____
- Home Address:** Street _____
City _____ State _____ Zip _____
- Has Lived In This Residence Since** ____ - ____ / ____ - ____ / ____ (mo/day/4 digit yr)
- Date Of Birth:** ____ - ____ / ____ - ____ / ____ (mo/day/4 digit yr)
- Agency/Provider Name:** _____ Code: _____
- Interviewer’s Code** (*optional*): _____

Report Attachment D

Note to the states: Data collected from this point on will be reported to HSRI for analysis. If you are sending raw data, please remove the first two pages and block out any names or other identifying information written on the forms before returning them.

- SURVEY CODE (Does not identify consumer – for data analysis purposes only. The code format should be five digits, beginning with the 2-digit state postal code followed by a number 001-999 assigned to the consumer. The same code number should be recorded on the individual’s ICAP form):** _ _ _ _ _

- Date survey was completed:** __-__/_-__/_ __ __ __ __ (mo/day/4 digit yr)

- State (use 2 digit postal code):**_____

- Region Or County, If Applicable:**_____

- Age of consumer:** _____

- Sex of consumer:** ___ Male ___ Female

Report Attachment D

SECTION I. QUESTIONS TO ASK THE INDIVIDUAL RECEIVING SERVICES & SUPPORTS

Instructions to the Surveyor: This section may only be completed by direct interview with the individual. Do not use responses from any other individual to complete this section. Consumers may skip any question. If there is no response or an unclear response, code as "9."

Read the following introduction to the consumer :

I am going to ask you several questions about your home, where you work, your friends and family, and the supports you receive. This is not a test and there are no right or wrong answers to these questions. Your answers to these questions will be kept confidential. We would like to know your opinions, how you feel about things. If you wish to skip any questions you may do so. Please answer these questions based on how you honestly feel.

HOME

[] **Do you like living in your home or would you like to live somewhere else?** [CI-16] *(Do you like living where you live or would you like to move to a different place?)*

- __2 Like where I live now - stay
- __1 In-between
- __0 Somewhere else – move
- __9 No response, unclear response

[] **Do you feel safe in your home?** [CI-40b]

- __2 Yes, feel safe there
- __1 In-between
- __0 No, don't feel safe
- __9 No response, unclear response

[] **Do you feel safe in your neighborhood/community?** [CI-40a]

(Do you feel safe close to home, outside your home?)

- __2 Yes, feel safe there
- __1 In-between
- __0 No, don't feel safe
- __9 No response, unclear response

[] **Can you be alone at home when you want?** [CI-49] *(If you live with others, do you have enough privacy? Do you have places or times when you can be alone?)*

- __2 Yes, can be alone at home when I want to be, lives alone
- __1 Sometimes
- __0 No, cannot be alone at home when I want to be
- __9 No response, unclear response, of doesn't ever want to be alone

Report Attachment D

- Would you like to live somewhere else or would you like to keep living where you live now?**
[CI-consistency]
__0 Somewhere else – move
__1 In-between
__2 Like where I live now - stay
__9 No response, unclear response

WORK

- Do you like _____** [enter your job, school name, day activity, etc. as appropriate from pre-survey PS-9]? [CI-17]
__2 Like
__1 In-between
__0 Dislike
__8 N/A – no job, school, or day program
__9 No response, unclear response

- (Surveyor - only ask this if they have a job – see PS-9) **Do you work enough hours or do you want to work more hours?** [CI-18]
__2 Yes, work enough or could work fewer hours
__0 No, want to work more hours
__8 N/A – doesn't work
__9 No response, unclear response

- Do you dislike your _____** [enter job, school name, day activity, etc. as appropriate from pre-survey PS-9]? [CI-consistency]
__2 Like
__1 In-between
__0 Dislike
__8 N/A – no job, school, or day program
__9 No response, unclear response

DIRECT SUPPORT STAFF

- Do staff or other people who support you treat you with respect; are they nice and friendly?** [CI-53]
__2 Yes, most staff, most times
__1 Sometimes, some staff
__0 No, some staff often are not nice
__9 No response, unclear response

- Has anyone ever explained to you what your rights are?** [substitute for CI-52] (Surveyor – you can use these examples if needed to clarify the question. For example, can you go to the church of your choice, do you have privacy, can you speak up for yourself, can you vote, can you send and receive mail, can you select your own friends, etc.)
__2 Yes
__1 Maybe, not sure

Report Attachment D

- _0 No
- _9 No response, unclear response

Do you feel that staff respect your rights? [CI-47a]

- _2 Yes, most staff, most times
- _1 Sometimes, some staff
- _0 No, some staff do not
- _9 No response, unclear response

FRIENDS AND FAMILY

Do you have friends you like to do things with, such as see movies, eat out, or play sports?

[CI-12] *(Surveyor - if he/she answers 'yes,' ask who the friends are and try to determine if they are family or staff. If they say yes, you can use prompts such as: Are these friends staff or your family? That's nice. Do you have some other friends who aren't staff and aren't your family? That's nice.)*

- _2 Yes, non-staff
- _1 Yes, staff or family
- _0 No
- _9 No response, unclear response

Do you feel extra close to anyone? Is there someone you can talk to or share private things with?

[CI-13] *(Surveyor - if they ask for clarification, say: "a real good friend, a best friend, someone you can share secrets with, tell problems to." It doesn't matter if they are family or staff here.)*

- _2 Yes
- _1 Sometimes
- _0 No
- _9 No response, unclear response

Can you see your friends when you want to see them? [CI-14a] *(Surveyor – we are trying to determine if there are restrictions on when he/she can see his/her friends – i.e., can he/she pick the times and if travel arrangements are made for him/her when he/she wants to see friends. Try to factor out situations where the friend themselves are not available – this is not the issue.)*

- _2 Yes, can see them when I want to
- _1 Sometimes
- _0 No
- _8 N/A – don't have any friends
- _9 No response, unclear response

Can you contact your family when you want to see them? [CI-14b] *(Surveyor – we are trying to determine if there are restrictions on when he/she can see his/her family – i.e., can he/she pick the times and if travel arrangements are made for him/her when he/she wants to see family. Try to factor out situations where the family themselves are not available – this is not the issue.)*

- _2 Yes, can see them when I want to, or choose not to see family
- _1 Sometimes
- _0 No

Report Attachment D

- 8 N/A – don't have any family, or live with my family
- 9 No response, unclear response

Report Attachment D

[] **During the past month, have you felt lonely?** [CI-15] *(Surveyor – if he/she responds “yes,” probe to determine how often he/she feels lonely.)*

- __2 Never feel lonely
- __1 Sometimes, a few times, rarely felt lonely
- __0 Always or often felt lonely
- __9 No response, unclear response

[] **Could this section be completed?**

- __1 Yes, the consumer answered the questions independently
- __2 Yes, the consumer answered the questions with someone else’s assistance, specify type of help provided_____
- __3 No, consumer could not communicate sufficiently to complete this section
- __4 No, consumer was unwilling to participate
- __5 No, was unable to schedule interview or other reason, explain_____

Report Attachment D

**SECTION II. QUESTIONS TO ASK EITHER THE INDIVIDUAL OR A PERSON WHO
ADVOCATES FOR THE INDIVIDUAL**

Instructions to the Surveyor: Please interview the person receiving services if possible. If the person cannot be interviewed or is no longer interested in continuing this interview, then interview the advocate identified via the pre-survey (PS-5) for this person – i.e., that person who helps to represent him/her at planning meetings and in making important decisions. This could include a guardian, parent, or some other form of a personal representative. **Do not interview staff for this section. If you are interviewing the advocate, it is recommended that you conduct this portion of the questionnaire by telephone.**

Ask individual if he/she wishes to continue with the survey.

If you are not interviewing the consumer, then you will need to modify the language of the questions. The wording for interviewing the advocates is provided in parenthesis.

SERVICES/SUPPORTS COORDINATION

Do you know who to ask if you have questions about your services and supports? [CI-28]

(Surveyor – if yes, probe to see who he/she would ask. If staff, code as “1”)

(Advocate version - Do you know who to ask if you have questions about the services and supports of the person that you represent?)

- 2 Yes, people other than staff
- 1 Yes, staff only
- 0 No
- 9 No response, unclear response

Do you get to see _____ [please enter name of service coordinator, case manager, or caseworker –see pre-survey PS-4] when you want to? [CI-21]

(Surveyor – If the person has a new case manager whom they have not met, ask about the most recent one.)

(Advocate version - Can you and the person you represent see the case manager or service coordinator when either one of you wants to?)

- 2 Yes
- 0 No, or only sometimes
- 8 N/A, doesn't have a service coordinator
- 9 No response, unclear response

(Surveyor - skip this question if you are not interviewing the consumer) **Can you call _____ [please enter name of advocate – see pre-survey PS-5] when you want to?** [CI-36]

- 2 Yes
- 0 No
- 8 N/A, doesn't have an advocate
- 9 No response, unclear response

Report Attachment D

At your annual _____ [please substitute the word used in your state for service plan – see pre-survey PS-3] **meeting, did people listen to what you had to say?** [CI-22] (Did you feel like you had input? Did people ask you what you thought?)
(*Advocate version* – At the annual planning meeting, did people listen to what he/she had to say and to what you had to say? Did you feel like you both had input? Did people ask you both what you thought?)
__2 Yes
__1 Sometimes
__0 No
__8 N/A, did not have an annual meeting
__9 No response, unclear response

Did you get what you wanted in your _____ [Please substitute the word used in your state for service plan – see pre-survey PS-3]? [CI-22] (Did people do what you asked?)
(*Advocate version* – Were your requests or comments included in the plan?)
__2 Yes
__1 Somewhat
__0 No
__8 N/A, did not have an annual meeting
__9 No response, unclear response

Are the things that are important to you in your _____ [Please substitute the word used in your state for service plan – see pre-survey PS-3]? [CI-8] (Are there things in your plan which you want to learn, things you want to do, etc.?)
(*Advocate version* – are the things in the annual plan which you believe are important to him/her – things he/she would choose to have in the plan?)
__2 Yes
__1 Some, a few
__0 No
__8 N/A, doesn't have a plan
__9 No response, unclear response

Are there things that are important to you that are not in your _____ [Please substitute the word used in your state for service plan – see pre-survey PS-3]? [CI-8] (Are there things you want to learn, things you want to do, that are not in your plan?)
(*Advocate version* – are there things that you believe are important to him/her that are not in the plan?)
__2 No
__1 Some, a few
__0 Yes
__8 N/A, doesn't have a plan
__9 No response, unclear response

In the last year, did you receive help to learn new things that are important to you? [CI-19]
(*Advocate version* – Did he/she get supports to learn new things that were important to him/her in the last year?)
__2 Yes
__1 Some, a few
__0 No
__9 No response, unclear response

Report Attachment D

[] Please indicate who completed this section.

- 1 Consumer
- 2 Advocate, Parent, Guardian, Personal Representative, Relative
- 3 Section II could not be completed because consumer was not interested in continuing, or could not communicate and no advocate was available

Note to Surveyor:

If the consumer did not complete this section, please indicate the last question he/she responded to. Question number: _____

If someone else finished answering the questions in this section, please indicate that person's name and relationship to the consumer.

Name: _____

Relationship: _____

Report Attachment D

SECTION III. QUESTIONS TO ASK EITHER THE INDIVIDUAL OR A PERSON WHO KNOWS THE INDIVIDUAL

Instructions to Surveyor: Interview the person receiving services if possible. Other persons may be interviewed (family, staff) if the consumer cannot be and if these persons are knowledgeable in the areas below. Note: If the person receiving services has completed Section I and II, but has become tired or disinterested in continuing this section, you may interview other persons.

Ask individual if he/she wishes to continue with the survey.

COMMUNITY INCLUSION

- [] In the last month, have you (has the consumer) gone shopping for groceries, household items or other goods, such as clothing, sporting goods, music tapes, etc. ? [CI-6a]**
__2 Yes
__0 No
__9 No response, unclear, don't know
- [] In the last month, have you (has the consumer) gone out to use community services, such as the bank, doctor, dentist, post office, hair dressers/barber, dry cleaner, laundromat, etc.? (taking care of business, chores) [CI-6b]**
__2 Yes
__0 No
__9 No response, unclear, don't know
- [] In the last month, have you (has the consumer) gone into the community for sports or exercise, such as to go walking, hiking, jogging, skating, biking, fishing, bowling, putt-putt, golfing, swimming, etc. ? [CI-6c]**
__2 Yes
__0 No
__9 No response, unclear, don't know
- [] In the last month, have you (has the consumer) gone out for other entertainment such as to see a movie, play, concert, museum, library, art gallery, etc.? [CI-6d]**
__2 Yes
__0 No
__9 No response, unclear, don't know
- [] In the last month, have you (has the consumer) gone to a social event such as a party, dance, date, eating out with friends, etc.? [CI-6e]**
__2 Yes
__0 No
__9 No response, unclear, don't know

Report Attachment D

In the last month, have you (has the consumer) gone to a group event, such as a club, social group, community organization, church, synagogue, or other religious event? [CI-6f]

__2 Yes

__0 No

__9 No response, unclear, don't know

Have you (has the consumer) ever gone to meetings or participated in self advocacy groups or other groups which address rights, like People First, Speaking for Ourselves, Arc, Legal Center, etc.? [CI-48]

__2 Yes

__0 No

__9 No response, unclear response, don't know

CHOICES

Note to surveyor: In this section, code "yes" only if you can convince yourself that the person made a real choice. Choices made with spouses/partners are considered "unassisted."

Did you choose the place where you live? [CI-7a] *(Surveyor – see PS-7 to find out if he/she lives with parents/relatives. Did you look at other places before moving here?)*
(Advocate version – Did the consumer choose the place where he/she lives?)

__2 Yes, unassisted

__1 Yes, with assistance

__0 No, someone else chose for me

__8 N/A, live in parent/relative's home (See PS-7)

__9 No response, unclear response, can't remember – too long ago

Do you choose your daily and weekly schedule (such as when to eat, clean house, or do laundry)? [CI-7c] *(Do you decide what time of day you should bathe, eat your meals? Who decides when in the week you should do laundry, clean house, or other tasks that occur weekly?)*
(Advocate version – Does the consumer choose his/her daily and weekly schedule, such as when to eat, clean house, or do laundry?)

__2 Yes, unassisted

__1 Yes, with assistance

__0 No, someone else chooses for me

__9 No response, unclear response, can't remember – too long ago

Did you choose the people you live with? [CI-7b] *(Did anyone ask you who you'd like to live with? If so, did you get to live with the people you said you'd like to live with? Were you given choices, did you get to interview people? Surveyor – if you need to, you can use the names of their roommates here from PS-7)*
(Advocate version – Did the consumer choose the people he/she lives with?)

__2 Yes, unassisted

__1 Yes, with assistance or some of the roommates

__0 No, someone else chose the people I live with

Report Attachment D

- 8 N/A – lives at home with parents or other relatives (See PS-7), or lives alone
- 9 No response, unclear response

Did you choose or hire _____ *[insert first name of paid staff who provide supports within their home, if any – see pre-survey PS-8]* **to help you at home?** [CI-7d] *(Did anyone ask you about hiring them? Did you get to talk to several possible people and help pick one?)*
(Advocate version – Did the consumer choose or hire staff to help him/her at home?)

- 2 Yes, unassisted
- 1 Yes, with assistance or some staff
- 0 No, someone else chose for me
- 8 N/A, no support staff in the home (see PS-8)
- 9 No response, unclear response

Did you choose or hire _____ *[insert first name of paid staff who provide supports at work or day program from PS-8 and reference work/day program as is relevant per PS-9]* **to help you at your work or day program?** [CI-7d] *(Did anyone ask you about hiring them? Did you get to talk to several possible people and help pick one?)*
(Advocate version – Did the consumer choose or hire staff at work or at their day program?)

- 2 Yes, unassisted
- 1 Yes, with assistance
- 0 No, someone else chose for me
- 8 N/A, no support staff for day program/work (see PS-8)
- 9 No response, unclear response

Did you choose or hire _____ *[insert first name of service coordinator/case manager from PS-4]* **to help you get what you need?** [CI-7d] *(Did anyone ask you about hiring them? Did you get to talk to several possible people and help pick one?)*
(Advocate version – Did the consumer choose or hire his/her service coordinator?)

- 2 Yes, unassisted
- 1 Yes, with assistance
- 0 No, someone else chose for me
- 8 N/A, no support staff for day program/work (see PS-8)
- 9 No response, unclear response

Do you choose the things you do for fun? [CI-7e] *(Do you choose how you spend your evenings, weekends, or time off from work, school, or day program? Who chooses what activity to do and where you do it? Ex: Whether to take a walk, play a game, watch TV, select what's on TV, etc.)*
(Advocate version – Does the consumer choose the things he/she does for fun?)

- 2 Yes, unassisted
- 1 Yes, with assistance
- 0 No, someone else chooses for me
- 9 No response, unclear response

Report Attachment D

Report Attachment D

- Can you have your own money whenever you want it, or do you ask someone for your money?** [CI-11a] *(Surveyor – we are trying to determine if he/she accesses his/her money at will or if they have to get someone else’s permission to use their money .)*
(Advocate version – Can the consumer have his/her own money whenever he/she wants it, or does he/she ask someone for his/her money?)

- _2 Yes, can get to my money by myself, have cash or can get to my bank unassisted
_1 Yes, can get my money whenever I want, but need some assistance to do that
_0 No, have to ask someone for my money
_9 No response, unclear response

- Do you choose the things you want to buy, or does someone else choose what you buy?**
[CI-11b] *(Surveyor – give examples, do you pick how to spend your money on things that are important to you, like games, clothes, music, movies, etc.? We are asking about spending money only; do not include groceries/food shopping.)*
(Advocate version – Does the consumer choose the things he/she wants to buy, or does someone else choose what he/she buys?)

- _2 Yes, unassisted
_1 Yes, with assistance
_0 No, someone else chose for me
_9 No response, unclear response

RIGHTS

- Does anyone ever open your mail without first asking if it’s okay with you?** [CI-47b] *(any mail that is addressed directly to him/her, including bills, paychecks, assistance payments, personal letters, junk mail, etc.)*
(Advocate version – Does anyone ever open the consumer’s mail without permission?)

- _2 No, his/her mail is not opened without his/her permission
_1 Yes, mail is sometimes opened without his/her permission
_0 Yes, always opened without his/her permission
_9 No response, unclear response

- Can you have privacy to be alone or to be alone with guests somewhere in the home when you want to be?** [CI-47c] *(Can you/he/she have privacy when you/he/she wants, such as to be alone with guests? Can you/he/she have overnight guests?)*
(Advocate version – can the consumer have privacy to be alone or to be alone with guests somewhere in the home when he/she wants to be?)

- _2 Yes, can have privacy or be alone when he/she wants to be with a guest and overnight guests
_1 No, not always, there are some restrictions on being alone, alone with guests, or can’t have overnight guests

Report Attachment D

- __0 No, never has privacy
- __9 No response, unclear response

- [] **Does anyone enter your home without asking you first?** [CI-47d] *(Excluding other people who also live in your/his/her home. We are talking about staff, case managers, landlords, etc. Do they knock and wait to be invited in?)*
(Advocate version – Does anyone enter the consumer’s home without asking first?)

- __2 No, people who do not live here knock first and wait to be invited
- __0 Yes, people not living there do enter without knocking first or they knock, but then walk in without being invited
- __9 No response, unclear response

- [] **Are there any restrictions on your use of the telephone?** [CI-47e]
(Advocate version – are there any restrictions on his/her use of the telephone?)

- __2 Yes, there are some restrictions, or person is not allowed to have a phone
- __0 No, there are no restrictions
- __8 N/A doesn’t have phone or unable to use phone
- __9 No response, unclear response

ACCESS

- [] **Are there services or supports that you needed that you couldn’t get in the past year?** [CI-30]
(Advocate version – Are there services or supports that the consumer needed that he/she couldn’t get in the past year?)

- __2 No
- __0 Yes
- __9 No response, unclear response

- [] **Are the places where you go for service or support easy to get to?** [CI-29] *(Give examples: work or day program, seeing case manager, therapist, etc.)*
(Advocate version – Are the places where the consumer goes for services or support easy to get to?)

- __2 Yes
- __1 Somewhat
- __8 N/A, doesn’t go anywhere to get services
- __0 No
- __9 No response, unclear response

- [] **When you want to go somewhere, do you have a way to get there?** [CI-20]
(Advocate version – When the consumer wants to go somewhere, does he/she have a way to get there?)

- __2 Most of the time

Report Attachment D

- __1 Some of the time
- __0 Almost never
- __9 No response, unclear response

Report Attachment D

- Do you and the staff understand each other when you communicate?** [CI-62] *(Surveyor – see PS-2. This question primarily applies to individuals who do not use spoken English as their primary way of communicating. Please attempt to find out if the communication mode used by the individual is understood by most staff and if staff can use a communication mode that the consumer understands. For example, if this persons speaks Spanish, then do most staff interacting with him or her speak Spanish? If this persons uses sign language, then do most staff interacting with him/her know sign language?)*

(Advocate version – Do the consumer and staff understand each other when they communicate?)

- _2 Yes, most times and most staff and I understand each other
_1 Some staff, sometimes
_0 No, few or no staff, rarely
_8 N/A, spoken English is primary communication mode
_9 No response, unclear response

- Do you have communication devices, interpreters, or other things you need in order to communicate?** [CI-10a] *(Surveyor – attempt to get at whether such devices are available, accessible from most location – i.e. not just at home, but at work/day sites, and that he/she knows how to use them.)*

(Advocate version – Does the consumer have communication devices, interpreters, or other things he/she needs in order to communicate?)

- _2 Yes, complete access and knows how to use
_1 Yes, limited access, need more devices or need to better understand use
_0 No access
_8 N/A- none needed
_9 No response, unclear response

- Do you have adaptive equipment and home modifications that you need, such as glasses, hearing aids, wheelchairs, braces/splints, ramps, etc.?** [CI-10b]

(Advocate version – Does the consumer have adaptive equipment and home modifications if needed, such as glasses, hearing aids, wheelchairs, braces/splints, ramps, etc.?)

- _2 Yes, complete access and knows how to use
_1 Yes, limited access, need more devices or need to better understand use
_0 No access
_8 N/A- none needed
_9 No response, unclear response

Report Attachment D

Please indicate who completed this section (*Relationship to Consumer – check all that apply*)

- 1 Consumer
- 2 Advocate, Parent, Guardian, Personal Representative, Relative
- 3 Staff who provides supports where consumer lives
- 4 Staff who provides supports at a day or other service location
- 5 Case Manager, service coordinator, social worker, resource coordinator
- 6 Other, Specify _____

Note to Surveyor:

If the consumer did not complete this section, please indicate the last question he/she responded to. Question number: _____

If someone else finished answering the questions in this section, please indicate that person's name and relationship to the consumer.

Name: _____

Relationship: _____

Report Attachment D

SECTION IV. QUESTIONS TO ASK THE CASE MANAGER OR OTHER AGENCY STAFF PERSON WHO CAN DIRECTLY CHECK RECORDS

The questions in this section are best answered by reference to agency records or computer system reference (dependent on availability by state). It is suggested that this section be completed by mailing this page of the form to the appropriate agency staff member, such as case manager or service coordinator.

Please complete the following information regarding

Consumer Name: _____ SSN/ID Code: _____

Return this form to: _____ by _____ (date)

ACCESS

Look at the case records and indicate the dates for each of the following events. [CI-31]

- ___ / ___ / _____ Date of intake (mo/day/4 digit yr)
- ___ / ___ / _____ Date of eligibility determination (mo/day/4 digit yr)
- ___ / ___ / _____ Date of first service plan (mo/day/4 digit yr)
- ___ / ___ / _____ Date that services commenced (mo/day/4 digit yr)

STABILITY

How many different places has the consumer lived within the past year (do not include moves within the same facility)? [CI-57]

___ Number of places

HEALTH

How many days in the past month (4 weeks) has the consumer's normal routine been interrupted because he/she was sick? [CI-41] *(i.e., did not go to work, school, day program or other scheduled activity outside the home due to being sick)*

___ Number of days

Does he/she have a primary care physician? [CI-44]

- __2 Yes
- __0 No
- __9 Unknown - cannot determine from records

When was his/her last physical exam? [CI-42]

___ / ___ (Mo/4 digit Yr -- put '99' in month if cannot determine)

When was her last OB/GYN exam? [CI-43]

___ / ___ (Mo/4 digit Yr-- put '99' in month if cannot determine))

Put N/A in month if consumer is a male

When was his/her last dental check-up? [CI-45]

___ / ___ (Mo/4 digit Yr -- put '99' in month if cannot determine)

Report Attachment D

WORK

If this individual has a job, answer the following questions:

What is the weekly wage he/she is earning now? [CI-1]
(If multiple jobs are held concurrently, then please average those wages)
\$ __ __. __ __ **per week**
__8 N/A, does not work

What are the number of hours per week he/she is working now? [CI-2] (Only include hours of paid work - please sum across jobs if multiple jobs)
Works __ __ hrs per week in a community integrated job
Works __ __ hrs per week in a non-integrated work setting
__8 N/A, does not work

How many weeks did he/she work in the past year? [CI-3] (Only include paid work – sum across multiple jobs if more than one held over last year.)
__ __ number of weeks of paid work in last year
__8 N/A, does not work

What was the date he/she was hired for his/her current job? [CI-5]
(If more than one job is held currently, then pick job held the longest.)
__ __/__ __/__ __ __ __ (mo/day/4 digit yr) – use 00 if day unknown
__8 N/A, does not work

SUPPORTS AND SERVICES

Please answer the following questions about the supports and services the person receives. The definitions may not be identical to the services and supports provided in your state; one purpose of this section is to compile standard definitions across states. Choose the responses that most closely match the service and support categories you are familiar with. [CI-27]

Does the individual receive residential supports in an out-of-home placement (includes supported living)?
__2 Yes
__0 No

Is the placement state operated or privately operated?
__1 State
__2 Private
__8 N/A, does not receive out-of-home residential supports

How many people live in the residence?
__ __ enter number or N/A (does not receive out-of-home residential supports)

Report Attachment D

[] Is the residence authorized (e.g. certified, accredited, licensed)?

- _1 Authorized
- _2 Unauthorized
- _8 N/A, does not receive out-of-home residential supports
- _9 Don't know

[] How would you characterize the place where the person lives?

- _1 Residential facility
- _2 Group home
- _3 Apartment
- _4 Foster care or host home (lives with unrelated paid family in family's home)
- _5 Independent home (leases or rents own home)
- _6 Parent/relative's home
- _7 Other (specify) _____

[] Does person receive in-home supports (e.g. personal attendant, housekeeping, etc.)?

- _2 Yes
- _0 No
- _8 N/A, lives in out-of-home placement

[] Other Supports Person is Currently Receiving (Check all that apply)

- _1 Service Coordination/Case Management
- _2 Vocational – Community Integrated Individual setting
- _3 Vocational – Community Integrated Group setting (enclave, mobile crews)
- _4 Vocational – Facility based (shelter workshops, work activity centers)
- _5 Non-vocational day service – Facility based (day habilitation, day treatment, 'seniors programs', etc.)
- _6 Community participation/accessibility supports/community connections – Specialized but NOT facility based (supports used to get people into the community)
- _7 Assistive Technology (e.g. supports to facilitate the use of adaptive equipment)
- _8 Clinical Services (therapies, behavior management, psychological services, etc.)
- _9 Transportation Services
- _10 Respite
- _11 Other, specify _____
- _12 None of these apply (1-10 do not apply)

Report Attachment D

Instruments consulted:

Ask Me! Survey. The ARC of Maryland (Draft).

Behavior Development Survey (1995). Philadelphia: Temple University Institute on Disabilities/UAP.

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Heal, Laird W., Harner, Cathy J., Novack Amado, Angela R., and Chadsey-Rusch, Janis. The Lifestyle Satisfaction Scale (1992). IDS Publishing Corporation.

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Schalock, Robert L. and Keith, Kenneth D. Quality of Life Questionnaire (1993). IDS Publishing Corporation.